Background

A challenge in many developed countries is effecting the transformation of a long-term care disability system from one that has focused on supports and services for children and adults with intellectual and developmental disabilities (I/DD) to one that incorporates services for adults dually challenged by lifelong disability and emergent mild cognitive impairment or dementia. Although the rising incidence of dementia among adults with I/DD is mirroring that of the general population, it has the added dimension of loss of function among adults already disadvantaged. The problem involves consideration of how to transform existing supports and services provided to work-age adults with lifelong I/DD to those more appropriate to older-age adults with I/DD and affected by cognitive decline and functional impairment.

Methods

A recent effort in the United States was undertaken using a ‘voluntary involvement model’ to create and implement a national action plan for transformative disability management supports and services related to the growing rate of dementia-related secondary impairment among adults with I/DD. The model employed:
1. obtaining aegis for the formation of a national working group,
2. drawing in volunteer membership from across the country and from various constituencies,
3. infusing interest in providing pro-bono work and contributions in support of the working group’s efforts (including the creating of a national plan), and
4. drawing in key governmental and national organizational officials to support its efforts and implement its recommendations.

Results

The National Task Group on Intellectual Disabilities and Dementia Practices (the ‘NTG’) was created in 2010 to correspond with American efforts being undertaken in response to the federal National Alzheimer’s Project Act (the ‘NAPA’) to create a national Alzheimer’s Plan. The NTG was a collaborative endeavor of several national professional organizations and aging/disability university centers. It was charged to examine the impact of dementia on adults with I/DD and their carers, identify a means of effectively undertaking an early identification effort and defining best fit community care, and develop a series of dementia-related practice guidelines for health and social care practitioners. Since 2010, the NTG has contributed to the national conversation on transformational community-care dementia practices, producing a report and national action plan (“My Thinker’s Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports”), and increasing public education and professional training, formal practice guidelines for innovative care practices.

Conclusion

The NTG was able to effect change by highlighting community care models designed to divert institutional admissions, enhancing the awareness to early signs of dementia among carers and practitioners, and addressing health disparities within provider services.

The NTG was effective in mobilizing a varied constituency to focus on a significant national disability management issue. This process helped bridge the extensive networks found within various constituent organizations, from the Alzheimer’s care to the disability supports communities.

Also, the NTG was able to establish a successful interface with the federal NAPA process with respect to disability management on a broader scale with respect to generically addressing dementia in the United States.

Organizing a national effort, based on a ‘voluntary involvement model’ is an effective means of affecting and shaping public policy, educating stakeholders, and improving quality of services.