

## 1102 IDD Task Force Community Living Expansion Initiative

The 2011 Indiana General Assembly incorporated important initiatives to House Enrolled Act 1001, otherwise known as the Budget Bill. Section 144 of the Budget Bill charged the Division of Disability and Rehabilitative Services (DDRS) to report to the Select Joint Commission on Medicaid Oversight a plan to reduce the aggregate and per capita cost of the Developmental Disability Waiver program. Section 144 identified six categories DDRS should consider to develop a plan to reduce the per capita and aggregate costs of Indiana's waiver program:

1. Calculating budget neutrality on an individual rather than an aggregate basis
2. Instituting a family care program to provide recipients with another option for receiving services
3. Evaluating the current system to determine whether a group home or a waiver home is the most appropriate use of resources for placement of the individual
4. Evaluating alternative placements for high cost individuals to ensure individuals are served in the most integrated setting appropriate to the individual's needs and within the resources available to the state
5. Migrating individuals from the waiver to a redesigned waiver that provides options to individuals for receiving services and support appropriate to meet the individual's needs and that are cost effective and high quality and focus on social and health outcomes
6. Requiring cost participation by a recipient whose family income exceeds five hundred percent (500%) of the federal income poverty level, factoring in medical expenses and personal care needs expenses of the recipient

In April of 2012 DDRS issued the required Section 144 report with the following program and policy proposals:

### **Develop a Quality and Outcome Based Provider Reimbursement Methodology**

*Establish a performance-based reimbursement methodology to incentivize providers to seek non-government supports, including employment, for the individuals in their services. As a component of this reimbursement methodology, allow the state to keep a portion of the savings resulting from non-government resources being utilized. Raise standards for service providers to promote the hiring of more qualified staff, which in turn, results in higher quality services for waiver consumers.*

### **Outcomes were developed but the reimbursement methodology was never implemented**

#### **Institute a Family Supports Waiver**

*Create a waiver to better serve individuals contingent upon living in the family home. Specific supports would be available to individuals served by this waiver. An emphasis on identification and utilization of natural supports would be a component to help meet immediate needs of consumers in a*

*more efficient manner. The new waiver would encourage more at-home placements and drive the state's per capita cost of HCBS spend below the national average.*

The State has fully implemented this recommendation. DDRS recently confirmed the number of people they are targeting for the FSW is still 300 per month and also provided information regarding the fact that BDDS is completing more intakes in district offices than the targeting process is removing from FSW waitlist. The waitlist (approximately 1400) has essentially grown, not because BDDS is targeting less people, but because BDDS has seen an uptick in intake activity in the districts.

In addition, and in coordination with the beginning of the Family Support Waiver, The Developmental Disabilities Waiver (formerly the ICF/MR waiver) and the Autism Waiver were combined into the current Community Integration and Habilitation Waiver (CIH). In 2010, the DD waiver had 7000 individuals served. Today the CIH waiver serves nearly 9000 individuals. The increase in the number of participants in the CIH waiver from 2010 to 2017 occurred primarily as the result of several systemic factors listed below:

- Combining the Autism and DD waivers into a single CIH waiver
- Closure of the last three Large Private ICF/DD facilities collectively serving approximately 300 individuals
- Moving some individuals with IDD as their primary diagnosis from the Aging and Disabled Waiver
- Closure/Conversion of several 4-8 bed group homes across the State
- Waivers targeted to individuals meeting the waiver emergency priority criteria

**Listed below are the currently available Services on the FSW and CIH waivers.**

#### **Available Services- Family Supports HCBS waiver**

- Adult Day Services
- Behavioral Support Services
- Case Management
- Community-Based Habilitation- Group
- Community-Based Habilitation- Individual
- Extended Services ( provides on-going follow along to persons employed)
- Facility-Based Habilitation-Group
- Facility-Based Habilitation-Individual
- Facility-Based Support Services
- Family & Caregiver Training
- Intensive Behavioral Support
- Music Therapy
- Occupational Therapy
- Participant Assistance and Care
- Personal Emergency Response System
- Physical Therapy
- Prevocational Services
- Psychological Therapy
- Recreational Therapy

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- Respite
  - Specialized Medical Equipment & Supplies
  - Speech/ Language Therapy
  - Transportation Services
  - Workplace Assistance

#### **AVAILABLE CIH HCBS WAIVER SERVICES**

- Adult Day Services
- Behavioral Support Services/ Crisis Assistance
- Case Management
- Community-Based Habilitation-Group
- Community-Based Habilitation-Individual
- Community Transition Services
- Electronic Monitoring
- Extended Services
- Environmental Modifications
- Facility-Based Habilitation-Group
- Facility-Based Habilitation-Individual
- Facility-Based Support Services
- Family & Caregiver Training
- Intensive Behavior Intervention
- Music Therapy
- Occupational Therapy
- Personal Emergency Response System
- Physical Therapy
- Prevocational Services
- Psychological Therapy
- Recreational Therapy
- Rent & Food for Unrelated Live-In Caregiver
- Residential Habilitation & Support
- Respite
- Specialized Medical Equipment & Supplies
- Speech/ Language Therapy
- Structured Family Caregiving
- Transportation
- Wellness Coordination
- Workplace Assistance

#### **Develop Equal Assessments and Restructure Group Home Case Mix and Function**

*Develop a new process to assess individuals and determine if Supported Group Living (SGL or Group Home) placement is appropriate. Identify individuals who may be better served through HCBS Medicaid waiver programs. For those consumers appropriately placed in a group home, the rate setting*

*process will change to reflect per diem rates based on the individual's Algo level, rather than home classification. Providers may also choose to voluntarily change their group homes to waiver homes.*

**This recommendation has not been implemented.**

**Enhance Services for High-Cost/High-Needs Individuals**

*Create a new system to serve individuals with the highest budgets and highest needs in the most appropriate and cost-effective manner. Pre-qualified providers would review an individual's information and put together a proposal to care for the individual, with an emphasis on decreasing needed specialized services over the period specified by the contract.*

**This recommendation has not been implemented.**

**Summary from April 2012 Report**

*The recommendations detailed in this report will offer cost-effective, efficient, and more meaningful service provision to Indiana's HCBS waiver consumers. The timeline was set to serve as a roadmap to guide next steps whereby specific details, processes, and procedures will be further developed. By 2017, the stakeholders anticipate the elimination of the DD Waiver waitlist and increased access to residential services through the new Family Supports Services Waiver. Moving toward a pay for performance reimbursement model for providers will drive costs and facilitate quality service.*

At the time of the 144 report the per capita cost for waiver services was approximately \$70,000 and as the report states:

*Historically, DD and Autism Waivers were the only waivers with a residential service component. In order to accurately compare Indiana's per capita waiver costs to other states' per capita waiver costs, the Support Services Waiver was excluded from these calculations, as it had no residential service. The cost of the DD and Autism Waivers has remained relatively flat as budgets established for individuals varied little from year to year. As a result of the addition of a residential service component onto the Support Services Waiver, this waiver can be included in the per capita cost calculation. These changes will result in a dramatic decrease in per capita spending as more individuals are transitioned onto this waiver.*

As of June 30, 2017, the per capital cost across both the Community Integration and Habilitation and the Family Support waiver is approximately \$24,000 which is consistent with the 144 report projections.

Again as noted in the 144 report:

*The Family Supports Waiver is not meant to be a "placeholder waiver" for the DD Waiver. The number of new slots for the DD Waiver is limited, and accessibility will be available under new, more detailed criteria. Currently, approximately 500 waiver slots are budgeted and allocated to the DD Waiver each year, with access granted through a wide array of priority criteria and wait list reduction strategies. **With the newly proposed initiative, there will no longer be a wait list for the DD Waiver. The new number of slots budgeted and allocated to the DD Waiver will be determined through the continued analysis of need of individuals who meet certain qualifying criteria.***

The limited availability noted above is as follows both in statute and in the approved waiver applications:

Before October 1, 2011, the office shall apply to the United States Department of Health and Human Services for approval to amend a waiver to set an emergency placement priority for individuals in the following situations:

- (1) Death of a primary caregiver where alternative placement in a supervised group living setting:
  - (A) is not available; or
  - (B) is determined by the division to be an inappropriate option.
- (2) A situation in which:
  - (A) the primary caregiver is at least eighty (80) years of age; and
  - (B) alternate placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.
- (3) There is evidence of abuse or neglect in the current institutional or home placement, and alternate placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.
- (4) There are other health and safety risks, as determined by the division director, and alternate placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.
- (d) The division shall report on a quarterly basis the following information to the division of disability and rehabilitative services advisory council established by IC 12-9-4-2 concerning each Medicaid waiver for which the office has been approved under this section to administer an emergency placement priority for individuals described in this section:
  - (1) The number of applications for emergency placement priority waivers.
  - (2) The number of individuals served on the waiver.
  - (3) The number of individuals on a wait list for the waiver.
- (e) The office may adopt rules under IC 4-22-2 necessary to implement this section.

#### **Need for Expansion of Community Living Opportunities**

While recognizing the valuable contributions to the Indiana IDD system, particularly the expansion of the Family Support Waiver initiated as a result of the Section 144 process and recommendations, a clear need to expand community living options for persons with IDD who desire to live outside of the home of their parents has emerged.

Throughout the public comment portion of the five previous 1102 Task Force meetings, many family members and individuals with IDD have indicated they want to live as independently as possible and to make the transition from the family home to “their home” early and in non-emergency situations, which we know is the best way have a successful transition.

INARF members have engaged individuals they support and their families in many meetings, surveys and forums in their local communities between the start of the 1102 Task Force in November of 2017 and the most recent meeting in June of 2018. Over 35 organizations have submitted written comments from these sessions on the needs and preferences for the support of individuals with IDD. It is very clear that what adults with IDD and their families want is the opportunity for individuals to live outside of the home of their parents, and we (the 1102 Task Force) need to find a way to increase opportunities to make this possible.

In the 11<sup>th</sup> addition of The State of the States in Intellectual and Developmental Disabilities published in 2017, Indiana ranked 42<sup>nd</sup> out of 50 states in the percentage of persons with IDD in out of home settings with 1-6 individuals. Data from the 2015 University of Minnesota RISP project reflects national data that

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52% of persons with IDD receiving IDD support services live with their families, while in Indiana 67% of persons with IDD receiving IDD support services live with their families. This data supports a clear need for Indiana to do more in creating opportunities and choices for persons with IDD to live outside of the home of their parents.

As noted above regarding the current CIH waiver priority criteria mandated by Indiana code, the first priorities for the CIH waivers included caregivers over the age of 80. The age of 80 was arbitrarily chosen when these criteria were enacted. There are many caregivers over the age of 65 who have cared for their child with a disability, some utilizing no state services, throughout their children's lives. However, they will be unable to do so forever. We need to help these families make a smooth transition to their son or daughter living in an community based setting of their choice before a tragedy occurs that leaves the child vulnerable and without the natural supports needed to facilitate a successful transition.

### **Conclusion**

Although three of the four primary recommendations from the DDRS Section 144 report have not been implemented, the implementation of the recommendation to have a Family Support Waiver in order to reduce the waiting list for the Community Integration Waiver has had a dramatic impact on the IDD system in Indiana. As noted, the prior public policy of budgeting and allocating 500 CIH waiver slots to those on the CIH wait list was discontinued in favor of targeting over 3,000 individuals for the FSW annually, resulting in limited access and choice to persons with IDD to live outside of the home of their parents.

As has been noted through the public comment process, some family members would like to assist their family member in moving from their family home to a more independent living arrangement prior to the caregiver reaching the age of 80 or prior to health or safety risks occurring to make their family member eligible for emergency placement priority. We have received comment from individuals with IDD who want to have the choice and the opportunity to live outside of their parents' home. We also know that Indiana has a higher percentage of persons receiving supports services living with their families than in other states.

The 1102 Task Force has the opportunity to recommend changes to the IDD system to address the needs outlined in this white paper through the expansion of community living options.

### **Recommendations for the Task Force to Consider**

1. Modify the current legislation dictating waiver placement priority to reflect a priority waiver would be offered in a situation in which the primary caregiver is at least 65 years of age. This would require an additional appropriation to implement this change to the waiver priority criteria. (*Fiscal Note: Based on data provided by DDRS to the 1102 Task Force regarding the ages of persons currently served on the FSW waiver it appears there is approximately 2800 individuals on the FSW waiver 35 years or older who are likely to have a parent(s) caregiver 65 years of age or older.*)
2. In addition to changing the current emergency priority criteria, seek an appropriation to be known as the **1102 IDD Task Force Community Living Expansion Initiative** which will fund 500 Community Integration and Habilitation waiver slots per year to be utilized for non-emergency priority placements using criteria developed by DDRS to allow some level of expansion of individuals seeking to live in the community away from their family, while creating the opportunity for families to support individuals in making this transition to living away from their family.