

LIGAS EVALUATION ANNUAL REPORT: YEAR 2 REPORT

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Executive Summary

In 2011, the *Ligas v. Hamos* consent decree was approved by the Court. It provides for community-based services for individuals with intellectual and developmental disabilities (IDD) living in a private Intermediate Care Facility for Developmental Disabilities (ICF/DD) with 9 or more residents who want to move into a community based settings and for individuals living in the family home seeking services; and for whom the State of Illinois has received a “current record” of the person affirmatively requesting to receive community-based services or placement in a community-based setting. Through funding from the Illinois Department of Public Health, the Institute on Disability and Human Development at the University of Illinois at Chicago is evaluating the implementation of the Ligas consent decree. The main purpose of this evaluation is to investigate the process of transition and outcomes of class members who move off the waiting list for services, and those who move out of private ICF/DDs during the first two years.

The evaluation includes multiple data sources including the following pertaining to both groups:

1. Pre and post surveys of completed by Ligas families and guardians
2. Interviews with Ligas individuals with IDD
3. Focus groups with PAS agencies and ICF/DD provider agency staff

The current report addresses findings from the 741 pre-surveys, 49 pre-interviews and 6 focus groups (through the spring of 2015). The final report will include the findings from the follow-up surveys and interviews.

Are individuals and their families satisfied with the transition process?

Waiting list

The majority (59%) of the caregivers of the waiting list class members who received a selection letter for services were satisfied with the transition plan. On average, it took 4.6 months for class members to receive services after receiving their selection letter. Fifty-one percent of the caregivers felt that it took too long for the person with a disability to receive services.

ICF/DD

Among caregivers of the class members who moved out of ICF/DDs:

- 60% were satisfied with the transition plan.
- 54% felt their opinions were respected during the transition.
- 47% felt the opinions of the person with a disability were respected during the transition.

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- 47% felt the transition process moved at a good pace, with 36% reporting the process moved too quickly.
- 90% were satisfied with the current living situation of the person with a disability, and significantly **more** satisfied with the current placement than with the former ICF/DD.
- 89% indicated the person with a disability was satisfied with his or her current placement, and the persons with disabilities were significantly more satisfied with the services received in the current placement compared to the services in the ICF/DD.

How are class members doing (e.g., health, employment, social networks, leisure)?

Waiting list

Among class members with disabilities interviewed prior to receiving services:

- 88% liked where they were living.
- 45% wanted to live somewhere else (on their own or with roommates).
- 55% felt they did not have enough things to do in their free time.
- 51% spent time visiting with friends in the last month and 27% felt alone.
- 67% reported they did not work, but 83% wanted to work.

Class members off the waiting list (and already receiving services) had the following outcomes in comparison to class members still on the waiting list (and not yet receiving services):

- experienced significantly fewer unmet service needs
- participated significantly more frequently in community and social activities
- conducted more future planning activities
- were more likely to be employed or be in a day program

ICF/DD

Caregivers of class members who moved out of ICF/DDs were satisfied with various aspects of the current placement of the person with a disability. Seventy-nine percent of the caregivers of the class members who moved out of ICF/DDs felt the choices of the person with a disability were honored at the current placement. Eighteen percent of class members in ICF/DDs had their own room. Of those class members who moved out of ICF/DDs 56% had their own room. Class members who moved out of ICF/DDs had the following characteristics in comparison to class members still living in ICF/DDs:

- experienced significantly more daily choice
- displayed significantly less behavioral problems

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To what extent does the service plan facilitate choice?

Waiting list

Thirty-seven percent of caregivers of waiting list class members reported that the person with a disability had an individual service plan. Caregivers of class members who received services were significantly more satisfied with the individual service plan than the caregivers of those who were not receiving services.

ICF/DD

Caregivers of class members who moved out of ICF/DDs felt they had significantly more input in the individual service plan of the person with a disability than caregivers of class members who still lived in ICF/DDs.

How was choice communicated prior to the transition?

ICF/DD

Of the caregivers of class members who moved out of ICF/DDs:

- 88% of caregivers visited the new placement before the move.
- 36% reported the person with a disability did not visit any placements before making a decision on where to move to; 53% reported the person with a disability visited one new placement before making a decision; 9% reported the person with a disability visited 2 to 3 agencies and 2% reported the person with a disability visited 4 or more agencies.
- 84% stated that the person with a disability visited the new placement at least once before moving.

What are the barriers to accessing supports (e.g. rural areas, limited providers)?

PAS and ICFDD agency staff (total of 45 staff from 3 PAS and 3 ICF/DD agencies) reported on many barriers to implementing Ligas:

- Transition timeline too rushed
- Lack of information and misunderstandings by families about Ligas
- Inadequate day and residential options that fit with the desires of persons with disabilities and their families
- Lack of community capacity of CILAs to accommodate people with more severe health and behavioral disabilities
- Inadequate state funding for community providers

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ICFDD staff reported additional barriers:

- Worry that the person-centered transition process focused on dreams and hopes sets unrealistic expectations for families that are difficult to meet
- Families not being offered choices other than CILAs

RECOMMENDATIONS

The results of the evaluation to date suggest the following recommendations:

1. Expand community capacity to serve people with IDD that require more medical and behavioral needs, including enhanced rates when needed
2. Increase flexibility of CILA regarding daytime activities
3. Increase employment options that fit with the needs and preferences of individuals with disabilities and their families
4. Evaluate the reasons that families chosen off the waiting list do not choose to receive the services that they identify in their services plans
5. Improve the transition process so that people with IDD and their families' input is included in their transition plan
6. Provide more time for the transition to occur

Background to the Ligas Evaluation

In 2011, the *Ligas* consent decree was signed which provides for community based services for individuals with IDD living in a private Intermediate Care Facility for Developmental Disabilities (ICF/DD) with 9 or more residents who want to move into a community based settings and for individuals living in the family home seeking services; and for whom the State of Illinois has received a “current record” of the person affirmatively requesting to receive Community-Based Services or placement in a Community-Based Setting. For class members, moving away from their current residence the State mandated that a transition plan be developed that identifies necessary supports, is created in collaboration with the individual and their guardian/family, is person-centered, offers services in the most integrated setting in accordance with the class member’s choices, and is not limited to services currently available.

Through funding from the Illinois Department of Public Health, the Institute on Disability and Human Development at the University of Illinois at Chicago is evaluating the implementation of the *Ligas* consent decree. The main purpose of this evaluation is to investigate the process of transition and outcomes of class members who move off the waiting list for services, and those who move out of private ICF/DDs during the first two years.

Overview of Ligas class members

The following was the planned timeline for implementation as of April, 2013 for the waiting list and ICF/DD members (Records, 2012).

WAITING LIST CLASS MEMBERS

- Class members who move to ICFs/DD after 6/15/11 and request community services will be placed on the waiting list.
- Class members residing at home but not in crisis will be placed on the waiting list.
- 1,000 class members from the waiting list will receive community services by 6/15/2013
- 500 additional by 6/15/2014
- 500 additional by 6/15/2015
- 500 additional by 6/15/2016
- 500 additional by 6/15/2017
- At the end of six years class members will move off the waiting list at a reasonable pace.

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ICF/DD CLASS MEMBERS

The Division of Developmental Disabilities has developed an implementation plan to accomplish the obligations and objectives set forth in the Ligas consent decree. This plan contains the following:

- Within two and one half years, (12/15/13) one third of class members in ICFs/DD who request community services will move.
- Within four and one half years, (12/15/15) an additional one third (not less than two-thirds) of class members in ICFs/DD who request community services will move.
- Within six years, (6/15/17) all class members who live in ICFs/DD who request community services will transition to community settings. Within six years (6/15/17) 3,000 individuals on the waiting list for community based services or placement in a community-based setting will be served with home-based support services or in community-based residential settings (1,000 by 6/15/13 and 50 each year the next four years). After 6/15/17 all class members on the waiting list shall move off the waiting list at a reasonable pace.

UPDATE OF LIGAS CLASS MEMBERS AND NUMBER SERVED

Table 1 shows the numbers of Ligas members reported in the Monitor's reports and progress towards this timeline.

Table 1. Ligas class members

YEAR	WAITING LIST		ICF/DD		DATE	SOURCE
	Number of class members	Number served	Number of class members	Number served		
1	10,894	135	697	113	9/12/2012	First Annual Report of the Monitor
2	14,110	1356	892	519	9/15/2013	Second Annual Report of the Monitor
3	15,190	1969	1,217	741	9/23/2014	Third Annual Report of the Monitor

Methodological Overview

DESIGN

This evaluation includes Ligas class members who transition off the waiting list for services and their caregivers/guardians as well as Ligas class members who transition out of private ICF/DDs and their caregivers/guardians.

For both groups (waiting list and ICF/DD) we are addressing the following questions in this report:

- Are individuals and their families/guardians satisfied with the transition process?
- How are class members doing (e.g., health, employment, social networks, leisure)?
- To what extent does the transition plan (and service plan) facilitate choice?
- How was choice communicated prior to the transition?
- What are the barriers to accessing supports (e.g. rural areas, limited providers)?

The evaluation includes multiple data sources including the following pertaining to both groups:

- Pre and post surveys of Ligas families and guardians
- Interviews with Ligas individuals with IDD
- Focus groups with PAS agencies and ICF/DD provider agency staff

In the late fall of 2013, pre-surveys were mailed by the Department of Human Services to a random sample of 3,000 of the 10,894 caregivers and guardians of class members on and off the waiting list for services. Of these surveys, 556 (19% response rate) were completed and mailed back to the research team. Additionally, 892 surveys were mailed to all ICF/DD Ligas class members. Of these 892 surveys, 185 were returned (21% response rate), 101 surveys for members who moved out of ICF/DDs and 84 for members who still lived in ICF/DDs.

Forty-two individual interviews were completed with class members on the waiting list, and 7 interviews with class members transitioning out of ICF/DDs. Additionally, 3 focus groups with PAS agencies and 3 focus groups with ICF/DD agencies were completed with a total of 45 participants.

In early spring of 2015 post-surveys were mailed to families and guardians in both the ICFDD and waiting list groups. Currently, we are still receiving these post-surveys. Additionally, post-interviews are being conducted with class members with IDD. The current report discusses the results of the pre-surveys, pre-interviews and focus groups. The final report will include the results of the post-surveys and interviews.

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DATA COLLECTION MEASURES

Caregiver Surveys

Measures filled out by family/guardians included demographic characteristics of the family/guardian (referred to as caregivers throughout) and the person with IDD. Caregiver information included: relationship to the person with IDD, age, marital status, gender, employment status, household income, highest level of education, and perceived health status.

The demographics for the member with disabilities included: age, gender, race, primary mode of communication and mobility, level of intellectual disability, additional disability diagnoses, vocational status, current residence, and level of adaptive functioning. The level of adaptive functioning of the adult with IDD was assessed with scores on seven Activities of Daily Living (ADLs) and eight Instrumental Activities of Daily Living (IADLs) (Lawton, Moss, Fulcomer, & Kleban, 1982). Each activity was rated on needs for assistance: “total assistance” (1), “some assistance” (2), and “no assistance” (3).

Caregivers were asked to report on the person with IDD’s physical health by completing the Physical Health Philadelphia Geriatric Center Multi-level Assessment Instrument (PGC-MAI; Lawton et al., 1982) which included the following questions: “In general, would you say the health of your family member with a disability is: “poor”, “fair”, “good”, “very good”, or “excellent”? Do your family member with disabilities’ health problems stand in the way of him/her doing the things he/she wants to do: “not at all”, “a little”, or “a great deal”? How would you say your family member with disabilities’ health compares with most people his/her age: “better”, “about the same”, or “not as good”? (Cohen-Mansfield & Frank, 2008).

Several scales measured outcomes for the person with IDD, including measures of problem behaviors, daily choice making, and community participation. Problem behaviors, that were rated on their frequency included: being hurtful to self, being hurtful to others, destructing property, displaying unusual or repetitive behaviors, displaying socially offensive behavior, displaying withdrawal or inattentive behavior, and displaying uncooperative behavior.

The Daily Choice Inventory (Heller et al., 1999) asked caregivers to report the level of choices the person with IDD gets to make on a daily basis. Responses included ‘never’ (1), ‘sometimes’ (2), and ‘whenever he/she wants’ (3).

The Community Participation Scales (Heller et al., 1999) asked about the frequency which with the person with IDD engaged in various community activities during the last month: (e.g., volunteer work, shopping, visiting friends outside of his/her residence). Responses on the scales included ‘none’ (1), ‘1 to 3 times a month’ (2), ‘weekly’ (3), and ‘2+ times a week’ (4).

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Several questions addressed unmet service needs, individual service plans, and participation in advocacy activities. Waiting list caregivers reported on the burden, satisfaction and self-efficacy they experience as a caregiver to the individual with a disability. The caregiving burden scale (nine items) measures how caring for a relative with IDD affects job opportunities, finances, future concern, personal time, social opportunities for leisure, and caregiver's marriage (Heller et al., 1999). The caregiver satisfaction scale consists of five statements about satisfaction in the role of caregiver (Lawton et al., 1982). Statements include "my family member shows real appreciation for what I do for him/her," and "my family member's pleasure over some little thing gives me pleasure." The caregiver self-efficacy scale includes seven items with statements such as "I feel I can manage my family member's behavior" and "I feel that what I do can help improve my family member's situation" (Heller et al., 1999). All statements in the above scales are rated on a Likert scale from "strongly disagree" (1) to "strongly agree" (4).

The future planning scale asked waiting list caregivers to indicate which future planning activities they had conducted for the person with a disability. Examples of items are: 'located an attorney knowledgeable about disability issues', 'made residential plans', 'established powers of attorney for health care', and 'discussed future plans with the person with a disability'.

Waiting list class members answered a number of questions about their experiences on the waiting list, including the currently received services, the type of services sought, and the preferred future living arrangement of the person with IDD. Families who received a letter indicating they were no longer on the waiting list were asked additional questions about the time it took for the person with a disability to receive services after receiving the letter and their satisfaction with the transition plan.

ICF/DD caregivers were asked about the person with IDD's experiences in the ICF/DD. Additionally, caregivers of class members who moved out answered questions about their experiences during the transition to the current placement, and their satisfaction with the current placement.

Interviews with Individuals with Disabilities

The interview asked persons with disabilities about their experiences with their free time activities, employment, current living situation, physical and mental health, health behaviors, and self-advocacy. In addition, the class members answered items of the daily choice inventory and the community participation scale (Heller et al., 1999).

Focus Groups with PAS and ICF/DD Service Provider Agencies

The focus groups with staff from PAS agencies and ICF/DDs focused on four topics: the characteristics of the transition processes, the use of the transition forms, the process of linking

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families with services, and the perceived quality of the transition processes. This included the agencies' roles in the transition processes, the appropriateness of the timelines for transition, strengths and weaknesses of the transition processes, transition steps for families, the level of inclusion of individuals with disabilities and their family members, and the protocol for when questions regarding the procedures or policies arose.

Background and Demographic Information

The following section presents the demographics of the two groups: the class members on the waiting list and their families/guardians, and the ICF/DD class members and their families/guardians.

WAITING LIST

Class members

The persons with disabilities on the waiting list were on average 27 years old and their ages ranged from 18 to 71. Fifty-seven percent of the persons with disabilities were male. The racial background of the persons with disabilities was as follows: 74% White, 16% African American, 5% Hispanic or Latino, 1 % Asian American and 3% of another racial background or had two or more races. Seventeen percent of the waiting list class members had a mild intellectual disability; 41% had a moderate intellectual disability; 16% had a severe intellectual disability; and 5% had a profound intellectual disability. Eighty-three percent of the waiting class members used speech as their primary method of communication; 7% used signs; 18% used non-verbal communication; and 7% used assistive technology devices. Eighty-six percent of the persons with disabilities walk with or without aids and 13% of them use a wheelchair.

The majority of waiting list class members lived with a family member (83%); 7% lived in an independent home or apartment; 1% lived in a group home with four people or less; 2% lived in a group home with five or more people; less than 1% lived in an agency sponsored apartment; 1% of the individuals lived in more than one setting; and 8% lived in other arrangements.

Of the 556 waiting list class members, 136 had received services, and 420 had not received services at the time of the survey. There were no significant differences in the two groups (received versus not received) in age, gender, race, level of intellectual disability, method of communication and level of mobility as shown in Table 2.

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Table 2. Demographics of waiting list class members

Characteristic	Group who received services (n=136)		Group who did not receive Services (n=420)	
	n	%	n	%
Gender				
Male	70	52.2%	245	58.8%
Female	64	47.8%	172	41.2%
Average Age	27		27	
Race/Ethnicity				
American Indian or Alaska Native	2	1.5%	3	0.7%
Asian	1	0.7%	7	1.7%
Black or African American	21	15.7%	66	15.9%
Hispanic or Latino	98	73.1%	307	73.8%
White	6	4.5%	23	5.5%
Other or unknown	1	0.7%	2	0.5%
Two or More Races	5	3.7%	8	1.9%
Primary Diagnosis of IDD				
Does not have IDD	2	1.6%	12	3.0%
Mild	21	16.3%	70	17.6%
Moderate	63	48.8%	156	39.2%
Severe	17	13.2%	70	17.6%
Profound	12	9.3%	19	4.8%
Don't Know or Unspecified	14	10.9%	71	17.8%
Other Diagnosis (more than one)				
Mental illness (e.g., depression)	21	16.8%	73	18.3%
Autism	29	23.2%	124	31.2%
Cerebral palsy	25	20.0%	67	16.8%
Brain injury	8	6.4%	31	7.8%
Seizure disorder/neurological problem	32	25.6%	96	24.1%
Chemical dependency	1	0.8%	0	0.0%
Vision or hearing impairments	25	20.0%	77	19.3%

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Table 2. Demographics of waiting list class members (continued)

Characteristic	Group who received services (n=136)		Group who did not receive Services (n=420)	
	n	%	n	%
Other Diagnosis (more than one) (continued)				
Physical disabilities	30	24.0%	98	24.6%
Communication disorders	33	26.4%	83	20.9%
Alzheimer's disease	1	0.8%	1	0.3%
Intellectual disability	61	48.8%	174	43.7%
No other disabilities	6	4.8%	19	4.8%
Don't Know	3	2.4%	15	3.8%
Other disabilities	31	24.8%	87	21.9%
Communication (more than one)				
Speech	108	79.4%	353	84.2%
Signs	10	7.4%	31	7.4%
Non-Verbal	31	22.8%	66	15.8%
Uses Assistive Technology	5	3.7%	32	7.6%
Mobility				
Walks (with or without aids)	113	86.3%	348	86.1%
Uses a wheelchair	16	12.2%	52	12.9%
Limited to the bed for part of the day	2	1.5%	3	0.7%
Limited to the bed the whole day	0	0.0%	1	0.2%

N.B. Valid percentages are used in this table, additionally, percentages for characteristics without mutually exclusive categories may not add up to 100.

Caregivers

Ninety-five percent of the respondents of the waiting list surveys were primary caregivers to the person with IDD. Henceforth respondents will be referred to as 'caregivers'. Caregivers of waiting list class members were on average 56 years old, and ranged from 20-89 years of age. Most of the caregivers were women (84%), who were employed (60%), and married (66%). The vast majority of the caregivers to the persons with disabilities were a parent (89%). Four percent of the caregivers were siblings, and 7% responded "other" as their relationship to the person with a disability (this included but was not limited to: friends, extended relatives, guardians). The majority of caregivers reported that they were the legal guardian for their family member with

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disabilities (70%). There was a significant difference in the gender of the caregivers of the waiting list class members who received services versus those who did not receive services. There were significantly more male caregivers among the group of waiting list class members who did not receive services and more female caregivers among the group of class members who received services ($\chi^2 (1, N = 132) = 4.65, p < .05$) as shown in Table 3.

Table 3. Demographics of caregivers of waiting list members

Characteristics	Group who received services (n=136)		Group who did not receive services (n=420)	
	n	%	n	%
Gender*				
Male	13	9.8%	73	17.7%
Female	119	90.2%	339	82.3%
Average Age	55		55	
Marital Status				
Married	92	70.8%	26	64.6%
Unmarried	37	28.5%	140	34.1%
Domestic Partner /Civil Union	1	0.8%	5	1.2%
Relationship to Person with IDD				
Parent	122	89.7%	372	88.8%
Sibling	9	6.6%	12	2.9%
Other	5	3.7%	35	8.4%
Primary Caregiver	130	95.6%	394	94.5%
Legal Guardian	99	73.3%	290	71.1%
Educational Level				
Some high school	4	3.0%	16	3.9%
High School or GED	25	18.9%	82	20.0%
Some College	32	24.2%	94	22.9%
Trade/Vocational School	6	4.5%	23	5.6%
College	28	21.2%	106	25.9%
Some Graduate School	7	5.3%	15	3.7%
Graduate Degree	30	22.7%	74	18.0%

* Significant difference between groups on characteristic.

N.B. Valid percentages are used in this table, additionally, percentages for characteristics without mutually exclusive categories may not add up to 100.

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ICF/DD

Class members

Persons with disabilities in the ICF/DD group were on average 51 years old and their ages ranged from 22 to 89 years. The majority were White (81%). Sixteen percent of them were African American, 2% Hispanic or Latino, and 1% had two or more races. Seven percent of the ICF/DD members had a mild intellectual disability; 21% had a moderate intellectual disability; 27% had a severe intellectual disability; and 42% had a profound intellectual disability. Seventy-two percent of the persons with disabilities' walked with or without aids and 27% of them used a wheelchair. Fifty-three percent of the ICF/DD class members used speech as the primary mode of communication; 4% used signs; 36% used non-verbal communication and 7% used assistive technology devices. Thirty-three percent of the individuals had lived in an ICF/DD for over 20 years.

The majority of individuals who had moved out of ICF/DDs had moved into CILA arrangements (94%). Class members who lived in ICF/DDs and those who moved out did not differ significantly in age, race, level of intellectual disability, method of communication and level of mobility but there were significantly more men among those living in ICF/DDs versus among those who moved out of ICF/DDs ($X^2(1, N = 181) = 10.701, p < .001$). Table 4 displays the demographic information for the ICF/DD class members who still live in ICF/DDs and for those who have moved out.

Table 4. Demographics of ICF/DD class members

Characteristic	Group that has moved out of ICF/DDs (n=101)		Group that still lives in ICF/DDs (n=84)	
	n	%	n	%
Gender*				
Male	41	41.0%	53	65.4%
Female	59	59.0%	28	34.6%
Average Age	52		49	
Race/Ethnicity				
American Indian or Alaska Native	0	0.0%	0	0.0%
Asian	0	0.0%	1	1.2%
Black or African American	16	15.8%	14	16.7%
Hispanic or Latino	2	2.0%	2	2.4%
White	82	81.2%	67	79.8%
Other or unknown	0	0.0%	0	0.0%

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Table 4. Demographics of ICF/DD class members (continued)

Characteristic	Group that has moved out of ICF/DDs (n=101)		Group that still lives in ICF/DDs (n=84)	
	n	%	n	%
Race/Ethnicity (continued)				
Two or More Races	1	1.0%	0	0.0%
Primary Diagnosis of IDD				
Does not have IDD	1	1.0%	1	1.2%
Mild	6	5.9%	8	9.6%
Moderate	23	22.8%	15	18.1%
Severe	28	27.7%	21	25.3%
Profound	41	40.6%	37	44.6%
Don't Know or Unspecified	2	2.0%	1	1.2%
Other Diagnosis (more than one)				
Mental illness (e.g., depression)	21	24.4%	28	37.8%
Autism	6	7.0%	9	12.2%
Cerebral palsy	13	15.1%	10	13.5%
Brain injury	7	8.1%	3	4.1%
Seizure disorder/neurological problem	28	32.6%	33	44.6%
Chemical dependency	1	1.2%	0	0.0%
Vision or hearing impairments	24	27.9%	25	33.8%
Physical disabilities	30	34.9%	22	29.7%
Communication disorders	8	9.3%	10	13.5%
Alzheimer's disease	2	2.3%	1	1.4%
Intellectual disability	0	0.0%	0	0.0%
Other Diagnosis (more than one)				
Intellectual disability	0	0.0%	0	0.0%
No other disabilities	11	12.8%	0	0.0%
Don't Know	2	2.3%	0	0.0%
Other disabilities	8	9.3%	7	9.5%
Communication (more than one)				
Speech	59	62.1%	41	48.8%
Signs	9	9.5%	10	11.9%
Non-Verbal	33	34.7%	40	47.6%
Uses Assistive Technology	1	1.1%	0	0.0%

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Table 4. Demographics of ICF/DD class members (continued)

Characteristic	Group that has moved out of ICF/DDs (n=101)		Group that still lives in ICF/DDs (n=84)	
	n	%	n	%
Mobility				
Walks (with or without aids)	71	71.7%	59	72.0%
Uses a wheelchair	27	27.3%	21	25.6%
Limited to the bed for part of the day	1	1.0%	2	2.4%
Limited to the bed the whole day	0	0.0%	0	0.0%

* Significant difference between groups on characteristic.

N.B. Valid percentages are used in this table, additionally, percentages for characteristics without mutually exclusive categories may not add up to 100.

Caregivers

Seventy-eight percent of the respondents to the surveys for ICF/DD class members were women. Over half of the respondents were family members, particularly parents (35%), siblings (13%), and other relatives (5%). Thirty-six percent of respondents were state guardians and 12% reported “other” but did not specify their relationship to the person with a disability.

The state guardians did not complete questions designed for informal caregivers. Therefore, the demographic information reported henceforth reflects informal family caregivers. There was no significant difference in the number of state guardians who filled out the surveys for those ICF/DD class members who moved out of ICF/DDs (32% of respondents) versus those who still lived in ICF/DDs (40% of respondents).

Caregivers of members who remained in the ICFDD were significantly older than families of those who moved out (68 years of age versus 60 years of age; $t(98) = -3.932, p < .001$). Table 5 displays the demographic information for the caregivers of the ICF/DD class members who still lived in ICF/DDs and for those who have moved out.

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Table 5. Demographics of caregivers of ICF/DD class members

Characteristic	Group that has moved out of ICF/DDs (n=101)		Group that still lives in ICF/DDs (n=84)	
	n	%	n	%
Gender				
Male	13	22.0%	9	20.9%
Female	46	78.0%	34	79.1%
Average Age*	60		68	
Marital Status				
Married	41	73.2%	26	61.9%
Unmarried	15	26.8%	16	38.1%
Domestic Partner /Civil Union	0	0%	0	0%
Relationship to Family Member with IDD				
Parent	33	32.7%	30	36.6%
Sibling	14	13.9%	9	11.0%
Other	54	53.5%	43	52.4%
Legal Guardian	99	13.4%	84	11.3%
Educational Level				
Some high school	5	8.8%	1	2.3%
High School or GED	12	21.1%	10	23.3%
Some College	10	17.5%	10	23.3%
Trade/Vocational School	16	28.1%	8	18.6%
College	5	8.8%	2	4.7%
Some Graduate School	9	15.8%	12	27.9%
Graduate Degree	0	0.0%	0	0.0%

* Significant difference between groups on characteristic.

N.B. Valid percentages are used in this table, additionally, percentages for characteristics without mutually exclusive categories may not add up to 100.

HEALTH & BEHAVIOR

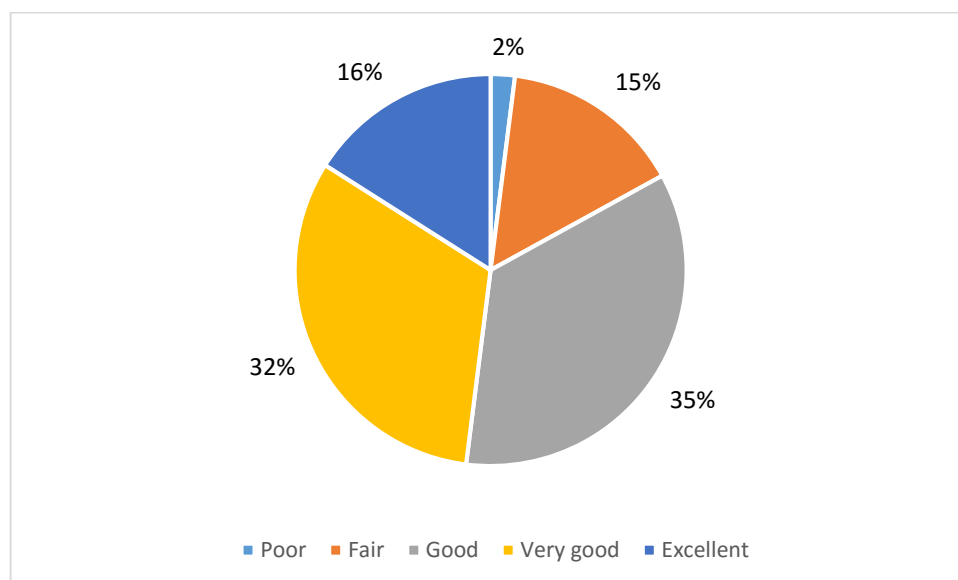
WAITING LIST

Class members

The majority of class members on the waiting list were in good (35%), very good (32%) or excellent health (16%). Fifteen percent of the caregivers indicated that the person with a disability was in fair health, and 2% of the caregivers indicated the person with a disability was in poor health (see figure 1).

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Figure 1: Overall health waiting list class members



For 34 % of the class members, their health somewhat stood in the way of them pursuing desired activities and for 17% of the class members their health stood in the way a great deal. When the caregivers were asked how the health of the person with a disability compares to others the same age, 12% of them reported that it was better; 55% reported that it was about the same, and 32% reported that it was not as good. There were no differences in health status between class members who received services and those who did not receive services.

With regards to activities of daily living, class members needed the most support with managing money, getting to places out of walking distance, shopping for groceries, preparing meals, laundry, taking medication, and housework. The class members needed less support with using the telephone, grooming, bathing, dressing, going to the bathroom, eating, getting around the home, and getting in/out of bed. There was no significant difference in the activities of daily living scale between class members who received services and those members who did not receive services. However, class members on the waiting list who received services did need more support to get to places out of walking distance than class members who did not receive services ($t(247) = -2.543, p < .05$).

Problem behaviors that occurred more than once a month included disruptive behaviors, uncooperative behaviors, withdrawal or inattentive behaviors, and unusual or repetitive habits. Behaviors that occurred less than once a month included being hurtful to others, being destructive to property, being hurtful to self, and being socially offensive. There were no

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differences in the frequency of different problem behaviors between those class members who received services and those who did not receive services. Table 6 demonstrates these findings.

Table 6. Health and behavior of waiting list class members

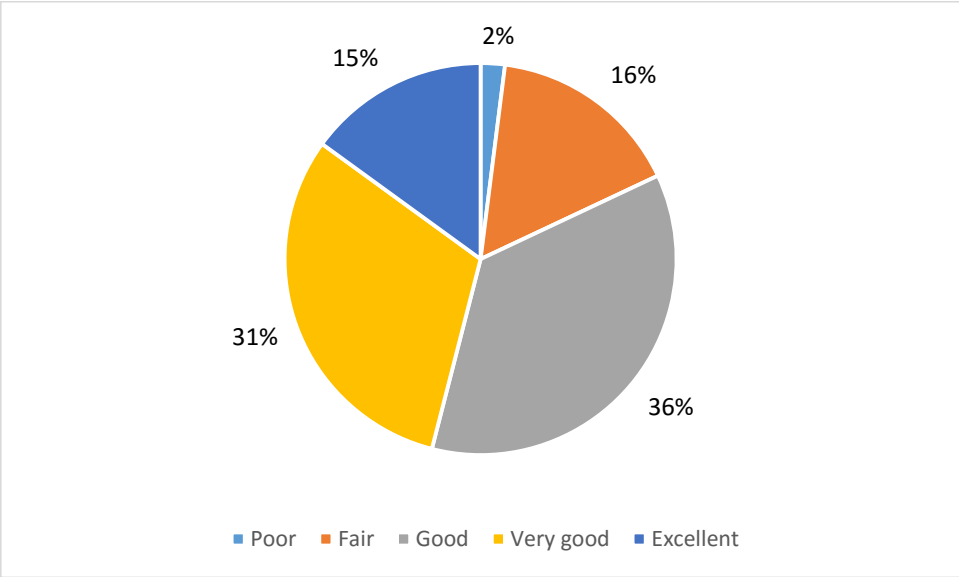
Characteristic	Group who received services (n=136)		Group who did not receive services (n=420)	
	n	%	n	%
Health status				
Poor	1	1%	11	2%
Fair	16	12%	65	15%
Good	44	32%	148	35%
Very good	48	36%	129	32%
Excellent	26	19%	64	16%
Health interference with activities				
Not at all	76	57%	191	49%
A little	40	30%	147	34%
A great deal	18	13%	76	17%
Health compared to others same age				
Better	20	15%	48	11%
About the same	69	52%	235	57%
Not as good	45	33%	132	32%
	Mean	SD	Mean	SD
ADL scale	2.01	.49	2.03	.53
Problem behavior scale	1.95	.89	1.91	.85

Caregivers

Most caregivers of the waiting list class members reported to be in good health (36%), very good health (31%) or excellent health (15%). Only 16% of caregivers reported being in fair health and 2% reported that their health was poor (see figure 2). There were no differences in health status between caregivers of class members who received services and those who did not.

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Figure 2: Overall health caregivers of waiting list class members



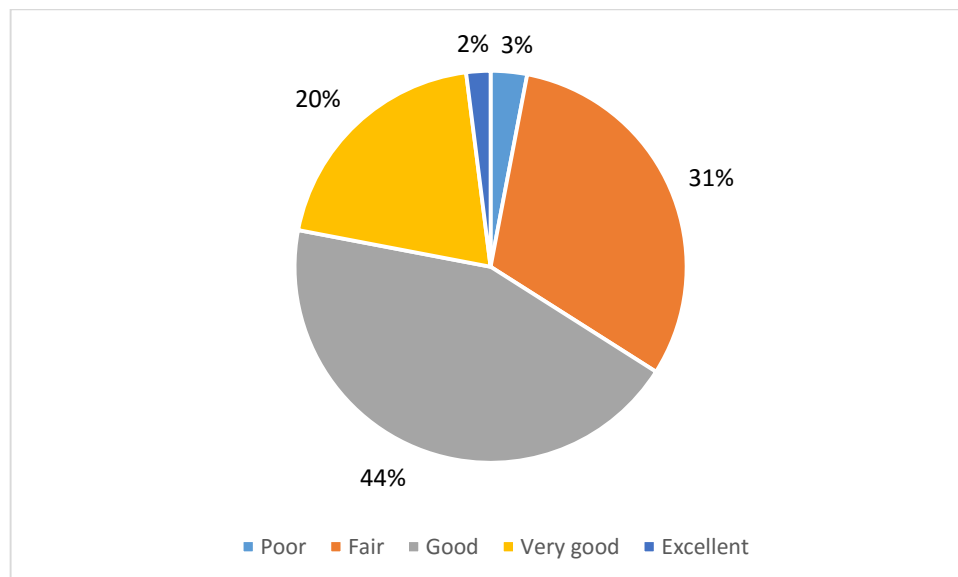
ICF/DD

Class members

The majority of ICF/DD class members were in good (44%), very good (20%) or excellent health (2%). Thirty-one percent of the caregivers indicated that the person with a disability was in fair health, and 3% of the caregivers indicated the person with a disability was in poor health (figure 3).

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Figure 3: Overall health ICF/DD class members



For 47% of the ICF/DD class members, their health somewhat stood in the way of them pursuing desired activities and for 19% of the class members health stood in the way a great deal. When the caregivers were asked how the health of the person with a disability compares to others the same age, 9% of them reported that it was better, 44% said that it was about the same, and 47% stated that it was not as good. There were no differences in health status between class members who moved out of ICF/DDs and those who still lived in ICF/DDs.

With regards to activities of daily living, class members needed most support with preparing meals, managing money, shopping for groceries, laundry, using the telephone, housework, getting to places out of walking distance, and taking medications. The class members needed less support with grooming, bathing, dressing, going to the bathroom, eating, getting in/out of bed, and getting around the home. There was no difference in the extent of support needed with regards to activities of daily living by class members who moved out of ICF/DDs and who still lived in ICF/DDs.

Problem behaviors that occurred more than once a month included being socially offensive, disruptive behaviors, uncooperative behaviors, withdrawal or inattentive behaviors, and unusual or repetitive habits. Behaviors that occurred less than once a month included being destructive to property, being hurtful to others, and being hurtful to self.

Overall, class members who still lived in ICF/DDs displayed significantly more problem behaviors than class members who moved out of ICF/DDs ($t(177) = -2.199, p < .05$). The class members who

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moved out were significantly less likely than class members who still lived in ICF/DDs to be destructive to property ($t(95) = -2.671, p < .01$), exhibit unusual or repetitive habits ($t(152) = -2.234, p < .05$), to be socially offensive ($t(154) = -2.376, p < .05$), and to display withdrawal or inattentive behaviors ($t(154) = -2.012, p < .05$). Table 7 demonstrates these findings.

Table 7. Health and behavior of ICF/DD class members

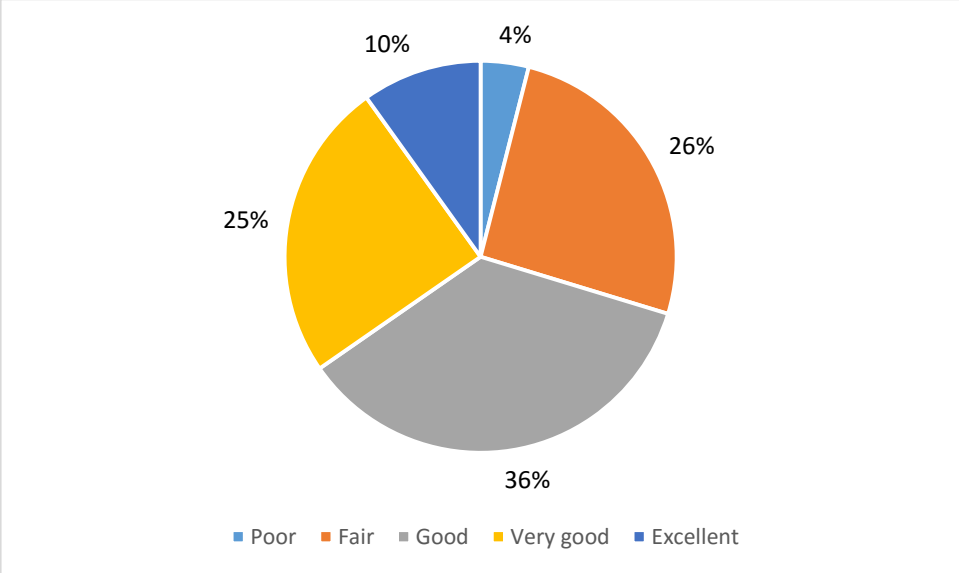
Characteristic	Group that has moved out of ICF/DDs (n=101)		Group that still lives in ICF/DDs (n=84)	
	n	%	n	%
Health status				
Poor	4	4%	2	3%
Fair	29	29%	29	31%
Good	49	48%	32	44%
Very good	18	18%	19	20%
Excellent	1	1%	2	2%
Health interference with activities				
Not at all	31	31%	32	38%
A little	49	48%	38	46%
A great deal	21	21%	13	16%
Health compared to others same age				
Better	9	9%	7	9%
About the same	44	45%	35	43%
Not as good	45	46%	39	48%
	Mean	SD	Mean	SD
ADL scale	1.66	.47	1.67	.47
Problem behavior scale*	1.85	.93	2.15	.85

Caregivers

Most caregivers of the ICF/DD class members reported to be in good health (36%), very good health (25%) or excellent health (10%). Twenty-six percent of caregivers reported being in fair health and 4% said that their health was poor (see figure 4).

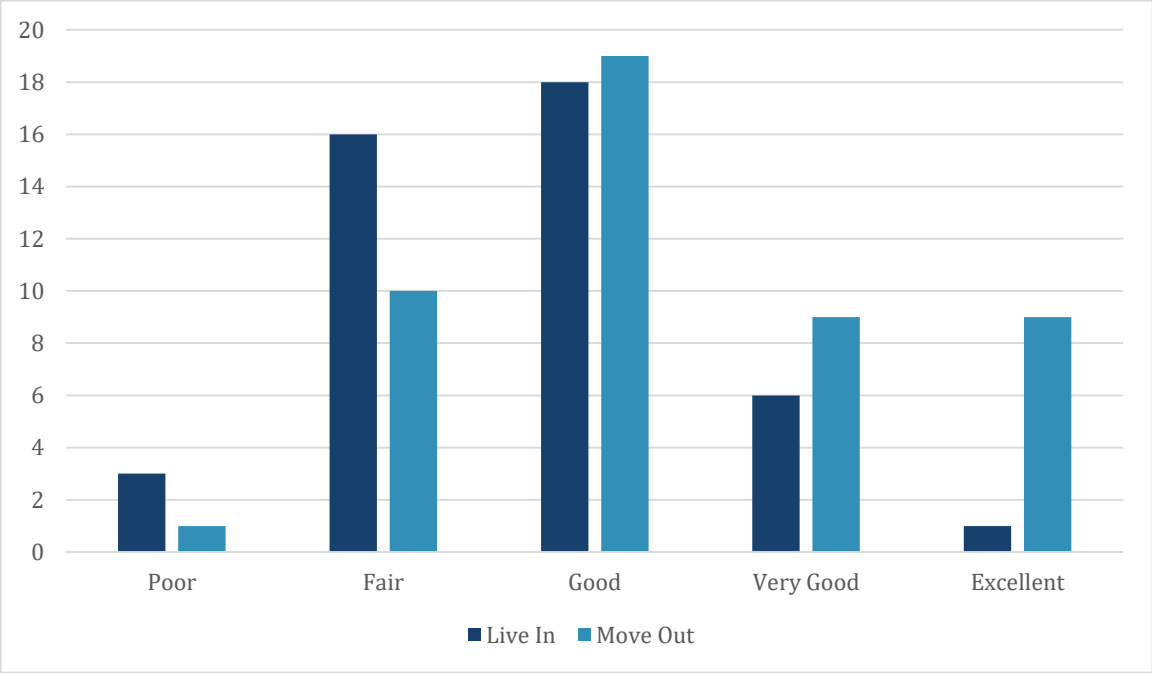
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Figure 4: Overall health of caregivers of ICF/DD class members



Caregivers of class members who moved out of ICF/DDs were in significantly better health than the caregivers of the class members who still lived in ICF/DDs ($X^2 (4, N = 102) = 13.912, p < .01$) as illustrated in figure 5.

Figure 5: Health of caregivers of ICF/DD class members who live in ICF/DDs and who moved out



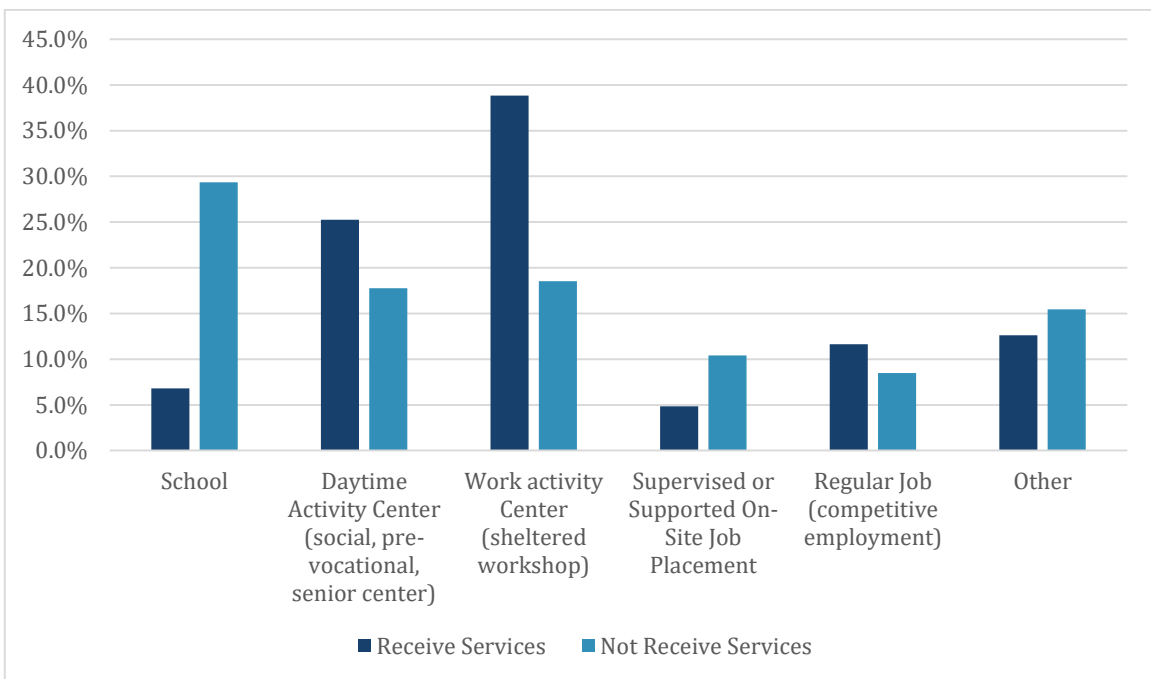
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EMPLOYMENT WAITING LIST

Class members

There were significant differences between the employment status of waiting list class members who received and those who were still waiting for services. Seventy-three percent of class members who received services were in a day program or employed, while only 55% of those members who did not receive services were in a day program or employed ($X^2 (1, N = 537) = 13.416, p < .001$). As Figure 6 shows, individuals with disabilities who had received services had a significantly lower rate of staying at school (7%), compared to those who were still waiting for services (29%). Over 39% of individuals who had received services attended work activity centers, compared to a significantly lower rate of 19% among those who had not received services ($X^2 (5, N = 362) = 34.679, p < .001$).

Figure 6. Type of employment of waiting list class members



Caregivers

Sixty percent of the caregivers of the waiting list class members were employed. Caregivers who were employed worked an average of 33 hours per week. Sixteen percent of the caregivers reported an average annual taxable income of below \$15,000; 14% between \$15,001 and

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\$25,000; 21% between \$25,001 and \$50,000; 17% between \$50,001 and \$75,000; and 32% over \$75,000.

ICF/DD

Class members

Ninety-five percent of individuals with disabilities in the ICF/DD class were reported to be in a day program or employed. ICF/DD class members were primarily involved in daytime activity centers and work activity centers. No significant differences in employment status were found between class members who moved out of ICF/DDs and those who were still living in ICF/DDs.

Caregivers

Forty-six percent of the caregivers of the ICF/DD members were employed. Caregivers who were employed worked an average of 33 hours per week. Fourteen percent of the caregivers reported an average annual taxable income of below \$15,000; 12% between \$15,001 and \$25,000; 28% between \$25,001 and \$50,000; 22% between \$50,001 and \$75,000; and 24% over \$75,000.

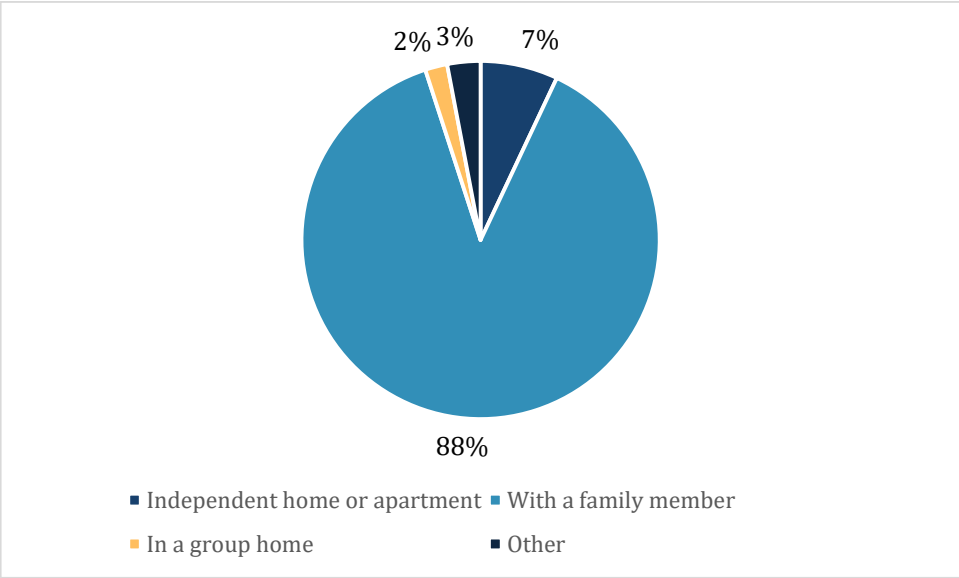
Survey and Interview Findings

CLASS MEMBERS ON THE WAITING LIST

Where did waiting list class members live?

As can be found in figure 7, the vast majority of waiting list members lived at home with family (88%).

Figure 7. Living arrangement for waiting list members



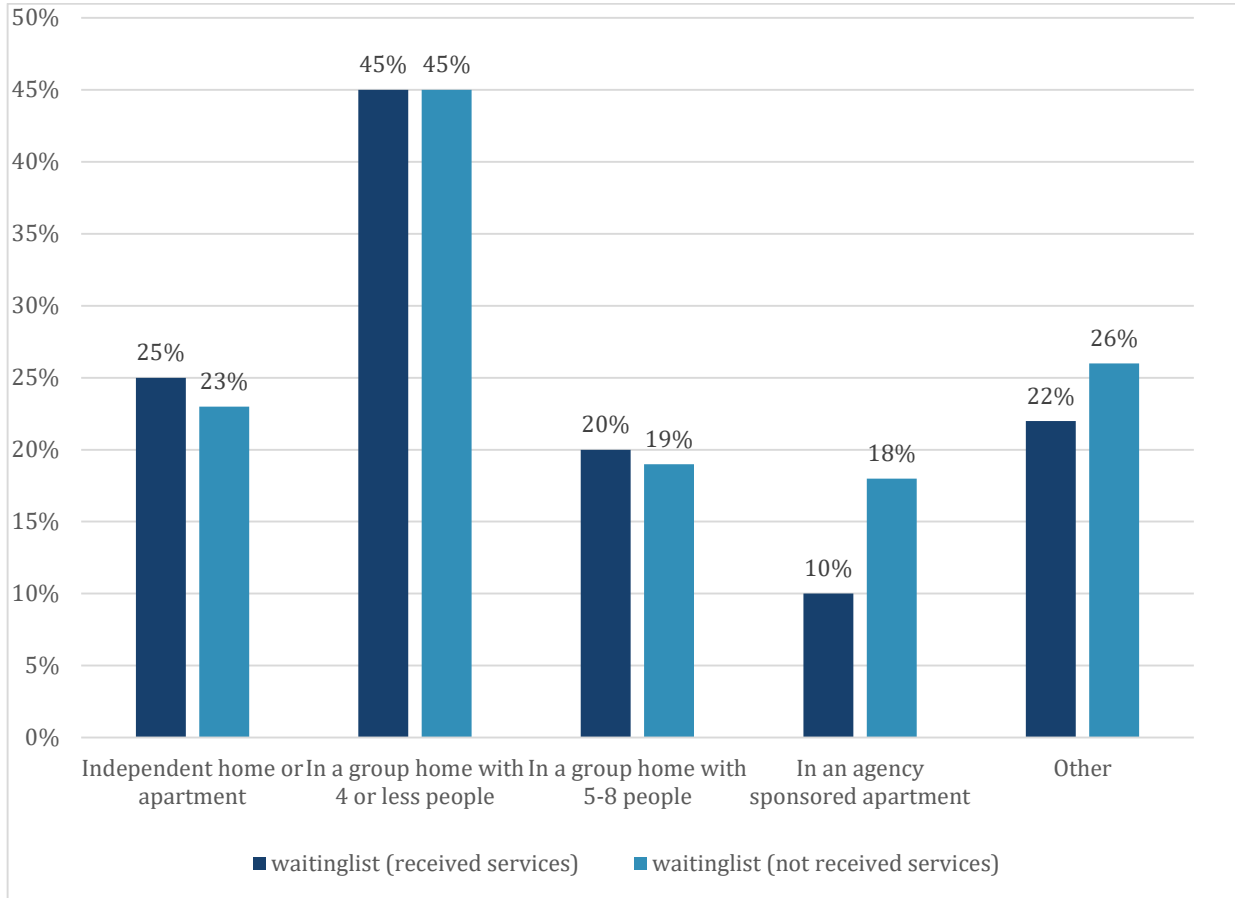
The vast majority of class members who are off the waiting list lived with a family member as well (90%).

Where did waiting list class members want to live?

While the majority (89%) of waiting list members (both those receiving services and still waiting for services) were still currently living in the family home, their caregivers reported that 40% wanted to live in a CILA (evenly split between those receiving services and those not), and 13% wanted to live in an independent home or apartment (see figure 8).

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Figure 8: Desired living arrangement for waiting list members



How satisfied were caregivers with the members' individual service plans?

When asked if the person with a disability had an Individual Service Plan (ISP), 37% of the caregivers responded that they did and 30% responded they did not. Thirty-three percent of caregivers did not answer this question. An ISP is only required for persons with disabilities who receive services. Caregivers of class members who received services were significantly more satisfied with the ISP than the caregivers of those who were still waiting for services ($t(304) = 3.351, p < 0.01$).

How long did it take for members to receive services after receiving a selection letter?

On average, caregivers reported that it took 4.6 months from the time they received their selection letter for their family member to receive services. When asked how they felt about the time it took for the person with IDD to receive services, 51% of caregivers who responded said that it took too long and 50% said that it took sufficient time.

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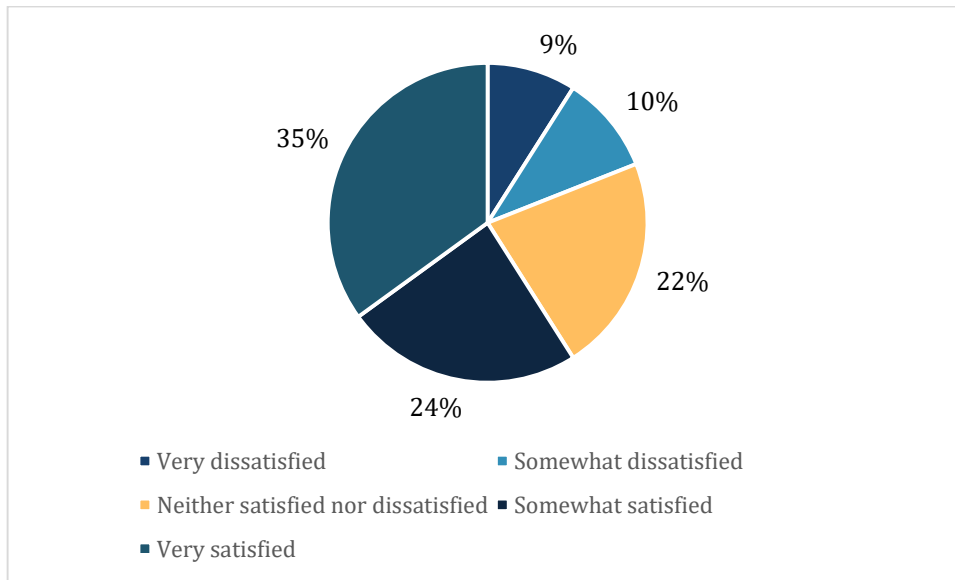
What services do class members off the waiting list receive?

Caregivers were asked to indicate all the services the persons with IDD receives. Over sixty-seven percent of class members off the waiting list received home-based services. Five percent received community-based services (e.g., supported employment), and 6% received residential services (e.g., group home).

How satisfied were caregivers with the class members' Ligas transition plans?

As illustrated in figure 9, the majority of the caregivers whose member with IDD received a selection letter (not all of these class members already received services) were either very (35%) or somewhat (24%) satisfied with the transition plan in respecting the choices of their member with a disability. Twenty-two percent of the caregivers were neither satisfied nor dissatisfied with the plan in respecting the person with a disability's choices; 10% were somewhat dissatisfied; and 9% were very dissatisfied.

Figure 9. Satisfaction with transition plan in respecting choices of member



During the transition process, the vast majority of caregivers (80%) did not speak with another family with a person with IDD who was also transitioning off of the waiting list.

What unmet support needs do class members experience?

Hierarchical multiple regression analysis indicated that class members who were off the waiting list experienced significantly less unmet needs than class members who did not receive services

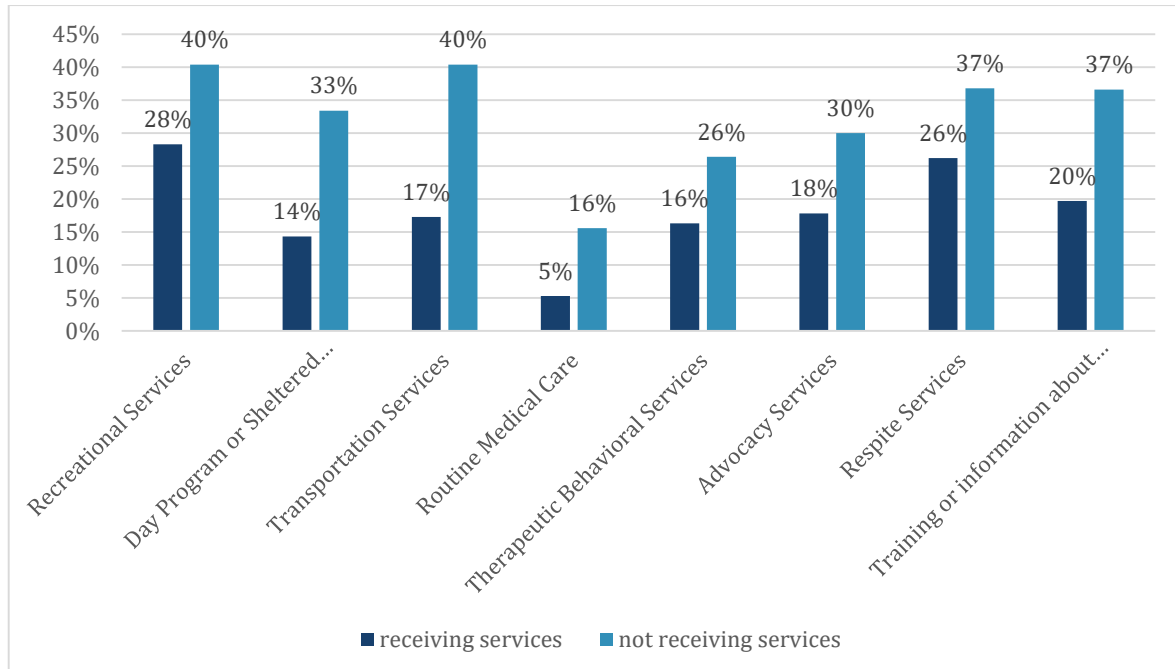
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(after controlling for gender of the caregiver, and race, level of adaptive functioning and age of the family member with a disability; [R^2 change = .027, $F(1,513) = 15.525$, $p < .001$ }).

Race ($\beta = -2.12$, $p < .001$) and age ($\beta = -1.48$, $p < .001$) of the class members were significant independent contributors to the regression model. Minority class members experienced significantly more unmet needs than white class member;, additionally younger class members tended to have significantly more unmet needs.

Z-tests indicated that class members who did not receive services experienced significantly greater unmet needs for recreational services, day program or sheltered workshop services, transportation services, routine medical care, therapeutic behavioral services, advocacy services and respite services. Additionally, caregivers of waiting list class members who did not receive services were more likely to indicate they needed training or information about the Ligas consent decree than the caregivers of those who already received services. These findings are illustrated in figure 10.

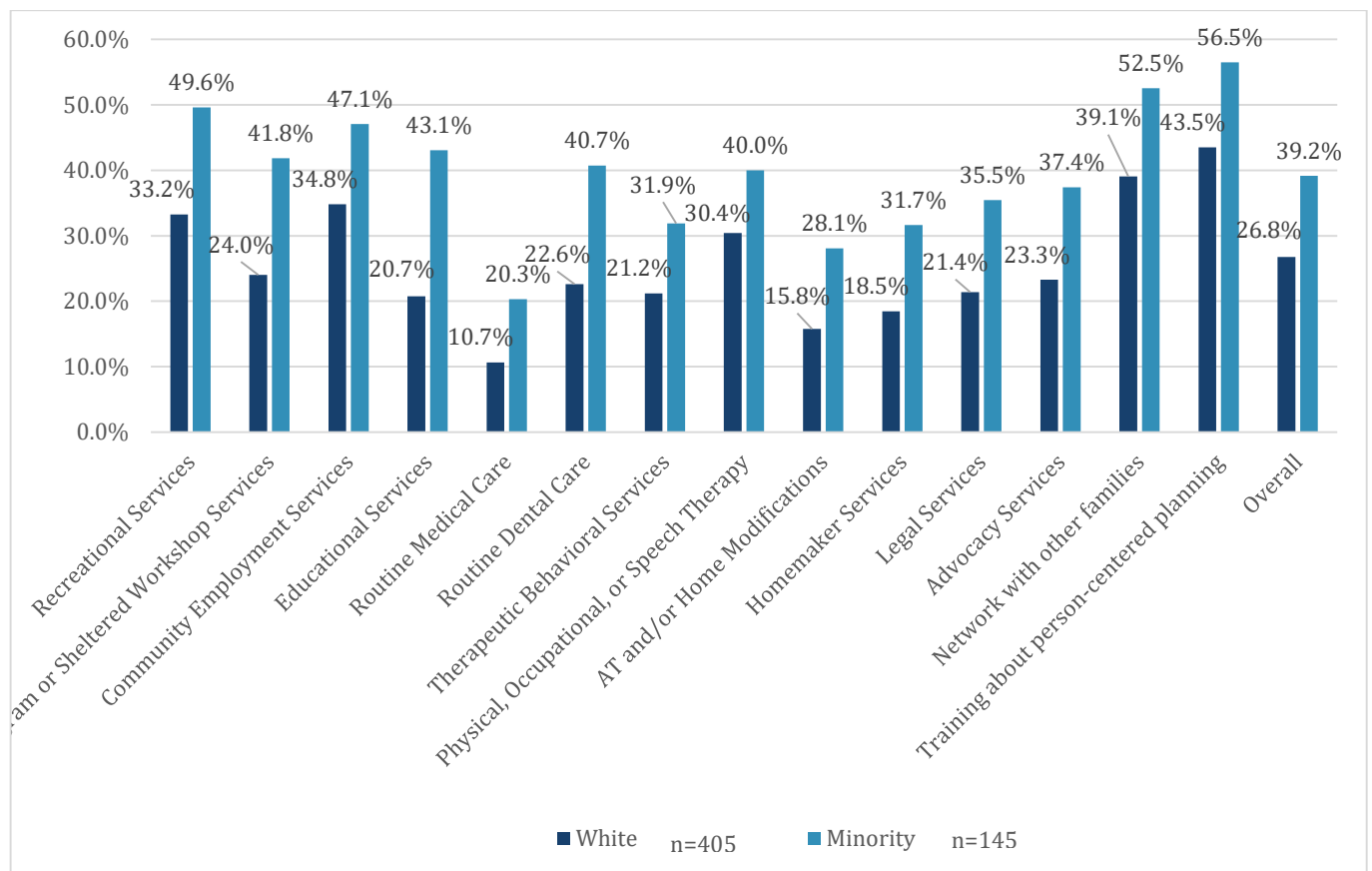
Figure 10: Significant unmet needs of waiting list members who received (n = 136) and did not receive services (n = 420).



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As demonstrated in figure 11, members from minority backgrounds experienced significantly greater unmet needs than white class members in a large number of services.

Figure 11: Unmet needs by race/ethnicity



What is the impact of transitioning off the waiting list to services on class members?

Hierarchical multiple regression analysis indicated that class members who received services participated significantly more frequently in community and social activities than class members who did not receive services (after controlling for gender of the caregiver, and race, level of adaptive functioning and age of the family member with a disability); [R² change = .013, F(1,522) = 8.449, p <.01].

Hierarchical multiple regression analyses also indicated that families of class members who received services were significantly more likely to conduct future planning activities than families of class members who did not receive services (after controlling for gender of the caregiver, and race, level of adaptive functioning and age of the family member with a disability); [R² change = .020, F (1,510) = 10.686, p <.001].

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CLASS MEMBERS IN INTERMEDIATE CARE FACILITIES (ICF/DD)

Of the respondents surveyed, 84 had a family member/ward who was living in an ICF/DD and 101 had a family member/ward who had moved out of an ICF/DD.

How satisfied were caregivers and class members with services in ICF/DDs?

Eighty-one percent of caregivers/guardians of class-members who were still living in ICF/DDs were somewhat or very satisfied with their family member's current living situation. These caregivers and guardians reported significantly greater satisfaction with the services received at the ICF/DD than caregivers and guardians of individuals who had since moved out [$\chi^2 (4, N = 184) = 10.70, p < .05$].

Caregivers and guardians of class members who had moved out felt their choices and the person with disability's choices in ICF/DDs were respected significantly less than caregivers and guardians of class members who still lived in ICF/DDs [$\chi^2 (4, N = 182) = 17.10, p < .01$; $\chi^2 (4, N = 182) = 15.37, p < .01$].

Finally, caregivers of individuals who had moved out of ICF/DDs were significantly more likely to respond that they felt their family member was unsafe while living in the ICF/DD than caregivers of class members who still lived in ICF/DDs [$\chi^2 (2, N = 183) = 6.76, p = .034$].

Where did class members move to?

The vast majority of class members (94%) moved in to CILA arrangements and only six of them (6%) moved to a family home.

Only 18 % of class members in ICF/DDs had their own room. Fifty-six percent of the class members who moved out of an ICF/DD had their own room. Fifty-three percent of class members who moved out of an ICF/DD into a CILA had their own room and eighty-three percent of class members who moved out of an ICF/DD into the family home had their own room.

The vast majority of respondents reported they visited the new placement before making the decision for the person with disability to move there (88%). There was no significant difference between informal caregivers and state guardians in the likelihood of visiting the new placement during the decision making process and before the move.

Thirty-six percent of the respondents of the class members who moved out of the ICF/DDs reported that their member with a disability did not visit any placements before the decision was made on where to move to. Fifty-three percent of the class members visited one new placement before making a decision. Only 11% of the class members visited more than one placement before making a decision. Class members with a state guardian were more likely to visit new placements

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before making a decision than class members with an informal caregiver. Once a new placement was selected, 84% of the class members visited the new placement at least once before moving.

Ninety-four percent of the respondents reported that their preferred setting after the move out of the ICF/DD was a CILA.

How satisfied were caregivers/guardians and class members who moved out of ICF/DDs with their current placement?

Ninety percent of the respondents were somewhat or very satisfied with the class member's current living situation. They were significantly more satisfied with the current placement than they had been with the services at the ICF/DD ($t=5.121, p <.001$).

A vast majority of respondents reported that the person with a disability was satisfied with his or her current placement (89%). They also reported that the person with a disability was significantly more satisfied with the services received in the current placement compared to the services received in the ICF/DD ($t=3.958, p <.001$).

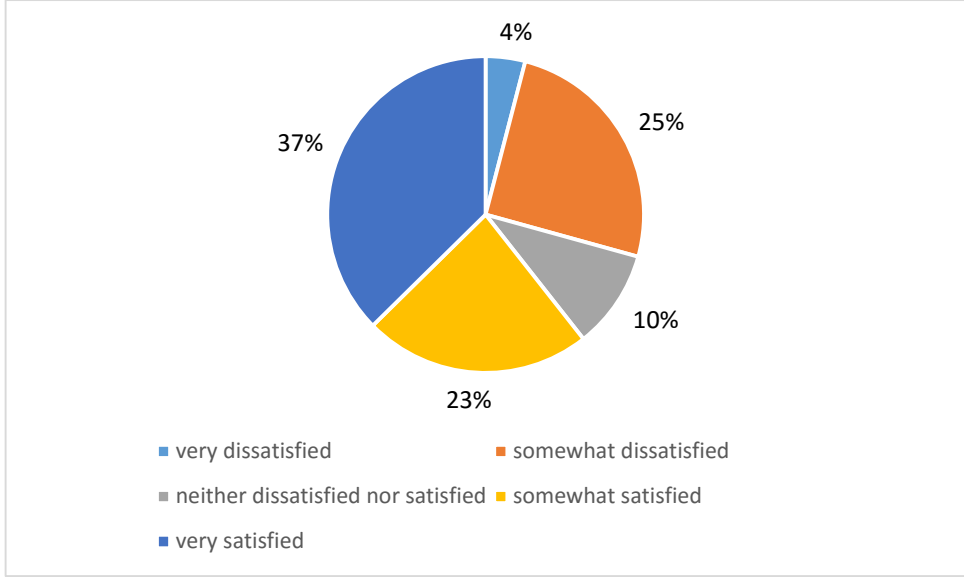
How did caregivers/guardians and class members experience the transition out of the ICF/DD?

Fifty-six percent of caregivers/guardians were satisfied with the transition out of the ICF/DD overall.

As demonstrated in figure 12, of the 99 caregivers of class members who moved out of ICF/DDs, 4% were very dissatisfied with the transition plan; 25% were somewhat dissatisfied; 10% percent were neither dissatisfied nor satisfied; 23% were somewhat satisfied; and 37% were very satisfied with the transition plan.

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Figure 12: Satisfaction with transition plan of caregivers/guardians of class members who moved out of ICF/DDs



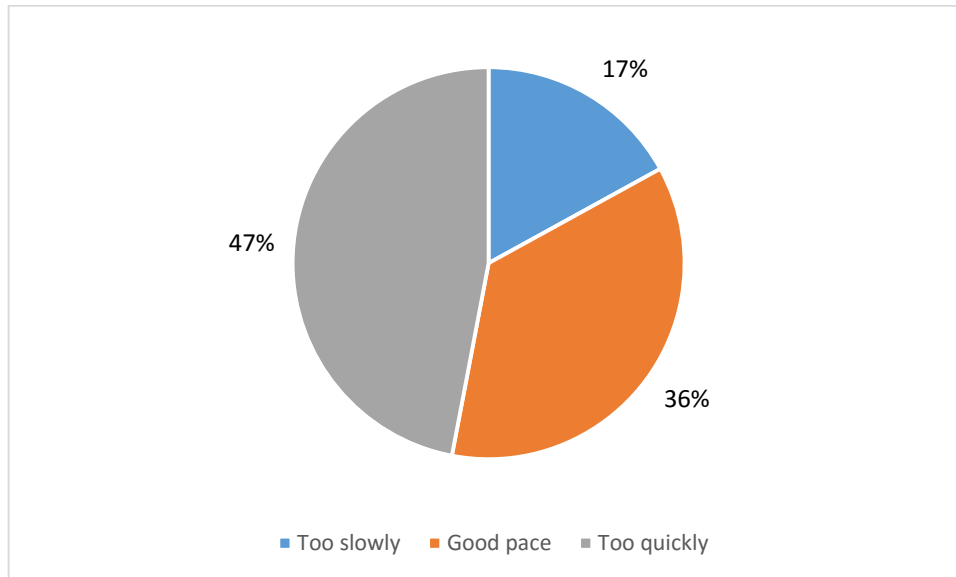
About half (54%) of the caregivers/guardians of class members who moved out of ICF/DDs felt that their opinions were respected often or very often during the transition. Only 2% of the respondents felt their opinions were not respected at all.

Forty-seven percent of the caregivers/guardians of members who moved out of ICF/DDs felt the person with disability's opinions were respected often or very often during the transition. Seven percent of caregivers/guardians indicated the person with disability's opinions were not respected at all during the transition.

As illustrated in figure 13, almost half of the caregivers felt the transition process moved at a good pace (47%). Thirty-six percent of the caregivers felt the process moved too quickly and 17% felt the process moved too slowly.

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Figure 13: Pace of transition process as perceived by caregivers/guardians



The vast majority of caregivers/guardians (89%) felt they received adequate information about various living options. Eighty-six percent of the caregivers/guardians stated that the advice they received during the transition process was somewhat or very helpful to them. About half of the caregivers/guardians (50%) reported they attended information sessions about the Ligas consent decree often or very often.

Ninety-two percent of the caregivers/guardians reported that their family member with a disability moved to the setting of the caregiver's first choice.

How satisfied were caregivers with the members' individual service plans (ISP)?

There was no significant difference between caregivers/guardians of class members who moved out of ICF/DDs and who were still living in ICF/DDs in satisfaction with the individual service plan.

However, caregivers/guardians of class members who moved out of ICF/DDs felt they had significantly more input in the individual service plan of the person with a disability than caregivers/guardians of class members who still lived in ICF/DDs ($t(1,77) = 2.849, p < .01$).

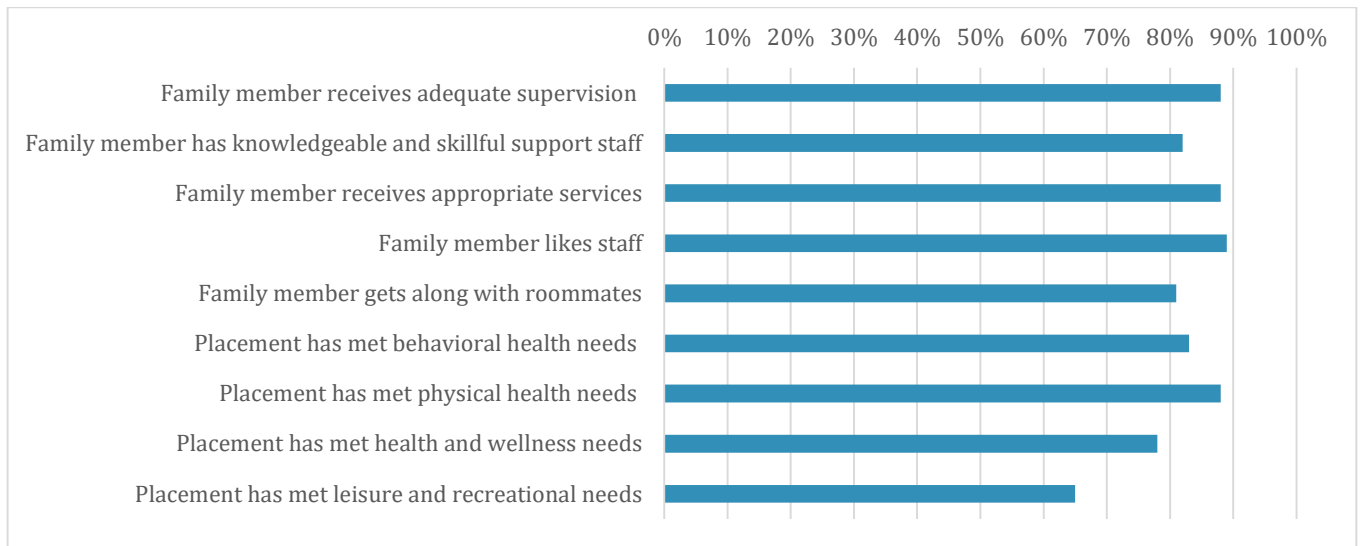
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How are class members doing after moving out of the ICF/DD?

Seventy-nine percent of the caregivers/guardians of the class members who moved out of ICF/DDs felt the class member's choices were often or very often honored at the current placement.

As demonstrated in figure 14, the majority of caregivers/guardians felt satisfied with various aspects of the member's current placement.

Figure 14: Caregiver/guardian satisfaction with the current placement



What unmet support needs do class members experience?

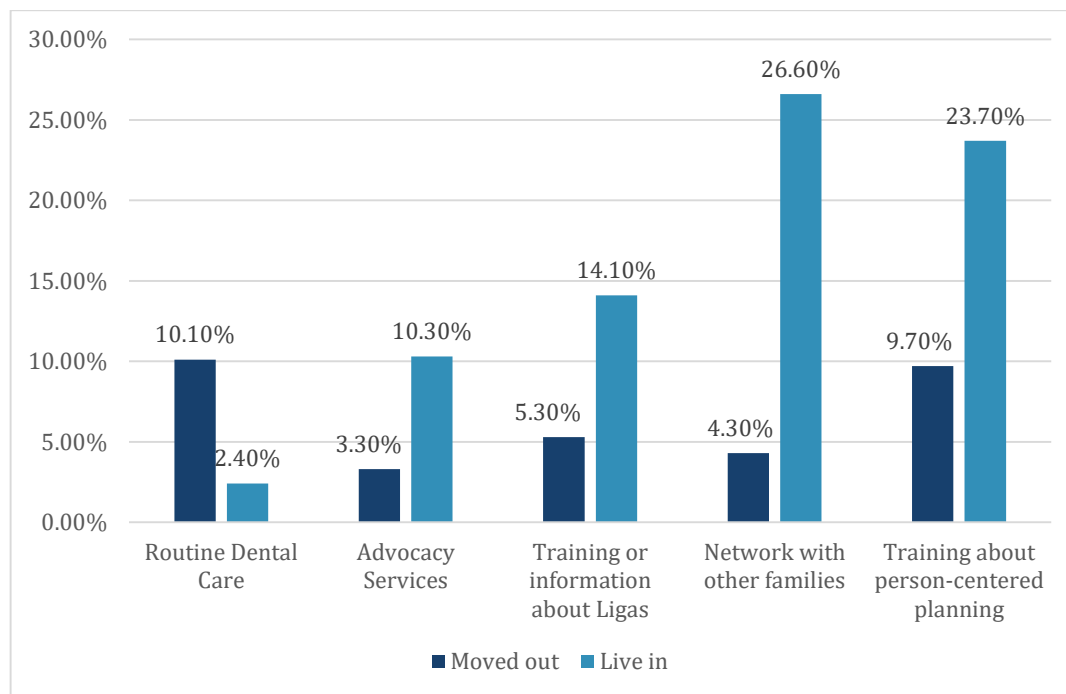
Hierarchical multiple regression analysis did not find a significant difference in the overall unmet needs between class members who moved out of an ICF/DD and who still lived in an ICF/DD. None of the demographic variables (race, gender and level of adaptive functioning of the individual with disability and age of the caregiver) made significant contributions to the regression model.

However, there were some differences between the two groups in individual unmet service needs. Z-tests indicated that class members who moved out of an ICF/DD had a significantly greater unmet need for routine dental care services compared to class members who still lived in an ICF/DD. On the other hand, class members living in ICF/DDs had a greater unmet need for advocacy services, were more likely to indicate they needed training or information about the Ligas consent decree and about person-centered planning, and had more unmet needs to network

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with other families than the caregivers of those who moved out of ICF/DDs. Figure 15 below demonstrates these findings.

Figure 15: Unmet needs by moved out of or live in ICF/DD



Class members from minority backgrounds experienced significantly greater unmet need for respite services than white class members.

How does moving out of an ICF/DD impact class members?

Hierarchical multiple regression analysis indicated that class members who moved out of ICF/DDs experienced significantly more daily choice than class members who still live in ICF/DDs (after controlling for adaptive functioning, race and gender of the person with a disability, and age of the informal caregiver); [R^2 change = .037, $F(1,73) = 5.030$, $p < .05$].

Interview findings

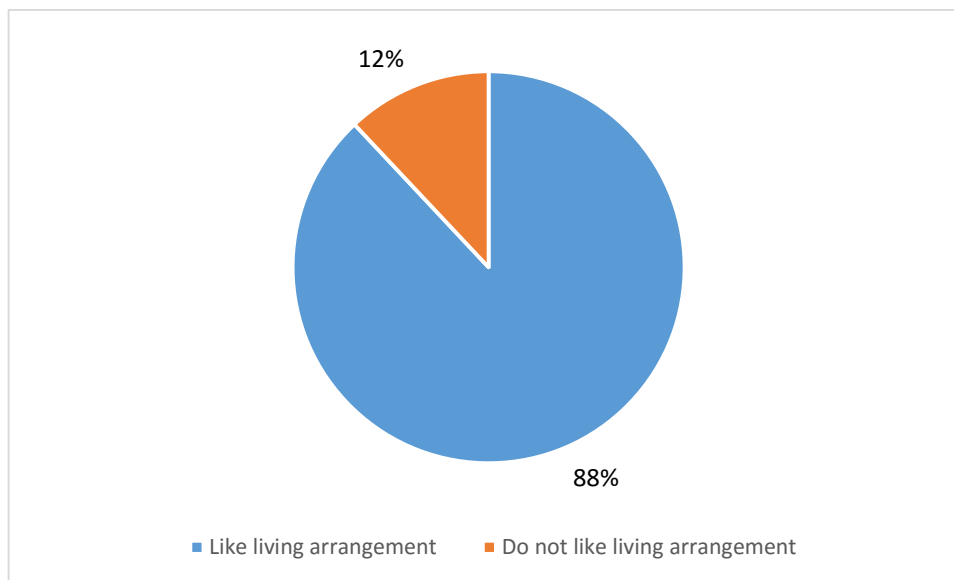
The section below reports on findings from interviews with waiting list class members who had not yet received services. Analyses focused on this group as only a small number of interviewees had started to receive services and very few interviews could be completed with ICF/DD class members.

HOME

Of the waiting list class members interviewed, 91% lived at home with family of which 93% had their own room. Ninety-three percent of the adults with IDD reported they did not choose where they live and 90% did not choose who they live with.

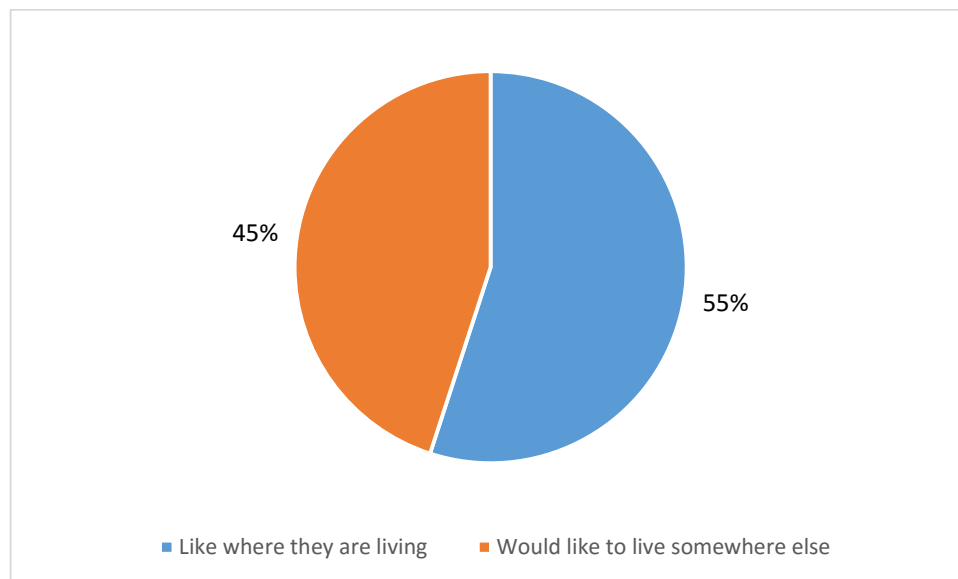
As demonstrated in figures 15a and 15b, while 88% of the adults with IDD liked where they were living, 45% still wanted to live somewhere else. Some of the reasons given were that they wanted to live on their own or that they wanted to live with roommates.

Figure 16a: Satisfaction with living arrangement of waiting list class members yet to receive services



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Figure 16b: Intention of future living arrangement of waiting list class members yet to receive services



FREE TIME

Overall, 76% of the adults with IDD were happy with their free time activities. Yet, 55 % felt they did not have enough things to do in their free time.

HEALTH

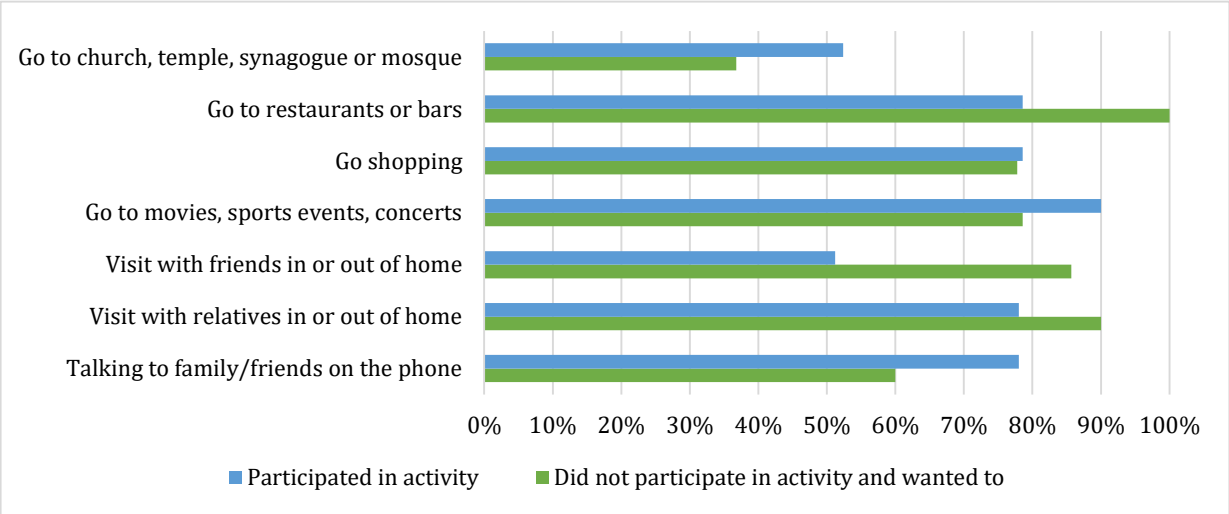
In general, 86% of adults with IDD indicated they were in good health. The health of 70% of the adults allowed them to pursue their desired activities; 76% of adults with IDD stated they exercised for fun or to be fit in the last month, and 85% of adults with IDD indicated they had eaten healthy foods in the last month.

COMMUNITY AND SOCIAL PARTICIPATION

Figure 17 shows the various activities that the adults with IDD participated in during the last month. The majority (78%) of these adults visited with relatives and spoke to family and friends on the phone during the last month. However, only 51% of the adults spent time visiting with friends in the last month; 27% felt alone; and 54% indicated they had only some friends or none at all. The majority of adults who did not participate in the activities stated they would like to do so, with the exception of visiting a church, temple, synagogue or mosque.

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Figure 17: Community and social activities



WORK

Of the adults with IDD interviewed, 67% reported that they did not work. The remaining 33% of adults participated in a combination of work-related activities. They attended a day program or a sheltered workshop, volunteered, and/or held part-time employment in the community. Only 24 % of all interviewed adults held a job in the community. Of the adults without work, 83% wanted to work.

Focus Group Findings

THE TRANSITION PROCESS

PAS agencies saw their role¹ in the transition process as more than simply conducting pre-admission screening for individuals with IDD and working with those individuals and their families to develop a transition plan. Rather, PAS agencies saw themselves as a resource for families, educating them on Ligas and the options available so that they can make informed choices and actively helping families locate and receive referrals to providers of their choice. The PAS agencies saw themselves as having responsibility to follow up and ensure it was a good match and that the individual and families' needs were being met. ICF/DD agencies saw their role somewhat differently, in that the focus was less on the case management approach that PAS agencies used in working with other providers. Instead, ICFDD agencies focused on working within their existing organization to create CILAs or smaller, more individualized programs. ICF/DD agency staff also stated that they saw their role as addressing the needs of people with more severe disabilities and medical support needs.

When asked how appropriate staff members felt the transition timeline was, staff at both ICF/DD and PAS agencies expressed frustration at the outset with the lack of transparency regarding the waiting list for services. Specifically, they were unsure of the time frame that individuals could expect to stay on the waiting list and what exactly the selection criteria were, despite the fact that these aspects are stated in the Ligas Implementation Plan. With regards to the Ligas transition timeline itself, staff at PAS agencies unanimously felt that six months was unrealistic. Transition hardly ever happens unless someone already has a CILA in mind, and these transitions sometimes can take up to thirty months if there are complications. Often transition begins before staff can do the screening with collecting all the necessary documents and dealing with Medicaid, social security, and redetermination, etc. Further, families want to take time to think about choices and weigh their options/providers before making a decision because it is a major life change. What has the biggest influence in how long transition takes, however, is actually finding a CILA that has an opening, which meets all of their needs.

When asked about who they contact if they have a question regarding Ligas procedures or policies, the staff working at ICFDD agencies referred to written materials that had been provided to them. Of the staff working at PAS agencies, for some it was not seen as effective to talk to people from the State. However, others reported having a contact person assigned to them from

¹ Staff working at PAS agencies expressed that it was hard to describe what Ligas is and why they were there (i.e. what the agency's role is). PAS staff reported spending a lot of time and effort educating families, individuals with IDD, and providers.

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the State and, if that individual did not know the answer to a question, they would contact Jim Eddings at the Illinois Department of Human Services, Division of Developmental Disabilities.

Steps in the Transition Process

ICF/DD staff. The following delineates the steps reported by staff working in ICF/DD agencies taken in the Ligas transition with each individual:

1. Individuals already have caseworkers assigned.
2. Families receive the Ligas letter or were approached with the option.
3. Initial contact varies: the ICFDD may make contact on behalf of the family or families may make contact directly with PAS agencies.
 - a. Some agencies contact families to raise awareness and to see if families are interested in community living because they are not likely to identify themselves.
 - b. Often families come to agencies because they received the Ligas letter and do not know what to do with it.
4. Screening takes place of who has a Ligas transition plan along with other necessary documentation and clinical records.
5. Attend individual staffing to find out preferences based on the individual, family, and their history with them.
6. Talk to families and look at whether it is going to work for a specific person to meet their needs.
7. Give them time: Families and individual with IDD may need time to consider their options. Some families may need a slower or faster transition depending on their individual needs.
8. Find which facility (within the organization) can support them: if it is possible to modify the ICF environment to meet their needs or if they need to look outside the organization.
9. Encourage a trial visit at that facility. This varies between organizations. One agency suggests a 30 day visit or longer if necessary, while another suggests a three day visit and sometimes do a second trial if necessary. The last agency provides several options in their visiting process that allow individuals to come for a tour, come for dinner, come stay overnight, come for a weekend, and come for a Monday-Friday week to see how the routine would be. At this agency it is also possible to try a day program for a day.
10. For one agency, the next step was to start the process of requesting funding.
 - a. It is unclear at what point the other agencies start this process. It appears that their belief about the successfulness of getting funding plays into all of the steps mentioned above as mediating factors.

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PAS staff. The following includes the steps reported by staff working in PAS agencies taken in the Ligas transition with each individual:

1. Put them on the PUNS/Waiting List if they are reaching 18 years old, and apply for Medicaid and social security even if they are not chosen for Ligas. This may include getting a special needs trust.
2. Families receive the Ligas letter or were approached with the option.
3. Initial contact varies: the majority of families will call or make contact and talk to an intake person if the agency does not already know them.
4. Screening with the family is scheduled and completed along with necessary documentation, which includes Medicaid, a psychological/psychiatric evaluation, ICAP, and a physical exam.
 - a. Pre-admission screening for individuals that come off the PUNS list to determine if they are eligible to apply.
 - b. One agency found it effective to contract with a physiologist who conducts the screenings and explains options and timeframe.
 - c. The agencies have to pay for the psychological evaluation (for which the PAS agency receives funding), and it is hard to find a psychiatrist that accepts Medicaid.
5. Send out “referral packets” for the screenings and link families.
 - a. The referral process can sometimes drag out for months, but they are supposed to determine eligibility before they even start referrals.
6. Talk with families: discuss the Ligas letter, explain what it means, explain what services they can choose from, and see if/how they want to proceed. Give families the choices for the areas they want, depending on whether they want CILA or home-based (i.e. a list of providers).
 - a. For home-based, they can submit the application and get the award letter and be able to start the programming at this point.
7. Give families time to consider their options in light of their needs and the different providers.
8. Sit down with families and people with IDD and complete Ligas transition service plan.
 - a. Interview family and enroll them in database.
 - b. Determine whether the person with IDD needs a modified transition plan. Type up transition plan or modified transition plan and submit it.
9. Start the referral process for CILA providers, which is a different referral process than for psychological or medical services. This may involve going on another waiting list until there is an opening available.
10. Help families schedule trial visits.
11. Submit the transition plan to a potential provider for review.

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Including Families and Individuals with IDD

When asked how they included families in transition planning, staff working at ICF/DD agencies said that they begin by providing families with all of the available options, including ICF/DD. Staff felt that the Ligas process was biased towards CILA placements and that many families do not know that ICFDD is an option. They also work with families to find out what their family member's medical care and support needs are, talking "one-to-one" and being "realistic" about services in the community. For example, discussing funding for physical therapy and speech therapy, and informing them about what services ICFDDs provide (e.g. staffing ratios and intense supervision). One organization in particular works with families to create CILAs for their family members.

For staff working at PAS agencies, family are involved if the individual wants them to be. One focus group in particular articulated the need to be careful because sometimes there are disagreements between what families want and what the person with a disability wants. When the family is involved, they are encouraged to do as many tours and trial visits as possible and the staff try to inform families with questions to ask providers when they visit. Some staff working at PAS agencies also encourage other people who know the person with disabilities well to participate and give input in the transition plan, such as respite workers or job coaches.

When asked how they included individuals with IDD in transition planning, staff working at ICFDD agencies get to know the person with disabilities and to get information from the individual themselves through staffing meetings and through trial visits. They try to be person-centered and assess people with disabilities for who would be a good fit and/or whether they would benefit from moving, what they would gain in a different setting, and what their medical and nursing needs are. ICFDD staff emphasized looking at what is realistic. ICFDD staff reiterated the perspective that such a small number of people wanted to move. They also expressed concerns about Ligas for individuals with lower functioning levels and/or more significant disabilities and medical needs.

Staff working at PAS agencies also aim to be as person-centered as possible, ideally getting the majority of their information from the individual directly and have the parent or guardian add supplementary information. The person with disabilities is required to be at the transition meeting and involved as much as they can, which can be more difficult for individuals who are non-verbal. Staff address on a case-by-case basis how best to involve the individual. Sometimes they do an observation if they are non-verbal to learn more about what they like and their needs. PAS staff also encourage individuals with disabilities to take tours, do dinner visits, and do overnight visits or longer if that is what is needed.

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TRANSITION FORMS

These questions were only asked of staff working at PAS agencies

When asked if they liked the transition forms, staff at two of the three PAS agencies responded that they “love it” and that “it’s a living, breathing document.” It is long, at eleven pages, and can take approximately two and a half hours to complete. Some staff felt that it was too long whereas others remarked that it depended upon the individual and the others contributing information. For example, it can be difficult to fill out if the guardian does not have much to say or if the family has not thought much about future planning or transition yet. The transition form can be a useful tool for getting them to begin thinking and visualizing for the future. One staff member made an interesting remark, “I do like the signature page because it identifies that everyone is an active participant in the process, and I make a big deal about that” (PAS staff member).

Regarding whether they would change anything about the transition forms, PAS agency staff would like additional information asking about employment, particularly as they have concerns about the availability of employment options offered by providers. Also, PAS staff felt some questions are repetitive and redundant with other paperwork (e.g. medical questions) and could be combined to shorten the process. Some of these recommendations have been updated in the current transition forms.

When asked if they felt they needed more training, there was a distinct difference between PAS agencies who had been pilot agencies and ones that had received a consultant from the State who trained staff. Pilot agency staff felt they had to “learn the hard way” and did not receive formal training. PAS agency staff who received training with a consultant found it helpful to understand the whole concept of Ligas and the transition process, but felt some case studies would be helpful. Providers are the ones they feel really need training and education at this point. What would be helpful for agency staff would be training on the different models of CILA and how new providers can become providers, because agencies find themselves educating providers about different options when trying to be creative and work together. Also, PAS staff expressed a need for increased cooperation with ICF/DD providers. Some appear to be acting as a roadblock in not sharing information or in sharing inaccurate information. As a result, some families are fearful about repercussions from ICFDD providers.

QUALITY OF THE TRANSITION PROCESS

When asked about the strengths of the current transition process, staff working at ICFDD agencies reported that it has worked well for people who they have been trying to move out of the ICFDD, who want to be more independent but have been unable to. PAS staff felt that the greatest strength of Ligas was inclusion – it gives voice to individuals with IDD – but only if the practice and implementation of it actually reflects the philosophy of it. It can serve to increase their own

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knowledge about the issues people are facing, and also raise service providers' awareness of the barriers. Overall, PAS staff felt that although there were several problems that need to be addressed, it was a starting point and they were glad that at least the state of Illinois is doing something that has potential to empower individuals with disabilities.

When asked about the weaknesses of the transition process, staff at both types of agencies identified several key barriers. One of the largest barriers identified by staff working at PAS agencies was the lack of information and misinformation about Ligas. Staff spent a lot of time working with families to answer questions and concerns. In particular, families do not understand that when an individual is "pulled"/selected, it does not necessarily mean that they are eligible, as they are not screened prior to placement on the waiting list. Therefore, for staff at PAS agencies, it is important to do the screening as early as possible so that families are not introduced to services that are not eligible for. In particular, PAS staff were concerned that social workers at schools appear to be uninformed about the appropriate steps in transitioning from child services to adult services and when/how/if to get on the PUNS list.

Staff working at ICFDD agencies were concerned that CILAs are not a long-term solution, but rather a temporary placement. They felt that the process was laborious, requiring a lot of paperwork that can delay the process for individuals. Also, it was unclear why so much emphasis was being placed on the Ligas transition plans as they had not found them to be more beneficial than other, existing plans (e.g. ISP). Further, staff at ICFDD agencies felt that the process, which is based on person-centered planning as required by the Ligas Consent Decree provides information that isn't that "helpful or useful" (e.g. hopes and dreams) and expressed concern that this does a disservice to consumers by setting up unrealistic goals that focus on an individuals' failures when they are unable to meet those goals. Rather, they felt the transition plan should focus on immediate needs and strengths, not ideals, and should establish realistic goals. Additionally, there was concern that the transition plan did not take medical needs and services into consideration enough.

While staff working at PAS agencies agreed unilaterally about the centrality and importance of understanding the hopes and dreams of Ligas members in order to have person-centered services and supports, they also recognized that medical needs posed a barrier, in particular for people with diabetes who need insulin injections that can only be provided by a nurse. Typically CILAs do not receive funding for or provide nurses or certified nursing assistants (CNA), "so CILAs won't take individuals with tubes, anything that requires nursing, like somebody that is non-ambulatory" (PAS staff member). Nursing services are based on individual need in the CILA rate methodology. The Medicaid process can be a huge barrier if people were previously denied or not financially supported. Documentation is also an issue if families do not update their information or if previous transition information is lost. In particular, if a previous caregiver passes away and does not communicate plans and hopes for the person with disabilities with other family

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members or inform them that person was put on the waiting list for Ligas. It slows down the process and demonstrates the need for future planning with families.

Staff working at PAS agencies also acknowledged that the paperwork can sometimes itself be a barrier that delays the process for individuals with disabilities and their families. This is further complicated by the waiting list, as staff found many families want to be put on the waiting list too early and get selected too early, while others wait too long and do not start until their family member is about to exit school. Often this is because families are concerned about the future and want to have options, but when they get “pulled” it may be too soon for what they are prepared for. PAS staff also had concerns about unrealistic expectations, however, these differed distinctly. Staff at PAS agencies indicated that a tension exists between focusing on the transition plan as a person-centered document that may set unrealistic expectations, versus “downplaying” the transition plan so one does not get one’s hopes up, and also to make individuals look more “marketable to a provider.”

There was an element of skepticism from staff at both PAS and ICFDD agencies towards providers, although more so by staff at PAS agencies. Some ICF/DD staff reported that providers sometimes weren’t truthful or realistic with families. PAS staff were overwhelmingly concerned that providers were not paying close attention to the Ligas transition plan. PAS staff also found there to be a substantial lack of education – initially for providers in the early stages of Ligas implementation and for families who may not understand what CILAs look like, what their choices are, or what questions they should be asking providers. This puts families and individuals with disabilities at risk of being unable to make a truly informed choice or being taken advantage of by providers.

Staff at both types of agencies, PAS and ICF/DDs, agreed that it was difficult to find accessible and affordable housing. For ICF/DD staff, this meant finding homes that both met their needs and follow DHS criteria. For PAS staff, it was part of a larger conversation about the lack of availability of qualified providers. As more and more people are getting selected for Ligas, the options are getting fewer and far between, “You need to find the right fit, and sometimes the right fit isn’t there” (PAS staff member). Providers are being more selective about who they accept since they know that there are going to be other Ligas class members. Providers can be “choosy”, whereas consumers (and the staff facilitating placement) have to compete. Staff at one PAS agency felt that the tension mentioned earlier regarding the concern around unrealistic expectations would not exist if there were a greater availability of providers and resources to make person-centered transition plans happen. Currently, PAS staff worry that the transition plan may block an individuals’ placement, “... I think what it comes down to when a provider makes a decision is they are trying to run a business so they can get more from this person and not from this person” (PAS staff member).

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The location of available providers is also important as it affects whether one will be able to live in an area they want to live in, be near family and friends, use public transportation or paratransit services, and participate in work and recreational activities. It is important to note that not all providers offer services that families write into their transition plans, such as employment or transportation to work/employment. For example, one family that a staff member was working with who was trying to move from home-based to a group home had fewer opportunities for employment and day activities in the group home:

This is really sad, but we are going to have to give up this opportunity because if we move their son to a group home... basically he's going to regress. He is going backwards, which shouldn't be that way. But in Illinois unfortunately is. It is going to restrict his life rather than expand. (PAS staff member)

Staff at ICF/DDs felt that their facilities were not being offered as a choice along with the CILA or home-based options, although staff felt ICF/DDs had a better infrastructure to offer support, particularly for individuals with medical needs. While they recognized that families are “always looking for a smaller CILA,” staff felt that in some cases that might not be the most realistic environment for their family member with disabilities. Staff also felt that families may have unrealistic expectations of what an ICF provides. One example given was that some families who want their family member to be active do not understand that many ICFs do not allocate funds for recreational expenses.

For PAS staff, the rate structure in Illinois poses a barrier that incentivizes providers to take some individuals over others based on the rate and supports they come with. The staff working at PAS agencies speculated that people are settling for home-based services because it offers a quicker solution. Often it is being used as a transition step towards something else for people who want CILA placements in the long-term, but for whom home-based offers a better, quicker, or more realistic option in the short-term. According to some PAS staff, the trend appears to be that more people are choosing to keep family members who are higher functioning and with less support needs in their home and community unless someone dies, “If there isn't anything open in the area, then they keep them in the home” (PAS staff member).

Staff at both PAS and ICF/DD agencies agreed that state funding was a significant barrier to providing adequate support for people with disabilities to live in smaller settings in the community:

Conceptually, we can do it. Fiscally, the State doesn't put in the money to do it. That is the reality of how the world works. Theoretically, we can support everyone with medical support needs in the community, but it isn't reality. (ICFDD staff member)

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Some of what we are expressing is the bottom line reality: not only what we have to offer, but the funding that has kind of landed us here.... We would subscribe to "smaller is beautiful," but then we go to what we can afford to provide. It is more driven by that than what we have in our hearts. (ICF/DD staff member)

Decreases in funding results in loss of staff and lack of services in the community. Yet this speaks to a larger, structural barrier encountered in the Ligas transition process. As staff working at ICF/DD agencies put it, the options are changing before the system can change, so it is creating a demand before supply. The resources are not in place yet and the biggest barrier is, "... the community system not being supportive and not prepared to receive all these people. This is a very commonly known issue. We know the community system hasn't been financed in a way to respond to Ligas" (ICF/DD staff member).

LINKING FAMILIES WITH SERVICES

These questions were only asked of staff working at PAS agencies. However, data from other questions asked of staff at ICF/DD organizations are incorporated here to provide context.

Generally, staff working at PAS agencies were not satisfied with the resources available to transition families to services. This is because they did not feel the resources had changed or increased with Ligas. One change that PAS staff have noticed is ICF/DDs downsizing creating opportunities. ICF/DDs are downsizing and moving from larger 16-bed settings to 8-bed settings and even further to opening 4-bed settings and CILAs. For ICF/DD staff, this was in order to meet demand for smaller settings and individualized choices between different sized settings. One PAS staff member remarked on being surprised to see this change, but hoped to see more of it.

Overall, staff working at ICF/DD agencies spoke about accommodation in two distinct ways. Individual needs and preferences were accommodated either by 1) changing, specializing, and/or individualizing the environment at the ICFDD somehow; or by 2) creating and/or looking for other options outside of the facility. Staff expressed the mindset of having to maximize their resources, and individual accommodations can make that difficult as it is not the "normal" way they do things.

PAS staff were satisfied with the transition process itself, and found it helpful in informing the family about the agency and Ligas. This was seen as particularly important as many families and individuals do not know what Ligas is, are misinformed about it, and may not come away with a thorough understanding of it after the first meeting. The transition process also helps the agency get to know the individual and their family, and ensuring that everyone is on the same page with similar person-centered goals. It also helps to identify where there are gaps in support or where individuals and families have different goals, and that can be a tricky situation to navigate.

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PAS staff felt that providers lack the necessary resources, which was believed to be due to a larger systemic problem or a lack of funding for those resources to, "... support the initiatives and the best practices that we already know are out there" (PAS staff member). Further, there is a significant lack of education of providers regarding what Ligas is and how it can benefit them. For instance, it can be an opportunity to expand their programs.

Staff working at PAS agencies also recognized that, in trying to link families with services, families can get discouraged waiting. After being selected from the waiting list for PUNS and going through the Ligas transition process, they may still wait years for a placement due to the lack of availability. Often this results in families who end up going back to home-based services because it provides a more immediate solution for their needs, if not the best or optimal solution. However, PAS staff noted that resources are available for those who can afford to pay out-of-pocket (OOP) or who create their own means:

Well, we have some really great, innovative programs that the State doesn't pay for that are out there. Okay, um I think that the families with means can access. And some have gotten together and developed their own, because they knew just what is out there "is not where I want my child to go." Their kid is not going from school to sitting in a day program. It wasn't going to happen. (PAS staff member)

This was spoken of particularly with regards to families coming together to create their own CILAs as well as opportunities for work and employment that were non-traditional, requiring private pay since the provider did not have a contract with the State because they did not want to live with the restrictive requirements for a developmental training (DT) program.

How PAS Staff Find Out About Community-Based and Home-Based Options

Staff find out about options in the community through the following ways:

- State webpage of listings for CILA providers and home-based service facilitation agencies
- Receive a vacancy list
- Receive phone calls and emails about vacancies
- Have to call around and use word of mouth
- Blanket referrals to targeted geographies

Reasons Families Are Choosing Not to Move

For one PAS agency, they found that at least half of families chose not to move. This is not to say that individuals do not select a service, but rather it may not be a CILA service. Another PAS agency found that while most people select a service, people who came from PUNS usually chose not to participate in the service they selected for various reasons:

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- Change their minds
- Sign up, thinking about the future, and get selected sooner than expected
- Not ready yet (e.g. people already in home-based who ask for an extension before moving to CILA)
- Choose home-based because do not want to have to give up community job, or have to cut down their work or go to a DT because of lack of work options at the CILA
- Cultural reasons
- Lack of availability of qualified providers
- If have in-home services through the Department of Rehabilitation Services (DRS)
- May not want to give that up for CILA or home-based if it is meeting their needs, if they are used to/familiar with it, or if they get more hours that way
- Some get insurance that way
- Some get nursing services that way
- Individuals may be without services while transitioning from DRS, while CILA providers are recruiting staff
- Financial difficulties, especially during transition period for families where a member was receiving payment through home-based who are then being paid less.
- Individuals decline services or remove themselves from the PUNS list due to lack of understanding

Based on their experiences thus far, staff members working at PAS agencies recommended that families not be too set on one option and be open to exploring alternatives in case the first choice was not available. However, this runs the risk of families who choose an option “for now” until a provider opens up something more preferred, who then find the provider has changed their minds and decide not to open up that option. There are no guarantees.

RECOMMENDATIONS FROM STAFF FOR IMPROVING THE TRANSITION PROCESS

In addition to what has been mentioned previously, ICF/DD staff suggested that more communication and transparency in the transition process is necessary. Also, families need better information and access to information so that they can make an informed decision. There is a need for improved funding (possibly start-up funding) and improved communication flow from the current provider agency. Finally, it is important to make sure we are not setting up people to fail. For example, this change requires thinking about long-term planning and transition out of the ICF world in terms of nursing services and medical needs.

Staff working at PAS agencies agreed with the need for better funding to “make the change real... it feels really unrealistic currently” (PAS staff member). The sentiment expressed was that Ligas is a great idea and a decent tool, but more needs to be done to make it a reality. They suggested

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higher rates for bills, transportation, and individuals requiring more care. PAS staff also suggested the State could increase and make new connections with business to expand opportunities for people with disabilities the agencies are serving, and should use tax breaks as an incentive. Staff also remarked upon disincentives that penalize creativity among agencies and providers in the Ligas implementation, attributed to inflexibility in the process imposed by the State. Rather, the State should be incentivizing agencies to think outside the box. It would also be helpful for providers to have “transition money” as it takes time for families and individuals to weigh options and complete trial visits. Providers often lose money when an individual takes time to make a decision and then chooses to go somewhere else. Also, some of the staff working at PAS agencies felt there is a lack of incentive to open homes versus CILAs.

Suggestions from PAS staff members included appointing a Medicaid and social services liaison with the State; better coordination between the child and adult service systems; more flexibility in DT programs and more individualized programs. With regards to employment opportunities, one staff member remarked that day programs need to change, “because people just aren’t going to them... unless they absolutely have to. And there is a number of people that use a day program just for supervision purposes. They are working. They need somewhere for their loved one to go. So they settle” (PAS staff member).

The State webpage listing CILA providers and home-based service facilitation agencies could be improved by having better search functionality. More importantly, there is a need for a better way of licensing CILA providers. One focus group recommended providing training for providers through a University. Further, staff requested there be an increase in accountability in Ligas implementation to ensure they were complying with the transition plan. This might include making it a requirement for CILA providers to read the transition document and have an outcome they need to meet, such as a certain number of needs they have to meet and to develop a plan to meet those needs.

PAS staff also commented that after receiving training on the Ligas transition forms and process, some of them were given an opportunity to provide feedback. They would like to know whether and to what extent that feedback is being used.

Recommendations

The results of the evaluation to date suggest the following recommendations:

1. Expand community capacity to serve people with IDD that require more medical and behavioral needs, including enhanced rates when needed
2. Increase flexibility of CILA regarding daytime activities
3. Increase employment options that fit with the needs and preferences of individuals with disabilities and their families
4. Evaluate the reasons that families chosen off the waiting list do not choose to receive the services that they identify in their services plans
5. Improve the transition process do that people with IDD and their families' input is included in their transition plan
6. Provide more time for the transition to occur.

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