

Executive Summary

Planning for the Needs of Aging Individuals with Developmental Disabilities

In the past, most persons with an intellectual disability (ID) had a relatively short lifespan and many spent much of their lives in institutions. Consequently, their aging was not of immediate societal concern. Today, increased longevity and the presence of individuals with intellectual disabilities living in the community have heightened awareness of this population's emerging needs.

In Connecticut, the Department of Developmental Services (DDS) is the state agency with the authority and responsibility to provide services to persons with intellectual disabilities. However, the provision of services are not mandated nor entitlements. DDS delivers services and supports through available resources.

The study's focus, approved by the committee, was to examine DDS efforts to address and plan for current and future service needs of the aging population with intellectual disabilities in Connecticut. The study concentrates on two target populations: 1) individuals age 45 or older who are or would be eligible for DDS services, and 2) DDS clients' caregivers over the age of 65.

Based on the PRI review, it is clear DDS has already engaged in a number of efforts to plan for clients' needs as they age:

- preparation of several documents to guide the agency's vision;
- implementation of many recommendations made by the DDS-initiated Focus Team on Aging;
- the creation of a coordinator position for aging services; and
- offering some education and support to aging caregivers.

The report contains the results of the committee examination of the department's efforts, and of other areas pertinent to aging persons who have an intellectual disability. Where relevant, the committee proposes recommendations for improvement.

Given the current fiscal climate, the program review committee tried to be cognizant of potential cost-neutral recommendations in terms of state and/or federal funding, whenever possible. However, certain policy decisions will have to be made with respect to specific aspects of the department's delivery of services – in particular managing the wait list. As such, some of the committee recommendations will require financial investments now or in the future when budgetary conditions improve. Also, some of the committee findings and recommendations address system-wide issues, rather than specific issues related to clients age 45 or older, because the processes around resource allocation and service delivery are the same for all clients.

Prioritizing Financial Resources

Since this study was initiated in April 2008, the financial status of the national and state economy has spiraled downward. Current estimates project state budget deficits over the next two fiscal years will near \$6 billion.¹ Undoubtedly, difficult decisions will have to be made. All agencies are being asked to provide more services and programs with fewer real dollars. There is an urgent need to examine policy and financing issues to find methods of collaboration across service systems and cost-effective strategies.

Confronted with a dramatic growth in the numbers of aging individuals served by DDS, it is timely for policymakers to begin to consider cooperative efforts and rebalancing how care is delivered. The demographics alone are cause for a fundamental re-evaluation of current expenditures as decision-makers weigh the influx of an increasingly aging population on Medicaid budgets. Nationally, states have been moving away from traditional institutional settings, and exploring new ways to reinvest public dollars in order to serve more individuals in cost-effective ways in the community. In many cases, simple supports to an existing situation may mean the difference between continuing to reside at home or having to be institutionalized.

In a time of continuing budget cuts and subsequent decreases in programs or services, setting priorities and planning are paramount. The aging population of individuals with intellectual disabilities is just one segment of the overall aging population in Connecticut. In addition to competing with other aging groups, older individuals with intellectual disabilities face competition for resources even within the agency responsible for their specialized services and supports (e.g. Birth-to-Three, autism, graduates, and age-outs).

Therefore, the development of an effective fiscal plan using solid data to forecast service requirements for persons with intellectual disabilities and their caregivers is crucial. DDS has information about its consumers currently being served in state-sponsored programs. However, some of the information is not centralized or maintained in a useable fashion for planning purposes. In addition, little to no information is available regarding individuals who may need DDS services and supports in the future. These individuals, not presently in the system, may make an impact on the need for future aging services provided through both public and private sectors.

DDS Delivery System

Individuals with intellectual disabilities may require a vast array of supports and services depending on the type and degree of the disability. As such, the DDS delivery system provides for individualized services and support that range from providing minimal assistance to continuous around-the-clock care.

Despite the level of care required, persons who are eligible for DDS services must be assessed and evaluated by regional planning and resource allocation teams (PRAT) to receive funding for services and support. DDS services are not an entitlement and are contingent upon

¹ OFA Projections & Governor's Report (January 2009).

available resources. With limited funding, DDS maintains wait and planning lists based on a priority ranking system to guide allocation decisions and determine who receives services.

Individuals with the most pressing needs (e.g., emergencies) are considered first for services. However, as the limited funding tends to serve the individuals at the “top of the list”, those who continue to hold on at the lower end of the list either never get served or eventually become emergencies themselves creating a continuous cycle. Because crises frequently occur, the department often must use one-time funds in order to close service gaps until more stable resources are available. Thus, PRATs are constantly balancing resources in order to meet demand for services.

In addition, if a person has been found eligible for Medicaid waiver services, the department is required, under federal law, to meet all health and safety needs. This means some individuals receive an extensive amount of services and supports while others may be under-served or receive no services at all.

Current federal funding and the department’s policy are aimed at providing services and support to individuals in the community, preferably in their homes. This approach becomes more difficult as persons with intellectual disabilities and their caregivers age and their needs increase. Age-related changes in an individual’s overall abilities often necessitate increased programmatic and health supports. This may require individuals to transition from a less restrictive setting to one that provides more supports, or, if they are able to age-in-place at home, they may need additional modifications such as accessible doors, entrances, ramps, or bathrooms. In some instances, nursing home care may be the necessary alternative.

Recognizing the growing presence of the aging population, DDS has taken some initiatives to address the challenges of the issue. It has reinstated a Focus Team on Aging and hired an aging services coordinator. However, it has not adopted a formal plan on the types of services or placements that should be developed as its population ages. At the same time, the department faces the end of funding to address its wait and planning lists.

Increasing needs of aging individuals with intellectual disabilities. All people, regardless of their background, feel comfortable in surroundings for which they feel an affinity and which contain things that are familiar. For that reason, most advocates and social service professionals encourage the approach of aging-in-place, which simply means growing older where you are – in your home, with your family, in a group home, or any other place in the community. This approach requires planning to consider the changes that occur as people age. A system of supports that may have been ideal at age 50 may not be at age 70. Therefore, planning must occur to accommodate needs in one year, two years, or even five years out.

Uncounted individuals. Although estimates are not available, most disabilities professionals believe that there are uncounted numbers of families living with a relative who has an intellectual disability. There may be several reasons for these families being unknown to the department. One may be a generational thinking or attitude. Years ago, medical professionals often encouraged institutionalization for families of a child with disabilities. The stigma created around the care of the child may have led families to be reluctant to ask for help, preferring to

keep their needs to themselves. It is also possible the types of services needed were not available when the now-adult child was young and families may have felt they had no options. The adult child may not have been part of any system including educational and simply been cared for in the family home. These families may be unfamiliar with or wary of government services and may be unaware of the advantages. These uncounted families have the potential to overwhelm the system as the parents age, enter nursing homes, or die. By the time DDS discovers these families, it may be a crisis situation requiring emergency intervention. These unknown growing numbers of aging individuals will place even greater demands on a service system that is already stressed and unable to meet current needs.

Aging caregivers. Hundreds of older adults with an intellectual disability still live with their parents or other family caregivers. Many are growing older together and will likely require additional assistance. They may need greater services and supports both in- and out- of the home; legal or financial guidance; and/or preparation for alternative living arrangements. Some families recognize the importance of planning for the future but may feel too overwhelmed by the ongoing caregiver duties to focus on the issue. Others may be reluctant to even think about the implications of when they are no longer able to provide care. In some families, the aging caregiver and the adult child with an intellectual disability may be co-dependent to maintain their home and independence.

Proactive financial planning is also important for families who have a relative with an intellectual disability. If appropriate, they could avail themselves of legal vehicles that allow individuals with intellectual disabilities to receive assets without jeopardizing eligibility for government benefits.

In addition, the need for respite for families becomes more critical as the philosophy is to continue to provide residential services and supports in the family home. The provision of respite for older caregivers is especially vital as their physical energy and stamina may decrease with age.

Without proper planning, emergency situations arise that require crisis intervention (e.g., finding immediate residential placement for an individual with intellectual disabilities because a caregiver is hospitalized or dies). These crises frequently cost more than services provided through long-term planning.

Community supports. Aging adults with intellectual disabilities face many of the same challenges as other aging adults and some may derive benefit from programs and services provided in different service systems. Whenever possible, all aspects of the DDS delivery system must collaborate, coordinate, and leverage federal, state, and municipal resources to develop a full range of services to support aging individuals with intellectual disabilities. This is particularly important in the current financial climate.

The inclusion and integration into existing programs involves networking, planning, awareness, and education in order to be successful. These efforts require a key individual, such as the newly designated DDS aging coordinator, to broker and advocate for change to advance

the interests of older individuals with intellectual disabilities as well as staff to work directly with the persons being integrated and someone to guide and evaluate the integration effort.

Historically, agencies and providers tend to be reluctant to cooperate with each other in order to protect their jurisdiction and funding. However, in these troubling economic times, the need to work together rather than compete against each other may benefit multiple systems with cost-savings and common program options.

For example, senior centers offer a wide range of services geared for the over age 60 population. They provide opportunities to socialize and enjoy recreational or other structured activities. For some older individuals with intellectual disabilities, participation in local aging programs may provide a link to the community, when that is possible and appropriate. There may be need for collaboration and perhaps training with senior center program staff to ensure that older adults with intellectual disabilities can participate. Of course, the opportunities for leveraging resources may be limited. Senior centers do not only offer traditional activities such as bingo or arts and crafts. Today's older demographic and those aging baby boomers seeking to participate in senior centers will be looking for more diversity in activities. The anticipated "senior boom" will mean more of the general population will be in need of these services as well.

Nursing homes. Another area impacted by the growing numbers of aging individuals is long-term care. The need for and appropriateness of admission to long-term care facilities has been a particular issue for advocates for persons with disabilities. When faced with an adult who may appear to need the services of a nursing facility, the preferred practice is to find an alternate living arrangement in the community. The federal Omnibus Budget Reconciliation Act (OBRA) of 1987 instituted procedures for the admission and retention of persons with intellectual disabilities in nursing facilities. The law requires a preadmission screening for mental illness and intellectual disability for every person prior to admission to a nursing facility. It also requires that if an individual is found to have an intellectual disability, the need for specialized services be identified and provided. However, there is a growing concern among advocates for persons with disabilities about the implementation of these requirements.

Finally, as the demand and need for in- and out of home support increases, the pool of workers to provide these supports is dwindling. Furthermore, siblings or other relatives, who are expected to assume a larger role in providing primary care as parents' age or die, may not be prepared for this responsibility. As such, a key strategy is educating and training health professionals, direct-care workers, and new caregivers about challenges of caring for persons with intellectual disabilities.

Committee 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.**
 - 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.**
 - 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.**
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- 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;**
 - 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.

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.

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.