



GLENWOOD AND WOODWARD RESOURCE CENTERS ANNUAL REPORT OF BARRIERS TO INTEGRATION

Calendar Year 2017

Introduction

Purpose of this report:

The Department of Justice settlement with the state Resource Centers (RCs) in November 2004 includes an agreement that the major barriers to each individual's move to the most integrated setting will be identified. The information is to be collected, aggregated, and analyzed. Annually the information is to be used to produce a comprehensive assessment of barriers that is provided to the Mental Health and Disability Services Commission and other appropriate agencies. Per the settlement, "If this information indicates action that the State can take to overcome barriers, taking into account the statutory authority of the State, the resources available to the State and the needs of others with mental disabilities, a plan will be developed by the State and appropriate steps taken."

Subject of this report:

This report contains data about the identified barriers of all persons residing in the Resource Centers' Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IDs) programs as of December 31, 2017 and who have been identified as having at least one barrier to moving from the campus to a community setting. The data, analysis, and actions are for Glenwood Resource Center (GRC) and Woodward Resource Center (WRC) combined.

Number of Individuals Residing at Resource Center ICF/IDs
(December 31, 2017)

	Adults	Under Age 18
GRC	214	1
WRC	132	1
Total	346	2

Definition of barrier:

Barriers are defined as "what prevents an individual from living in the community." These barriers indicate there is a need to increase community service providers' capacity to effectively meet the needs described in the barriers and help to address concerns of the individual, guardian or legal representative regarding living successfully in an integrated community setting.

Barrier Data and Discussion**Major Barrier Prevalence**

(A person may, and often does, experience more than one barrier category)

Barrier	Definition	Minor %	Adult %
Interfering behavior makes it difficult to ensure safety for self and/or others	The person has significant interfering behavior that requires supports for a person's safety or the safety of others. Interfering behaviors most commonly included in this category are aggression toward housemates, co-workers or staff, self-injurious behaviors, unhealthy obsessions (Pica, water intoxication, etc.), leaving the home or work area without notifying staff if unsupervised time creates a risk of harm to self or others, sexual offending behavior or sexual assault, over-familiarity or sexual promiscuity that could lead to victimization, and fire-setting.	100%	64%
Under-developed social skills	The ability to practice what community members commonly consider appropriate social skills is significantly impaired and affects the person's housing, jobs, support staff, or housemates. Examples include extreme screaming, repeated verbal threats that result in concerns about safety for others, multiple unfounded accusations against staff, repeatedly invading personal space, inappropriate touch, loud or rude behavior that disrupts housemates' sleep or ability to interact with others.	50%	20%
Health and safety	The person has multiple, severe, and/or sensitive health concerns that contribute to very fragile health and complex health care needs. The person may be unable to verbally report symptoms or accurately identify and request assistance with symptoms that could indicate that their health is at risk. The person may require specialized medical treatment and/or monitoring that is not readily available in the area of choice or the level of care they would prefer (e.g. assistance with monitoring and administering injections for diabetes, fast and frequent access to monitoring/adjustment of adaptive equipment).	0%	17%
Individual, family or guardian reluctance	Individual, family and guardian reluctance to moving from RC environment to community supports. Examples of concerns cited are community providers' ability to provide the level of support necessary for success, lack of a safety net when support needs become more intense, family member has lived in the RC setting for many years and considers it to be their home, difficult adjustment to change, community ability to provide the medical support and consistency of care as provided at the RC.	0%	60%

Discussion

Category: Safety due to Interfering Behavior

This includes safety of the individual, as in areas of self-injury, leaving the home or work area without notifying staff if unsupervised time creates a risk of harm, behavior toward others that invites others to cause harm to the individual, or lack of understanding of situations that place the individual at risk. A second, but equally important concern is safety of others, such as situations involving aggression, sexual assault, or fire-setting. The cost and ability to hire and maintain staff and training to provide these supports at the frequency, consistency, or level of need for the individuals served in the RCs often can be a challenge, especially for community providers. To be included in this category, interfering behavior(s) have been determined to currently be at a level of frequency or intensity that the supports needed are greater than are commonly offered by community providers. The percentage of people experiencing this barrier has risen slightly at 60% in 2014, 61% in 2015 and 2016, and 64% in 2017.

Category: Underdeveloped Social Skills

This area has to do with a need for further social skill development. Disruptive behavior is at a level of intensity that people around the person are unwilling or unable to tolerate living, working or socializing with the individual and making it very difficult for the individual to find housing, work, and staff support. Housemates may not have the opportunity to participate in activities because this person has to be removed from social events, the provider may have difficulty maintaining consistent staff due to burn out or repeated threats and accusations, staff may have difficulty supporting others in the setting because of the intensity of need of this person. The number of people experiencing this barrier decreased from 35% of adults in 2012 to 25% in 2013, 11 % in 2014, and 8% in 2015. The number increased slightly to 9.6% in 2016 and significantly to 20% in 2017. The significant increase in 2017 may be due to a closer look at some of the people who have reluctant guardians and whether there were additional barriers beyond guardian reluctance.

Category: Health

This category has to do with individuals with significant medical needs. Barriers tend to be grouped into two specific areas. Often these individuals are older and are medically fragile; they frequently experience communication difficulties and rely on staff who knows them well enough to understand non-verbal signals and recognize signs of discomfort or medical need. Health is fragile enough that without staff ability to quickly recognize early and subtle signs of illness, the persons' health would be compromised. The other area is the need for quick access to adjustment and repairs for adaptive equipment (lifts, wheelchairs, bath carts, etc.) and the supports provided by quick access to professionals available at the RCs (doctors, nurses, physical, occupational and speech therapists on grounds or on call). It is difficult for many guardians to consider a move to a setting where those resources may not be as readily available. The number of people experiencing this barrier was 30% of adults in 2011, 2012, and 2013 and decreased to 22% in 2014, 20% in 2015, and 16% in 2016. There was a slight increase to 17% in 2017. The decreasing trend may have in part been due to more accurately determining what things are actual barriers. Other factors include some individuals passing away and some individuals moving to hospice or a skilled health care setting.

Category: Family/Guardian Reluctance

For many of the older individuals living in the Resource Centers, families have indicated that this has been their home for many years, and have expressed concern that a move would cause significant stress and loss for the person. For others, the move to the RC occurred following multiple discharges from community providers' services. Family members often react emotionally when approached about transitions to community services; they talk about their fears that a move to a community setting may not last, that their loved one will experience a long-term hospitalization due to a lack of community services to meet their support needs or that family members will be required to provide a home and care without enough support available to them. Family members express concern that the health of their loved one will be in jeopardy without the health care services at the RC and the trained, long term staff who know the person well and can identify early signs of a health concern. The number of people experiencing this barrier increased from 61% of adults in 2012 to 68% in 2013. The percentage continued nearly steady at 69% in 2014 and 68% in 2015 and 2016. In 2017 there was a decrease to 60%. We believe one reason for this decrease is the result of many years of continued efforts by the social workers talking with guardians about discharge planning. Another reason is that some individuals who had lived at the RCs many years passed away. A final reason is that the guardians of quite a few of the people who moved into a RC in 2017 support the person moving out again.

Additional Comments:

We did not include data on lack of jobs or day activity as a barrier area because it is often not identified formally until a specific transition is being pursued. It is still important to note that this is a large concern. Day activity is key to success for many people, whether employment related or in a structured activity or volunteer setting. Meaningful day activity may be important for self-esteem, social, earning, and structure of the day. Lack of meaningful activity often leads to difficulty with interfering behaviors. Another barrier we continued to hear identified by community providers is difficulty finding staff to hire in order to support current programs or to expand services. An additional barrier we continued to hear is whether the managed care organizations will consistently reimburse providers at high enough rates to be able to support individuals with higher needs. A new concern we heard since the implementation of tiered rates for ID waiver is that sometimes the payment rate is not enough to provide the needed level of staff support.

County Preference by Age Range & Gender

While some individuals have specified counties, cities and even neighborhoods where they would prefer to live, the people served at RCs have often searched for support options in those areas without success prior to their move to the RC. Many have indicated that they would consider options near, rather than in, their chosen area, in order to move more quickly back to the community setting. See Appendix A for map of regions.

REGION	AGE RANGE	MALE	FEMALE	Total
Central Iowa	Under 18			
	18 to 25	3		3
	26 to 40	25	5	30
	41 to 65	18	7	25
	Over 65	5	4	9
East Central Iowa	Under 18			
	18 to 25	2	1	3
	26 to 40	5	1	6
	41 to 65	4	4	8
	Over 65	2		2
North Central Iowa	Under 18			
	18 to 25	1		1
	26 to 40	3		3
	41 to 65	3	3	6
	Over 65	1	1	2
Northwest Iowa	Under 18			
	18 to 25			
	26 to 40	4		4
	41 to 65	2		2
	Over 65		1	1
Northeast Iowa	Under 18			
	18 to 25	1	1	2
	26 to 40	6		6
	41 to 65	3	3	6
	Over 65	2	1	3
South Central Iowa	Under 18			
	18 to 25		1	1
	26 to 40	1	1	2
	41 to 65	1		1
	Over 65			
Southeast Iowa	Under 18			
	18 to 25	2		2
	26 to 40	3		3
	41 to 65	1		1
	Over 65			
Southwest Iowa	Under 18	1		1
	18 to 25	4	1	5
	26 to 40	9	14	23
	41 to 65	17	5	22
	Over 65	3		3
West Central Iowa	Under 18			
	18 to 25	1		1
	26 to 40	2		2
	41 to 65			

REGION	AGE RANGE	MALE	FEMALE	Total
	Over 65		1	1
Out of State	Under 18			
	18 to 25			
	26 to 40			
	41 to 65	1		1
	Over 65			
Whole State	Under 18			
	18 to 25	1		1
	26 to 40	1		1
	41 to 65	3		3
	Over 65			
No Preference identified	Under 18			
	18 to 25	4		4
	26 to 40	15	6	21
	41 to 65	77	20	97
	Over 65	24	4	28

Actions this Reporting Period

Overall

- Expanded Medicaid managed care, IA Health Link, has been effective since April 1, 2016. The case managers from the Managed Care Organization (MCOs) cover most individuals living at the Resource Centers (RCs). The MCO Case managers assigned to individuals at the Resource Centers are included as Interdisciplinary Team (IDT) members. Members served by AmeriHealth Caritas transitioned to UnitedHealthcare in December 2017. Case managers met individuals, were given each individual's Individual Support Plan which includes information about preferences related to moving out and barriers to that, and began participating in some meetings and routinely receiving information. For people with Money Follows the Person (MFP), MFP transition specialists and MCO case managers were provided each other's contact information to assist in working together. The case managers are a resource in the transitioning process.
- Continued to welcome providers to meet with us to learn about the support needs of individuals living at the RCs.
- Providers continued to visit people on campus and individuals continued to visit providers.
- For people moving in, typically requested guardian permission and if approved, made a referral to MFP grant services at or prior to a person's admission to the RC for assignment of a Transition Specialist.

- MFP transition specialists provided us some information about provider openings.
- Encouraged new providers or expanding providers to develop services in areas identified by families as needed.
- Participated in the start of an Amerigroup project identifying people to move out of WRC.

Interfering Behavior and Underdeveloped Social Skills in the Resource Centers

- Provided therapy and counseling support services at the RCs within groups and individually. Some topics and interventions include social skills; Dialectical Behavior Therapy (DBT) including mindfulness, anger management, and interpersonal communication skills; human sexuality; sex offender; social boundaries; reality therapy, victim support; positive life skills; relationships; problem solving.
- Used the trauma screening tool to ensure that all mental health needs are being covered for the persons in residence at GRC.
- Provided DBT training for new staff at orientation and offered this training as needed to individual team members. We trained the 'Replacing Buts with Ands' skill from Acceptance and Commitment Therapy (ACT) at the WRC annual staff Skills Fair.
- Expanded and improved skills and training in applied behavioral analysis, positive behavior supports, DBT, sex offender treatment, and acceptance and commitment therapy.
- Expanded and improved skills in working with individuals with inappropriate sexual behavior through literature reviews.
- Continued learning and incorporating ACT into practice – groups, programming, and individual.
- Continued developing curriculum using the Good Lives Model of sex offender treatment
- The FACT (Functional Analysis Clinical Team) provided consultations for individuals on campus.
- Offered consultation and training to providers regarding people who do not live at the RCs. This expands provider skills, which may increase their ability to eventually support individuals moving from the Resource Centers. For the time period December 2016 - November 2017, the I-TABS program (Iowa Technical Assistance and Behavior Support program) provided support to 188 stakeholders via on-site and/or phone peer reviews and consultations, responded to requests for information from numerous callers, and did

37 presentations reaching 1588 attendees. Training topics included Autism: Introduction, Autism/Sexual Offending, Helping Relationship, I-TABS Overview, Feeling Hurt Without Hurting Back, Validation, Supporting Psychological Needs/Trauma, Clinical Behavior Analysis: Intro., Sexuality in Nursing Facilities, Behaviorally Based Treatment Plans, Reducing Aggression, Psychotropic Medication Advocacy, Building Agency Wide Capacity to Support Individuals Who have Experienced Trauma, Tips for Case Managers: Autism Spectrum Disorder, Personality Disorders, Sexually Concerning Behavior, Therapy; Relational Frame Theory: Intro., Analyzing and Managing Challenging Behaviors. Audiences for training included Residential and Vocational Service Providers, Nursing Facilities, MCOs, EMS Conference, Mental Health Conference, Iowa Mental Health Counselors Association Conference, Cherokee MHI Conference, Iowa Medicaid PASRR, Courage League, Iowa's Board for the Treatment of Sexual Abusers (IBTSA), Des Moines Foster Grandparents, and Iowa Veteran's Home.

- I-TABS noted these trends:
 - Members: Youth/adolescent; complex/multi-faceted needs involving child and parent; referral for person supported in previous years; multi – meeting/year cases.
 - MCOs: AmeriHealth made the most referrals.
 - Provider consultations: Limited staff, tier rates, less staff attends consultations.
 - Continuing increase in Board Certified Behavior Analysts (BCBAs) employed directly by provider agencies.
 - Increased interest in ACT and relational frame theory and related strategies.

- Agencies, both residential and vocational/day activity, received training as part of individuals' transitioning to their services. Topics included such things as individual routines, communication techniques, behavioral support plans, anticipated adjustment behavior, and autism. Training involved agency staff spending time at the RCs shadowing RC staff, RC staff spending time at the agency prior to move, day of move, and some overnights following move. If the individual had a day activity or job site, RC staff also accompanied individuals there and assisted staff as they helped the person adjust to new tasks and environments. A variety of staff were involved in providing the training such as direct support staff, supervisors, treatment program managers, psychologists, psychology assistants, physical nutritional management specialists, vocational staff, and social workers. Follow-up training was provided as needed during the transition period.

- The Autism Resource Team continued providing training to all new WRC staff at orientation and consulting to the teams on campus.

- WRC provided services to individuals on campus in the area of inappropriate sexual behavior through the APPLE team which included staff trained by the Iowa Board for the

Treatment of Sex Abusers. The APPLE team provided consultation and training to community providers regarding people they are serving in the community at this time.

- A Drake student in the area of applied behavior analysis completed an internship with the WRC Psychology Department.

Family/Person Reluctance

- Continued sending the guardians/families information about MFP and a provider list from the person's area of choice with the invitation to the person's annual review.
- Involved RC staff beyond social workers in visits with providers and follow-up visits to increase staff's comfort level with moves which in turn may increase confidence of families and individuals living at the RCs that community services can be successful in supporting an individual.
- Encouraged and assisted people to identify a preferred area of the state to live in so we can provide more detailed information about services available in that area and encourage guardians to develop relationships with providers and coordinators of disability services in the regions and educate them on the support needs of the individuals.
- Invited families to visit providers with us.
- Shared stories about people who have successfully moved via individual discussions with guardians and family.
- Interdisciplinary teams continued to talk with guardians reluctant to move to obtain more specific information about their concerns in order to address those.
- Worked with MFP in the statewide stakeholder's workgroup.
- Social workers continued to familiarize themselves with services and supports available across the state through visits to providers and providers meeting with the social work department on campus. Information about services available are shared with families/guardians as providers are identified who may be able to meet the needs of each individual.
- Social workers continue to have more frank discussions with guardians on census reduction, house consolidation, and general characteristics of the individuals who typically move into the RCs.
- Discussion with MCO case managers about guardian reluctance and the reasons. Some involvement from the case managers in talking with guardians.

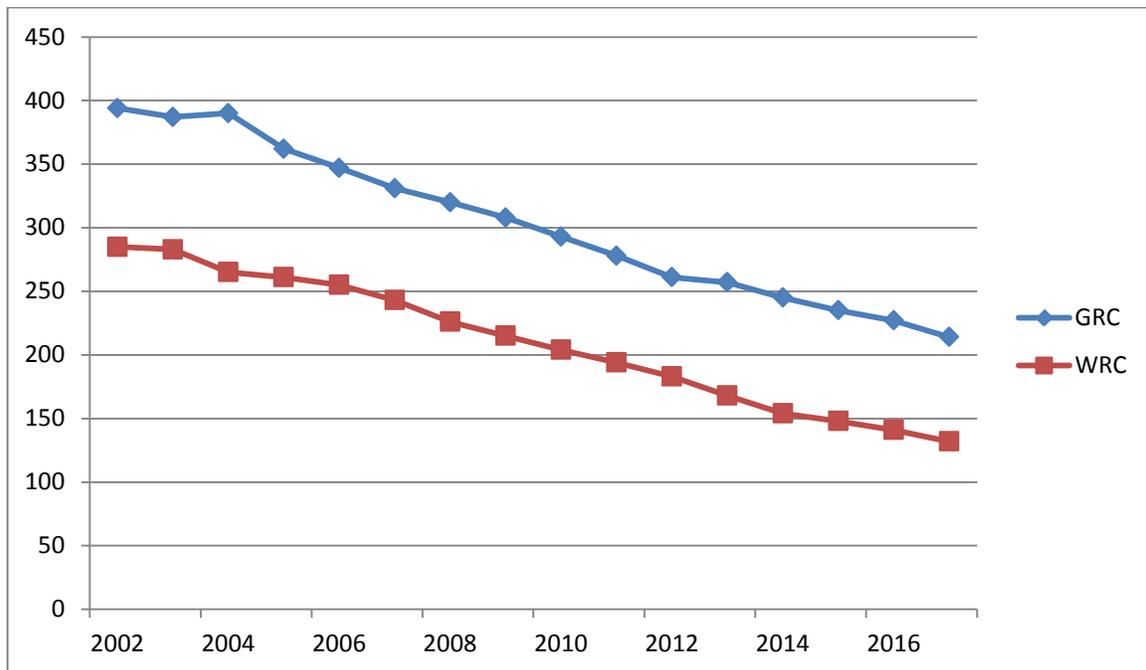
Health

- Increased our knowledge of community providers' ability to provide health supports.
- Increased our awareness of providers who offer accessible housing and transportation via visits to providers, provider visits to campus.

Vocational

- Worked with the vocational specialist with the MFP grant.
- Implemented changes to the Workforce Innovation and Opportunity Act. This included educating individuals and providers about their rights to work in the community and making referrals to Iowa Vocational Rehabilitation Services as requested.

Census Reduction



The census of the RCs has decreased as people have successfully moved to services with community providers. For a number of years, the RCs have had a specific census reduction goal and have accomplished this through helping people secure services with community providers and helping prevent the need for people to move in.

The RCs are committed to continuing to help people move to and stay in the communities of their choice. Some of the actions taken to accomplish this include:

- Educating others about the RCs' shift in role to shorter rather than long term residential services.

- An RC admission inquiry process that focuses on preventing the need for admission
- Treatment focus on the specific reasons the community providers are unable to support the person.
- Changing practices at the RCs to replicate what people experience living in the community.

The RCs place an emphasis on ensuring that people are moving with the appropriate services and supports to meet their needs and the moves can therefore be successful. The transition process includes:

- Comprehensive functional assessment to ensure essential supports for health and safety are identified
- A written transition plan developed by the IDT including the person, family/guardian, community provider(s), and case manager and includes a crisis plan.
- An individualized physical transition process that includes the person having visits from the provider staff and making visits to their new home before the move.
- Training of provider staff by the RC staff.
- Follow-up by the RC staff after the move.
- Inclusion of the case manager throughout the planning and move process and transfer of oversight to the case manager for follow-up after discharge from the RC

AREA OF CHOICE-MAP OF REGIONS

