

HCBS and Waiver Redesign

The central tenet of the LifeCourse Framework is that all people have the right to live, love, work, learn, participate, play and pursue their dreams in their community. To accomplish this tenet and achieve their vision for a good life, people need a place to live, meaningful activities to do, and friends. Home and community based services (HCBS) provide opportunities for people with intellectual and developmental disabilities (IDD) and other Medicaid recipients to receive services in their own home or community. Since the 1990s when the state shifted funding from state-operated facilities to expanded community-based supports and services through our Medicaid waivers, Indiana has made great strides toward ensuring access to community-based supports.

Although we have made notable progress in ensuring access to the community and community-based supports, there is still work needed to address challenges faced by individuals and families every day and barriers obstructing them from accessing the community to the greatest extent possible.

Housing

Safe, affordable, accessible housing is an essential component of a good life for all people. In order for people to have the highest level of independence possible, they must have an affordable, accessible, safe place to live. Outside of the family home, the majority of people with IDD rent apartments or live with other people with IDD in rented houses. We anticipate that the demand for safe, affordable, accessible housing will continue to increase as more individuals transition from living in the family home to living independently.

Indiana already faces a critical shortage of safe, affordable, accessible housing options. Although there are many housing initiatives supported by HUD and the Indiana Housing and Community Development Authority, there is still an insufficient supply of housing to meet the demand. Recognizing this need, service providers for people with IDD have created housing options for individuals with IDD using a variety of federally-funded home loans or supported housing federal funds including Rental Housing Tax Credits (RHTC), HOME Investment Partnerships Act, and Affordable Housing Program (AHP) Federal Home Loan Bank funds. However, those programs often require only individuals with disabilities or only individuals who are elderly to live in those federally funded settings.

Housing options must complement HCBS options in order for individuals with IDD to fully live and participate in the community. We recommend that the Task Force adopt the housing recommendations presented to the Task Force on June 27, 2018, by Jason Meyer, Passages, Inc.; John Niederman, Pathfinder Services, Inc.; and Andy Rosentahl and Len Grabovsky, Terebinth Group, LLC.

Recommendation: Adopt the housing recommendations presented to the Task Force on June 27, 2018, by Jason Meyer, Passages, Inc.; John Niederman, Pathfinder Services, Inc.; and Andy Rosentahl and Len Grabovsky, Terebinth Group, LLC.¹

¹ See presentations from the June 27, 2018 Task Force meeting for additional information.

HCBS Rule Compliance

The Home and Community Based Services (HCBS) Settings Rule was released by the Centers for Medicare & Medicaid Services (CMS) in January 2014. The Rule reflects the intent by CMS to ensure that individuals receiving services and supports through Medicaid's HCBS program have full access to the benefits of community living and are able to receive services in the most integrated settings, emphasizing choices, access, and an array of options. The Rule defines and describes the residential and non-residential settings that are considered to be home and community-based and outlined requirements for compliance that must be attained by March of 2019. Each state must develop a plan to transition to compliance with the Rule. Indiana's plan received initial approval in November 2016. In 2017, the Division of Disability and Rehabilitative Services (DDRS) conducted assessments of settings where residential and non-residential services are delivered through the waivers they administer. In May 2017, CMS extended the time period to be compliant from March of 2019 to March of 2022. We anticipate that CMS may issue some additional guidance regarding the heightened scrutiny process, but other compliance decisions and implementation activities will be left to the discretion of states.

To date, providers are still awaiting the results of their residential and non-residential assessments and information regarding remediation actions needed to achieve full compliance. DDRS is re-convening a workgroup of stakeholders that last met in 2016 to assist them in working through implementation issues. While we appreciate the State's stakeholder engagement in working through implementation issues, we encourage the state to expeditiously communicate needed remediation activities to allow providers as much time as possible to complete them and achieve full compliance.

In light of the core concepts of choice, access, and an array of options, we recommend that the HCBS compliance activities in Indiana focus on:

- more choices in people's lives
- improved person-centered planning and behavior through the LifeCourse Framework
- continue improving on the day habilitation and employment supports we have
- increased engagement and participation in our communities
- more experiences in small groups of people in non facility-based settings
- a full day of meaningful activities from an array of options including paid employment, volunteer experiences, and recreational activities
- greater variety of facility-based experiences including using technology to experience and interact with our environment
- Empowering individuals with IDD to experience and be a part of well planned, exciting change around the array of choices, options and experiences created for individuals with IDD²

While we want to focus on improving on what we have in the short term, we believe that Indiana's HCBS delivery system and waivers create barriers to achieving full access to the benefits of community living and ensuring that individuals receive services in the most integrated settings. Achieving the full intent of the HCBS rule with an emphasis on choices, access, and an array of options will require long term transformational systems change, including a redesign of Indiana's HCBS delivery system and waivers.

² See Appendix A - HCBS Solutions presentation dated July 23, 2018 for additional information.

Waiver Redesign

Throughout the public comment portion of the six previous 1102 Task Force meetings, many family members and individuals with IDD have indicated that the current system of HCBS service delivery, the two current DDRS HCBS waivers, and the current mix of services available on each waiver are not meeting the needs of individuals with IDD and their families. Comments have indicated that the current waivers and services are not flexible enough, and systems are currently too siloed for families to understand and be able to obtain the supports they need for their loved ones.

The two current DDRS administered waivers were implemented in 2013. The CIH waiver replaced the Autism and Developmental Disabilities (DD) waivers and the Supports Service Waiver was changed to the FS waiver. These changes were important steps forward in addressing the needs of Hoosiers with IDD and families as they were identified at the time. Since then, the needs and preferences of Hoosiers with IDD and their families, as well as the demographics of individuals receiving services, have changed significantly. More than 5,000 individuals under the age of 18 are now receiving services through the DDRS waivers. The vast majority of individuals on the FSW live with their family, while the majority of individuals on the CIHW live in shared living settings.³

For SFY 2016, the top services utilized on the CIHW were RHS Hourly, Behavior Management, Transportation, and Community Habilitation Individual. Conversely, the top services utilized for the FSW over the same time period were Participant Assistance and Care, Behavior Management, Respite, and Facility Habilitation Group. The differing levels of utilization of services on each waiver further highlights the differences in demographics and living situation of individuals served. The spend data illustrates a clear dichotomy between individuals who are receiving an average of \$8,667 in services on the FSW and individuals receiving an average of \$70,686 in services on the CIHW. With up to \$17,300 in services available under the artificial cap but average FSW service utilization remaining fairly steady around \$8,000, the data supports anecdotal information from individuals and families that the mix of services currently available on that waiver are not adequate to meet individuals' needs, particularly the individuals under the age of 18.

In redesigning Indiana's HCBS waivers, DDRS has the opportunity to develop a navigable, person-centered system that promotes quality of life, quality of care, and the individual's freedom to choose from an array of services, and addresses the individual's needs across their lifespan. The redesigned waiver and services should be flexible enough to meet each person's individual needs, whether the individual needs only a few hours of case management per month or the individual needs 24/7 wrap-around residential, behavioral, and medical supports. Individuals and families need to have confidence that as their needs change, the type and amount of waiver supports they receive will also change.

DDRS could develop a waiver with tiers based on the level of need of the individual and their LifeCourse Trajectory and vision for a good life. For example, an individual living with his/her family might need minimal waiver supports, and a lower waiver tier would allow the individual to receive services such as Case Management, Respite, and at home educational activities. An individual who is highly independent but needs some assistance in maintaining their employment might receive an intermediate tier of waiver supports to receive Case Management and Extended Services. Individuals who needs more physical assistance with activities of daily

³ See Data Specifics Required by HEA 1102 presentation from the February 23, 2018 Task Force meeting for additional information.

living but wants to transition out of the family home could receive a higher tier of waiver supports, allowing them to receive wrap-around services.

Additionally, building on the foundation of existing services that currently meet individuals' needs, DDRS can modify these services as needed to increase their flexibility and person-centeredness. Information conveyed by individuals and families in public comments to the Task Force can serve as a starting point to identify gaps and needed additions to the array of services. DDRS can also implement innovative service delivery approaches such as individuals with IDD serving as peer support staff to other individuals.

Recommended Modifications and Additional Services:

- Transportation –Increase the number of trips available per day to ensure flexibility and person-centeredness of service, decrease one of the most significant barriers to community access
- Day Services The current reimbursement system for day services based on staffing ratios is a deterrent to individual choice and is not person-centered. In 2016, INARF provided a proposal regarding a day service model that would better promote community integration and choice, and we recommend that DDRS consider this model when redesigning the waivers
- Family Caregiver Training Broaden the service definition to include coverage of training materials, programs, workshops, and conferences. Incentivize participation in the service
- Broaden the service definitions for waiver services supporting employment to increase flexibility and utilization to support more people working in the community
- Modify the Wellness Coordination service to increase flexibility and person-centered approach to address individuals' changing medical needs, allow telemedicine
- Modify services available on waivers administered by the Division of Aging and the Division of Disability and Rehabilitative Services as needed to allow shared staffing
- Self-Directed Services options for individuals and families to determine how they will use services (see Massachusetts, Wisconsin, Connecticut models)
- Use of Peer Specialists to teach and train other individuals with IDD
- Incentivize connecting to natural unpaid supports⁴

Additionally, CMS recently affirmed its support for the incorporation of technology in the delivery of services to people with disabilities under HCBS programs. Indiana has been a leader in implementing technologies such as electronic monitoring in HCBS, and we have the opportunity to continue to do so with emerging technologies such as virtual assistants, home automation systems, online grocery ordering and delivery, ridesharing, and many others. As DDRS redesigns the waiver, we encourage you to include flexibility for implementing emerging technologies to promote independence for individuals, stimulate innovation in service delivery, and assist in alleviating the DSP workforce shortage.

Recommendations:

- DDRS to develop a comprehensive waiver with a full array of services and tiered supports to ensure flexibility of services and systems to meet the unique needs of all individuals served, accounting for age, family support systems, behavioral and mental health needs, and health factors.
- DDRS to convene a group of diverse stakeholders to assist with waiver redesign
- DDRS to encourage the use of emerging technology in HCBS waiver service delivery

⁴ See Appendix B for additional recommendations from the INARF Membership Development Committee.



July 23, 2018



Background

- March 2014 CMS issued federal waiver rules after a ten year rule making process and after over 30 years of HCBS waiver services.
- March 2014 started a long waiting period for guidance on "what we should do".
- In May 2017, CMS extended the time period to be compliant from March of 2019 to March of 2022.



Members, their boards, individuals they support, and families have been engaged in local discussions on what would help the IDD system do a better job for individuals with IDD and their families.

Approximately 10,000 family members and over 7,500 individuals with IDD have responded

- Board Meetings
- Consumer "speak outs"
- Family and consumer meetings
- Consumer surveys
- Family surveys



What is important for families

- Supports for individuals that enable family members to work; economic security
- Supports for individuals that enable family caregivers to have respite and experience at least some periodic relief from care giving
- Peace of mind knowing that their loved one will have a place to live, people who care, and something meaningful to do each day



What is important for consumers

- Friends
- Family
- Not feeling lonely
- Work
- "Things to Do"
- Purchase power: "buy things"
- Transportation
- Housing, "home"
- Church
- "Going Places"; "New and Favorite Places"
- Art



CMS more recently has communicated that they are focused mostly on additional guidance on heightened scrutiny; stop waiting, start improving your current level of community integration.

What do you want?



What do we want?

- We includes consumers, their families, and INARF members
- We want more choices in people's lives
- We want to stop waiting and start improving on what we have (four years [2014 to 2018] is a long time to be stuck in neutral)
- We want more than access and presence in our communities – we want engagement and participation



What do we want?

- More experiences in small groups of people in non facility-based settings
- A full day of meaningful activities from an array of options including paid employment, volunteer experiences, and recreational activities
- Greater variety of facility-based experiences including using technology to experience and interact with our environment

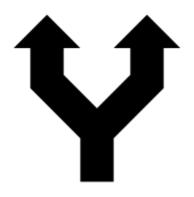


What do we want?

 We want to experience and be a part of well planned, exciting change around the array of choices, options and experiences created for individuals with IDD.



IDD Facility-Based Experiences



Experiences utilizing resources and businesses in the communities where people live other than IDD facility-based experiences

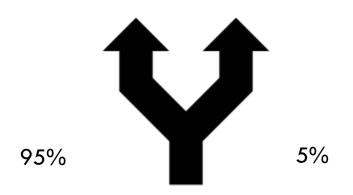
Access to Community

Less Integrated

More Integrated



IDD Facility-Based Experiences



Experiences utilizing resources and businesses in the communities where people live other than IDD facility-based experiences

Access to Community

Less Integrated

More Integrated



We can do better



Better with offering choices to individuals with IDD

Daily

Weekly

Monthly

Annually

Life

INARF will provide technical assistance to members in order to create a culture of offering choices to individuals in all aspects of their lives.



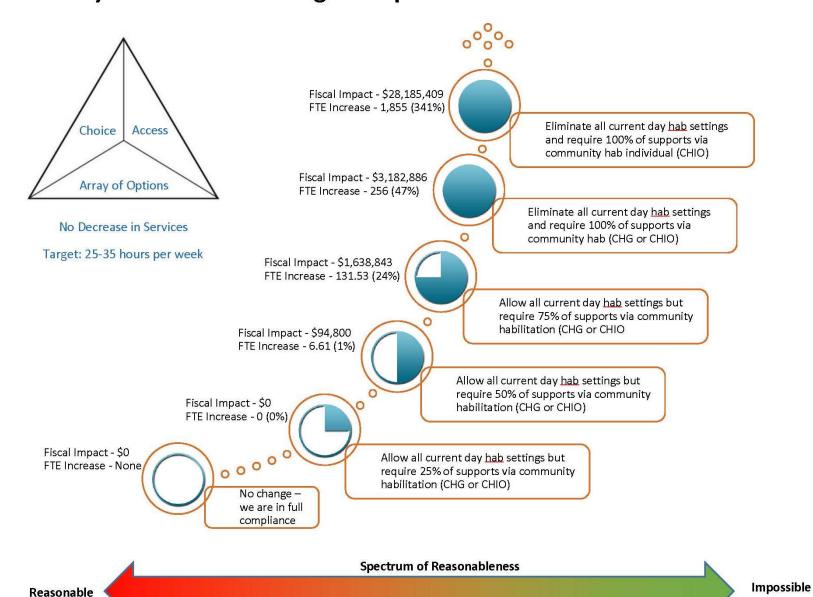
We can do better by having individuals in less facilitybased experiences and more community based experiences.



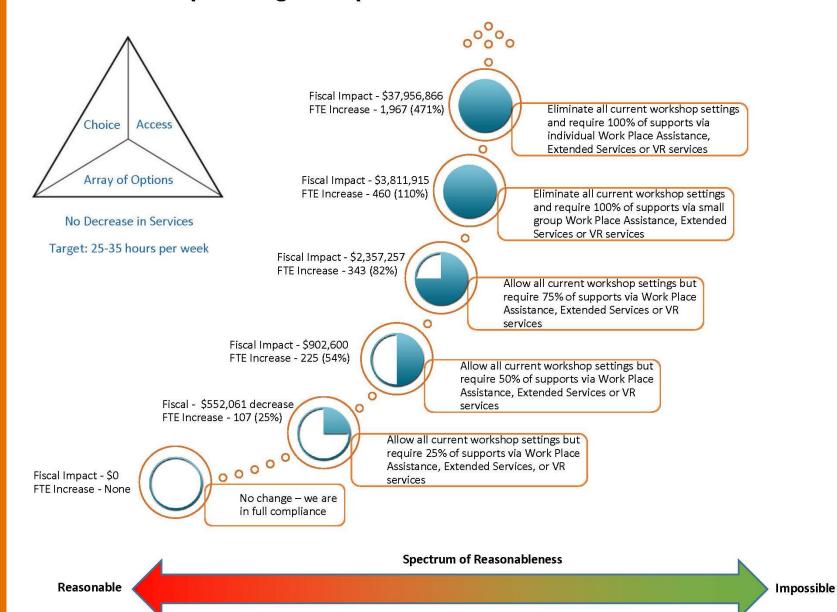
Keys to Success

- Start doing and stop waiting
- More and better paid direct support staff this will be one of our 2019 legislative priorities
- Technical assistance, especially around offering choice –
 INARF will provide technical assistance to its members
- More age and developmentally appropriate facility-based activities
- Delivering more services in the community will require more funding because smaller community groups cost more than large facility-based groups
- Refer all individuals in workshops to VR services

HCBS Day Habilitation Settings Compliance



HCBS Workshop Settings Compliance



HCBS Residential Settings Compliance



No change – we are in full compliance



Allow congregate settings such as apartments or grouped single family homes up to 8 individuals total



Allow congregate settings such as apartments or grouped single family homes up to 24 individuals total



Place no limits on group residential configurations/locations

Choice Access

Array of Options



Timeline

September -December

INARF to Conduct Member Training and Education

July -December

Community Habilitation experiences move from 5% to 10%

January -December

Community Habilitation experiences move from 15% to 20%



2018



2019



2020



2021



2022



January -June

INARF to provide Individual **Technical** Assistance to **Members**

January -December

Community Habilitation experiences move from 10% to 15% January -December

Community Habilitation experiences move from 20% to 25%



The rule reflects the intent by CMS to ensure that individuals receiving services and supports through Medicaid's HCBS program have full access to the benefits of community living and are able to receive services in the most integrated settings.



We believe our proposed solutions are congruent with the FSSA & ISDH Settings Rule Transition Value Statement to "realign incentives to support a navigable, person-centered system that promotes quality of life, quality of care, and the individual's freedom to choose if he/she resides in a community-based setting."



2018 Membership Development Committee Workgroup

Workgroup Issue Brief

Topic: Medicaid Waiver Rewrite

Team Members:

Angie Tyler, Chris Nabors, Lyn Feldman, Donna Elbrecht, John Niederman, Kristine Turner, Marcie Brabenter, Mindy Dupler-Singer, Steve Hobby, Todd Fricke, Yolanda Kincaid, Carmela Toler, Pam Verbarg

Purpose / Reason for Creation:

Provide a brief purpose statement for the topic.

The purpose of this workgroup is to look at potential of waiver rewrite. The state has indicated an interest in rewriting the waiver to align with the Lifecourse Framework in response to the HCBS Rule. Providers want to be sure any changes in the waiver are focused on dealing with issues with the current system as well.

Data Collected:

Provide insight as to the data used and/or research conducted to develop your recommendation(s).

Research done on both HCBS compliance plans and waiver documents for the states listed in the Actions Section.

Actions Taken:

Provide a brief update of action taken to date.

Reviews of the following:

- HCBS Transition Plan and recent update from the State
- Review of notes related to Extended Services (from VR Workgroup)
- Review of various Family Caregiver training opportunities (Indiana, Kentucky, Tennessee, Nebraska, Ohio)
- Review of other states including those with comprehensive waivers: Connecticut, Arizona, Colorado, Virginia, Georgia, Pennsylvania
- Compilation of current issues with Indiana Waiver Services
- Compilation of critical components of Indiana Waiver Services moving forward.

Current Status:

Provide a brief purpose statement for the topic.

Current Pain Points/Challenges/Barriers

- Wellness coordination is not sufficiently reimbursed and requirements to get the monthly fee
 <u>structure</u> needs reconsidered (the weekly/monthly consults/face to face)
- Consistent staffing especially with those who have high behavioral needs adequate training, and sustaining those staff
- Insufficient family supports
- Inability to share staff with different waivers
- When medical needs become greater than the disability needs and ability to manage in the person's home – and nursing facilities that are not able to meet the person's behaviors or disability needs.

- Inappropriate service mix for kids
- Lack of incentive for true community integration
- Transportation lacking ability to link people to services, especially in rural areas insufficient for individuals with physical disability needs
- Problems with extended services and what is included in that
- Staff training no training for specialized needs burden on providers to develop their own.
- Complexity in day services delivery and billing
- Due to limited CMS guidance, lack of clarity on the direction of service compliance with the HCBS Rule, especially for day services and prevocational services, and the isolation of residential sites issues.
- Addressing challenges of providing services in rural areas
 - Limited jobs
 - Limited transportation options
 - Limited opportunities for community integration
 - o Potential for geographic rates based on area demographics
 - Staffing when limited populations and limited numbers of providers
- Community integration expectations for individuals with high behavioral needs and those in need of accessible vans (with limited mobility).
- Lack of specialized services for individuals with dementia and memory care needs
- Lack of uniform crisis services.
- Concerns that managed care could negatively impact the services for persons served.

Components that should be considered in waiver rewrite:

- Comprehensive Waiver able to meet people's needs at different life phases, needs, etc.
- Assessment Tool and criteria which fits age, disability, life phase, etc.
- Self-Directed Services options for families to determine how they will use services (see Massachusetts model – both with and without providers – Wisconsin. Connecticut)
- Services which meet needs at different life phases: such as senior, family training, specific health needs, etc.
- Family Training (see attachment) some states have an annual limit, others have hourly rate (look at requirements for the trainer) online training platform considered reimbursable
- Technology use electronic monitoring, adaptive equipment, allowable use of "facetime" for mentoring, support
- Wellness especially telemedicine consider a monthly rate that has a better reimbursement rate that is tied to the tier of expected services rather than a specific number of consults/face to face visits. This will allow greater flexibility and avoids excessive time documenting services in very small intervals.
- Additional flexibility in Extended Services for individuals in community employment (see attachment)
- Transportation in some states, they roll it into the waiver less administrative burden if rolled in. Would need to account for needs (accessibility needs) something that shows how the transportation rolls in. Rural transportation as a barrier to employment is an issue)
- If cost based, reimbursement need to show the costs of the service breaking it down (W VA)
- It would be nice if the TBI and A&D waivers were set up like the CIH waiver had the same services and would allow for shared staffing.
- BDDS has set up a training program that everyone uses for Core A and Core B. It would be
 nice to have some other certified courses such as for Tube Feeding, Seizures, and
 Diabetes...
- Community Integration is generally not too difficult for ambulatory individuals. It becomes
 more of a problem with individuals in wheelchairs and those with high behavior needs or
 those that damage the vehicles they ride in. Maybe our focus needs to be on this group and
 what is needed to incentivize community integration.

- Defining what is meant by community integration might be helpful. Just the number of times one leaves one's home is far different than getting out in the community with 1:1 staff so as to get the attention needed to develop skills and become more involved in the community.
- Resources for managing memory care and dementia needs.
- Uniform crisis intervention. Need for a statewide system of supports for individuals in crisis.
 Need to consider behavioral needs, mental health needs, housing emergencies and other needs that may arise.
- Address issues of rural areas such as transportation, staffing, jobs, community integration opportunities.
- Employment opportunities for persons with disabilities which allow for choice and meets their needs. See Sheltered Work attachment.
- Comprehensive statewide training with a certification system to ensure high quality, professionally trained staff.
- Updated training expectations for staff (Oklahoma has a statewide training system as an example)

Future Steps / Analysis Needed:

Provide an update on next steps and further action needed to complete the work.

Continued monitoring and advocacy during the process of waiver redesign. Need to ensure that there is adequate provider representation when this occurs.

This topic should be brought to the 1102 Task Force in near future.

Recommendation(s):

As a result of the teams review and research, provide recommendations as to how the current process could be improved.

- 1. Should the state proceed with a consolidated waiver, consideration needs to be given to consolidate rates for consistency and ability for individuals to share staffing when appropriate.
- 2. A comprehensive waiver should be developed that allows for life changes so that there are no waits and gaps in services as life transitions occur, such as the ability to transition from child to adult services and for persons with increasing medical needs as they age to be able to live in their own homes as long as possible.
- 3. Development of white paper comments on some of the current issues for the 1102 Task Force.
 - a. See document on extended services
 - b. See document on family caregiver training
 - c. See Suggested Related to Medicaid Waiver Rewrite document
 - d. Sheltered Employment and alternatives to employment see attached document
- 4. Encourage the state to consider not moving to managed care for Waivered Services due to concerns that this could move outcomes for persons in a negative direction. (see Iowa presentation on Managed Care at Conference)
- 5. Assign member(s) to testify at an upcoming 1102 meeting, in the June/July timeframe
- 6. Keep this issue on the list for MDC to continue to monitor and reactivate as needed.
- 7. Federal reimbursement models may also change what we can do. Will need to monitor this closely (already identified for a sub-group).
- 8. Advocate for comprehensive statewide training with a certification system to ensure high quality, professionally trained staff.
- 9. More formalized study of service need differences between rural, suburban and urban areas.

Anticipated Outcome(s):

Based on the research conducted, identify 3-4 anticipated outcomes to be achieved.

1. A waiver system that aligns with the LifeCourse Framework – providing flexibility to change as a persons' life changes without having to apply for new or different services.

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- Services that do support individuals to be actively engaged in their communities.
 Consistent training should lead to more consistently trained staff who provide better services.