

Key Points

PLANNING FOR NEEDS OF AGING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Section I: DDS Wait and Planning Lists

- The Association for Retarded Citizens of Connecticut (ARC/Connecticut) filed a federal lawsuit in October 2001 on behalf of individuals waiting for residential supports and/or day services from the then- Department of Mental Retardation (DMR) and the Department of Social Services.
- The parties negotiated and eventually entered into a five-year settlement agreement (FYs 2005-2009), which resulted in \$33.8 million wait list initiative funding to move clients off of the wait list.
- The five-year initiative has moved many individuals off the DDS wait list, including many over the age of 45.
- The end of wait list funding will stop the momentum made in serving persons on the wait list and create another definite backlog and possible risk of further litigation.

Proposed Recommendations

1. **Funding for the wait list initiative should continue at current level for another five-year period. In addition, a separate, non-lapsing General Fund account should be established to receive any proceeds from the sale, lease, or transfer of any DDS property. The fund must be used, as appropriated by the General Assembly, to supplement the funding for DDS plans to provide services to individuals on its wait list. Any investment earnings on the fund's balance must be credited to the fund.**
2. **DDS should analyze the wait and planning lists to identify individuals who will need services within the timeframes established under the priority categories and compare the results to the types of housing available to ensure homes are in similar geographic locations.**

Section II: DDS Policy, Procedure, and Services

- The DDS policy and procedures manual provides no guidance or directives for what would constitute a change in situation in a client's life that would prompt a new level of need assessment.
- Older individuals residing in their own or family home with few or no supports and perhaps with an aging caregiver should be monitored on a more frequent schedule.
- A comprehensive look at the demands of DDS case management services should be considered.

Key Points

- The committee interviews and observation of the planning and resource allocation team (PRAT) meetings revealed some examples of regional difference.
- The scope and multitude of duties associated with the DDS aging coordinator position is immense.
- There is no direct central point-of-contact person assigned at DDS to handle basic estate planning inquiries.
- It appears that DDS has provided respite services within available resources whenever possible. However, the funding for and access to respite services have been limited.
- The need for respite services becomes more important as the state policy approach is to continue to serve individuals at home.

Proposed Recommendations

- 3. DDS should establish minimum criteria for what constitutes a significant change or situation prompting a level of need review.**
- 4. DDS should increase the minimum frequency of case manager face-to-face contacts for DDS clients residing with aging caregivers as well as for aging individuals receiving DDS case management services in all residential settings.**
- 5. DDS should request additional funds to provide lower case management ratios after it has examined its case management services.**
- 6. DDS should evaluate and standardize the PRAT process used in each region to improve consistency.**
- 7. DDS should reconsider the level of staffing dedicated to aging services when resources are available. At a minimum, a staff person in each region should be delegated to assist the central office aging coordinator in the efforts to develop new service alternatives and to leverage existing elder programs in order to integrate aging DDS consumers whenever possible.**
- 8. DDS should designate a central office point-of-contact to assist families seeking legal and/or financial guidance regarding planning for the future of their children.**
- 9. DDS should incorporate an additional component to the individual plan of aging clients that would reflect the individual/family's desired long-term care plan along with alternative contingencies if the desired long-term care plan is not viable.**
- 10. DDS should consider the expansion of respite services when appropriations become available.**

Key Points

Section III: Long-Term Care Provided in Nursing Homes

- Several concerns were raised by advocacy groups regarding the care provided to individuals with intellectual disabilities who reside in nursing homes.
- A broader, more philosophical issue was also raised regarding how long-term care, in general, should be provided to individuals with intellectual disabilities who reside in nursing homes.
- Recent efforts, such as the federal Money Follows the Person (MFP) Demonstration grant, spearheaded by the Department of Social Services (DSS), are aimed at moving people out of institutions and nursing homes into the community in an effort to rebalance the long-term care system.
- Other advocates think that long-term care for persons with intellectual disabilities should be provided in specialized nursing homes that only admit individuals with an intellectual disability, so that any unique needs can be met.
- There is no comprehensive policy that encourages community providers to provide certain medically-related services so that clients can return home following a hospital admission.
- The federal Omnibus Budget Reconciliation Act of 1987 mandated Preadmission Screening and Resident Review of individuals for serious mental illness and/or mental retardation prior to nursing home admission to ensure that individuals are not inappropriately placed.
- The committee found it difficult to determine the effectiveness of the screening process because of the lack of any aggregated data related to DDS clients residing in nursing homes.
- The Alternative Care Unit within DSS found evidence that there were potentially many individuals with an intellectual disability residing in at least one nursing home that have never been DDS clients and did not have preadmission screens.
- The Office of Protection and Advocacy for Persons with Disabilities recently identified many areas of concern regarding DDS clients in nursing homes including: infrequent case management contact, lack of notification regarding significant changes in client condition, incomplete medical histories for individuals moving from a community-based setting to a nursing home, reasons why people are placed in nursing homes, and people being placed far away from friends and family.
- Clients placed in nursing homes are at risk of “falling through the system cracks” since there is no adequate quality assurance check in place that tracks them.
- Certified nurse aides are required to complete at least 100 hours of a training program in order to become certified. In Connecticut, at least 25 of those hours must include specialized

Key Points

training in understanding and responding to challenging behaviors related to physical, psychiatric, psychosocial, and cognitive disorders.

- In addition, recent state legislation increased the requirement that Alzheimer's special care units or programs annually provide Alzheimer's and dementia-specific training to all licensed and registered direct care staff and nurse aides who provide direct patient care to residents enrolled in those units or programs from three to eight hours.
- Since clients leaving nursing homes under MFP funds will eventually need to transfer to one of the two home-and-community based Medicaid waivers, the committee believes that DDS needs to set a clear policy direction on the types of services that should be provided in the community with the goal of reducing nursing home placements.

Proposed Recommendations

11. As part of its audit of nursing home records currently conducted by DDS, the following minimum information should be collected on and verified for clients currently living in nursing homes:

- a. case managers are assigned and have met the requirement of quarterly contact and annual face-to-face contact;
- b. whether or not the nursing home has notified DDS if a client has had a significant change in condition, been hospitalized, or died;
- c. health records are complete and accurate; and
- d. emergency contact information is contained in the file.

12. The term “significant change in condition” be defined in guidelines, including the process that nursing facilities must follow in notifying DDS, what actions must be taken by DDS upon receipt of such notification, and circumstances that should initiate face-to-face contact between a client and his or her case manager, and/or require an assessment by a DDS nurse consultant. The roles and responsibilities of the case manager supervisor and regional manager-on-call should also be defined, including any actions that must be taken by them when such notification occurs.

13. DDS should establish a centralized data system to capture information on clients residing in nursing homes in order to document:

- a. reason(s) for nursing home admission;
- b. lengths of stay;
- c. admitting rates to nursing homes by hospital;

Key Points

- d. frequency of case manager contact, with uniform documentation and alerts generated when frequency of contact is not being met; and
 - e. notification of a significant change in a client's condition, including an identification of the change.
 - f. DDS should randomly audit a sample of cases in the database to ensure its accuracy.
14. DPH shall notify the appropriate Regional OBRA Liaison of the results of its review of the PASSR Level II screens conducted in each nursing home. If DPH finds that the services identified in the Level II screen are not being provided by the nursing home, it should determine the reason why. The Regional OBRA Liaison should forward the results to each client's case manager who is responsible for following up with the nursing facility to ensure the client has received the services identified in the Level II screen within 30 days of receipt of DPH findings.
15. DDS should partner with the two nursing home associations in Connecticut to provide targeted training around some of the specific issues related to providing care to individuals with intellectual disabilities who reside in nursing homes. Although training efforts could be aimed at a variety of audiences, it should, at a minimum, include:
- Registered Nurse (RN) nursing home directors responsible for client services; and
 - DPH surveyors who conduct nursing home inspections and record reviews.
16. DDS should survey the types of medical care provided in each private provider home and whether or not it is delegated to unlicensed staff. Based on the survey results, the department shall assess what is lacking in services among providers and establish a policy that provides for a comprehensive system of supports which will encourage providers to provide certain types of care to clients and allow them to age-in-place.

Section IV: Continued Planning Efforts for the Aging Population

- More specific objectives are needed in the agency's overall five-year plan to convey a clear vision or at least an anticipated picture of where the department wants to be in the future

Key Points

with regard to its aging consumers.

- DDS is involved in multiple initiatives such as the Connecticut Long-Term Care Needs Assessment and others by the Departments of Social Services and Public Health.
- A significant number of individuals (approximately 50 percent) initially seek DDS services but for unknown reasons either withdraw their applications or simply discontinue contact with the department.
- A comprehensive cost-analysis decision for Southbury Training School is critical and overdue.

Proposed Recommendations

- 17. DDS should, when revising its five-year plan and internal strategies, incorporate the action plans of the various work group reports it intends to implement and ensure that the goal statements include specific steps and dates of accomplishment for what the department is trying to achieve.**
- 18. DDS should continue to collaborate with groups with similar objectives and report any accomplishments and expected or required DDS commitments to external projects in the department's five-year plan.**
- 19. The Commissioner of Developmental Services, in consultation with the Commissioner of Public Works and the Office of Policy and Management, shall evaluate the feasibility and appropriateness of a continuum of options for Southbury Training School. At a minimum, the range of options shall include property closure and sale, continued or modified use as a DDS residential facility, and alternate uses for other state agency services. Each option considered shall provide:**
 - the underlying rationale for the option;
 - the populations affected;
 - associated costs and/or revenue generated; and
 - a specific outline of the required action steps, potential entities involved, and anticipated timeframes for implementing the option.

The DDS commissioner shall hold public hearings to solicit input and opinion of interested stakeholders. The DDS commissioner shall submit a report containing the criteria and standards used to form the basis of the evaluation, transcript of any hearing(s) held, as well as findings and recommendations to the governor and the legislature no later than December 31, 2010.

Section V: Cost of Client Care and Planning

Key Points

- Since DDS services are not an entitlement, many families providing care to family members with an intellectual disability receive no services beyond case management, while other DDS clients receive very intensive and costly services and supports.
- A discussion needs to occur around the factors that influence the costs of care delivered in various settings and whether rebalancing the system would allow for more individuals with intellectual disabilities to be served, while still ensuring the health and safety of all individuals receiving DDS services.
- Before such a discussion can occur, however, more analysis needs to be performed in order for valid comparisons to be made regarding the costs of providing care in one setting versus another.

Proposed Recommendation

- 20. The Department of Developmental Services, in consultation with the Department of Social Services, shall conduct a detailed cost review of per capita, per diem costs of care provided in institutional settings to care provided in the community. The cost methodology should include, but not be limited to the following factors: resident acuity, collective bargaining agreements, Medicaid costs, and the differences in staff costs between public and private providers. The report shall be presented to the legislative committees of cognizance by February 1, 2010.**