



POSITION STATEMENT

WAIVER SERVICE REDUCTIONS

People with intellectual disabilities¹ have the right to a full life in their community where they can live, learn, work, and play. Since many individuals require supports for community life, TennCare and the Division of Mental Retardation Services Home and Community Based (HCBS) Waivers must provide funding to ensure that all people with intellectual disabilities have access to necessary health care and long-term supports.

ISSUE

The Tennessee Division of Mental Retardation (DMRS) provides supports to individuals with intellectual disabilities through three Medicaid HCBS waivers: the Statewide Waiver, the Self-Determination Waiver and the Arlington Waiver. DMRS and TennCare are implementing regulatory changes and budget cuts to reduce Medicaid funding while ignoring the significant gaps in service which exist in Tennessee. In order to respond to the needs of individuals with intellectual disabilities, Tennessee's Home and Community Based Services Waivers must maintain a positive, person-centered direction.

Waiver services are already seriously underfunded, as evidenced by the failure to address many systemic issues, including:

- low pay and lack of benefits for direct support workers;
- growing waiting lists; and
- the projected increase in needs for long-term supports as individuals and their family caregivers age.

Further cutbacks are heightening the crisis in Tennessee's long-term care system, through:

- reducing opportunities for self-direction;
- limiting choice;
- reducing access to therapies, nursing, transportation, and other necessary supports;
- severely threatening compliance with court-ordered actions;
- and delaying the transition from segregated institutions to community-based services.

DMRS and TennCare have developed a three tiered process to reduce waiver expenditures. First, DMRS is *reviewing individuals' ICAPs*, (Inventory for Client and Agency Planning), which frequently results in the assignment of a lower "Level of Need," and thus, a significantly decreased funding rate. Second, DMRS *reduced provider payments* and has announced

¹ "People with intellectual disabilities" refers to individuals with a disability which begins before the age of 18 and is characterized by significant limitations both in intellectual functioning and in adaptive behavior. Professional, legal and service systems may still use the outdated term "mental retardation."

indefinite *rate reductions*. Finally, TennCare and DMRS have adopted a set of *protocols*, or Service Definitions, that will drastically reduce the intensity, frequency and/or duration of services an individual is eligible to receive.

Rate Reductions

In October 2007 DMRS announced that every service plan would be reviewed with the aim of reducing the overall costs for the HCBS waivers back to the 2007-08 budgeted amounts. In December 2007 DMRS reduced *reimbursement payments* to service providers by 6.1% across the board. The payment reductions remained in place from January 2008 through April 2008, and were intended to be short term.

Effective November 1, 2008, DMRS reduced *payment rates* on 46 services and raised rates on 12 services. Unlike the payment reductions, the rate changes will continue indefinitely. The stated purpose of the rate reduction is to “incentivize” agencies to move people into 3-person and 4-person homes. Consequently, rates were *increased* on services to people living in homes with 3 persons in Supported Living and 4 or more persons in Residential Habilitation.

At the same time, rates for the Special Needs Adjustment and Level 4 Day Services were significantly reduced. These reductions make it more difficult for agencies to serve people at the lower rate when their support needs fall between levels, or to support people with very significant behavioral or health needs in day service programs.

Because **the rate reductions do not directly reduce or eliminate** a person’s services, there is no means of appealing these cuts. Nonetheless, the rate reductions will have a significant impact on people’s services, because agencies/providers will receive less money with which to provide **the services** people need.

Rate reductions limit the ability of providers to deliver services as defined in each individual’s Individual Support Plan and to maintain each person’s health and safety. As a result of the previous payment reduction, some agencies were forced to lay off staff, which reduced opportunities for community participation for people they supported, and put the health and safety of some individuals at risk.

ICAP

The Inventory for Client and Agency Planning (ICAP) is a standardized assessment, administered by independent assessors. The ICAP results in the assignment of a Level of Need, which is then used to establish the funding level for each individual. ICAP scoring and administration are not transparent or clearly understood by the community. Many believe it is being administered unfairly.

- The ICAP focuses on what a person cannot do rather than on the services or supports needed to be successful.
- Behavioral or other incidents more than 90 days old are not considered.
- No consideration is given to the importance of maintaining supports in order to prevent loss of skills or recurrence of negative behaviors.

- There are many reports of dramatic shifts in individuals' scores, with recalculated Levels of Need decreasing one, two or even three levels, even though the person's circumstances have not changed.
- Families/conservators and Direct Support Professionals are not consistently informed about or prepared for the interview process.
- The interview format does not prompt respondents to provide the most essential information.
- Families/conservators may be rushed into meeting an assessor's timelines.
- No information is routinely provided on how to obtain a reassessment or challenge ICAP results.

Protocols

The Arc of Tennessee supports efforts to clarify guidelines for decision-making, to increase cost-effectiveness and to bring consistency to the DMRS service system. The current service delivery system in Tennessee is in serious need of meaningful reform.

However, the recently established protocols, paired with changes to the ICAP and rate reductions, go far beyond clarification or standardization, and reflect a fundamental, undesirable shift in values and philosophy. The HCBS waiver was established to provide the supports an individual may need to avoid institutionalization, and to become or remain independent, healthy and safe in her/his own home and home community. In contrast, the protocols:

- *Shift the HCBS system to a medical model.* The protocols apply an extremely restrictive interpretation of “Medical Necessity” which excludes many areas of daily life. Services and supports required for community involvement and recreation, for example, are not considered medically necessary.

The protocols force families to provide care and interventions that the state has deemed “not medically necessary,” such as bathing, lifting or eating, until they have exhausted their financial or physical ability to do so. Adults with intellectual disabilities should have the right to choose to live separately from their families. The protocols severely limit that option, so that in some circumstances, individuals may have no opportunity to work, learn independent living skills or engage in social relationships.

- *Redefine the purpose of home and community based long-term care services.* The protocols underscore the state's view that HCBS services are only intended to supplement care which parents, brothers or sisters and others “should” provide for an individual with intellectual disabilities. The state's position shifts an unrealistic and inequitable share of responsibility to already overtaxed, stressed families. At the same time, the other, more restrictive service option, Intermediate Care Facilities (ICF-MRs), continues to offer a “full menu” of services and supports, without requiring that families provide direct care.
- *Reflect a shift away from family-centered and person-centered services to a bureaucracy-driven, professional-controlled program focused on cost savings rather than cost-effectiveness.*

POSITION

Tennessee's Medicaid waivers and other state long-term care programs should assist people with intellectual disabilities to live full lives in the community, experience a high quality of life and as adults, achieve economic security and personal independence to the extent possible for the individual. To address the present and future long-term care needs of individuals with intellectual disabilities and their families in Tennessee, we affirm that:

- All decisions and planning processes must be person-centered and family-centered. People's lives should not be uprooted to correct past mistakes made by DMRS.
- People with intellectual disabilities must be safe, healthy, and free from abuse.
- Tennessee's Home and Community Based Services should not place an undue burden on families to provide care and treatment of their family member.
 - Individuals and their families should not have to wait until they are faced with a crisis, such as homelessness, a medical emergency or the death of a caregiver, to access necessary long term care.
 - Families should not be forced to exhaust their personal resources of time, health and energy before appropriate long term care and supports are provided to their sons or daughters.
 - Long term care planning, at the individual and systems levels, must take into account the advancing age and health limitations of elderly family caregivers.
 - Necessary personal care assistance and/or supervision (beyond what a typical child or youth requires) should be provided through Medicaid-funded programs to support children and youth with intellectual disabilities in the home or other less restrictive settings.
- The ICAP process should provide an accurate, individualized assessment of the needs of each person.
 - The ICAP process should be transparent to everyone involved, including how the interviews are processed, who makes final decisions on the ICAP score, and how to request a reassessment.
 - ICAP scoring must take into consideration the importance of maintaining supports that *prevent* negative behaviors.
 - Families/conservators and Direct Support Professionals should be educated in the ICAP process so that they can provide meaningful information. Interviews should be scheduled at times that are convenient for families/conservators.
 - Decisions about termination or decrease in services/supports should be made on an individual basis with maximum involvement of the family and individual.
- Rate reductions must not be punitive to individuals or agencies.
 - Homeowners should not have to leave their homes.
 - Homeowners should not be forced to accept housemates not of their choosing.
 - Rates should be sufficient to ensure the health, safety and community participation of each individual.
 - People currently living in 1-person and 2-person homes should be "grandfathered in" and allowed to maintain their living arrangements if they so choose.
 - Decisions about services and living arrangements should be person-centered rather than driven by reduced rates.

- Resources should be allocated in a rational and defensible way and primarily be used for direct services, keeping administrative costs as low as possible.
- Any cost savings from rate reductions should be directed to serving people on the Waiting List.
- Supports should be provided in the communities and settings of people's choice, including previously untried options.
- Supports and services should be cost-effective without compromising safety, quality, community involvement or choice.
- People should be supported in exercising an increasing amount of control and choice in their lives while being protected from imminent risk of serious harm.
- Services, including therapies, behavioral and mental health supports, should be provided in a proactive and preventative fashion rather than in reaction to a crisis or loss of function.
- Services should not be withdrawn solely because an individual does not meet an arbitrary timeline for skill acquisition; conversely, individuals should not be penalized for gains by having necessary services and supports terminated prematurely.
- Services and expenditures should continue to be redirected from institutional care to more cost-effective home and community-based supports.
- All waivers should have a self-direction component, giving individuals and families opportunities to design and direct their own services to the extent that they wish and with the assistance they need.
- DMRS must assure sufficient training and appropriate pay for direct support professionals.
- Any effort to change or restructure TennCare or Tennessee's Home and Community Based Services program must proactively involve families, self-advocates, advocacy organizations and the provider community.

Tennessee's Home and Community Based Services system reform must address *waiting lists*, the *quality of care* and services, and *increased availability* of truly home and community based services and supports. Tennessee's system of care must reduce its overreliance on costly institutional care and provide real, cost-effective choices to individuals with intellectual disabilities and their families.

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