

Research Conducted for Rhode Island Developmental Disabilities Council State Plan 2012-2016

The RI Developmental Disabilities Council is in the process of developing its new five-year state plan. This plan will be in effect for federal fiscal years October 1, 2011 through September 30, 2016. The plan will be submitted to our federal oversight agency, the Administration on Developmental Disabilities on August 15th, 2011. The State Plan is our strategic planning document for the next five years, and it will serve as a framework for our planning, implementing and evaluation activities. Each year, the plan will be updated, particularly the goals and objectives section of the plan.

A couple of key components to the process of developing the state plan are public input and public review.

Public Input: Most often the public input comes during the needs assessment process of the plan development. Through a number of activities, the Council solicits information from the public regarding how the Rhode Island service system is working, where the gaps in services are, and what are the major issues that need to be addressed in the service system. The information developed from the needs assessment activities then drives the development of the goals and objectives for the new state plan.

We obtained data from 10 different sources and activities using an Appreciative Inquiry (AI) Process, dedicating the Council Annual Meetings in 2008 and 2009 to this process. AI helps groups think about the best of the current system, challenges and solutions that work for people, and the future that members would like to see. This process is used across the country as a positive starting place for planning. Input was also collected from: focus groups with seven (7) Advocates in Action local self-advocacy focus groups, as well as a public opportunity at the Advocates in Action annual statewide conference in 2010; current Council project summary reports; national and local research results; the most recent PAL Quality of Life Survey; the 2010 DDNetwork Forum; the Council's Cross-Disability Project; reviews of state agency plans; and the annual listening sessions held by the Governor's Commission on Disabilities. Participation in the most recent strategic planning for TechACCESS, the technology project in RI, yielded more information.

From the information gathered, Rhode Island is doing well in some areas, and has needs in other areas. In the order of the Federal Areas of Emphasis:

Employment:

Having a job is a high concern for many people. While the Office of Rehabilitation Services is making gains replacing staff as they are recovering from budget cuts as well as a large loss of veteran counselors from retirement in 2009, new counselors have less experience with people with developmental disabilities. The Division of Developmental Disabilities is partnering with the

UCEDD to develop a baseline on employment rate and type, so that changes can be made in the provider system for employment supports and practices. People with developmental disabilities across the country are setting up their own businesses based on individual interests. "The Discovery Process" can be used in place of a conventional work evaluation to identify interests and possible supports to get employment. The Office of Rehabilitation Services is interested in Discovery, and its potential to get more people working in jobs that are personally meaningful.

Several other barriers to work were identified: people believe the myth that they shouldn't seek work because they will lose benefits; employers are still reluctant to hire people with disabilities; there is more information and support needed in the employment arena around the ADA.

Education:

The Council scan focused on transition, post-secondary, Adult Education and opportunities for lifelong learning. Anecdotal information identified the following: lack of resources and supports, although direct support professionals are interested in tools for activity in this area: few or scattered postsecondary education and lifelong learning opportunities; and need for information about supports and reasonable accommodations in these activities. Stakeholders wanted increased and improved: opportunities to learn, specifically learning to read; professional development for those serving people with I/DD; and transition planning, with early links to the Office of Rehabilitation Services and the Division of Developmental Disabilities.

Formal and Informal Community Supports:

Individuals and families in Rhode Island have increased choices for living, housing and working. The Division of Developmental Disabilities is working on improving the eligibility process, services and supports, and transparency in rate-setting through "Project Sustainability." Gaps in specific community services were identified as: waiting for respite, assistive technology and durable medical equipment, and services targeted to the Hispanic/Latino communities.

Additionally, the following issues were identified: the need for more review in Direct Support Professional training; reducing DSP turnover, having input to the hiring and releasing of staff; and more self directed services.

The PAL Quality of Life Survey identified that less than 1% of people report knowing how much money is in their budget for DDD services, or how much is spent on paying staff. Council experience continues to demonstrate a gap in knowledge of a person's financial situation. With increasing interest in self-direction, information and support in the areas of financial literacy and asset development is needed.

The Developmental Disabilities subcommittee of the Medicaid Global Waiver Long-term Care Workgroup recommended an articulation of the system of care so that people with developmental disabilities do not need to enter a new door at

every life stage (Early Intervention to Preschool; Pre-K to K-12; K-12 to Transition; Transition to Adult System). While there is a documented process for bridging the last link, there is a need for more information for families about what goes into the process, and what opportunities the services and supports can provide. This is another element being developed in Project Sustainability.

Housing:

Primary need expressed in housing was in locating safe, affordable, accessible housing. Registries exist for each municipality, but a centralized resource that is searchable by these three key housing attributes is lacking. Specific needs are: shortage of this kind of housing in general; development of partnerships with existing housing organizations; and the expansion of Section 8 vouchers. People want more ability to choose where they live and with whom they live. Aging parents and their adult child with developmental disabilities specifically need more information about the supports available to them at the Division of Developmental Disabilities.

Health:

Most people who live with or whom their families support or who live in provider-run homes and apartments are up-to-date on medical care. However, people who are outside of this system, who may be living on their own may not be accessing needed health care. With changes in Medicaid managed care, there may be times when some visits are not covered services. Also, specialists, specifically psychologists who provide learning disability assessments, and oral surgeons are mentioned as difficult to find.

Technology:

TechACCESS, RI's local Assistive Technology Access Partnership demonstration center, conducted a stakeholder retreat in 2008. In this "RoadMap for Adult Service," they identified need areas in: information and resources about assistive technology; opportunities for hands-on assessments; the need for technology to be considered across all life areas; the ability to re-visit changing needs without re-entering the system; technology considered as one part of the whole-person approach to self-determination. Stakeholders in our focus groups identified wait-times for delivery and repair of durable medical equipment as well as assistive technology; and support-staff knowledge about AT as areas needing improvement.

Transportation:

Transportation is one foundation of a productive, meaningful life. Needs are identified in availability, affordability, and accessibility in public and private transportation; expansion of and more flexibility in routes. Partnership with RI Public Transit Authority on bus driver awareness about people with developmental disabilities was suggested.

Recreation:

Increased awareness about the availability and calendar for inclusive, accessible year-round recreation and arts opportunities was cited as an on-going need.

Self-advocacy/ leadership, advocacy and diversity:

Respect was the most discussed topic across the self-advocacy groups. Public attitude is still one of the most challenging barriers to full inclusion. Having the respect of others, feelings of competence and confidence, and being treated equally was the most common topic discussed. Conversations in this area were strongly tied to an expressed need for opportunities for self-improvement (see Education).

Diversity (Ethnic/race barriers) – need areas identified include addressing service issues of un/underserved populations, promoting self-determination, and addressing language barriers.

Other advocacy issues – the need for advocacy training for families and involvement in decision making; build new leaders, youth development advocacy base; law enforcement training regarding I/DD; and generally inclusive communities (programmatically, and attitudinally, also linked to almost all other areas).