

DDAN ISSUES REPORTS:

Adequacy of System Funding & Medicaid

Issue:

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 actively monitoring and transferring of funds from the developmental centers (DCs) to HCBS, as the population living in the DCs continues to decline¹. 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 11 % of the FY22 system funding is allocated to less than 5% of beneficiaries². 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 and aspire to be informed stakeholders in this critical component of the budget process as well as the entire budget process.

Additionally, the DDAN supports the Home and Community Based Access Act which makes HCBS services mandatory Medicaid services, provides funding to build capacity and eliminate waiting lists, increases funding for the Direct Support Professional wages, and makes Medicaid portable across state lines. It will ensure that people with disabilities can lead full lives in the community with the proper supports and services they need to succeed.

2. Components of the DD System that Require Increased Funding

¹The cumulative census of all five centers is 1,238 as of February 2020. Source: <https://nj.gov/humanservices/ddd/individuals/developmental/> (Retrieved 6/24/21)

² Source: <https://www.nj.gov/treasury/omb/publications/22budget/pdf/FY22GBM.pdf> (Retrieved 7/7/21)
D-207 (DC's) – "Grand Total of all funds" \$290,688
D-211 (Community) - "Grand Total of all funds" \$2,286,083

➤ **Direct Support Professionals**

DSPs are the indispensable backbone of our intellectual/developmental disabilities (I/DD) service system. They are responsible for the health, safety, well-being, happiness and fulfillment of the highly vulnerable individuals whom they serve. Unfortunately, they are 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. This growing staffing shortage affects both I/DD service provider agencies and individuals and families who self-direct services. In addition, the system is contending with the state's minimum wage which is set to rise every year through 2024. In the FY21 and FY22 Budgets, funding was appropriated by the Governor to keep DSP wages ahead of the rising minimum wage. It is imperative that funding continue to be included each year so that DSPs are paid above that which is paid to entry-level workers. The labor shortage currently affecting the retail, restaurant and hospitality industries is also impacting the service delivery system's ability to attract and retain workers. This is causing a workforce crisis that can be remediated in part by higher wages.

➤ **System-Wide Review**

Furthermore, the rates for the service delivery system as a whole require examination and evaluation as they were set in 2014 and many of the rates no longer reflect the cost of delivering services. An across the board assessment of current rates is required to determine which services need additional funds and specific attention must be paid to rates that are particularly low and problematic. If rates continue to stagnate without intervention, the services that individuals with I/DD depend on will be in jeopardy.

3. Limited Flexibility and Options

Since the shift to a fee-for-service system, some individuals and families feel that 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. Individuals who live in a residential program cannot receive support from their staff during hospitalization. It is considered as duplication of services. Because hospital staff are not familiar with each individual's unique and complex needs, safety, health and well-being are often compromised.

Services and rates in the system serving children must also be addressed. The Children's System of Care, housed in the Department of Children and Families, must increase funding to support this population and address long-standing obstacles that make it difficult for families to access care. It is difficult to find workers based on current rates and the struggle is being exacerbated by the rising minimum wage. This in turn is hurting a family's ability to obtain the respite they need. In addition, many families struggle when contacting PerformCare. More education must be done to ensure a

smoother experience so that families can get the support they require to keep their loved one in the home.

4. Waiver Renewal

The upcoming 1115 Demonstration Renewal is an opportunity to provide input on a number of critical issues affecting individuals with I/DD and the service delivery system. Specifically, services included in the Waiver must be comprehensive in order to meet the varied and extensive needs of all those served. In addition, the NJ CAT, the assessment tool used to determine eligibility and level of need, does not appropriately capture support needs and it therefore must be addressed. Furthermore, more attention must be placed on viable rates that allow for a robust workforce and network adequacy, as well as more flexibility for those who self-direct services. Families must be educated about the upcoming Waiver renewal and ways they can participate in shaping the document. This includes opportunities for providing input and weighing in with feedback throughout the process.

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 annual 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 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.
- c. Advocate for the passage of the HCBS Access Act

2. Components of the DD System that Require Increased Funding

- a. DSP Wage Increase
- b. Analyze current Medicaid rates across the system and identify areas for increases

3. Limited Flexibility and Options

- a. Increase flexibility, such as introducing “therapeutic leave” and “health and safety support during hospitalization,” so that they can visit their families, go to camp,

take a vacation, and receive necessary medical care without jeopardizing their health, safety or residential service

- b. 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)
- c. DDAN to create concrete recommendations to submit to the State for consideration including flexibility in employment options and remote day program services

Next Steps:

- Advocate for the increase of funding for home and community-based services and support to increase individual budgets and rates for services
 - DDAN to request and review Developmental Center data including (1) census of residents and staff and (2) cost analysis
 - Plan to shift resources from DCs when appropriate to Home and Community Based Services
- State budget process
 - DDAN to create short-term suggestions around budget development and timing of stakeholder input to promote early engagement
- DDAN to write concrete and specific recommendations to allow more flexibility in the way individuals and their families use their DDD budgets
- Work with FFS Transition Oversight Board to analyze current rates and make recommendations for appropriate increases to the rate
- Advocate for the passage of the HCBS Access Act
- Develop recommendations and submit comments throughout the Waiver Renewal process