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**Program Review and Investigations Committee  
Testimony: Provision of Selected Services for Clients with Intellectual Disabilities  
September 27, 2011  
Submitted for the record by Nora Duncan, Executive Director**

The Arc Connecticut is a 60-year old advocacy organization committed to protecting the rights of people with intellectual, cognitive, and developmental disabilities and to promoting opportunities for their full inclusion in the life of their communities. With 22 chapter organizations around the state providing community based supports to individuals and families, The Arc Connecticut is uniquely positioned to speak to the quality and efficiency of services being provided in the community, and also to the principles that should be considered by the Committee in its work on this important matter.

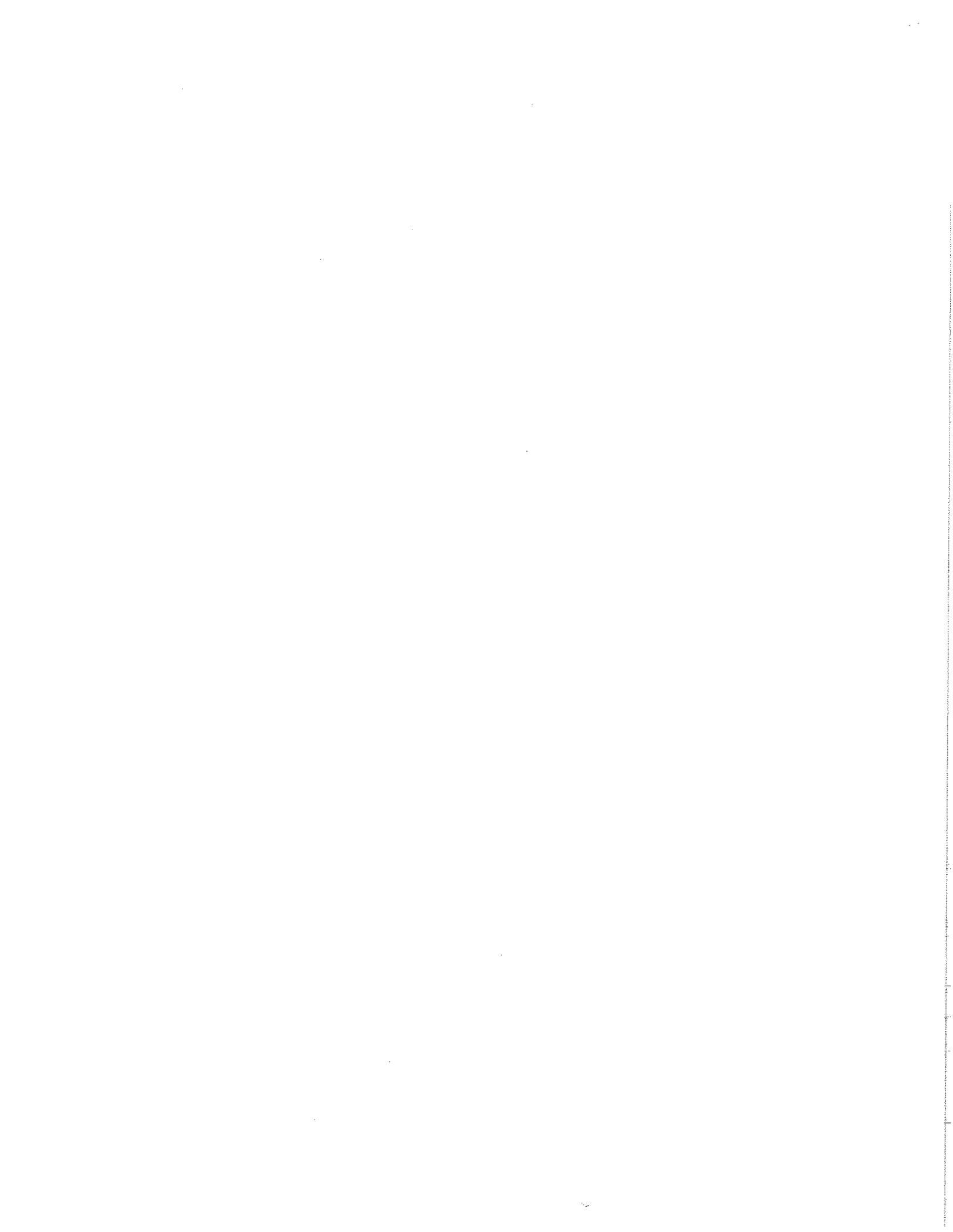
The recommendations made by staff are good ones and they should be commended for their thorough work. The recommendations are primarily related to financing, mandates, data collection and analysis. This is extremely important due to the chronic under-funding and significant mandates experienced by the private nonprofit provider system, as well as the absolute necessity to utilize every dollar efficiently and effectively to meet the needs of as many people as possible. However, as further study is conducted and input is collected, it is also keenly important to remember that behind every dollar spent and every technicality identified, there is a person with rights, feelings, family and friends.

Each person living a public residential setting can live a meaningful life in a private nonprofit residential setting, as is shown in the analysis done by Committee staff and in the testimony presented by parents, self-advocates and providers. The Arc Connecticut strongly recommends that input from self-advocates and family advocates be sought by the Committee, and related subcommittees, regarding any planning for services for individuals with intellectual and developmental disabilities.

The Arc Connecticut operates with guiding principles specific to 24-hour residential care that the Committee is urged to consider in all of its study, planning and deliberations. They are that:

- Large congregate facilities are unnecessary and inappropriate, regardless of type or severity of disability;
- People must receive individualized supports, including housing, as they leave institutions, as well as their family homes. Public funds must be shifted from institutions to the community to accommodate these moves; and
- The health and safety of people must be safeguarded wherever they live, including when a facility is closing, and whenever a person is transitioning from one living environment to another.

Your time and consideration is appreciated. Committee members and staff are encouraged to view The Arc Connecticut as a resource. We look forward to working together and encourage each member to read our Platform of Reform (attached).



## **Platform for Reform:**

# **A Better Plan for Supporting Individuals with Intellectual and Developmental Disabilities in Connecticut**

**BY:**

**The Board of Directors of the Arc of Connecticut**

**and**

**The Connecticut Conference of Executives of The Arc of Connecticut**

The Board of Directors of the Arc of Connecticut and The Connecticut Conference of Executives of The Arc outline below a Platform for Reform with regard to delivery of services and supports for people with intellectual and developmental disabilities in the State. We present this Platform to the Governor of the Great State of Connecticut for consideration.

### **I. Begin with *people* first**

**In our constitution, all people are created equal and possess basic and powerful rights. In accordance with these rights, we must make the supports necessary for inclusion and full participation in the community available and affordable, so each individual with intellectual and/or developmental disabilities can live, learn, work, worship and play alongside others who have no such disabilities. This way of life is the most beneficial and cost-effective support option.**

The Arc has supported this commitment to all members of the community for decades. To see it fully implemented in Connecticut, the State must:

- Recognize that people with intellectual and/or developmental disabilities have the same right to self determination as all people. They must have opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.
- Develop strong social supports within our communities, specifically with regard to: Employment, volunteerism, leisure, worship and recreation. In the past, the State funded building bridges between individuals and organizations within the community, based on common interests, with successful results. The State must return to its leadership role in this area by including such relationships in a reformed and strengthened system.
- Recognize that private providers are integral parts of their communities; and, thus, uniquely suited, qualified and positioned to develop such supports.

- Realize that maximum independence is the most beneficial option for community members with intellectual and/or developmental disabilities, as well as the most cost-effective option for the system overall.

**Full Empowerment of Families and Self-Advocacy** The State must embrace the idea that knowledge empowers and that the empowerment of individuals with intellectual and/or developmental disabilities and their families leads to positive outcomes. To achieve these outcomes, the State must:

- Acknowledge that families represent the largest group of providers in the state, whether or not they are receiving State funding, and therefore are our greatest resource. As such, accept that it is family involvement that provides the greatest opportunity for savings.
- Recognize that when an individual with intellectual and/or developmental disabilities is not receiving State-funded supports, it is the family that shoulders the lion's share of effort and cost. By cutting certain targeted supports, the State is, effectively, further shifting the responsibility for care and related costs onto a population ill-prepared to respond. As a result, the individual and the family will suffer, and most likely need more extensive supports in the future. Therefore, denying families case management and other basic supports is counter-productive and, in fact, more expensive in the long term.
- Understand that families make good partners and should have access to helpful resources.
- Realize that any communication tool, including the Department of Developmental Services website, must be user-friendly so that families, individuals, self-advocates and providers have the tools they need to succeed.

## **II. Implement strategies to *effect real inclusion* in all areas:**

**Choice and self-determination must exist in at least the areas of transportation, living arrangements, employment, education and spiritual pursuit. To ensure true inclusion, the State must allow for community instruction, mentoring and access to support, so that each community is able to reach out to all its people.**

In the following areas, the State must:

### **Transportation**

- Improve its transportation system in order for individuals with intellectual and/or developmental disabilities to realize any of the life experiences that most people take for granted.

## **Living Arrangements**

- Provide for individual choice regarding any housing opportunity, whether it involves shared housing, living with roommates or living alone.
- Eliminate the waiting list. The State can accomplish this goal by utilizing savings created by the closure of Southbury Training School and other DDS-operated institutions. Further, by funding real options for inclusion and, ultimately, true independence, the State will effectively make room for those next in line as greater levels of independence are attained by those currently receiving supports.
- Make the roommate referral system that the State purchased accessible to families, individuals, providers and case managers.

## **Employment**

- As referenced under *Begin with People First*, develop and maintain employment models that support employers in ways that lead to real job creation and real success, through development of real relationships and opportunities.
- Encourage private providers to facilitate relationships between people with disabilities and employers in the community. Private providers have the opportunity, due to their unique positions within the community, to develop employment opportunities that are a good fit for individuals and to train possible employers to create a positive, receptive and self-sustaining environment for individuals. By funding this type of system rather than relying on paid minders, which results in decreased independence and permanent costs, the State can provide better situations for its citizens with disabilities and ultimately achieve cost savings – along with bona-fide independence.

## **Education**

**Implement full inclusion for individuals with intellectual disabilities in classrooms with their peers so as to prepare them better for transition into adult life with the rest of their community.**

- Aid individuals with intellectual and/or developmental disabilities in their transition to adult life by promulgating change in the school-to-work system.
- Provide transition planning and services that help students transition to working in their communities. Seize the opportunity to capitalize on dollars invested in education. These services are currently limited or non-existent, limiting individuals from realizing their full potential and moving directly into adult life with optimal independence and minimal supports.
- Make a minor additional investment to expand transition supports for students exiting high school (and for their families); soon after, major cost savings can be realized as the individuals successfully transition into independent living.

- In addition to expanding transition services, provide guidance for parents navigating transition challenges so they can support their family members in making informed decisions and setting themselves up for success in their communities.
- Seize opportunities to utilize State employees in situations involving overstaffing to facilitate an expanded transitional supports area, which currently is understaffed. As noted, moving said State personnel to school transition coordination or other venues involving instruction of families in optimal use of existing services would eliminate gaps in service in these areas due to understaffing, the long-term consequences of which are costly on all sides.

### **Spiritual Pursuit**

- Ensure that funded programs afford individuals with disabilities the same freedom to pursue spiritual interests afforded to all citizens.

### **Community Outreach and Instruction**

- Foster initiatives, including programs run by private providers, to reach out to and instruct the community, as described in previous bullets throughout this document. More specifically, real independence for people with disabilities can be achieved via the establishment of circles of care whose roots spring forth from deep within our communities. Evidence indicates – and enlightened programming in other areas of the country proves – that full community involvement to the greater support of community members with disability is the most cost effective way to encourage and maintain independence; however, such supports must be nurtured, grown, encouraged and facilitated for results to be achieved and maintained.
- Educate and inform specifically first-responders and police about effective and appropriate interactions with people with disabilities. These efforts should extend beyond first responders to all emergency personnel.
- Sustain all such initiatives to their natural conclusion, to create the best situation within all areas of the community for individuals with intellectual and/or developmental disabilities.

### **III. Follow a *Common-Sense Plan for Reform***

**The State must first recognize philosophically that self-determination requires additional initial investment through fiscal supports, but that the up-front investment will ultimately lead to greater efficiency and cost savings. Conversely, continuing present practices that do not provide such an investment not only lead to higher long-term costs, but also undermine empowerment and provide excuses for poor service at various levels within the system.**

To take advantage of the following areas of opportunity, the State should explore...

- Opportunities for revenue:
  - Maximize revenues by seeking out other CMS-Authorized services, now unfunded or solely State-funded, that can be included in the waiver. By bringing such services and programs under federal funding, the State can alleviate much of its own burden.
- Consistency among regions:
  - Develop a system in which services and supports are fairly and equitably available to all individuals with intellectual and/or related disabilities across the state, regardless of regional boundaries.
  - Implement all of the reforms undertaken uniformly across all regions.
- Segregation of functions:
  - Segregate functions, as appropriate. It is **critical** that case management, licensing/inspections of all group homes and Quality Service Review/Inspection of all services be completely independent of DDS.
  - Segregate assessment and funding. The level of need assessment should be done independently of DDS, with the department providing the funding. Additionally, the level of need assessment should identify every support and resource that each individual needs, to allow for full funding and funding that is equitable across the state. The assessment must also take into consideration wrap-around supports for people who are medically fragile.
- Other efficiencies within the system:
  - Allow individuals who require intermittent supports to use them as needed, rather than use them continually when not needed in order to maintain the level of funding. The State could use the savings realized under this system to create a pool of emergency support services, to which the State has alluded in the past.
  - Modify quality assurance requirements so they are not so onerous as to impede the provision of services to individuals who need them. While quality services are critical, documentation requirements can be inordinately difficult to navigate.
  - Eliminate dual systems of funding (funding both private provider and institutional systems), which dramatically increase costs for the state. The State should move toward a single system, in which the State of Connecticut funds and monitors the quality of services, while private providers supply the funded services.

- Partnerships and relationships with families and private providers:
  - Provide families and providers alike with the truly service-based Department of Developmental Services system that they deserve. Real teamwork would support resourceful collaboration for savings and success.
  - Provide a system that does not confuse families and individuals on the services available, and have policies and procedures that are clear, understandable and implemented equitably and fairly across the state.
  - Provide a system in which families are not in a position of building budgets five years in advance in order to have sufficient funding available when needed for independent living. The current policy unnecessarily encourages hoarding of services, when a more practical and cost-effective approach would be to adequately fund the move to independent living at the appropriate time.

**This document represents our input into a system change that would best meet the needs of the individuals for whom we advocate. In order for individuals to receive consistent, quality services, a strong, healthy private provider service system must be in place. Our additional recommendations for assuring a healthy, responsive system are below.**

To appropriately support the private provider system, the State must:

- Actively support private providers. Individuals will only receive services if providers of those services continue to exist, and current statistics show that 70% of private providers are running in deficit. The safety net **will be** destroyed if the State does not take swift action.
- Provide families and providers the truly service-based DDS system that they deserve. Real teamwork would support resource collaboration for savings and success.
- Implement uniform reimbursements, policies, procedures, mandates and forms across all regions of the state.
- Eliminate unfunded mandates. It is unreasonable that DDS should enforce requirements without funding the cost.
- Discontinue considerations of proposals to cost settle at the end of a contract year and to cost settle on a daily basis through attendance; such proposals may prove unenforceable. Creative solutions are available, and private providers are willing to develop alternatives and solutions to these and other issues.

- Discontinue the current DDS plan to build an information storage and sharing system at a cost of some \$60 million dollars. The plan is inadvisable for the following reasons:
  1. DDS has not proven itself to be a competent builder of information technologies in the past.
  2. Workable technologies already exist that DDS can adapt at an exponentially lower cost.
- Refer to the final report of The Commission on Health and Human Services issued April 1, 2011 as an additional resource for recommendations for private provider services.

**The Board of Directors of the Arc of Connecticut and The Connecticut Conference of Executives of The Arc of Connecticut created this Platform for Reform and present it to our Governor for consideration. We further advise that a panel of self-advocates, family members, support staff and providers convene to effect real system changes. We need to return Connecticut to its original standing as leader in supports for individuals with disabilities.**

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