

**Connecticut Long-Term Care Needs Assessment  
Focused Report IV: June 2008  
Experiences of People Using Disability Programs**

Connecticut maintains numerous programs for people of all ages with disabilities, including people with physical disabilities, mental illness, and intellectual challenges. These programs include five Medicaid home and community based services (HCBS) waivers as well as four state-funded programs. As part of Connecticut's 2007 state-wide Long-Term Care Needs Assessment (the "Needs Assessment"), state residents who participate in these programs were surveyed on a variety of topics. **All Needs Assessment reports available at: [http://www.uconn-aging.uchc.edu/res\\_edu/assessment.html](http://www.uconn-aging.uchc.edu/res_edu/assessment.html)**

This report examines key differences by program and takes an in-depth view of survey results and unmet needs for people with disabilities, as a group and by program.

The programs compared in this report include:

- Connecticut Home Care Program for Elders ("Elder")
- Personal care assistance waiver ("PCA")
- Acquired brain injury waiver ("ABI")
- Katie Beckett waiver ("KatieB")
- Department of Developmental Services waivers combined ("DDS")
- Department of Developmental Services waiting list ("DDS wait")
- Bureau of Rehabilitation Services programs ("BRS")
- Community-based services program ("CBS")
- Department of Mental Health and Addiction Services ("DMHAS")

Some key findings from survey responses in these areas include:

### **Health measures**

Large numbers of people are in poor health, with notable trends in some self-reported health measures

- CBS, Elder and PCA participants report the worst overall health.
- Depressive symptoms and incidence of falls is high in most programs, raising concerns about health complications and potential need for institutionalization or greater care needs.
- Lack of preventive health care in many programs is extreme
- Many programs have a high rate of hospitalization and emergency room visits, despite the fact that this population receives a great deal of home-based care, often including nursing.

### **Employment issues**

Employment is a significant issue for respondents in most programs.

- Very few respondents are employed full time, and while part time work is more common, only in two programs (BRS and DDS) are more than half of respondents employed in any capacity.
- Of those not currently working, a significant number of people in many programs do want to have a job.

### **Unmet need**

The rate of unmet need in all programs is extremely high. Programs that provide the fewest services (e.g. DDS wait, CBS, and PCA) have the highest overall rate of unmet need. The unmet need identified most often across programs is transportation.

An examination of both current use and unmet need for a variety of other community-based services reveals some additional conclusions:

- Elder respondents experience high use of most community services, but low unmet need, suggesting that the program is meeting a high proportion of the need as defined by program participants.
- By contrast, DDS wait and DMHAS have low current use but relatively high unmet need in many areas, particularly job-related services, suggesting that these programs may be meeting a smaller percentage of the need.
- Physical accessibility is a larger problem for recreation and shopping than it is for respondents in their homes

### **Quality of life**

A six-measure variable was created that is designed to combine factors considered most important to quality of life for survey respondents. It examines answers to survey questions concerning transportation, socialization, ability to meet financial needs, presence of unmet long-term care service or assistive technology needs, and self-rated health. By this measure, respondents with the highest quality of life are from DDS, Elder and BRS, with CBS and PCA at the low end.

### **Policy and program implications**

Connecticut's programs to aid people with disabilities are meeting many of the needs of their target populations, but numerous gaps remain. Moreover, the various measures of health status as well as unmet needs for long-term care services differ substantially by program. These results reinforce the need for acting in accordance with the guiding principles initially set out in the Needs Assessment:

- Create parity among age groups, across disabilities, and among programs through allocating funds equitably among people based on their level of need rather than on their age or type of disability.
- Break down silos that exist within and among state agencies and programs.

The nine programs examined in detail in the Needs Assessment and in this report, as well as other programs designed to meet the needs of people with disabilities in Connecticut, in many cases purposely differentiate their services based on age and/or type of disability. Moreover, they create silos that are difficult to penetrate, and achieve uneven results for their clients.

Of particular concern are rates of depressive symptoms, incidence of falls, lack of preventive health care, and high rates of hospital admissions and emergency room visits, which may be risk factors for future institutionalization or death. The transportation issue is shared by many in the general population. For people with disabilities, however, the issue is more acute, and is being tackled as a major initiative of Connecticut's Medicaid Infrastructure Grant ("Connect-Ability"). These efforts should be supported. The lack of employment supports and opportunities for those who want to work is also notable. On the positive side, interest in finding employment is high in many programs. Employment efforts for people with disabilities throughout the state are also being supported by Connect-Ability.

It is important that state officials with legislative, administrative and oversight responsibilities for these programs consider the recommendation in the Needs Assessment to strive for a universal waiver with consistent requirements across ages and disabilities. At the program level, administrators and others concerned with the well-being of the population within each program can derive additional insight into the extent of missing services and their effect on quality of life by examining the detailed results contained in this report.