National Task Group on Intellectual Disabilities and Dementia Practices

A Roadmap to the Future
Background

• National Alzheimer’s Project Act – President Obama – 2011
• NTG (National Task Group) charged with complementing the effort on behalf of individuals with dual diagnosis and their families
• Efforts are ongoing
Who

• The NTG is a coalition of interested persons and organizations
• Composed of families, association and organization representatives, practitioners, academics and others
• Supported by the A.A.D.M.D., A.A.I.D.D (Gerontology Division), R.R.T.C. (University of Illinois) & University of Albany
My Thinker’s Not Working

• Initial document – summative report of challenges and recommendations
• 20 point action plan for moving forward
Key Findings

- Most people living in community settings
- There are not reliable population counts
- Dementia has a devastating impact
- Providers facing aging of population & are challenged in providing care
- Services & supports can support staying in community
- Providers adapting small group homes
- Professional staff lacking ability to I.D. and support interventions
Key Findings

• Primary health care providers lacking in knowledge & training
• Need specialized assessment and diagnostic resources
• Usefulness of a common screening instrument
• Need for national training, information & education programs
• Improvement of access to resources in rural areas
• Funders could improve on forecasting and budgeting for supports
Main Recommendations

• Dementia often hits harder – require the same level of services offered to others

• Lifelong caregiving – invest in increased home-based supports for caregivers
Education

• Staff unfamiliar with signs and symptoms
• Invest in more education & training of staff
• Promote best practices amongst providers
• Awareness & information at all levels
Final Words

• Early identification with a standard screening instrument
• Commitment to living in the community
• Expansion of community care options & dementia capable group homes
Guidelines for Structuring Community Care and Support

Covers early diagnosis thru to end-of-life

Goal to facilitate planning to remain in community

Pairs staging model with recommended actions

Symptoms, care focus, training & environmental adaptations
Pre-diagnostic

• Utilization of a detection/screening tool on a regular basis
• Assessment for medication side effects
• Advocate for trained professional involvement for formal assessment and diagnosis
• If diagnosis received then meet with all parties to explain the diagnosis and map out future supports
Early Stage

- Engage in advance care planning
- I.D. & plan to adapt environment
- Establish purposeful daily regime
- Adapt day activities so still engaged and respite provided
Mid-Stage

• Plan for increased assistance with personal care & hygiene as needed
• Secure housing options that can accommodate
• Continue periodic assessments/monitor for co-morbid conditions
• Monitor medications
• Enhance protection for abuse/harm
Mid-stage

- Enhance the training for staff and family so better able to cope with reactive behaviors & the need to adapt routines
- Plan for long term services and supports
Late and End Stage

• Focus on non-ambulant care
• Staff focus moves to nursing & personal care including supporting family caregivers
• Procedures re: dignity, comfort & pain & symptom management
End-of-life

• Organize end-of-life supports and post-death arrangements

• Obtain support from palliative care specialists
Differing Community Environments

- Private home/caregiver supports
- Alone or with a roommate
- Dementia capable home
- Group home or apartment
- Day services
Ancillary Issues

• Abuse
• Financial
• Managing Choice & Liability
  – Sharing the diagnosis
  – Decision making around life planning
• Medications
• Nutrition
Webinars

• http://aadmd.org/NTG
• Free on website: Dementia Evaluation and Care in Aging Adults with I.D.
• 4 part webinar series - $30
  – Introduction
  – Importance of Early Detection & Diagnosis
  – Systems Issues
  – Collaboration across networks