Functional Assessment Tool for Aging People with Disabilities

By Susan Craven, M.Ed., clinical director for day habilitation programs and behavior specialist at Bridgewell. Bridgewell is a private, nonprofit human service organization in eastern Massachusetts that provides support to people with disabilities and other life challenges.

In care settings, diagnosing dementia in people with intellectual disabilities has historically been a challenge. Diagnoses are often based on subjective input from caregivers who have infrequent or no formal training. Assessment tools also typically require verbal responses from the person receiving services, which is a difficult task for people who are nonverbal or have limited expressive language.

Barriers like these hinder objective measurement of baseline data and limit the gathering of ongoing information needed by neurologists and primary care physicians. Developing an appropriate care plan (including unique adaptations, testing, and consultations) is difficult without these data, and many people can be misdiagnosed as depressed or labeled as noncompliant.

About 15 years ago, caregivers at Bridgewell began to come across more and more research showing that individuals with intellectual disabilities develop dementia at a higher rate than people without similar disabilities. In particular, research revealed that people with Down syndrome are more likely to develop Alzheimer’s disease, often earlier in life than those...
without Down syndrome.

Because the team at Bridgewell strives to develop appropriate program planning based on baseline data, they realized a new tool was needed to better identify and track dementia for these individuals.

Creating the assessment tool

Susan Craven completes a task with a Bridgewell client as part of the assessment process

When Bridgewell’s team of specialists began work on designing the assessment tool, they knew it should be as user-friendly and intuitive as possible. They identified five general skill areas that were most important to assess: self-care, eating, independent living, mobility, and behavior.

Each of these skill areas was further broken down into specific skill activities, which are measured with a simple number rating representing an individual’s capabilities in that area. The number ratings are typically* on a scale of 0–4:

- 0 — completely independent
- 1 — initial verbal cue
- 2 — verbal prompt/point or gestural cue
- 3 — physical cue/hand-over-hand assistance
- 4 — totally dependent

* Some specific skill activities have different scoring and wording that is more specific to that activity.

The ratings for each specific skill activity are totaled and result in a numerical score for each of the five general skill areas. These are then tallied to give the individual an overall cumulative score for level of functioning.

The initial testing score is considered a baseline. The baseline
number is not relevant in itself, but is significant as a comparison for subsequent testing. An increase in the number rating indicates a decline in that skill area.

The primary condition of using this assessment tool is that only professionals, informed family members, or caregivers who are familiar with the individual and their daily routines should complete it. No special training is needed, and the tool can be quickly adopted and used to gather data.

The Functional Assessment Tool was trialed in different Bridgewell residential and day program settings. Bridgewell’s team felt there was value in the results of the trial and baseline scoring, so use of the tool was expanded companywide. Guidelines were established that individuals with Down syndrome should be tested at age 35 and other individuals with intellectual disabilities at age 55. Subsequent assessments are done at least annually, but more frequently if changes are observed.

Results of using the assessment tool

The ongoing use of this tool, and its easily interpreted numerical rating, have allowed family members and Bridgewell staff to know objectively if an individual is progressing or regressing in a specific skill area. This has increased accuracy in diagnosis and allows for more effective program and medical need planning.

When someone is showing a decline in a skill area, recommendations are made for further testing and possible adaptations. For example, a physical therapy consult might be needed for changes in ambulation. If balance is declining, use of a gait belt or walker may be implemented to keep the individual mobile. An individual’s ability to swallow is often affected with the onset of dementia, potentially putting him or her at risk for choking or aspiration. Therefore, a speech-pathology consult or swallow evaluation might be necessary if changes in the eating skill area are noted. An occupational therapy consult can be scheduled in response to changes in the self-care or independent living categories, and a behavior consult might be necessary to ensure consistency in approach and provide needed training.

The assessment tool in action

One example of how the Functional Assessment Tool has been used is from a woman named Julie who moved into a
Bridgewell residential program when she turned 22. She attended a prevocational day program and was fairly independent in self-care, needing only verbal and point cues to complete tasks. Julie had some expressive language and could receptively follow simple directions. She was able to walk independently and had no dining issues.

As Julie aged, the Functional Assessment Tool was used to quantify and track changes in her behavior along with some confusion and a decrease in skills. In 2005, Julie’s cumulative score at baseline was 168. Over the next 11 years, her cumulative score increased to 240. Specific changes in the general skill areas were: self-care: 53 to 86, Eating: 5 to 7, Independent Living: 103 to 116, Mobility: 6 to 29, and Behavior: 1 to 2.

The medical and clinical assessments identified needed adaptations over the years, such as the use of a gait belt and tilt-in-space wheelchair for mobility, implementation of pacing strategies and a texture diet for eating, and use of picture-and-object symbols to assist in self care and independent living. Julie now lives in a Bridgewell residence and attends a Bridgewell day program that both specialize in supporting people with dementia.

CARF recognized Bridgewell’s Functional Assessment Tool in a recent survey report for exemplary conformance, identifying it as a program with the potential to be adopted on a national level. For more information about Bridgewell’s Functional Assessment Tool, visit www.bridgewell.org. You may also contact Susan Craven, clinical director of developmental disability services; Joseph Aurelia, speech pathologist; or Kathryn Rodgers, physical therapist at (339) 883-1702.

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