

Some resources on intellectual disabilities and dementia

Many of these resources are free, others will be forwarded for the cost of duplication and postage and some can be downloaded directly from the websites noted. There are also a variety of books and journal articles on intellectual disabilities and dementia and even greater availability of material specifically on dementia. Contacts with local chapter and affiliates of the Alzheimer's Society or Alzheimer's Association are particularly recommended.

BOOKLETS AND WRITTEN MATERIALS

Alzheimer's Disease and people with intellectual disability: Common questions and concerns. A booklet for families developed by Mary McCarron, Ph.D. for NAMHI. The National Association for the Mentally Handicapped of Ireland, 5 Fitzwilliam Place, Dublin 2, Ireland.

Developmental disabilities and Alzheimer's Disease . . . What you should know A booklet for family members and staff. developed by Matthew P. Janicki, Ph.D. for the Arc of the United States and available at: www.thearc.org and www.uic.edu/orgs/rrtcamr/dementia.

What is dementia? and What is death? Pamphlets created by the Scottish Down's Syndrome Association to use with adults with intellectual disabilities. Download at www.uic.edu/orgs/rrtcamr/dementia

Alzheimer's Disease and intellectual disabilities (Down Syndrome): A toolkit. By Philip McCallion, Ph.D. and Matthew P. Janicki, Ph.D., the toolkit contains:

- a video and CD-ROM, 'Dementia and people with intellectual disabilities: What can we do?'
- a two CD-ROM self-instructional in-service and education kit.
- fact sheets and other informational sheets issued by Alzheimer Disease International; The ARC of the United States, the Alzheimer's Association, the University at Albany, the University of Illinois at Chicago, and the International Association for the Scientific Study of Intellectual Disabilities.
- The Edinburgh Principles for community care of adults with intellectual disabilities affected by dementia.
- a 20-item quiz on Intellectual Disabilities and Dementia.
- web-based bibliography on Alzheimer's disease and intellectual disabilities and a hard-copy of a bibliography from the Greenfield Library at the Alzheimer's Association.
- web-sites on Alzheimer's disease and Intellectual Disabilities.
- protocol for recording baseline information on behaviors of adults with intellectual disabilities.
- an evaluation form.

Copies may be obtained from: Center for Excellence in Aging Services, University at Albany, Richardson 207, Albany, NY 12222, USA.

Trainer's Guide End of life Care: Supporting older people with intellectual disabilities and their families Developed by L.T. Force, Ph.D. G. Abbatiello, Ph.D., K. Doka and L.R. Faulkner, Esq. for the NYS Developmental Disabilities Planning Council, copies are available from nysarc@nysarc.org

VIDEOTAPES AND CD-ROMS

When People with Developmental Disabilities Age Aging . . . A Shared Experience

Dementia and People with Intellectual Disabilities – What Can We Do? Intellectual Disabilities and Dementia – a two cd-rom training package

Copies may be obtained from: NYS Developmental Disabilities Planning Council, 155 Washington Avenue, Albany, NY 12210, USA. nrose@ddpc.state.ny.us

Face to Face: Respectful coping with dementia in older people with intellectual disability. Copies may be obtained from: Centre for the Study of Developmental Disabilities, National University of Ireland, Belfield, Dublin 4, Ireland.

RESOURCE WEBSITES (these are portals that will lead to multiple related sites).

Intellectual Disabilities and Dementia

<http://www.albany.edu/aging/IDD/index.html>
www.uic.edu/orgs/rrtcamr/dementia

Dementia specific

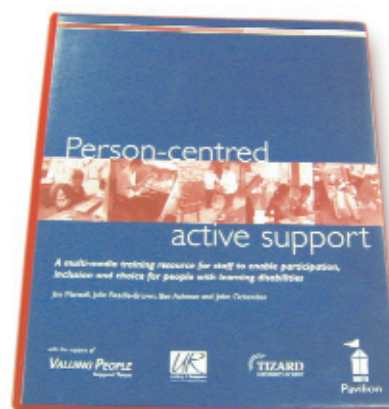
<http://www.alzheimers.org>
<http://www.albany.edu/aging/links.htm>
www.dementia.ie/index.html
<http://www.dementia.stir.ac.uk/>
<http://www.dementiasolutions.com/EDGE.htm>

Intellectual Disabilities and End of Life Issues

<http://www.albany.edu/aging/lastpassages/index.html>

Philip McCallion and Mary McCarron

frontline reviews



PERSON-CENTRED ACTIVE SUPPORT

by J. Mansell, J. Beadle-Brown, B. Ashman and J. Ockenden (2004). Pavilion Publishing, Brighton. ISBN 1 84196 131 0.

Person-Centred Active Support is a comprehensive

training resource aimed at enabling staff to promote participation, inclusion and choice for people with learning disabilities. The training pack is made up of six modules and employs a range of tools to assist presentation and learning, including ready-to-use overhead projector layouts; worksheets; questionnaires; case-studies; timetables; and video-clips (on CD-ROM)—all excellently integrated into the main body of supporting text. The pack is designed so that it can be used by a trainer to present to a group, or by an individual to learn independently.

The training material builds on work originally carried out in one of the first staffed houses for people with severe and profound learning disabilities in the United Kingdom (Mansell *et al.*, 1983). It was more recently influenced by increased emphasis on person-centredness and the call for improved quality of support as opposed to paper plans, in such services. The resultant approach is built around the principle that '*person-centred support is about enabling people to engage in meaningful activity and relationships, minute by minute, day by day and not about paperwork and plans*' (p.1).

Modules one and two concentrate mainly on challenging the learner to evaluate their own attitudes to the needs and rights of people with disabilities, and how a service can be designed to effectively address and promote these. This is achieved by directing the learner to relate their own needs to those of people with disabilities, and by emphasising engagement as the key to a high quality of life.

The related worksheets at this stage guide the user, through writing an individualised 'active support' activity plan aimed at illustrating that everyone can contribute to the world around them with appropriate support. It is through this meaningful contribution that new opportunities and experiences present themselves, which in turn lead to the person gaining more control to make informed and appropriate choices.

The emphasis is shifted in Modules three and four, from the change that needs to take place at an individual level, to what needs to happen at managerial and organisational level. The authors strongly advise intensive and on-going on-the-job coaching and evaluation of staff competencies, by first-line managers, and the consequent shifting of administration duties to senior managers. In Module Four, particular focus is put on the need for senior management to model and support good practice, provide appropriate and necessary training, and maintain high staff motivation levels. Managers