

## **Issue: DDAN ISSUE REPORT: ADEQUACY OF SYSTEM FUNDING**

### **Issue Description:**

The DDAN supports building a stronger and fairer New Jersey and recognizes the state's obligation to allocate finite funding across all areas of state services. Given the wide gap between available funds and often complex individual needs, advocates understand **they must** work with the Legislature, the Governor's Office, and Department of Human Services (DHS) and Division of Developmental Disabilities (DDD) leadership to identify and **generate** support for ways to maximize the existing funding for the greatest benefit.

#### **1. Redistribution of Existing Funding to Increase Funding for Home and Community Based Services (HCBS)**

One policy that could optimize allocation of existing funding to provide the greatest benefit would be active monitoring and transfer of funds from the developmental centers (DCs) to HCBS, as the population living in the DCs continues to decline<sup>1</sup>. Currently, per capita spending for residents of the DCs far exceeds per capita spending on recipients of home and community based services, many of whom have similar needs to DC residents. An estimated 33 percent of system funding is allocated to less than 5 percent of beneficiaries. This imbalance represents a tremendous opportunity to improve services for most beneficiaries for our community. As reliance on DCs decreases, so will the associated costs, freeing up desperately needed resources for home and community based services.

Individuals with developmental disabilities and their families have the most to gain and lose in this process. They aspire to be informed stakeholders in this critical budget process component as well as the entire budget process.

#### **2. DD System Components that Require Increased Funding**

##### **➤ Direct Support Professionals**

The DDD services system faces a worsening crisis caused by a growing shortage of direct support professionals (DSPs). DSPs are the indispensable backbone of our intellectual/developmental disabilities (I/DD) service system. They are responsible

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<sup>1</sup> As of February 2019, the DC census is 1290.

for the health, safety, well-being, happiness and fulfillment of the highly vulnerable individuals whom they serve.

Despite their critical role, DSPs went 10 years without a wage increase, while the longest economic expansion on record reduced unemployment to a near-record low and provided significant increases in government and private sector wages.

Today, DSPs are shamefully underpaid for their complicated, demanding job, which is both physically and emotionally taxing. This has led to an alarming increase in vacancies and turnover, significantly reducing the number of experienced, skilled DSPs, while the number of individuals requiring their services continues to increase. As a result, individuals with I/DD face a lack of services and meaningful engagements in their communities.

This growing staffing shortage affects both I/DD service provider agencies and individuals and families who self-direct services. For those who self-direct, the state's decision to eliminate health coverage and vacation pay for DSPs has further eroded their ability to attract and retain DSPs. Provider agencies typically provide healthcare coverage and vacation pay, but generally pay lower wages to their DSPs.

Instead of working for an agency or as a self-directed employee, DSPs can make more money doing far less challenging work for other employers. This unaddressed issue has resulted in a crisis, as the need for DSPs significantly exceeds the current workforce, a shortage expected to worsen, leading to a full-blown catastrophe unless action is taken soon.

➤ **Limited Flexibility and Options**

As New Jersey shifts to a fee-for-service system, some individuals and families feel they have lost flexibility and freedom of choice. For instance, individuals become hesitant to take a vacation, or stay at their friend or family's house because it can jeopardize their day or/and residential services. Additionally, DDD no longer approves certain specialized services under Goods and Services.

**Issue Action Items:**

**1. Redistribution of Existing Funding to Increase Funding for Home and Community-Based Services**

a. DC-specific

- i. Request that DHS supply semiannual census data and cost analysis at the five (5) developmental centers
  - ii. Review and analyze the data related to the DCs in order to advocate that a sensible fiscal plan be developed as utilization declines and costs rise
  - iii. Identify best practice across the nation and apply in NJ to accomplish successful deinstitutionalization
- b. State budget process
  - i. Ensure stakeholder engagement in the early stages (Dec/Jan) before major decisions are made.
  - ii. Request budgeted and actual spending in the following categories by fiscal year: DDD's total budget, contracts, FFS budgets, and DCs including personnel services, maintenance and operational expenses.

## **2. Components of the DD System that Require Increased Funding**

- a. **DSP Wage Increase (Federal/State/Media Level)**
  - i. Update [System Funding page](#) in the DDAN website
    - 1. Emphasize the imminent danger and urgency of DSP workforce crisis
    - 2. Add the link to the [Coalition of a DSP Living Wage](#)
    - 3. Encourage readers to take actions as suggested at the Coalition of a DSP Living Wage website, especially uploading videos and submitting testimonies
- b. **Limited Flexibility and Options**
  - i. Increase flexibility, such as New York's "therapeutic leave" so that they can visit their families, go to camp, and take vacation without jeopardizing their residential service
  - ii. Revise Supports Program and Community Care Program language to be less rigid in how people spend their budgets to allow flexibility across services to best serve the individual, if service cannot be funded under a listed service, can use another general bucket (e.g., Goods & Services)
  - iii. DDAN to create concrete recommendations to submit to the State for consideration

## **Next Steps:**

1. Advocate for increased home and community-based services and support funding
  - DC-specific
    - NJCDD to update its position paper regarding deinstitutionalization
    - DDAN to request and review developmental center data including (1) census of residents and staff and (2) cost analysis
    - DDAN to work in partnership with DHS to create a sensible plan for future of DCs based on census data
    - DDAN/State identify best practice (e.g. Ohio state) and plan how to apply them in the State of New Jersey
  - State budget process
    - DDAN to create short-term suggestions around budget development and timing of stakeholder input to promote early engagement
2. Strengthen the collaboration between DDAN and the Coalition of a DSP Living Wage
  - The Coalition of a DSP Living Wage explains 6 steps to take action. DDAN Adequacy of System Funding page should include the link to the Coalition of a DSP Living Page as landing Page. Families can report their crisis, upload the video and follow the six steps for advocacy.
3. DDAN to write concrete and specific recommendations to allow more flexibility in the way individuals and their families use their DDD budgets
  - Introduce a “therapeutic leave” policy like New York State and flexibility across services (see 5a above)
4. FFS Transition Oversight Board (See the law [here](#)) (State Level)
  - Law to be posted in the DDAN website
  - Monitor the progress of the FFS Transition Oversight Board
  - DDAN to make recommendations to the FFS Transition Oversight Board
5. DDAN to schedule a meeting with the Governor and his wife.

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1 2015 DDD Quality Improvement Stakeholder Report

([https://www.state.nj.us/humanservices/ddd/documents/stakeholder\\_input\\_report\\_on\\_quality\\_improvement.pdf](https://www.state.nj.us/humanservices/ddd/documents/stakeholder_input_report_on_quality_improvement.pdf))

2 CQL – 5 Factors of Quality (<https://c-q-l.org/files/2017Documents/CQL-Personal-Outcome-Measures-Factors-And-Indicators.pdf>)