Do You Really See Me? ACPE Webinar Series Resources

**Webinar 1: An Introduction to Understanding Models of Disability and Terminology**

**Web-based**
- **Advancing Effective Communication, Cultural Competence, and Patient- and Family- Centered Care: A Roadmap for Hospitals**
  [http://www.jointcommission.org/assets/1/6/aroadmapforhospitalsfinalversion727.pdf](http://www.jointcommission.org/assets/1/6/aroadmapforhospitalsfinalversion727.pdf)
- Language and terminology
  [https://www.disabilityisnatural.com/home.html](https://www.disabilityisnatural.com/home.html)
- **Portrayal of People with Disabilities.**
  [http://www.aucd.org/template/page.cfm?id=605](http://www.aucd.org/template/page.cfm?id=605)
- Variety of resources and published articles on the website

**Video:**
- **A Credo for Support:** (Five minutes. Powerful short history of disability and current requests for effective supports) People First Version:
  [https://www.youtube.com/watch?v=wunHDFZFxXw](https://www.youtube.com/watch?v=wunHDFZFxXw) Without narration:
  [https://www.youtube.com/watch?v=21uHYEqKO0w](https://www.youtube.com/watch?v=21uHYEqKO0w)
- **Ten Commandments for Communicating with People with Disabilities.** 25 minute videotape, perhaps available at local universities, libraries, or disability agencies. Excellent. Uses humor to illustrate ten common issues in communication with people with a variety of disabilities.
- Other resources to come with the 2nd and 3rd webinars

Invite some people with disabilities and/or their families and caregivers to come and share their hospital experiences with your CPE, chaplaincy program, and/or congregation.

Also a resource in every state:
- **Parent to Parent networks:** [http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx](http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx)
- University Centers of Excellence in Developmental Disabilities
  Find the one or two in your state through [www.aucd.org](http://www.aucd.org) and learn about training and education opportunities they sponsor and/or coordinate.

- **Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers.** Marc Markell, Ph.D. Fort Collins, CO: Companion Press. Chapters exploring use of ritual with photographs, memory objects, storytelling, stones, light, plants, drawings, food, and other rituals drawn from daily life. Also see the website for a wide number of useful resources in grief and loss. [www.centerforloss.com](http://www.centerforloss.com).


- **Helping Adults with Mental Retardation Grieve a Death Loss.** Charlene Lucterhand, Nancy Murphy. Taylor and Francis Group, 7625 Empire Drive, Florence, KY 41042. 1-800-634-7064. $22.95. An abbreviated form of this book is a booklet, Mental Retardation and Grief Following a Death Loss: Information for Families and Other Caregivers. 45 pp. Downloadable from [www.Thearc.org](http://www.Thearc.org) for members of their online community. (i.e., join, logout, wait for your notice, and then you can get into those publications).


- **Lessons in Grief and Death: Supporting People with Developmental Disabilities in the Healing Process.** By Linda Van Dyke, this book includes counseling techniques and activities, including music, art, and drama, to work through the grieving process. Available from High Tide Press, 2505 E. Washington, Joliet, IL 60433. Order toll free at 1-800-469-9461 or visit [www.hightidepress.com](http://www.hightidepress.com).
• End-of-Life Care - A Guide for Supporting Older People with Intellectual Disabilities and Their Families - and Resource Supplement 2 Volume Set - 2004; Anne L. Botsford, Ph.D. and Lawrence T. Force, Ph.D. A guide for supporting older people with intellectual disabilities and their families. Note – A publication fee of $19.95 plus tax where applicable (includes shipping), is charged for this publication. To order, contact the state office at 518-439-8311 or by email at info@nysarc.org

• When Somebody Dies. S.Hollins, S. Dowling, & N. Blackman. http://booksbeyondwords.co.uk Other titles in the Books Beyond Words series include When Mum Died, When Dad Died, Am I Going to Die?, and Ann has Dementia. Order from distributors: Turpin Distribution, tel 01767 604800, email: custserv@turpin-distribution.com. The series includes many other titles related to daily living skills, self care, health care, life in the community and psychological issues.

• The Thinking Ahead, My Life At The End project was developed through a focus group made up of individuals with developmental disabilities. Advocates from three California Regional Centers: Alta California, Eastern Los Angeles, and Golden Gate, came together to talk about healthcare treatment and related end of life decisions. They shared about what was important to them and what they would need to make informed end of life decisions. The workbook and DVD contains words, symbols and pictures that facilitate discussion and decision-making regarding individual values, goals, and treatment preferences at the end of life. The Workbook and DVD are both available in three languages [English, Spanish and Chinese] free of charge through the California Coalition for Compassionate Care -. http://www.coalitionccc.org/thinking-ahead.php Digital PDF workbooks are available through California Department of Developmental Services - www.dds.ca.gov/ConsumerCorner/Home.cfm. See a video about the Thinking Ahead project and resource at http://www.youtube.com/watch?v=pcs8BBQCbbs.

Ethical Issues, End of Life Considerations, and Developmental Disabilities.
Minnesota DD Council http://www.mnddc.org. Resources, including more than 50 short interviews with individuals, family members and others about end of life issues, and some videos including a news report about some of the things that have happened in the past (hopefully) in institutions both large and small.

The Quality Mall (This is an excellent listing of additional resources)

Online Webinars and Courses

The ARC.

“Being With” People with I/DD Experiencing Grief and Loss, Archived webinar by The ARC Future Planning Project.  Link to Archived Webinars

AAIDD Education Archives


Hospice Foundation of America


Other On-Line Resources and Websites

An email discussion about resources to support a young man with autism dealing with the suicide of his father led to other emails with resources that Karen Jackson of the Faith Inclusion Network (http://www.faithinclusionnetwork.org) collected for all of our use:

http://www.autismspeaks.org/family-services/resource-library/bereavement-and-grief-resources
http://www.autism.org.uk/bereavement
http://www.friendshipcircle.org/blog/2013/08/20/how-to-talk-to-your-child-with-special-needs-about-death/
http://www.griefspeaks.com/id96.html
http://autism.lovetoknow.com/Being_Autistic_and_Dealing_with_Death
https://expertbeacon.com/helping-kids-autism-spectrum-disorder-navigate-bereavement#.VpmOuPkr1rgs
http://www.amazon.com/Understanding-Death-Illness-Teach-about/dp/1932565566
http://blog.stageslearning.com/blog/understanding-death?topic=autism-emotions
http://benziesangmassocialstoriesforautism.blogspot.com/2013/05/when-someone-dies.html
http://www.archildrens.org/Services/Center-for-Good-Mourning/Good-Mourning-Resources.aspx
Webinar 3: Pastoral Care and Advocacy Beyond the Hospital Walls

There are multiple resources, faith organizations and networks that have resources for clergy: Here are some key online resources:

**Specific Faith Traditions and Denominations**
Almost every faith tradition has resources and/or an office or task force that provide resources and leadership in inclusive faith supports. Simply search using the faith tradition name and disability. A Google Search on Faith and Disability will give you quite a list. For example, a search of Judaism and Disability yield 465,000 results. There are also a number of organizations outside of any specific tradition that have extensive websites related to congregational inclusion. For example, some are *Joni and Friends, Inc.*, *The Inclusive Church*, *Key Ministries*, etc. (Those are Christian.) For a number of these resources, go to the Congregational Accessibility Network, https://www.canaccess.org/can/. There are also an extensive number of blogs written by families, clergy and others.

**Roman Catholic:** National Catholic Partnership with Disability. www.ncpd.org

**Jewish:** The past five years have seen a huge growth in Jewish organizations and resources, within and across the branches of Judaism. Those include inclusion initiatives, a designation of February as *Jewish Disability Awareness Month*, a national *Jewish Leadership Institute on Disabilities and Inclusion* and a professional organization for professionals from all of the streams of Judaism called *Hineinu: Jewish Inclusion for People of All Abilities*. Two gateways for finding out more about these are through http://inclusioninnovations.com and the Ruderman Family Foundation: http://www.rudermanfoundation.org

**Muslim:** In the States, there are at least three national networks and organizations working in the area of inclusion and faith based supports
- Enabled Muslim: http://www.enabledmuslim.org
- Equally Able Foundation: http://www.equallyable.org
- Muhsen: http://www.muhsen.org

**Disability Specific Organizations**
There are too many to list, but you can search the web by name of a disability and find networks for support and advocacy. Two cross disability news organizations are Disability Scoop and the American Association for Persons with Disabilities.

**Other:**

**Gleanings.** A free once-twise a month newsletter with new resources, ideas, projects, and events from a variety of sources pertinent to the intersection of faith and disability. See samples and register for the AAIDD Religion and Spirituality Division Newsletter
at http://www.aaiddreligion.org/newsletter. Paid membership in the AAIDD and the Division also brings an electronic subscription to the Journal of Disability and Religion, formerly the Journal of Religion, Disability, and Health. (See below)

The Journal is now in its 18th Volume with growing numbers of submissions. The site can be searched for articles from different faith traditions as well as different issues related to different kinds of disability.

Summer Institute on Theology and Disability: https://www.facebook.com/theologydisability for updates and related information. The Summer Institute will be under the Collaborative on Faith and Disability, http://faithanddisability.org
The project website will have the plenary sessions Mp3 audiotapes from 2010 and 2011, and plenary sessions videotapes from 2012 – 2015, as well as other videos. National and international speakers addressing multiple topics related to the intersections of faith and disability.

Collaborative on Faith and Disability: http://faithanddisability.org. A number of University Centers of Excellence in Developmental Disabilities are partnering in starting a national Collaborative on Faith and Disability. The website is based at the Kennedy Center in Nashville. Current Projects in addition to the Summer Institute on Theology and Disability include:

- Putting Faith to Work, a four state pilot project to work with and through congregations to help people with disabilities get jobs.
- National Webinar Series on Spiritual Supports. See website for details and archived webinars.

Some Key Online Publications

Spirituality: From Rights to Relationships
Fall, 2012 Issue of Connections, the national TASH newsletter http://tash.org/blog/2014/05/15/spirituality-rights-relationships/
If you share or reference the issue, TASH has requested that you note the origin and include a link to this page on the website: http://tash.org/blog/2014/05/15/spirituality-rights-relationships/ The title, volume number, issue and volume numbers are on the newsletter. You are welcome to share the link with others.

That All May Worship
**Welcoming People with Disabilities and their Families: A Practical Guide for Congregations.**
http://vkc.mc.vanderbilt.edu/assets/files/resources/CongregationPracticeGuide.pdf

The Kennedy Center itself (see Collaborative above) has a number of excellent resources on faith inclusion at [http://vkc.mc.vanderbilt.edu/vkc/resources/religionspirituality/](http://vkc.mc.vanderbilt.edu/vkc/resources/religionspirituality/)

**Autism and Faith National Initiative and Resources**

**Articles specifically on pastoral care and advocacy:**


**Books and more.**
There has been an explosion of good books at the intersections of theology and disability. Here are some of the titles:

• *Autism and Faith: A Journey into Community.* The Elizabeth M. Boggs Center
  This 50+ pp booklet, originally done several years ago, is now available in Spanish.
  [http://rwjms.umdnj.edu/boggscenter/products/Product_FaithBased.html](http://rwjms.umdnj.edu/boggscenter/products/Product_FaithBased.html)
• Amy Julia Becker. *A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny.* Bethany House
• Benjamin Conner. *Amplifying our Witness: Giving Voice to Adolescents with Developmental Disabilities.* Eerdmans Pub
• Ellen Painter Dollar: *No Easy Choices: A Story of Disability, Parenthood, and Faith in an Age of Advanced Reproduction*
• Stephanie Hubach. *Same Lake, Different Boat: Coming Alongside People Touched by Disability* P&R Publishing. 2006
• Mark Pinsky, *Amazing Gifts: Stories of Faith, Disability, and Inclusion.* Alban Institute
• *Supportive Care in the Congregation: Providing a Congregational Network of Care for Persons with Significant Disabilities.* MennoMedia
• Jeremy Schipper. *Disability and Isaiah’s Suffering Servant.* Oxford Press
• Amos Yong. *Theology and Down Syndrome: Reimagining Disability in Late Modernity.* Baylor University Press. 2007 and *The Bible, Disability, and the Church.* Wm. B. Eerdmans Publishing Company
• Frances Young. *Brokenness and Blessing: Toward a Christian Spirituality.* Baker Publishing