

PCAD Project

Training Protocol

Support Group Participation

Please select one person to organize and run 4, weekly or 8, bi-weekly support groups, 90 minutes in duration, for carers of an individual with an intellectual disability and dementia. The person selected should be comfortable with organizing a support group and serving as its facilitator.

- This person is asked to:
 1. Recruit participants for the group
 2. Serve as the facilitator of the support group
 3. Collect two sets of data (pretest and posttest)
 4. Insure confidentiality of all data within the agency (kept in a locked drawer or office) and that data is deidentified before being sent to the PCAD project. This will include a coding system given to you by PCAD
 5. Provide to PCAD the nature and structure of the support group
 6. Distribute informational materials to group participants as required by PCAD
 7. Recruit/hire speaker or guest to speak or share information on that day's or evening's topic (given to agency by PCAD)
 8. Provide a form of light refreshment at sessions

"Learn-at-Home" Information

Please select one person who will be responsible to distribute informational packets to families who are caring for at home, an individual with an intellectual disability and dementia and aid the carers with completing survey forms.

- This person is asked to:
 1. Recruit in-home participants
 2. Distribute informational material as required by PCAD
 3. Insure confidentiality as outlined above
 4. Collect data as required
 5. Advise carers as necessary

In terms of the overall project:

Agencies will:

- Select and allocate one staff person who will serve as the facilitator for group sessions and collect data as required and/or allocate one person to be responsible for overseeing in-home informational sessions and data collection
- Provide to PCAD the nature and structure of support groups and/or in-home informational sessions.
- Recruit willing participants for the support groups and/or at-home informational sessions
- Insure that all data collected by the agency remains confidential and is deidentified before return to PCAD
- Distribute and collect a total of two sets of data (pretest and posttest) from group sessions and/or in-home information participants
- Distribute informational materials as required by PCAD.

Preparing Community Agencies for Dementia-III will:

- Provide all instruments and materials necessary for the project
- Provide payment through the University of Maine of \$500 to be used for amenities at group sessions (i.e. refreshments, coffee, tea, and to offset attendance costs of a speaker or speakers at group sessions).
- Provide payment through the University of Maine of \$100 to be used to offset costs incurred in recruiting and distributing materials to the 'Learn-at-home' participants
- Supply stamped envelopes for data return.
- Provide PCAD staff to answer questions or give support to agencies when needed
- Provide DVDs and other informational materials that can be used in the topic discussions within the support groups

Content of support group training modules:

A. General Aging

This module involves a discussion of human aging, using materials developed by the National Institute on Aging, the Administration on Aging, and the University of Maine's Center on Aging. Topics covered include age span development, sensory and mobility capacity changes, general health and decline, and diseases associated with older age. Generally a speaker is invited who is a gerontologist or geriatrician and can discuss normal and pathological aging in the general population.

B. Nutrition and Physical Conditions

This module involves showing the DVD, "When People with Developmental Disabilities Age," developed by the New York State Developmental Disabilities Planning Council, as well as providing select handouts issued by the RRTC on aging with a developmental disability at the University of Illinois at Chicago. The 18-minute video outlines the major physical and social change issues affecting adults with intellectual and developmental disabilities as they age, including a brief mention of Alzheimer's disease and Down syndrome. Produced by the Brookdale Center on Aging, this is an excellent orientation and staff training video on the basics of aging among people with developmental disabilities. Generally a nurse or physician is invited to speak and help address issues related to the aging of people with intellectual disabilities.

C. Adult Dementia and Decline in Health

This module involves showing the DVD, "Dementia and People with Intellectual Disabilities – What Can We Do?" developed by the New York State Developmental Disabilities Planning Council, as well as providing select handouts issued by the RRTC on aging with a developmental disability at the University of Illinois at Chicago and the Alzheimer's Association. The 23-minute instructional video covers the basics of how dementia affects adults with intellectual disabilities. It provides information on diagnostics and suggestions on providing supports and services in community care settings. Produced by the University at Albany, this video serves as primer on dementia and intellectual disabilities and provides information on basic design and service issues in intellectual disabilities service settings. Generally a speaker from the agency's health services, a community health worker, or a representative from the local Alzheimer's Association is invited to come and present and help with the discussion.

D. General Information and Services

This module covers local services, resources available to carers, and other information useful for linking carers to services. Generally a speaker from the agency or one of the major providers for families is invited to be a speaker. Some agencies may choose to invite a speaker from the local Alzheimer's Association chapter or state developmental disabilities agency.