



Active Aging I/DD

Offering Information, Strategies and Networking Resources
To Support Older Adults with I/Developmental Disabilities

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Grief Support for Individuals with I/DD

"Grief is the price we pay for Love" —C.M. Parks

Staff, caregivers and family members are increasingly facing the challenge of how to assist the individual with I/DD to deal with grief. When a friend or family member passes grief is a natural process that a person may go through to deal with the loss. Individuals with I/DD are no different and in some cases may experience a deeper level of grief than non-disabled individuals. Research has investigated individuals with ID, as a whole, represent a group of high-risk mourners. The factors of emotional, situational and cognitive influence their ability and the way they cope with grief placing them under extraordinary stress in times of mourning.

Ms. Claire Brickell, BS and Dr. Kerim Munir, MD, MPH, DSc, Harv Rev Psychiatry. 2008; 16(1): 1-12.

Helping Individuals with Developmental Disabilities through the Grieving Process

Because the effects of bereavement may be prolonged with people with intellectual disabilities experiencing more anxiety, depression, irritability, and other signs of distress, staff and others may wish to seek further understanding and approaches to

support the individual in effectively dealing with the grieving process. Alejandro Moralez, LISW, Continuum of Care UNM noted helpful guidelines by Luchterhand and Murphy that could be very useful in helping most individuals with developmen-

tal disabilities through the grieving process: **Tell the Person That the Death or Loss Has Occurred, Provide Reassurance That He or She Is Not Alone and That Others Are There to Help, Remember That the Grief Process Takes Time and Be Patient.**

continued page 2



Best Practices: Siffrin Association, Canton Ohio.

The Siffrin Association was established in 1976 as a residential provider to serve individuals with I/DD and their families. Siffrin is a "not for profit" service organization and a CARF accredited program. Today they have grown to provide not only residential services but also community integration, employment, transportation and financial management services throughout Ohio while serving an estimated 800 individuals.

Siffrin's Community Housing Program serve older adults with I/DD. Kim Larson-Phillips, Chief Operating Officer states that thirty percent (30%) of the residents are over the age of 55 with the oldest being 82 years old. Ms. Larson-Phillips indicates that even though this has been a challenge, they have been able to initiate specialized services and supports to serve these Older Adults.

These services and supports for the Older Adult resident include training of staff in Alzheimer and Aging Dementia issues, health care, nutrition and meaningful activities. Specialized services and supports directed for the older adult resident include contracting

with a home health provider that conducts regular health care screenings as a preventive measure. Conditions screened include blood pressure, weight, diabetes, foot problems, and osteoporosis.

Ms. Larson-Phillips states that the main goal is to keep the older resident in their home for as long as possible. Personal care and daily living skills are supported by her staff in conjunction with the home health care. One of the main concerns she identified is finding doctors to serve this population through Medicaid. Another concern was finding new staff across the community housing program. Increased efforts have been made to provide bonuses to staff for referrals and hires.

Other services offered include the coordination between community partners such as Meals on Wheels for nutrition; Adult Day Services, Community Employment providers, Transportation providers, Prescription Assistance programs, and Community Hospice.

Community Hospice has been a valuable resource to the residents and staff as stated by Ms. Larson-Phillips. Local hospice services have provided palliative and end of life services to residents of the homes operated by Siffrin. She indicated that recently a 12 year resident who has since passed away received these services in her home. The residents and staff were consulted and asked for their agreement to allow this service. A substantial benefit to this was the grief counseling

For more information: Please, contact Kim Larson-Phillips, Chief Operating Officer at klars@siffrin.org

continued page 2

Morales also suggests that collaboration with a **Hospice Program** can be very helpful. Hospice staff and others who work in the field of grief know that one of the important guidelines to remember in helping someone who is grieving is to learn from that person. They quickly learn to “walk beside” the grieving person, rather than assuming that they know what the person is feeling and experiencing at any given time or trying to “lead “ him or her to a different state of mind. Each person’s experience is unique.

Key strategies include: The Vanderbilt Kennedy Center Knoxville Tenn.

- Provide reassurance
- Promote conversations about the loved one
- Provide opportunities for the individual to make connections to the past, present and future:
 1. Look at pictures and share memories
 2. Make a book or a memory box about the person who died
 3. Give them something that belonged to the person
 4. Light a candle in honor of the person
 5. Visit places they used to go together
 6. Talk about how much the person who is gone would be happy about a present activity.

Resources

- *End-of-life Care: A Guide for Supporting Older People with Intellectual Disabilities and their Families.* By A.L. Botsford and L.T. Force. Purchase price: \$21. From NYSARC, Inc, 393 Delaware Ave., Delmar, NY 12054. Phone: 518-439-1893. Email: nysarc@crisny.org.
- *When Somebody Dies.* S.Hollins, S. Dowling, & N. Blackman. Books Beyond Words, Gaskell/St. George’s Hospital Medical School-Royal College of Psychiatrists. 2003. Price \$20. Contact details: Publishers Storage and Shipping Company, 46 Development Road, Fitchburg, MA 01420, USA. Email: orders@pssc.com Tel: +1-978-829-2560. Fax: +1-978-348-1233. PSSC can take credit card orders from both individuals and orders from book shops
- *SUPPORTING PEOPLE WITH DISABILITIES COPING WITH GRIEF AND LOSS.* An easy-to-read booklet. HREPSIME GULBENKOGLU, 2007 Copyright © Scope (Vic) Ltd 2007. Published by Scope (Vic) Ltd, 830 Whitehorse Road, Box Hill, Melbourne, AUSTRALIA, 3128
- *Grief and Bereavement for Persons with Developmental Disabilities who are Aging*
John Guido, Outreach Officer at L’Arche discusses ways to support individuals to grieve well and find new life as they age. YOUTUBE.



ASSOCIATION ON AGING WITH DEVELOPMENTAL DISABILITIES

The Association on Aging with Developmental Disabilities will hold their 27th Annual Aging with Developmental Disability Conference on May 22nd and May 23, 2017. The conference will be held at the St Charles Convention Center, Missouri. Pam Merkel, Executive Director reports that speakers include Dr. John Morley and Dr. Max Zubatsky. For registration information call 314-647-8100 or visit the website www.agingwithdd.org.

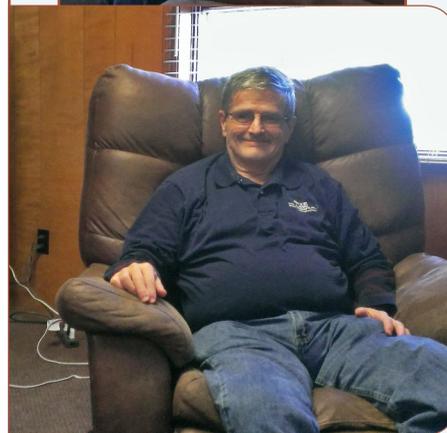
The Association on Aging with Developmental Disabilities (AADD) was initially formed in 1989 as a special interest group and became incorporated in 1994. The organization was created to support the increasing needs of older adults with developmental disabilities (mental retardation, cerebral palsy, epilepsy, autism, severe learning disabilities and head injuries that occur by the age of 21).

Best Practices—continued from page 1

provided to the staff and residents. Other resources she has found for this purpose has been funeral homes who offer bereavement services.

Siffrin has also provided in their homes Aging in Place and Universal concepts and designs to assure for the safety and longevity of their residents. These include safety audits, hand rails, grab bars, grips on stairs, walk in tubs and roll in showers and permanent ceiling Hoyer lifts in bedrooms.

A Tale of Two Brothers, a Tale of Two Lifestyles.



Charles C. and Ron C. are two residents at the Siffrin’s Swiss Street home where they share living arrangements with two other individuals I/DD ranging in age from 58 to 70 years old. Ron is 66 years old and his brother Chuck is 64. They have been long time residents of the Siffrin Association for over 15 years. Even though they are brothers and share the same home, their journey as older adults is quite different. Ron states he is retired and makes no question about it. He worked 20 plus years in a work activity center and chose to retire. He currently attends an Adult Day Service 5 days a week and thoroughly enjoys his activities and time away from work. Whereas, Chuck states he will never retire. He loves working and is glad he has an opportunity to work every day. He is employed in custodial services . One driving factor is his ability to make money as he receive a paycheck bi-weekly. He is very proud of this fact and states he will continue to work for as long as he is able. Chuck is able financially to vacation regularly. He tells of his recent cruise ship experience. But most noteworthy is his generosity to his brother Ron who was able to accompany him providing the financial assistance necessary.

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