



Giving a Voice to Families and Guardians

A Survey of Families and Guardians of Individuals with Intellectual and Developmental Disabilities In Various Residential Settings

April 2015

Prepared by

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Executive Summary

1. Introduction

VOR is a national nonprofit organization advocating for high quality care and human rights for all persons with intellectual and developmental disabilities (I/DD).¹

VOR advocates for the right of individuals with I/DD and their families and legal guardians to choose from a full array of high quality residential and other support options including own home, community-based, and congregate settings, such as Medicaid licensed and funded Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) and Skilled Nursing Facilities (SNFs).

Over the past 30 years, VOR has challenged the ongoing erosion of specialized supports including those provided in licensed, congregate settings such as ICFs/IID and SNFs.

For decades there has been pressure from federally funded disability agencies and disability advocacy groups supporting and promoting the deinstitutionalization of all people with I/DD, without regard to individual choice and the nature or severity of their disabilities.

a. The Perspectives Of Families Of Individuals In ICF Settings Are Under-Represented In Existing Surveys

Many of the organizations and agencies that conduct studies and surveys and issue reports are also dedicated to closing all specialized congregate settings for people with I/DD. Not surprisingly, these “objective” efforts produce expected results which support forced deinstitutionalization.

¹ The phrase “intellectual disability” equates to “mental retardation,” terminology which is no longer favored. Rosa's Law, 20 USC 1400 (2010), required the replacement of “mental retardation” for “intellectual disability” in several federal laws. Since its 2010 passage, many federal and state agencies and laws have followed suit.

As a result, individuals with I/DD who need specialized care, including ICFs/IID and SNFs, have not been fairly represented in policy discussions regarding the care of people with severe and profound disabilities, behavioral challenges, or ongoing medical concerns. The views of their families and legal guardians have been routinely dismissed or ignored.

According to the U.S. Supreme Court decision, [Olmstead v. L.C.](#), 527 U.S. 581 (1999), community placement is only required when supported by individual choice and need, expressly noting that smaller settings are not always able to provide adequate care for the most fragile residents who are severely or profoundly intellectually disabled, have multiple physical impairments, behavior challenges, and ongoing medical concerns. Despite the clarity of the *Olmstead* decision, the relentless pressure to force the deinstitutionalization of all people with I/DD, regardless of the nature and severity of disability, continues unabated.

b. The Impact Of Current Policy And Trends Is Felt Most Directly By Those Under-Represented In Existing Research

Policy favoring deinstitutionalization has had a major adverse effect on many individuals, with a shift in funding priorities from ICFs/IID and other specialized facilities, to smaller service options, such as Medicaid Home and Community-Based Services (HCBS) settings (hereinafter referred to as “Non-ICF” settings).

VOR has sought to tell the rest of the story.

Through a short survey, we asked to what extent families and legal guardians believe that their individuals are best served in their current setting, either in an ICF/IID or SNF (“ICF”) or a Non-ICF community setting.² The survey questions related to demographics, satisfaction, community integration, access to services, staff competency and vocational opportunities.

c. Current And Future Disability Demographics

Survey respondents for both the ICF and Non-ICF surveys predominantly identified themselves as either parent-guardians or guardians (80% of the respondents of the ICF-Survey and 73% of the Non-ICFs). The individuals they represented ranged in age from 18 to over 75, with the majority being 45-54 years old. 60% of the ICF respondents listed *at least* three disabilities to describe their individual, as compared to 43% of the Non-ICF respondents’ individuals.

d. Survey Purpose

This survey attempts to capture the viewpoints of family members of individuals who reside in ICF settings, a group under-represented in surveys, and to compare their responses with the responses of family members of individuals residing in Non-ICF settings, to the degree possible.

² As noted, for the purposes of this survey, “Non-ICF” refers to non-facility settings, including but not limited to Medicaid Home and Community-Based Services (HCBS) settings.

2. Methodology

In February 2014, 1,450 surveys were distributed to VOR members by email (using a well-recognized digital survey tool) or regular mail (not both). Respondents were asked to take only one survey and self-identified as either “ICF” or “Non-ICF,” according to where their individuals with I/DD lived.

A total of 291 surveys were returned by mail or electronically, an approximate 20% rate of return. 255 responses were received from ICF and other specialized facility respondents; 36 responses were received from Non-ICF respondents.

3. Results and Findings

a. Satisfaction

ICF respondents indicated a high degree of satisfaction with their individuals’ ICF homes, with the vast majority, 88%, rating the service as exceptional and 69% indicating that their individuals would do poorly in non-ICF homes.

In contrast, just 36% of Non-ICF respondents were highly satisfied with their individuals’ living situations. An equal number of Non-ICF respondents felt that their individuals would do poorly in ICF settings as those who thought they would do exceptionally well.

Most respondents for both surveys were informed about alternatives to their individuals’ current placements based on their own evaluations of different settings and, in some cases, the individuals’ prior placements in other settings.

b. Community Integration

72% of Non-ICF individuals enjoyed an average to high degree of integration. Significantly, a nearly equal percentage, 73%, of the ICF Respondents also indicated that the level of interaction by their ICF individuals with the broader community away from their homes (“integration”) was average to high.

c. Access To Services

When questioned about the adequacy of access to services, including access to medical care, almost all ICF respondents ranked access as high, as compared to the non-ICF group in which access ranged from low to high.

d. Staff Competency

More direct care workers in ICF settings are subject to background checks before being hired, as compared to direct care staff in Non-ICF settings, according to respondents. Staff training requirements were similar in ICF and Non-ICF settings according to respondents.

e. Vocational Opportunities

For both surveys, nearly half of the respondents indicated that their individual is unable to work. One ICF survey respondent indicated that her individual had “very limited work ability which is done on campus with staff assistance.” For both surveys, of those individuals who could work, most worked in sheltered employment.

4. Conclusion

The responses to the ICF survey revealed a sharp contrast between common misperceptions of “institutions” as segregating and isolating environments and the perceptions of family members and guardians of individuals living in these settings. Based on their own experiences, ICF respondents indicated a high level of satisfaction with their individuals’ ICF homes, staff competency, access to services and community integration.

Non-ICF respondents expressed general satisfaction in measures relating to integration, access to services, staff competency, and vocational opportunities but were evenly divided over whether their individuals would do poorly or well in an ICF as an alternative setting. ICF respondents by a strong majority believed that their individual would do poorly in a non-ICF community setting.

Most respondents for both surveys were informed about alternatives to their individuals’ current placements based on their own evaluations of different settings and, in some cases, the individuals’ prior placements in other settings.

Especially revealing were the personal examples and responses provided by respondents, primarily families, in response to this question:

“What would you like our government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities?”

What mattered most to families of those receiving care in both ICF and Non-ICF settings was that their family members with I/DD received the care they needed and that their right to individual choice was respected.³ As so aptly stated by one respondent –

“Good public policies should be based on experience, common sense and humanity. There should be deference and respect for the positions of families who have first-hand experience in the care and treatment of persons with life-long disabilities” (ICF Survey respondent).

³ All responses are available at <http://vor.net/images/WhatDoUWantGovt2Know.pdf>.

Acronyms

CMS:	Centers for Medicare & Medicaid Services.
HCBS:	Medicaid Home and Community-Based Services.
HSRI:	Human Services Research Institute.
ICF:	Intermediate Care Facility. For the purpose of this survey, ICF designates any specialized facility setting serving people with intellectual and developmental disabilities.
ICF/IID:	Medicaid Intermediate Care Facility for Individuals with Intellectual Disabilities.
I/DD:	Intellectual and Developmental Disabilities. This population includes but is not limited to individuals with intellectual disabilities.
NCI:	National Core Indicators
NF:	Nursing Facility. For the purpose of this survey, SNFs are included in the ICF survey.
Non-ICF:	For the purpose of this survey, “Non-ICF” includes all settings identified by respondents as “community” and not facility settings, including but not limited to Medicaid Home and Community-Based Services (HCBS) settings such as licensed group homes, apartments or family homes.
SNF:	Skilled Nursing Facility. For the purpose of this survey, SNFs are included in the ICF survey.
VOR:	VOR is a national nonprofit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities. Formerly, VOR stood for “Voice of the Retarded,” but the name was officially changed many years ago.

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Giving a Voice to Families and Guardians:

A Survey of Families and Guardians of Individuals with Intellectual and Developmental Disabilities In Various Residential Settings

1. Introduction

VOR is a national nonprofit organization advocating for high quality care and human rights for all persons with intellectual and developmental disabilities (I/DD).¹

VOR advocates for the right of individuals with I/DD and their families and legal guardians to choose from a full array of high quality residential and other support options including own home, community-based, and congregate settings, such as Medicaid licensed and funded Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) and Skilled Nursing Facilities (SNFs) (collectively referred to herein as “ICF settings”).

a) The Perspectives Of Families Of Individuals In ICF Settings Are Under-Represented In Existing Surveys

Over the past 30 years of advocating for individuals and their families and legal guardians, VOR has witnessed major changes regarding their rights and benefits.

In particular, VOR has challenged the ongoing erosion of specialized supports provided in licensed, congregate settings such as ICFs/IID and SNFs. As a bundled service program, Medicaid ICF settings provide a set of services according to a standardized set of guidelines across the nation. The “Social Security Act created this benefit to fund ‘institutions’ (4 or more residents) for individuals with intellectual disabilities, and specifies that these institutions must provide ‘active treatment,’ as defined by the Secretary” ([Centers for Medicare & Medicaid Services\(CMS\)](#)). Most ICF/IID residents have multiple disabilities and

¹ The phrase “intellectual disability” equates to “mental retardation” which is no longer favored. Rosa's Law, 20 USC 1400 (2010), required the replacement of “mental retardation” for “intellectual disability” in several federal laws. Since its passage in 2010, several federal agencies have followed suit.

“De-institutionalization has a far broader meaning to these advocates than just closing ICF’s. They also want to close group homes and all other congregate programs including work and day programs. They do not seek out opinions different from their own and are dismissive of family members and family organizations trying to preserve a full range of options. They also rely heavily on government funding, an inherently unfair and ultimately harmful use of taxpayers’ money.”

Non-ICF Survey
Respondent

limited functional abilities, in addition to severe and profound intellectual disabilities (“[Residential Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012](#),” (2014) at p. 127).

Section 1915(c) of the Social Security Act (Medicaid) gives States the option “to receive a *waiver* of Medicaid rules governing institutional care” and to provide Home and Community-Based Services (HCBS) as an alternative ([CMS](#), *emphasis added*). HCB services are unbundled, different in each state, and can be minimal and difficult to access.

The shift away from ICFs/IID and related specialized care – called “inclusion” and often demanded by federally-funded disability rights agencies and organizations – has often been justified by surveys which conclude that there is higher demand for small care settings for all people with intellectual and developmental disabilities, regardless of severity of disability. Yet these surveys often do not take into account the perspectives of individuals with I/DD who need specialized care, nor the views of their families and legal guardians.

For example, in its 2014 study, United Cerebral Palsy (UCP) made a hypothetical “[Case for Inclusion](#)” using, among other sources, the National Core Indicators Survey by Human Resource Services Institute and National Association of State Directors of Developmental

Disabilities Services’ “[Consumer Outcomes: 2011-2012 National Core Indicators \(NCI\) Adult Consumer Survey Data](#),” (May 16, 2013). The “Case for Inclusion” ranks each state largely on deinstitutionalization efforts.

The vast majority of “Case for Inclusion” respondents lived in non-facility settings; just **4.5%** of respondents across only 19 states resided in a “Specialized Institutional Facility.” [NCI Adult Consumer Survey Data, Table 5. Type of Residence (p. 47)]. By sharp contrast, **88%** of respondents to VOR’s ICF survey from 30 states had family members or wards residing in at least 117 specialized facility settings (e.g., ICFs/IID).

b) The Impact Of Current Policy And Trends Is Felt Most Directly By Those Under-Represented In Existing Research

Policy favoring deinstitutionalization has had a major adverse effect on many individuals, with a shift in funding priorities from bundled ICF services to smaller, unbundled service

options, such as Medicaid HCBS. Policy in support of deinstitutionalization is aided by assumptions that community care will always cost less, an assumption that has been disproven by peer reviewed research, state reports and other research. [see e.g., Walsh K., et al., "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Volume 41, Number 2: 103-122, April 2003; and Brown, G., CPA, Brady Ware & Co., "[Intermediate Care Facility Homes Financially Benefit the Ohio Waiver System](#)," *Disability Advocacy Alliance* (2015)]. Even some proponents of deinstitutionalization now acknowledge that providing adequate care in community settings will cost as much or more than facility-based care. [See e.g., Bagenstos, S., "*The Past and Future of Deinstitutionalization Litigation*", 34 *Cardoza L. Rev.* 1, 43 (2012)].

"The policy of deinstitutionalization of ICF residents is being forced upon families despite their objections. Families and other guardians are being ignored."

ICF Survey Respondent

The U.S. Supreme Court in its landmark *Olmstead* decision expressly acknowledged that smaller options are not always able to provide for the most fragile individuals who are severely intellectually disabled, have multiple physical impairments, behavior challenges, and ongoing medical concerns:

"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." [Olmstead v. L.C.](#), 527 U.S. 581, 601-602 (1999).

Despite the clarity of the *Olmstead* decision, the pressure to force the deinstitutionalization of *all* people with I/DD continues unabated and is far-reaching, affecting homes of four or more people. The National Council on Disability, an independent government agency charged with advising the President, Congress and federal agencies, published a policy paper and "how-to" toolkit in support of deinstitutionalization [("[Deinstitutionalization: Unfinished Business \(Companion Paper to Policy Toolkit\)](#)," NCD (October 23, 2012)]. The U.S. Department of Justice and Developmental Disabilities Act programs, including Protection and Advocacy systems, have pressured states with federally financed investigations and lawsuits to reduce and close specialized residential and work centers.

c) Current And Future Disability Demographics

In 2011, there were 1,389,611 individuals with I/DD supported in supervised residential settings, alone or with a roommate, or with non-family caregivers (Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013, *citing* Fujiura 2012 (www.stateofthestates.org at slide 26)).

Another 852,923 individuals are living with caregivers 60 years old or older (*Id.* at slide 27) and, according to UCP's 2014 "Case for Inclusion," there are almost 317,000 people with I/DD waiting for services.

Both of these groups represent a present and future tsunami of need. Yet, studies by government funded non-profit groups continue to support the closure of specialized facilities ("institutions") and shift funding to small homes which often lack the specialized services needed by the most fragile of the I/DD population.

d) Survey Purpose

It is the purpose of this survey to capture the viewpoints of family members of individuals who reside in ICF settings, a group under-represented in surveys, and to compare their responses with the responses of family members of individuals residing in Non-ICF settings, to the degree possible.

2. Methodology

a) Data Collection

In February 2014, 1,450 surveys were distributed by VOR to VOR members by email (using a well-recognized digital survey tool) or regular mail (not both). Recipients were given one month to complete the survey.

Respondents were asked to take only one survey, selecting the survey that best described their circumstances:

- One survey ("ICF Survey") gathered information from family members and legal guardians of individuals currently in ICFs/IID or nursing facilities for those with I/DD (See Appendix A.1, ICF Print Survey).
- The other survey ("Non-ICF² Print Survey") gathered information from family members and legal guardians of individuals currently living in licensed group homes or other community settings (See Appendix A.2, Non-ICF Survey).

A total of 291 surveys were returned by mail or electronically, an approximate 20% rate of return.

255 responses were received from ICF and other specialized facility respondents; 36 responses were received from Non-ICF respondents. As noted on the charts and tables herein, not every respondent answered every question.

² For the purposes of this survey, "Non-ICF" refers to non-facility settings, including but not limited to Medicaid Home and Community-Based Services (HCBS) settings.

b) Survey Form

Although personalized for each audience, both the ICF and Non-ICF Surveys sought essentially the same information from individuals, family members, and legal guardians, about individuals currently residing in ICF or Non-ICF settings, respectively.

The initial question on the ICF Survey sought to confirm that the respondent was ICF-associated:

Question #1: Does your family member or ward reside in an ICF/IID or other specialized, licensed I/DD facility?

(a) Yes

(b) No

Respondents selecting “(a) Yes” continued to “Question #2” on the ICF Survey. Respondents selecting “(b) No” were directed to the Non-ICF Survey where its “Question 2” asked:

Question #2: In what type of facility does your individual reside? (Circle or fill in the blank):

(a) Group Home:

1. Small Group Home (2-4 people)

2. Medium sized Group Home (5-8 people)

3. Large Group Home (9-16 people)

(b) Resides with family

(c) Other (please specify): _____

In all other respects, the Surveys were the same. ICF and Non-ICF Survey questions sought the same information about demographics, such as type of residence and age, gender and type of disabilities of individuals; overall satisfaction of current setting; perceived levels of community integration of individual; perceived level of access to services, including medical care; awareness of and/or requirements for staff competency including background checks, training and certification; and vocational opportunities.

c) Sample

The primary purpose of this survey was to present the views of families, guardians and others who are associated with persons residing in ICF settings, or have resided in ICF settings, because they have been consistently overlooked in the literature.

Thus, VOR derived its sample from its membership, the majority of whom are family members and/or legal guardians of individuals with intellectual and developmental disabilities who reside (ICF Survey) or have resided (Non-ICF Survey) in ICF settings, and also individuals whose family member or friend has never resided in an ICF setting (Non-ICF Survey).

Given the sample’s current affiliation with VOR, an organization known for its balanced position in support of both ICF and Non-ICF settings, it is expected that respondents are generally supportive of the ICF setting regardless of where their individual now resides and that most of the individuals represented by respondents experience up to three serious disabilities.

Table 2.1 provides additional background on the rate of return for the ICF and Non-ICF Surveys, and information on the demographics of both the respondents and the individuals they represent in ICF and Non-ICF settings.

Table 2.1 Characteristics of respondents and individuals represented in both surveys

Characteristics	ICF group (n = 255)	Non-ICF group (n = 36)
Number of Surveys Sent	1,450 (100%)	
Number of Surveys Received	255 (17.5%)	36 (2.5%)
Total Rate of Return	20%	
Number of States Represented	30	15
Number of ICFs or Non-ICFs represented	117	20 (incl. 2 family homes)
Individual Age (age range)		
18 – 24	4 in range (1.7%)	0 in range (0%)
25 – 34	9 in range (3.8%)	2 in range (4.5%)
35 – 44	42 in range (17.5%)	11 in range (25%)
45 – 54	91 in range (3.8%)	20 in range (45%)
55 – 64	61 in range (2.5%)	8 in range (18%)
65 – 74	26 in range (10.8%)	2 in range (4.5%)
75 and Over	7 in range (2.9%)	1 in range (2.3%)
Gender of Individual		
Male	147 (60.2%)	18 (58%)
Female	97 (39.8%)	13 (42%)
Survey Respondent (age range)		
35 – 44	11 in range (4.5%)	0 in range (0%)
45 – 54	9 in range (3.7%)	2 in range (6.5%)
55 – 64	58 in range (24%)	5 in range (16%)
65 – 73	68 in range (28%)	10 in range (32%)
75 and Over	98 in range (40%)	14 in range (45%)
Relationship of Respondent to Individual		
Parent/Guardian	143 (60%)	20 (69%)
Guardian	62 (26%)	6 (21%)
Other	35 (15%)	3 (10%)

Respondents were also asked to list “up to three” disabilities impacting their individuals in ICF and Non-ICF settings (“mentions”), beginning with the most serious disability:

What is/are the main disabilities that affect your individual? List up to three as follows:
Most Serious Disability: _____
Additional Disability: _____
Additional Disability: _____

These listings are reflected in **Table 2.2**, which provides the number of disability “mentions” by respondents. As reflected in the question above, “mentions” were unprompted, meaning no specific lists or types of disabilities were provided.

According to federal law, to be eligible for ICF/IID or Medicaid Home and Community-Based Services, a person has to have an intellectual disability.

Because “mentions” were unprompted, some respondents may have described their individuals’ disabilities as “severe” or “profound” intellectual disabilities, where another respondent would have described the same level of disability as an “explosive disorder.”

Furthermore, this question did not seek to ascertain the *effect* of multiple disabilities experienced by an individual and the need for specialized care. 60% of all respondents to the ICF Survey listed three disabilities to describe their individual. 43% of all respondents to the Non-ICF listed three disabilities to describe their individuals.

Table 2.2 continued on next page

**Table 2.2 Number of disability unprompted “mentions” by respondents
(this question offered 3 “fill in the blanks”; up to three mentions permitted)**

Characteristics	ICF group (n = 242*)	Non-ICF group (n = 30*)
Respondent listed 3 disabilities (not less)	145 (60%)	13 (43%)
Severe to Profound Intellectual Disabilities (ID) / Mental Retardation	71 (29%)	11 (37%)
Mild to Moderate ID/Mental retardation	38 (16%)	10 (33%)
Autism (multiple types)	24 (9.9%)	7 (23%)
Cerebral palsy	23 (9.5%)	3 (10%)
Non-Verbal/No Speech or speech problem	20 (8.3%)	8 (26%)
Behavior problems, explosive disorder, self- injury, etc.	17 (7%)	5 (16.7%)
Seizures	15 (6.2%)	1 (3.3%)
Mental Illness (bi-polar, OCD, social, PICA, etc.)	12 (5%)	2 (6.6%)
Micro-Cephalic, Rett Syndrome, Missing part of Brain injury, etc.	11 (4.5%)	2 (6.6%)
Physically disabled, bone loss, incontinence, etc.	10 (4.1%)	2 (6.6%)
Self-sufficiency, Self-Care Problem(s)	7 (2.9%)	1 (3.3%)
Non-Ambulatory	7 (2.9%)	2 (6.6%)
Feeding Issues, Dysphagia, Feeding Tube, etc.	7 (2.9%)	0
Spastic tetraplegia; Spastic quadriplegia, etc.	7 (2.9%)	2 (6.6%)
Blind	6 (2.5%)	1 (3.3%)
Epilepsy	4 (1.7%)	1 (3.3%)
Deaf	3 (1.2%)	0
Respiratory Issues, insufficiency, asthma	3 (1.2%)	0
Short Bowel Syndrome, Mal-absorption	3 (1.2%)	0
Down Syndrome	3 (1.2%)	3 (10%)
Physically Disabled, Cardiac Problem(s)	2 (.08%)	0
Physically Disabled, Diabetes, thyroid, etc.	2 (.08%)	1 (3.3%)
Renal Failure	2 (.08%)	1 (3.3%)
Med fragile, numerous Surgeries, etc.	1 (.04%)	0
Physical disability, Lupus	1 (.04%)	0

*Numbers don't sum to 100% (242 and 30, respectively) because each respondent was offered the opportunity of providing *up to* three mentions.

Table 2.3 shows the breakdown between state and privately-operated ICF and Non-ICF settings, and additional information about Non-ICF residences, with **Table 2.4** offering greater detail on the size of group homes for those respondents who indicated that their individual resides in a group home.

Table 2.3 Type of ICF and Non-ICF Residence

Type of Residence	ICF group (n = 230)	Non-ICF group (n = 26)
State-Operated	184 (80%)	5 (19%)
Privately-Operated	34 (15%)	17 (65%)
Other	12 (5.2%)	4 (15%)
Group Home		21 (80%)
Resides with Family	N/A	2 (8%)
Other		3 (12%)

Table 2.4 Size of group home according to Non-ICF Respondents

Group Home Size	Non-ICF group: Group Home Respondents (n = 21)
Small Group Home (2-4 people)	11 (52%)
Medium sized Group Home (5-8 people)	10 (48%)
Large Group Home (9-16 people)	0 (0%)

3. Results and Findings

a) Satisfaction

As shown in **Chart 3.1**, ICF respondents indicated a high degree of satisfaction of their individuals' ICF home, with the vast majority (88%) rating the service as exceptional, in contrast to just 36% of Non-ICF respondents. Notably, Non-ICF survey respondents expressed less confidence that the Non-ICF setting could provide high quality care.

Chart 3.1 Level of satisfaction in current Setting (%)

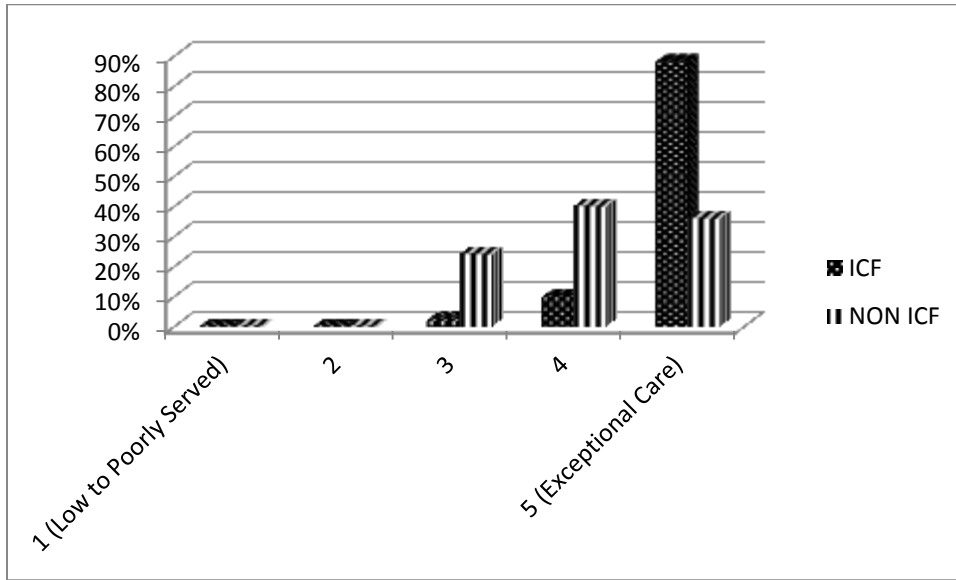
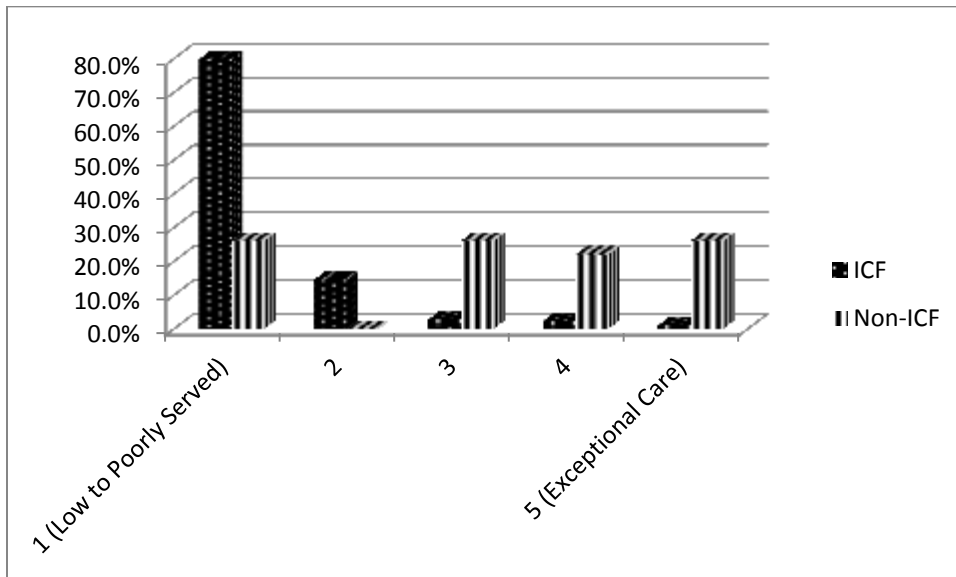


Chart 3.2 shows ICF and Non-ICF respondents’ perspectives with regard to alternative settings for their individuals, namely Non-ICF and ICF settings respectively. On **Chart 3.2**, a ranking of 1 represents a perspective that their individuals would do very poorly in an alternative setting and ranking 5 represents a perspective that their individuals would receive exceptional care in the alternative setting. ICF Respondents felt overwhelmingly (69%) that their individuals would do poorly in a Non-ICF home. Non-ICF Respondents were more ambivalent with an equal number (26%) feeling that their individual would do poorly and exceptionally.

Chart 3.2 Better served in alternative setting? (%)



In an effort to demonstrate that survey respondents were informed about setting alternatives, ICF and Non-ICF respondents were asked about prior placements of their individuals in the alternative setting, Non-ICF and ICF, respectively. As shown in **Table 3.1**, most respondents for both surveys were informed about other options based on prior placements and/or visits and evaluations. 44% of ICF respondents' individuals had lived in Non-ICF settings in the past, and 62% had visited and evaluated Non-ICF settings for their individuals. 68% of Non-ICF respondents' individuals had lived in ICF settings in the past, although none reported that their individual had returned to the ICF setting after leaving. 76% of the comments from Non-ICF respondents said closure or the threat of closure was the reason their individual left their ICF settings.

Table 3.1 Prior placements or visits and evaluations of alternative setting

Prior Placement in Alternative Setting	ICF group (n = 224)	Non-ICF group (n = 27)
Yes	99 (44%)	19 (68%)
No	125 (56%)	8 (32%)
ICF Survey Respondents' Prior Visits and Evaluations of Non-ICF Settings	ICF group (n = 226)	Non-ICF group (n = 25)
Yes	140 (62%)	N/A
No	86 (38%)	
Non-ICF Survey Respondents' Readmission to ICF Setting	ICF group (n = 224)	Non-ICF group (n = 27)
Yes	N/A	0
No		27 100%)

b) Community Integration

The surveys sought to assess perspectives relating to community integration opportunities by seeking input from ICF and Non-ICF respondents as to the degree their individuals interacted with the broader community through activities such as restaurants, work, shopping, sporting events, movies, fairs and festivals.

As shown in **Chart 3.3**, perceptions of community integration were comparable for both ICF and Non-ICF Survey respondents and nearly equal. 72% of Non-ICF and 73% of ICF respondents felt that their individuals enjoyed an average to high degree of interaction with the broader community away from their ICF and Non-ICF homes ("integration").

Chart 3.3 Perception of degree of community integration by ICF and Non-ICF Survey respondents (%)

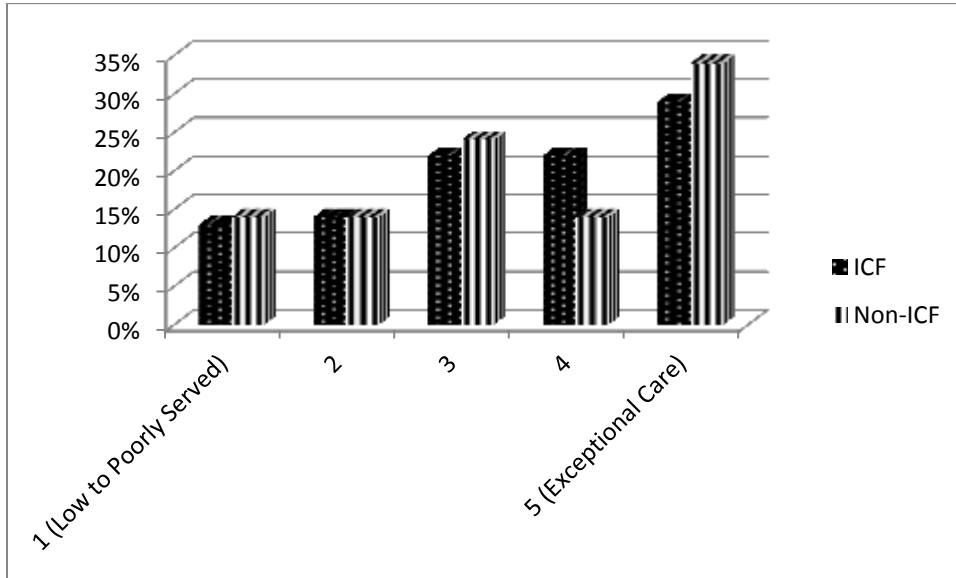


Table 3.2 shows the types of activities some individuals participated in, according to respondents who were given these categories to select from as they applied to their individuals (selecting all that applied). Although perceptions of community integration were nearly equal for both ICF and Non-ICF respondents (*see, Chart 3.3*), when asked about specific activities, a higher percentage of ICF respondents reported participation in nearly all activities.

Table 3.2 Integration activities offered to ICF and Non-ICF individuals

Integration Activities	ICF group (n = 216*)	Non-ICF group (n = 29*)
Church	111 (51%)	10 (34%)
Festivals	108 (50%)	10 (34%)
Fairs	122 (56%)	12 (41%)
Movies	96 (44%)	12 (41%)
Shopping	155 (72%)	19 (66%)
Sporting Events	79 (37%)	7 (24%)
Restaurants	156 (72%)	20 (69%)
Vocational	97 (45%)	15 (52%)
Other	113 (52%)	15 (52%)

*Numbers do not sum to 100% (216 and 29, respectively) because each respondent was offered the opportunity of selecting more than one activity, noted as “mentions.”

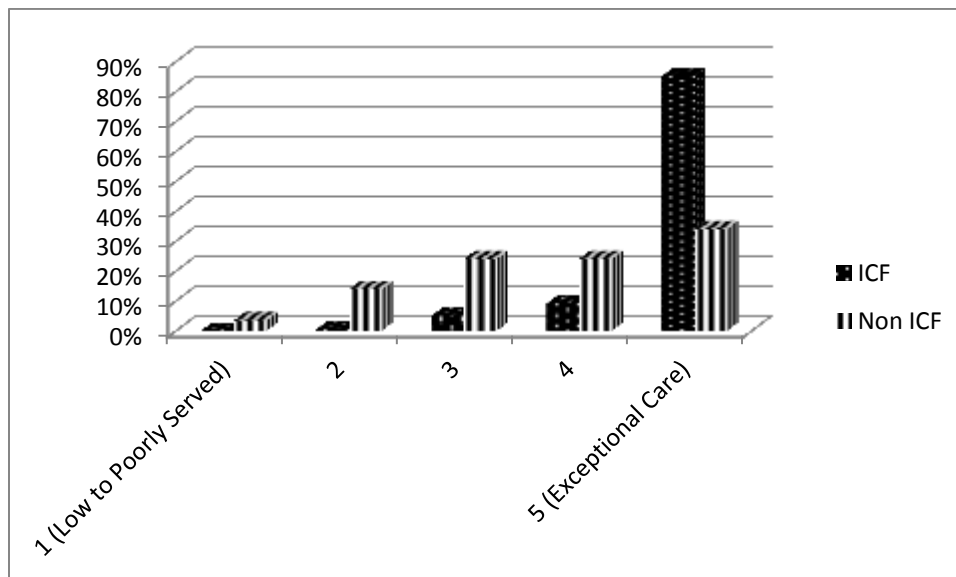
Other activities mentioned by ICF respondents included but were not limited to horseback riding, visits to parks, concerts, bowling, swimming, the zoo, day trips, summer camps, Special Olympics and family gatherings. Non-ICF respondents mentioned the movies, health care appointments, Special Olympics, day programs, and family gatherings as other activities participated in by their individuals.

c) Access to Services

Respondents to both surveys answered questions about their perceived access to an adequate array of services by their individual. It has long been understood that the required array of standard services in ICF settings may not be as easily accessible in Non-ICF settings. There is ample research finding that access to medical and dental services is often difficult for individuals with I/DD who live in Non-ICF (“community”) settings; however, in ICF settings, these are required services.

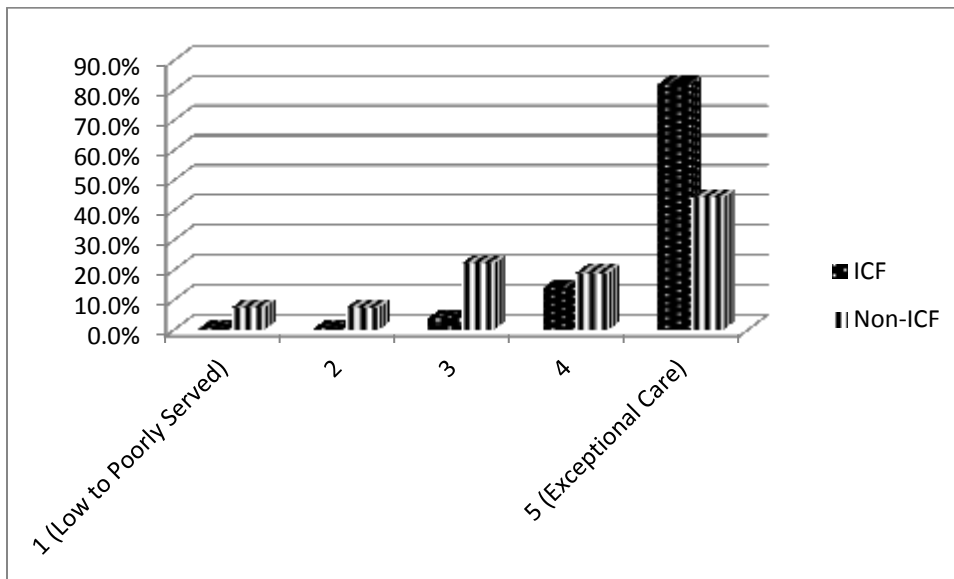
As shown on **Chart 3.4**, results clearly show that ICF Survey respondents are aware of the array of services that are available. 85% of ICF respondents rated this item 5 indicating “high-regular access.” Of interest is that in the non-ICF group, proportionally more respondents (66%) rated this item lower (ratings < 5), suggesting that Non-ICF respondents understand that accessing a full array of services in these settings may present additional challenges.

Chart 3.4 ICF and Non-ICF Respondents’ perception of access to adequate array of services (%)



Likewise, with regard to access to quality medical care, 82% of ICF respondents' perceived access to quality medical care as very high and only 1 (0.4%) respondent perceived access to medical care as very low, as shown in **Chart 3.5**. In contrast, 56% of Non-ICF respondents ranked access to quality medical care lower (ratings < 5), also suggesting that Non-ICF respondents understand that accessing quality medical care for individuals in Non-ICF settings may present challenges.

Chart 3.5 ICF and Non-ICF Respondents' perception of access to quality medical care



Respondents to both surveys were also asked about activities offered by the ICF and Non-ICF and were instructed to select all that applied. Some of the listed activities, as shown in **Table 3.3**, similar to **Table 3.2**, are measures of “integration.” Although perceptions of community integration were nearly equal for both ICF and Non-ICF respondents (*see, Chart 3.3*), as shown in **Table 3.3**, when asked about specific activities, a higher percentage of ICF respondents reported participation in nearly all activities.

Table 3.3 Activities offered to ICF and Non-ICF residents

Activities	ICF group (n = 226*)	Non-ICF group (n = 29*)
Vocational	146 (65%)	11 (38%)
Recreation (e.g., swimming, sports, exercise, etc.)	181 (80%)	21 (72%)
Transportation	200 (88%)	25 (86%)
Medical	207 (92%)	22 (76%)
Dental	200 (88%)	19 (66%)
Religious	171 (76%)	13 (45%)
Music	170 (75%)	15 (52%)
Equestrian	39 (17%)	1 (3%)
Onsite Shopping (e.g., thrift store, craft store)	83 (38%)	11 (38%)
Art	100 (44%)	6 (21%)
Other	87 (38%)	18 (62%)

*Numbers don't sum to 100% (226 and 29, respectively) because each respondent was offered the opportunity of selecting more than one integration activity.

Other activities mentioned by ICF respondents included but were not limited to swimming, dances, coffee house, parades, therapies, recreational outings, Special Olympics, shopping, family gatherings, prom, horticultural, massages and parties. Non-ICF respondents mentioned theme parks, swimming, parks, picnics, Special Olympics, family gatherings, Arboretum, libraries and day programs.

d) Staff Competency

Respondents for both surveys responded to questions asking about their individuals' direct care staff training and background check requirements. Results are shown in **Table 3.4** and suggest that respondents felt that more training and background checks were carried out in ICF settings than in Non-ICF settings, including those Non-ICF respondents who live at home and have non-family in-home caregivers.

As reported by respondents, more ICF direct care workers are subjected to background checks before hire (78%) as compared to Non-ICF direct care workers (56%). Both ICF and Non-ICF direct care workers receive ongoing training at nearly equal levels (75% and 67%, respectively), according to respondents.

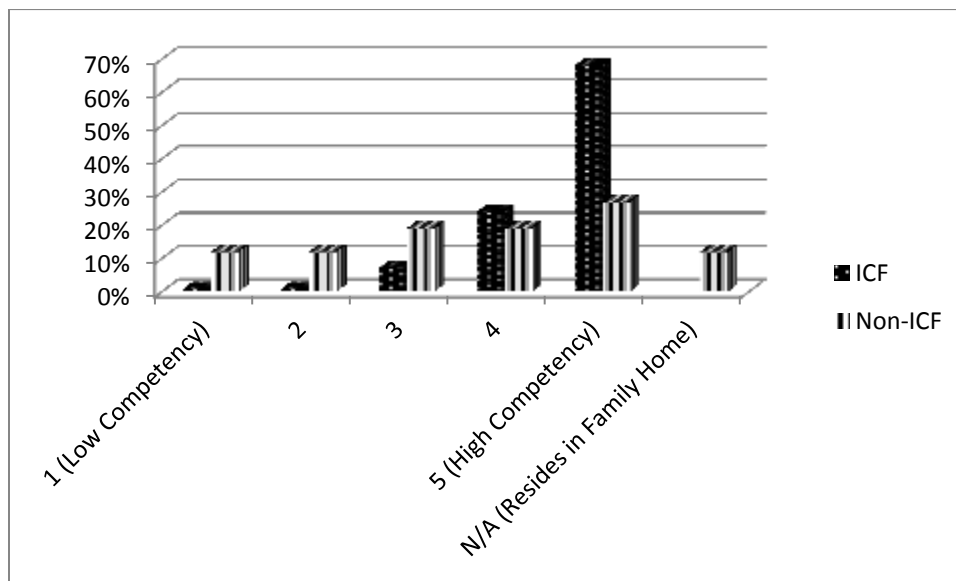
“Small community-based facilities will compromise the quality of life for residents. Direct care staffing will experience greater turnover, less training, less experience, less commitment to the job leading to less than adequate care for residents. Fewer staff to draw from will negatively impact the provider's ability to cover unplanned absences leading to periods of inadequate staffing and much lower levels of care.”
ICF Survey Respondent

Table 3.4 Staff training and background check requirements

Item	Responses	ICF Group (n=228)	Non-ICF Group (n=27)
“Are your individual’s direct care staff required to participate in ongoing training?”	Yes	172 (75%)	18 (67%)
	No	2 (.8%)	0
	I Don’t Know	54 (24%)	7 (26%)
	N/A (in own home)	N/A	2 (7.4%)
Item	Responses	ICF Group (n=227)	Non-ICF Group (n=27)
“Are your individual’s direct care staff subject to background checks before they are hired?”	Yes	177 (78%)	15 (56%)
	No	0	0
	I Don’t Know	48 (22%)	7 (26%)
	N/A (in own home)	N/A	5 (19%)

Respondents were also asked to what extent they believed their individuals’ ICF and Non-ICF settings provide “competent direct care staff who have a stable degree of longevity.” As shown on **Chart 3.6**, ICF Survey respondents indicated a far higher perception of confidence with regard to staff longevity and competence, with 68% of all respondents ranking staff longevity and competence as high (ranking 5), as compared to just 27% of Non-ICF Survey respondents who ranked staff longevity and competence as high (ranking 5). Likewise, 12% of Non-ICF Survey respondents ranked staff competence and longevity as very low, as compared to just less than 1% of ICF Survey respondents.

Chart 3.6 Respondents’ perceptions of staff competency and longevity



e) Vocational Opportunities

For both surveys, nearly half of the respondents indicated that their individual is unable to work. One ICF survey respondent commented that her individual has “very limited work ability which is done on campus with staff assistance.” Of those individuals who could work most worked in sheltered employment.

Table 3.5 Vocational experiences of individuals in ICF and Non-ICF Settings

Item	ICF Group (n=241)	Non-ICF Group (n=25)
My resident is unable to work	106 (44%)	11 (44%)
Sheltered workshop	75 (9%)	9 (36%)
Supported employment	15 (2%)	2 (8%)
Competitive employment	1 (.4%)	0
Other	44 (18%)	3 (12%)

f) Respondents’ Perceptions of Deinstitutionalization Trends and Policy

Respondents to both surveys were asked, “What would you like our government to know about the current move to deinstitutionalize ICF residents in favor of small community-based facilities?” Representative samplings of verbatim responses from each survey are provided in **Table 3.6**. All responses can be found at <http://vor.net/images/WhatDoUWantGovt2Know.pdf>.

Table 3.6 Respondents’ perceptions of deinstitutionalization trends and policy

	“What would you like our government to know about the current move to deinstitutionalize ICF residents in favor of small community-based facilities?”
ICF Respondents	“Community-based facilities are not the best living situation for everyone needing full time care services. Institutions provide excellent care and economy of scale. Institutions provide the opportunity for nurses, doctors, speech therapists, occupational therapists, physical therapists, nutritionists, etc, to be on site every day to meet residents needs at all times. Anytime a situation arises these people are right on site - and able to serve many people all in one place. This also allows for these employees to get to know these residents’ very well and understand their individual needs.”

	<p>“ICFs are a part of the community. ICFs provide a needed service for this fragile population.”</p> <p>“ICF facilities sometimes DO provide the best least restrictive environment for many disabled individuals who are unable to do things for themselves and who require 24 hour care and specialized medical attention. The ICF facility provides the special care, while at the same time they are able to provide activities on campus and provide transportation and appropriate activities off campus. These special citizens would NOT be given the same quality care or opportunities in a small setting away from a mainstream of experience and service availability.”</p> <p>“What we continue to need is a seamless continuum of residential choices that includes larger facilities that provide centralized, on campus services for those whose capacities and needs differ from those who can benefit from community-at-large inclusion. Olmstead supports the choice of institutions under circumstances in which the person's independence is better supported in an institution . . . I would like the government to reject all one-size-fits-all notions that assume everyone with I/DD should be housed in the community-at-large. Our society does not condemn universities for providing centralized services, nor do we insist all students live off campus. We don't prohibit seniors from living in congregate facilities with varying degrees of centralized services. We don't insist that all students be in classrooms of only 2 or 3 students. We utilize hospitals that centralize services, recognizing that there is efficiency and economic value in such sharing of resources. To deprive people with I/DD of the choice to live in congregate care adds up to ideological discrimination against them. To devote all or even the preponderance of public money to off-campus residential choices for people with I/DD is also discriminatory, especially when pressure is brought to deprive people of making such choices in the first place. “</p> <p>“[Deinstitutionalization] is a gross error that favors inappropriate care; incompetence and poor oversight. Governmental decision makers need to know that this family's personal experience found a lack of adequate medical care; a lack of adequate supervision; little, if any, agency or governmental oversight in three different, small community-based settings. After exhaustive years of trying small community options, our son's hospitalization finally brought us to his current ICF Care Facility in [City, State]. Our son, now 45, is thriving, productive and living a fulfilling life. The staff is remarkable, well trained and on top of the day to day challenges presented by autistic adult males. The worst part? The staff is poorly paid for the exhausting work and compassion they provide each resident.”</p> <p>“I would like [the government] to know that an ICF is the best choice for some disabled people. We need more choices for our most needy people – not less.”</p>
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	<p>"We need all levels of care and all types of homes for individuals to be served well and live good lives. Small community based homes should only be one choice of several available to a person. People with intellectual disabilities need the same range of choices as a senior citizen contemplating where they will live."</p>
<p>NON-ICF Respondents</p>	<p>"Before releasing individuals to the community make SURE there is an appropriate facility in place and then make SURE inspections and care are done properly in order to meet every human belongs need for cleanliness, nutrition, friendship, recreation, and dignity."</p> <p>"Institutionalization is not a sterile cold unfeeling choice for families whose loved ones live with multiple or profound disabilities. My sister lived at her facility for 37 yrs-she was taught to feed herself and walk, things that we, her family, would have never dreamed were possible. She had easy access to doctors and therapists and she lived with her peers. She has lost the ability to walk and feed herself after 2 yrs in the apartment. People with disabilities deserve better-shame on our government."</p> <p>"My child likes his group home. He enjoys going to accent, fair, church, circus, movies and Special Olympics."</p> <p>"I believe the home receives over \$20,000 monthly for his care, because he needs 2 or 3 people to restrain him when he becomes violent. Unfortunately, they have no training in this area, as was the situation at [the ICF]. Nothing could have been worse for him then being forced out to live in a community home . . . Because of his violence, I don't have any choice, especially now with all the unfair cutbacks. Maybe the situation would be different if some of the Congressional leaders had a child or other close family member in these inadequate group homes. All I can do is pray and be thankful for all your organization does. It is a sin for the government to shut down facilities which have trained, educated personnel, and adequate facilities for the care and safety of our loved ones."</p> <p>"This is blatant disrespect for family guardian choice."</p> <p>"While I understand that small group homes are not for every client, my son has benefitted greatly from being in a small group setting, as opposed to the state developmental centers and large group home he has resided in. He has been in two state developmental centers and one large group home where he experienced theft, fraud, abuse and neglect. He has received much more individualized care in the small group homes, and enjoys the many advantages and home-like setting they offer, as well as the regular medical care he receives. My son has many medical and behavioral problems, which [Group Home] has dealt with exceptionally well. I hope my son can stay there as long as he lives."</p>

	<p>“To deinstitutionalize means failure. The need for specialized caregivers would be far greater than they are now and I feel the cost would be prohibitive, especially since the salary to private providers is lacking and you start to go to the bottom of the barrel in who you hire and the responsibility and liability that goes along with this hiring.”</p> <p>“[Deinstitutionalization] is blatant disrespect for family guardian choice. The government's biases are no less than a declaration of war against vulnerable people.”</p> <p>“It is up to the families to decide. For some residents of ICF , it is too stressful for them to leave all they know. No one has the right to take them from their home and the people who have loved and nurtured them throughout their lives.”</p> <p>“These people are individuals and need to be offered the choices that best meet their needs whatever that choice may be.”</p>
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4. Conclusion

Survey results confirm that, contrary to common perceptions and current policy, ICF settings are not segregated and isolating.

Instead, by a very strong majority, ICF respondents indicated a high level of satisfaction with their individuals’ ICF homes, staff competency, access to services and community integration. The survey captured respondents’ perceptions of integration and actual measures of activities and access to an adequate array of services. There were high percentages of involvement in activities away from their ICF homes and access to medical and other services.

Non-ICF respondents expressed general satisfaction in measures relating to integration and vocational opportunities. With regard to staff competency, however, only 27% of Non-ICF survey respondents ranked staff competency and longevity high, with 12% ranking staff competency very low. Likewise, access to an adequate array of medical and other services was average, with 66% of Non-ICF Respondents ranking access as less than high. This could relate to perceptions. Non-ICF Respondents are likely aware that Non-ICF settings do not offer “bundled” services, as required by ICF settings; and there is ample research that medical and dental services are often difficult to access by individuals with I/DD who live in Non-ICF settings.

Most respondents for both surveys were informed about alternatives to their individuals’ current placements based on their own evaluations of different settings and, in some cases, the individuals’ prior placements in other settings.

Of paramount importance, both ICF and Non-ICF respondents were asked –

“What would you like our government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities?”

Comments from both ICF and Non-ICF respondents were consistent with survey results, spanning from expressing support for their individuals’ current settings to concerns about access to an adequate array of services in Non-ICF settings.³

Interestingly, regardless of individual experiences, the vast majority of ICF and Non-ICF respondents expressed strong objections to forced deinstitutionalization. These respondents (both ICF and Non-ICF) took great offense to the violation of choice. “Deinstitutionalization is blatant disrespect for family guardian choice,” wrote one Non-ICF Respondent. “[A]n ICF is the best choice for some disabled people. We need more choices for our most needy people – not less,” wrote an ICF Respondent.

Some respondents noted that individuals with I/DD were entitled by law to service choice and others expressed concern that failure to honor individual choice or meet individual needs has led and will lead to human harm.

This survey captured the perspectives of families of individuals residing in ICFs, an audience under-represented in surveys that have a profound impact on the care available to their family members with I/DD, and compared their perspective with families of individuals in Non-ICF settings. Upon doing so, commonly held perceptions with regard to both ICF and Non-ICF settings were largely debunked. ICF settings are not segregated and isolating and Non-ICF settings are not necessarily integrated.

What mattered most to families of those receiving care in both ICF and Non-ICF settings was that their family members with I/DD received the care they needed and that their right to individual choice was respected.

As so aptly stated by one respondent –

“Good public policies should be based on experience, common sense and humanity. There should be deference and respect for the positions of families who have first-hand experience in the care and treatment of persons with life-long disabilities.”
(ICF Survey Respondent)

³ All responses are available at <http://vor.net/images/WhatDoUWantGovt2Know.pdf>.

Appendices

a) VOR Policy and Position Statements

[VOR, May 2013 (<http://vor.net/about-vor>)]

VOR's mission is to advocate for high quality care and human rights for people with intellectual and developmental disabilities (I/DD). These rights include the right to appropriate services and residential options based on individual need and choice.

VOR supports individual and family participation in decision-making. "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." [Developmental Disabilities Act, 42 U.S.C. 15001(c)(3)(2000); *see also, Olmstead v. L.C.*, 119 S. Ct. 2176, 2187 (1999) (Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it")].

VOR supports both ICF/IID homes and quality community-based service options based on individual need. VOR advocates for the right of individuals with intellectual and developmental disabilities and their families to choose from a full array of high quality residential and other support options including own home, community-based, and large settings, such as licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID).

VOR supports safe and appropriate quality care in the community. When federally-licensed specialized settings (e.g., ICF/IID) are closed, individuals with profound I/DD, multiple disabilities, serious medical problems, and behavior challenges are removed to "community-based" settings often with poorly trained staff and inadequate health and safety measures in place. Individuals with severe disabilities living at home or in other community settings often experience the same problems with poor care. By developing and promoting community care standards, VOR aims to address this widespread concern and avoid predictable tragedies, as reported in the media, state audits and peer-reviewed studies.

VOR opposes the use of federal funds for any activity that would deny individuals with Intellectual and developmental disabilities benefits or rights available to them under federal law. Federal legal rights include those provided for in the 1999 U.S. Supreme Court Olmstead Decision (*see also, Rehabilitation Act of 1973*, Section 504 ("no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives Federal financial assistance or is conducted by any Executive agency"). This includes lawsuits, advocacy, publications and other activities that result in forcing residents of federally-licensed ICFs/IID from their homes or limit access to necessary specialized programs or residences in community settings.

VOR supports a full array of employment options, including sheltered workshops, supported employment, and competitive employment based on individual abilities. People with intellectual or development disabilities (I/DD), have a right to choose where they work and where they live.

VOR supports guardianship for individuals who cannot speak for themselves in some or all aspects of their lives, when in the best interests of the individual as determined by a court of law. VOR opposes efforts to prevent access to guardianship by families and friends of people with I/DD. VOR opposes efforts to remove guardianship from people with I/DD based on disagreements over the type or quality of care with government agencies, service providers, or advocates.

VOR supports a full array of education options for students with disabilities, from mainstreaming to special education settings, as required by federal law. VOR supports individualized education based on the needs of each student with disabilities and their parents.

b) Olmstead Supports Residential Choice

[VOR, revised 2013 (<http://vor.net/olmstead-resources>)]

The Supreme Court, in its *Olmstead* ruling, recognized the need for a range of services to meet to the varied and unique needs of the entire disability community:

- (1) **Unjustified isolation is discrimination based on disability.** *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999).
- (2) The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when – “[a] the State’s treatment professionals have determined that community placement is appropriate, [b] the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and [c] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. *Id.* at 587 (emphasis added).
- (3) The Supreme Court explained that this holding “reflects two evident judgments.” First, “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.” Second, historically “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” *Id.* at 600- 601.
- (4) However, a majority of Justices in *Olmstead* also recognized an ongoing role for publicly and privately-operated institutions: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” *Id.* at 601-602.

(5) A plurality of Justices noted:

“[N]o placement outside the institution may ever be appropriate . . . ‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times—perhaps in the short run, perhaps in the long run—for the risks and exposure of the less protective environment of community settings’ for these persons, ‘institutional settings are needed and must remain available’” (quoting Amicus Curiae Brief for the American Psychiatric Association, et al).

“As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’ [quoting VOR’s *Amici Curiae* brief].” *Id.* at 605.

(6) Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” *Id.* at 610.

c) **People as Pendulums: Institutions and People with Intellectual and Developmental Disabilities**

See next page

People as Pendulums: Institutions and People with Intellectual and Developmental Disabilities

by Tamie Hopp

Aggressive deinstitutionalization has caused more harm than good—people with mental illness now make up a good part of the population in this nation’s prisons and jails and on the streets. There is a lot at stake for past and present proponents of community integration—not least, the risk of losing future funding. But, as the author points out, where is our concern for the individual in this debate? While wholesale institutionalization was never the right answer, nor is the current lack of access to necessary supports.

Editors’ note: This article was originally published on NPQ’s website, on July 16, 2014.

DISABILITY ADVOCACY OVER THE PAST three decades has resulted in a largely decentralized, de-specialized system of care that has left many individuals with profound intellectual and developmental disabilities without adequate services, in spite of the valiant efforts of family advocates and the nonprofit organizations that represent them. These families, organizations, and others have widely distributed this article, recognizing their own story within its words and affording them credibility, because it was published by a well-respected organization that has no real skin in this complex and often emotional issue.

“People as Pendulums” has been posted, tweeted, blogged, cited, and shared with state law- and policymakers and with Congress. In time, it is hoped that the themes within “People as Pendulums” will help to repair what has become a fractured, fragmented, and sometimes

self-interested world of nonprofits purporting to advocate for the individual rights of all people with intellectual and developmental disabilities, or IDD. Due in part to our infighting, law- and policy-makers either persist in a state of inaction—loathe to take sides—or embrace the law of the majority, which sometimes does a tragic disservice to individuals with profound developmental disabilities. For some in this minority within a minority, a lack of access to necessary supports can be and has been a death sentence. Real progress—individualized choice and care according to the law—will not be achieved until we all come together.

• • •

Willowbrook State School: A Case Study

Willowbrook State School was a New York State–run institution that for forty years serviced people with

mental disabilities. Eighteen years into its operations, in 1965, then-Senator Robert Kennedy toured Willowbrook and offered this grim description of the individuals residing in the overcrowded facility: “[They are] living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo.”¹

The atrocities of Willowbrook ushered in a generation of advocates, nonprofit organizations, providers, and professionals who successfully pushed for massive reform, beginning in 1971 with the development of Medicaid Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR), later renamed ICFs, for Individuals with Intellectual Disabilities (ICFs/IID).

Families and advocates alike applauded this infusion of federal funding, licensing, and oversight for a program specifically designed to meet the needs of individuals with intellectual

and developmental disabilities (I/DD).

Still, as the ICF/IID program grew, so did calls for housing alternatives. Critics emerged, claiming that the ICF/IID federal standards of care promoted a non-individualized, inefficient model of care, and, due to federal financing incentives, discouraged states from developing alternate service options.² In 1981, Congress responded by providing for small (four- to fifteen-person) ICFs/IID and a Medicaid Home and Community-Based Services (HCBS) waiver, to allow states to “waive” certain ICF/IID requirements.

These early reforms were quite properly motivated by the need for a system of care and supports that responded to the very individual and diverse needs of the entire population of people with I/DD. These reforms, however, also set the stage for decades of ongoing deinstitutionalization, resulting in the elimination of specialized housing, employment, and education options for people with I/DD, leaving some to question the price of “progress.”

The Pendulum Swings

Even though initial reforms were motivated by a lack of service options (an over-reliance on the ICF/IID program), it was not long before efforts to “rebalance” our system of care shifted from the expansion of options to the dramatic reduction of ICFs/IID and other specialized options.

In 1999, the Supreme Court handed down its landmark *Olmstead v. L.C.* decision, which should have settled the deinstitutionalization debate. The Court expressly cautioned against forced deinstitutionalization—the “termination of institutional settings for persons unable to handle or benefit from community settings”³—finding instead that the Americans with Disabilities Act (ADA) only requires community placement when an individual’s treatment professionals determine community

placement is appropriate, such placement is not opposed by the individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with disabilities.⁴

However, masterful messaging by nonprofit organizations and federally funded lawyers with mission statements and funding aimed squarely at eliminating all “institutional” options quickly (and incorrectly) characterized *Olmstead* as a deinstitutionalization “mandate” requiring “community integration for everyone.”⁵ While deinstitutionalization proponents had successfully closed many ICF/IID homes by 1999, the time of the *Olmstead* decision, the decision has only further fueled their efforts in the years that followed.

Has the Pendulum Swung Too Far?

According to Samuel Bagenstos, former principal deputy assistant attorney general in the Obama Justice Department’s Civil Rights Division, and a key litigator in deinstitutionalization cases, the population of state institutions for I/DD now stands at approximately 16 percent of its peak.⁶

The exit of ICFs/IID from the service landscape created a vacuum that lured nonprofit and for-profit providers into the business of human services. Between 1977 and 2010, the number of residential settings that served people with I/DD increased by a remarkable 1,598 percent, with most of these new settings being small and privately operated. In 2010, non-state agencies served 98.5 percent of people living in places with six or fewer residents. The number of home- and community-based services recipients outpaced residents receiving specialized Medicaid licensed ICFs/IID by 676.1 percent, while the number of people receiving ICFs/IID care decreased by 63 percent.⁷

As early as 1993, then-U.S. Representative Ron Wyden (D-OR) pointed to the problems created by an unchecked expansion of providers rushing in to fill a need. “Increasingly, millions of Americans with these lifelong handicaps are at risk from poor quality of care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies,” wrote Wyden in a March 22, 1993, report in his capacity as Chairman of the Subcommittee on Regulation, Business Opportunities, and Technology of the U.S. House Committee on Small Business.⁸

In 2000, the *American Prospect* magazine reported similar problems in its article “Neglect for Sale,” by Eyal Press, which investigated a disturbing trend of large for-profit corporate providers capitalizing on what was then \$22 billion (now more than \$40.5 billion) in government spending on services for people with disabilities, turning care for individuals with I/DD “into a major growth industry.”⁹

“It should not be surprising,” Bagenstos wrote, “that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services.”¹⁰ State officials were not keen on investing in the development of adequate community services after being told that closing ICFs/IID would save them money, resulting in inadequate funding and compromised care. Bagenstos acknowledges that adequate investment in community services, especially due to the cost of quality staffing, will meet or exceed the cost of ICF/IID care.¹¹

The predictability of these outcomes make them all the more tragic. The failed deinstitutionalization of the mentally ill should have been an important lesson

learned. “As events played out, large state institutions [for the mentally ill] were indeed shut down in the 1970s, but the promise of high-quality community-based care collided with the fiscal cutbacks of the 1980s,” wrote Press.¹² Homelessness, incarceration, and violence raise questions about “whether society’s concern for the constitutional rights of people with mental illness has led to their abandonment.”¹³

Predictable Tragedies as the Price of Progress

Even if some license is afforded to “hope”—a “hope” that history would not repeat itself when deinstitutionalizing individuals with I/DD—there is no excuse for continuing down a path that has led to repeated, widely reported tragedies in small settings for people with I/DD.

More than 150 media reports in more than thirty states since 1997 reveal systemic concerns in small settings for people with I/DD, including deaths, abuse, neglect, and financial malfeasance. In November 2011, the *New York Times* wrote that more than 1,200 people with I/DD in the past decade have died in group homes due to “unnatural or unknown causes.”¹⁴ U.S. Senator Chris Murphy (D-CT) has called for a U.S. Department of Health and Human Services Office of Inspector General investigation to “focus on the prevalence of preventable deaths at privately run group homes across this nation and the widespread privatization of our delivery system.”¹⁵

Georgia offers a particularly poignant example of the extremes by which “success” is defined by proponents of forced deinstitutionalization. An October 2012 federal settlement calls for the transition of its I/DD residents from ICFs/IID to community settings. In 2013, the state’s own reports showed that 10 percent (forty people) of those transferred to community settings in 2013 had died.¹⁶ Yet, United

Cerebral Palsy, a national nonprofit organization, ranked Georgia fourth in the nation for its successful community inclusion of people with I/DD.¹⁷

Other symptoms of failed deinstitutionalization are less obvious but no less harmful to people with I/DD. Waiting lists for I/DD services now number nearly 317,000 people,¹⁸ emergency rooms have become de facto urgent care clinics for people with I/DD, and correctional facilities are replacement treatment centers for some individuals who experience both mental illness and developmental disabilities.

Conclusion: Why Does This Continue?

The original goal of deinstitutionalization, to provide opportunity to individuals not appropriately institutionalized and “rebalance” the system, was shared by advocates. We have passed the 50 percent mark in most states—that point of “balance” when half the Medicaid funding for people with I/DD was spent on HCBS options and half on facility-based (“institutional”) options. In fact, United Cerebral Palsy reported that “38 states now meet the 80/80 Community standard, which means that at least 80 percent of all individuals with ID/DD are served in the community and 80 percent of all resources spent on those with ID/DD are for community support.”¹⁹

As advocates marched toward “balance”—and in most states exceeded it—tragedies followed and seem to have become more widespread. These tragedies, which should have been a wake-up call, have done nothing to stem aggressive deinstitutionalization. State-level fiscal conservatives still loathe spending money, yet safely serving people with complex needs requires adequate funding. Proponents for “community integration for everyone”—advocates, nonprofit organizations, federal agencies and providers—have a lot at stake, past and present. To

change paths now is to admit failure and risk future funding.

Lost in this debate is concern for the individual. Person-centered planning, which is held up as the ideal by advocates, nonprofit organizations, and government alike, is shortchanged by system-change advocacy to eliminate specialized care options for those who need it. Instead, we must figure out ways to meet individual needs versus wholesale approaches to providing care that end up being as bad as or worse than an institution’s being the only option.

The legal framework is in place to support individualized care and choice. Advocates must set aside efforts to eliminate options for care and work together to expand options. This begins with a commitment to serving each individual: true person-centered planning.

NOTES

1. Wikipedia, s.v. “Willowbrook State School,” last modified on May 18, 2014. The referenced citation in full reads: “Staff (September 10, 1965). ‘Excerpts from Statement by Kennedy.’ *The New York Times*. Retrieved September 26, 2010.”
2. Sheryl Larson *et al*, *Residential Services: Status and Trends through 2011* (Univ. of MN, 2013), 55.
3. *Olmstead v. L.C.*, 527 U.S. 581, 601–2 (1999).
4. *Olmstead*, 527 U.S. at 587.
5. “Olmstead: Community Integration for Everyone,” Information and Technical Assistance on the Americans with Disabilities Act, accessed July 7, 2014.
6. Samuel R. Bagenstos, “The Past and Future of Deinstitutionalization Litigation,” *Cardozo Law Review* 34, no. 1 (2012): 30; see also *ibid.*, 8: “Since that time, states have closed hundreds of their institutions, and they have downsized others.” Note: The decline in the population of psychiatric hospitals for individuals with mental illness is even more dramatic, with current resident populations at just 9 percent of its highest numbers.
7. Sheryl Larson *et al.*, *Residential Services*

for Persons with Developmental Disabilities: Status and Trends through 2010 (Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2012), ix.

8. Select Committee on Small Business, Subcommittee on Regulation, Business Opportunities, and Technology, H. R. Rep. 103–8 (1993).

9. Eyal Press, “Neglect for Sale,” the *American Prospect*, November 30, 2000.

10. Bagenstos, “The Past and Future of Deinstitutionalization Litigation,” 21.

11. *Ibid.*, 43; compare to Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green, “Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research,” *Mental Retardation* 41, no. 2 (April 2003): 103–22. (“Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified.”)

12. Press, “Neglect for Sale.”

13. Stephanie McCrummen, “Behind the Yellow Door, a Man’s Mental Illness Worsens,” the *Washington Post*, June 28, 2014.

14. Danny Hakim and Russ Buettner, “Abused and Used: In State Care, 1,200 Deaths and Few Answers,” the *New York Times*, Nov. 5, 2011.

15. U.S. Senator Christopher S. Murphy to U.S. Department of Health and Human Services Inspector General Daniel R. Levinson, March 4, 2013.

16. Andy Miller, “Transfers of Disabled Patients Still a Problem,” *Georgia Health News*, June 23, 2014; see also Alan Judd, “Mentally Disabled Suffer in Moves from Georgia Institutions,” *Atlanta Journal-Constitution*, June 21, 2014; see also “Widespread Abuse, Neglect, and Death in Small Settings Serving People with Intellectual Disabilities,” revised July 2014.

17. Tarren Bragdon, *The Case for Inclusion 2014* (Washington, DC: United Cerebral Palsy, 2014), 8.

18. *Ibid.*, 7.

19. *Ibid.*, 6.

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d) ICF and Non-ICF Surveys

See next page

Contact Information (optional):

Name: _____ **E-Mail Address:** _____

Mailing Address: _____

Surveys on Two Intellectual and Developmental Disabilities (I/DD) Service Approaches:

- 1) **Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) or other specialized, licensed facility-settings serving people with I/DD (e.g., nursing facility); OR**
- 2) **Other I/DD residential settings (group home, home care, or other non ICF)**

You will take only one of these surveys.

Your survey will take about 5 minutes.

Question # 1: Does your family member or ward reside in an ICF/IID or other specialized, licensed I/DD facility?

- (a) Yes
- (b) No

Your answer here determines which survey you'll be taking.

If "**No**", skip to **page 4** for **Survey 2** with questions applicable to you.

If "**Yes**", Please continue to question #2

Survey #1

 – **Focus on ICF/IID and other specialized, licensed I/DD facilities (referred to herein as ICFs):**

Question #2: In which state is your individual's ICF located? _____ Name of ICF: _____

Is the ICF (*Please circle*) –

- (a) State operated? (b) Private? (c) Other? _____ (specify)

Question #3:

- (a) What is the individual's age? _____ (b) What is the individual's gender? M or F (c) What is your age? _____

Question #4: What is your relationship to the individual? (*Please circle*)

- (a) Parent/guardian (b) Guardian (c) Other (please state): _____

[Note: if you would like information about guardianship options, please contact VOR. See area below "Comments" section for contact information.]

Question #5: What is/are the main disabilities that affect your individual? List up to three as follows:

Most Serious Disability: _____
 Additional Disability: _____
 Additional Disability: _____

*Please answer the following questions using a scale of 1(low) - 5 (high), circling your response. For each question, we encourage you to **provide any additional comments or examples** in our Comments section.*

Question #6: To what extent do you believe your individual is best served in an ICF environment? (*Please circle*)

- 1 2 3 4 5

Question #7:

(a) To what extent do you believe your individual would do better in a smaller (non-ICF) setting? (*Please circle*)

- 1 2 3 4 5

(b) Have you ever visited and evaluated smaller community setting(s) for your individual? Yes or No (*Please circle*)

(c) Has your individual ever lived in a smaller community setting? Yes or No (*Please circle*)

Question #8:

(a) To what extent does your individual interact with the broader community in which the ICF is located? (e.g., at church, at festivals, fairs, movies, malls, sporting events)? *(Please circle)*

1 2 3 4 5

(b) My individual is involved in the following activities (circle all that apply):

Church Festivals Fairs Movies Shopping Sporting Events Restaurants Vocational Other

Question #9:

(a) To what extent does your resident have access to an adequate array of services and supports in a safe ICF environment? *(Please circle)*

1 2 3 4 5

(b) My individual's ICF offers the following services, supports and activities *(circle all that apply)*:

Vocational Recreation (e.g., swimming, sports, exercise, etc.) Transportation Medical Dental Religious
Music Equestrian Onsite shopping (e.g., thrift store, craft store) Art Other _____

Question #10:

(a) To what extent do you believe your individual's ICF home provides competent direct care staff who have a stable degree of longevity? *(Please circle)*

1 2 3 4 5

(b) Are your individual's direct care staff required to participate in ongoing training?

Yes No I don't know

(c) Are your individual's direct care staff subject to background checks before they are hired?

Yes No I don't know

Question #11: To what extent do you believe your individual receives quality medical care? *(Please circle)*

1 2 3 4 5

Question #12: Where does your individual regularly take part in some level of work for pay? *(Circle which answer below is most appropriate):*

My resident is unable to work Sheltered workshop Supported employment Competitive employment
Other: _____

Question #13: Would you be willing to share photo images of your individual interacting in a community activity for VOR advocacy usage? Yes or No *(please circle)*

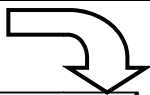
If YES, please provide information for us to follow-up with you. Your name: _____

Phone #: _____ E-mail: _____

Question #14: Would you be willing to ask others to become members of VOR? Yes or No *(Please circle)*

Question #15: What would you like our Government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities? (Use framed space below)

Please use this space and/or attach additional comments that you would like to share:



Survey #2 – Focus on: Other I/DD residential facilities (group home, home care, or other non ICF)

Based on your response to **Question #1** (page 1) your family member or ward resides in a setting other than an ICF or licensed residential I/DD facility. **Please take only one survey. Your survey will take about 5 minutes.**

Question #2: In what type facility does your individual reside? (Circle or fill in the blank):

- (a) Group Home:
 - 1. Small Group home (2-4 people)
 - 2. Medium sized Group Home (5-8 people)
 - 3. Large group home (9-16 people)
- (b) Resides with family
- (c) Other (please specify): _____

Question #3: In which state is your individual's residence located? _____ Name _____

Is the residence (Circle or fill in the blank):

- (a) State operated? (b) Private? (c) Other? _____ (specify)

Question #4:

- (a) What is the individual's age? _____ (b) What is the individual's gender? M or F (c) What is your age? _____

Question #5: What is your relationship to the individual? (*Please circle*)

- (a) Parent/guardian (b) Guardian (c) Other (please state): _____

Question #6: What is/are the main disabilities that affect your individual? List up to three as follows:

Most Serious Disability: _____

Additional Disability: _____

Additional Disability: _____

*Please answer the following questions using a scale of 1 (low) - 5 (high), circling your response. For each question, we encourage you to **provide any additional comments or examples** in our Comments section.*

Question #7: To what extent do you believe your individual is best served in the current non-ICF residential type?

1 2 3 4 5

Question #8: To what extent do you believe your individual would do better in a facility (e.g., ICF/IID) setting?

1 2 3 4 5

(a) Has your individual ever lived in an ICF or similar facility setting? Yes or No

(b) If yes, why did your individual leave the ICF residential setting? _____

(c) Has your individual ever left a facility for a smaller home, and had to return to the ICF or similar facility?

Yes or No (circle).

If yes, why? _____

Question #9: (a) To what extent does your individual interact with community outside of the current residence?

1 2 3 4 5

(b) My individual is involved in the following activities (check all that apply):

Church Festivals Fairs Movies Shopping Sporting Events Restaurants Vocational Other

Question #10: (a) To what extent does your individual have access to an adequate array of services and supports?

1 2 3 4 5

(b) My individual's residence offers the following services, supports and activities (check all that apply):

Vocational Recreation (e.g., swimming, sports, exercise, etc.) Transportation Medical Dental Religious
 Music Equestrian Onsite shopping (e.g., thrift store, craft store) Art Other _____

Question #11: (a) To what extent do you believe your individual's I/DD residence provides competent direct care staff who have a stable degree of longevity?

1 2 3 4 5 N/A (at my home)

(b) Are your individual's direct care staff required to participate in ongoing training?

Yes No I don't know N/A (at my home)

(c) Are your individual's direct care staff subject to background checks before they are hired?

Yes No I don't know N/A (at my home)

Question #12: To what extent do you believe your individual receives quality medical care?

1 2 3 4 5

Question #13: Where does your individual regularly take part in some level of work for pay? *(Circle which answer below is most appropriate):*

My resident is unable to work Sheltered workshop Supported employment Competitive employment
Other: _____

Question #14: Would you be willing to share photo images of your resident interacting in a community activity for VOR advocacy usage? Yes or No *(please circle)*

If YES, please provide information for us to follow-up with you. Your name: _____
 Phone #: _____ E-mail: _____

Question #15: Would you be willing to ask others to become members of VOR? Yes or No *(circle)*

Question #16: What would you like our Government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities? *(use framed space below)*

Please use this space and/or attach any additional comments that you would like to share:

Please use the enclosed reply envelope to return your survey and donations (optional) to:

Julie Huso, VOR Executive Director
 Attn: Survey Response
 3605 W. Ralph Rogers Rd., #106
 Sioux Falls, SD 57108
info@vor.net; 605-399-1631 fax

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