



# Religion and Spirituality Division Newsletter Winter, 2008

## From the President

Nella Uitvlugt

Every Tuesday evening I have the privilege of being with a large group of friends at my church. This is a rowdy, joyful, sharing group of about 70 folks who love to get together to sing, pray, do dramas as part of our worship and Bible Study, eat, create art projects, and design cards for people who are sick that we know. We go to a summer minor league baseball game, have a Christmas Party and in May an ice cream social for relatives and friends. About half of these friends have intellectual disabilities. Through all our activities there is a strong sense of community and caring for one another. One of the great aspects of this is that no one is paid to be a buddy, and no one gets credit in school. We simply like to be together. We have done this for over 18 years. We have shared sad times and cried together over something that concerned us. We have enjoyed successes together, learned much from each other and found that through the years we are all enriched. When I travel for work, I have the blessing of knowing that many of these folks will be praying for my safety and will want to know where I have been, and if it was a good trip.

When I think of the theme of the next AAIDD conference which is **Creating Enviable Lives** it strikes me that we all have an enviable life being part of this wonderful group. We experience the gift of being part of community inclusion in a religious setting. It is one of the richest experiences one can have. A couple of mothers whose sons are part of our group told me that this is the only place their sons are truly accepted exactly as they are. Yet when one of them sings with me I feel like I have received a gift.

The Conference in **New Orleans June 10-12** is only a few months away and I hope that you are considering attending. Here are some of our plans.

Thursday, June 11 we plan to have our famous **Division Dinner**. This will again include a time of sharing what you are doing in your locale. I can promise great food although I am not sure we can top last year's menu. The wonderful conversations are a highlight of the conference and renew relationships among those of us there. Please e-mail me if you are planning on attending the conference. It would be very helpful to have some idea of who is coming. Nella's e-mail: [friendship@friendship.org](mailto:friendship@friendship.org) or call me at 1-888-866-8966 ext. 2-1.

Friday June 12, 9am-12 noon will be our **Division Forum**. Last year's Forum was so well received we plan to use the same format again this year. One topic for discussion is regarding the barriers to congregational inclusion that group homes/provider agencies create. Michael Hoggatt has agreed to lead this discussion. He has extensive experience with group homes. Bill Gaventa will also participate.

Do you have input on this? Would you be willing to participate in a discussion on this? Jeff McNair, from our division leadership team, shared with me recently that he had a very difficult time with a group home that required him to be fingerprinted before he could be involved in the lives of the residents. The question he asked: would an entire congregation have to be fingerprinted before being able to be involved in the lives of the residents? Other issues that arise are transportation, or staff that is not helpful or interested. But when there is collaboration wonderful things can happen.

We are still hoping to receive **Nouwen Award nominations**. This is a very unique part of our division.

## Henri Nouwen Award Criteria

1. Demonstrates a devotion to follow a sense of call and vocation in relationships, or in community, with people having developmental disabilities
2. Demonstrates the understanding of and the capacity to blend the pastoral and prophetic dimensions of ministry and service to others.
3. Demonstrates a capacity to expand and enhance our understanding of the spiritual needs and gifts of people with developmental disabilities.
4. Demonstrates the competence to write and teach while also living in community, or having direct relationships, with people having developmental disabilities and their families.
5. Demonstrates, in one's life and writing, the competence to build bridges of understanding about individual spiritual needs and the ability to meet those needs by illuminating the strength of vulnerability and community.

Nominations should include:

- A brief biography/vitae
- A description of articles published, writings, etc.
- A description of professional and practical experiences related to the field of developmental disabilities
- A rationale for consideration of the nominee
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Please send to Kathryn Papaleo at [avatarassist@cox.net](mailto:avatarassist@cox.net) or by hard copy to her at 1704 Guava Lane, El Cajon, CA 92020. 619-920-7976. You must be a member of the AAIDD Religion and Spirituality Division to make a nomination.

### **Division Updates**

This past year we have implemented the online newsletter sending it only when there was pertinent news. It has been a delight to hear from some of you and learn more about what you are up to.

We have published the hard copy newsletter and sent it both by mail and electronically. We want to publicly thank Bethesda Lutheran Homes and Services, especially David Morstad, for ensuring

that our newsletter was printed and mailed. We couldn't do it without you.

There was an increase in members for our division. If you need a brochure to pass on to someone letting them know about our division please contact me. I can send it either in the mail or electronically.

It is time for renewal of your memberships. Don't forget to re-up. You can do so at the new website: [www.aaidd.org](http://www.aaidd.org)

We are looking to begin a more interactive presence on the web and hope some of you more techie folks will help us with that.

Do you have news to share with the division? Do you have a topic you would like discussed in a newsletter or blog? Be sure to contact either Bill Gaventa [gaventwi@umdnj.edu](mailto:gaventwi@umdnj.edu) or myself [friendship@friendship.org](mailto:friendship@friendship.org)

Nella Uitvlugt  
President

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## **News and Notes from Members and Friends**

As you all may know, Nancy Eiesland is in hospice care, or that is the last I know as of the writing of this newsletter. She had a wonderful short article last fall in an issue of Impact, the issue focused on Employment and Women with Disabilities. Volume 21. No.1. It is online at <http://ici.umn.edu/products/impact/211>.

Many of you also know that **Jay Turnbull**, son of Rudd and Ann Turnbull, died suddenly in early January. You can read more of the remarkable testimonies to the impact of his life on the website of The Beach Center. Rud and Ann have long been supporters of the Religion and Spirituality Division, and Jay's church, and faith, were key parts of his life. See later in this newsletter the remarkable eulogy by Jay's sister Kate.

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## The Mask Can Be Part of You.

by Aaron Abel.

Contact Aaron through The Institute for Abundant Living, 1915 Novato Blvd., Novato, CA 94947.  
email [jaledu@comcast.net](mailto:jaledu@comcast.net)

From Jim and Lorrie Lewis at the Institute for Abundant Living. "By the way we wanted to share with you something one of our students just wrote. After seeing it, and some of his notes that he has written over the years on his life, we are going to help him write it into a book form and perhaps he can get it published. He opens up so and can speak so well, that his story and the things that he has learned could sure help a lot of people! He wants to call the book: *The Mask Can Be a Part of You.*"

"My name is Aaron, I am thirty-five years old and I was born with a disability. It takes me longer to learn some things than it does for other people. I have learned to have patience. Having a disability has made me more sensitive than most people. Being sensitive has given me more awareness about people and their feelings; which has helped me to have a good relationship with people. The disability I have is called Down syndrome.

In my life I have had problems with people because people have problems with my disability. I learned that people didn't see me, they saw my disability. My disability became a mask, like a Halloween mask; people only saw the mask and really didn't see me. This was difficult for me; because I began to see myself as the mask that people had put on me. The mask kept me from knowing who I am. I learned that the mask of a "retarded person" was just a mask; a mask that needed to be removed. As I learned that the mask people put on me was not me, I made the choice to not wear it. I found that I could stand up for myself, know my rights, face my fears, and take action; because I knew who I really was. I was me. A person that God had made. I was not a mask I was made in God's image. We must remove the mask so people can learn who we are - people with the ability to learn, to work, to marry, to live, and help this world be a better place."

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## Exciting Developments and Resources in Spirituality, Theology, Disability, and Public Policy.

The **DD Council of Tennessee**, along with the Vanderbilt Kennedy Center, focused its January, 2009 Breaking Ground newsletter on "**Spirituality: A View of the World.**" Personal stories, reflections, and resources. The Vanderbilt Kennedy Center is also sponsoring a number of events for faith groups, and doing a survey, with the hope of developing further initiatives in disability and spirituality. To download a copy, go to [www.breakingground.org](http://www.breakingground.org)

The **Connecticut DD Council**, along with Hartford Seminary and others, is sponsoring a project to encourage congregations to take their role in shaping public attitudes about disability and others who often bear stigmatizing labels. This is in response to the movie Tropic Thunder last summer and other instances of devaluing people with labeled disabilities. The project includes a conference at Hartford Seminary on March 16 (see conferences) and a declaration by the Governor.

The **SPIRIT Project**, a collaborative project between OMRDD in New York, the New York Developmental Disabilities Project, and the Consortium on Innovative Practices, is developing strategies to help connect people living in group homes and provider run living arrangements with congregations and other spiritual supports. For information, contact Marcey Dolgoff, Project Director, at [marcey.dolgoff@thecip.net](mailto:marcey.dolgoff@thecip.net) or Bob Ciota, Local Coordinator, [bob.ciota@mac.com](mailto:bob.ciota@mac.com). They have done two newsletters.

For a beautiful **calendar** for 2009, with pictures and quotes, see the **allbornin** resources, a movement in pursuit of an inclusive civil society, from the Northwest Down Syndrome Association. [www.nwdsa.org](http://www.nwdsa.org).

The **Christian Century** had two articles on disability in its December 2, 2008 edition. *Able and Disabled: The Politics of Gentleness* by Stanley Hauerwas, and *Toward a Theology of Disability*, by Brian Volck, an extended review of three new books by Amos Yong, Tom Reynolds

and Sharon Betcher. Both great articles, and very nice to see the coverage in The Christian Century. Also see the article about listening to presentations by Stanley Hauerwas and Jean Vanier at Duke Divinity School.

**Exceptional Parent Magazine** is continuing its spiritual supports series, with approximately one article every quarter. The first one in 2009 is an overview article of developments in Jewish communities around the country, with the next one to be a similar article about new ministries and resources in the Roman Catholic Church. The articles are about 1800 words, and can include pictures. If you have an idea for one, contact Bill Gaventa at [bill.gaventa@umdnj.edu](mailto:bill.gaventa@umdnj.edu)

February, 2009 is the first **Jewish Disability Awareness Month**, a collaborative effort and initiative by all the branches of Judaism in North America. See Shelly Christensen's "B'Shalom Column."

The **Council on Quality and Leadership** now has a series of Quality Statements, including one on spirituality. Along with the Policy Statement on Religious Freedom by the AAIDD and the Arc, these two make great resources for working with agencies. The statement by CQL is the next article.

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## Quality in Practice Statement on "Spirituality" from The Council on Quality and Leadership

### *Spirituality*

Spirituality and the expression of that spirituality bring meaning to many people's lives. Belonging to a faith-based community is one of the most common ways to engage in spirituality with others. Organizations can support people to find and maintain such communities.

### Quality in Practice

- Actively ask people about their spirituality and how they would like to express it. Go beyond the simple question of "what religion

are you" to try to understand not only the denomination, but also the ways in which people might like to practice their religion.

- Support a person who expresses an interest in spirituality, but who does not already have a religious affiliation, to explore different options within the community. There are many, many different types of religious communities, and many people who have been segregated from the community for much of their lives may not be aware of all the possibilities.
- Spirituality and its practices are very personal and individual experiences – assure that people have the opportunity to explore and express their spirituality individually. Avoid taking a group of people with disability to the same church at the same time.
- Assure that people become members of their church/synagogue/mosque and have their names and pictures added to the member's directory.
- Assist people to participate in the life of the congregation — taking a role in the regular service or volunteering for special events.
- Assist people to make financial contributions to their religious community in whatever amount makes sense for that person.
- Expect the congregation and its leader to accept people with disability into the congregation as a matter of course, not expecting any different or charitable acts.
- Support people to learn the rituals and routines and expectations for members of the specific congregation so that the person will know what to do in different circumstances.
- If the first congregation does not work out, try another. Congregations are like any other association – some are warm and welcoming and open and others are more closed and restrictive.
- Honor the need and/or desire to practice spiritual rituals or follow religious rules within the person's home.
- If a person chooses not to practice any religion, respect and honor that decision.

- Support staff members to respect and honor the spiritual needs and expressions of the people they support. Religion is often a topic of debate and people must feel free to follow whatever spiritual course they want.

### **Quality in Practice**

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410.583.0060 [www.c-q-l.org](http://www.c-q-l.org)

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### **A Request from Karen Leventhal in Los Angeles: Looking for Faith Groups Involved in Inclusive Ministries in the LA Area**

Thank you for helping us find representatives who might be interested in joining our budding L.A. coalition. As we discussed, we have formed a partnership with American Jewish University to build an interfaith coalition of people who care about including people with disabilities in communities of faith. We have ample contacts in the local disability field. But we need some assistance locating partners within different communities of faith. We would be interested in connecting with congregation clergy or lay leaders, religious educators, seminary/religious training institutions or other relevant representatives. I know that you are connected with a number of national umbrella organizations who are interested in inclusive faith communities. Might you be able to tap those national representatives to help us identify Los Angeles area representatives? Let us know if we can provide any other information which might be useful to your contacts.

Karen Leventhal, M.S.  
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### **Hear Presentations by Jean Vanier and Stanley Hauerwas at Duke's Center for Reconciliation**

Listen to various workshops and lectures by Jean Vanier, founder of L'Arche communities, and Duke Divinity School theologian Stanley Hauerwas, who co-taught during the Center for Reconciliation's Teaching Communities Week, Nov. 8-10, 2008 at Duke Divinity School. Hear the recorded presentations.

<http://www.divinity.duke.edu/reconciliation/pages/programs/teachingcommunitiesweek08audio.html>

### **Living Gently in a Violent World featuring Jean Vanier and Stanley Hauerwas**

**Becoming Everyday Peacemakers:** This all-day workshop, led by Jean Vanier and members of the L'Arche communities, focuses on engaging a Christian vision of peace and life through the lens of L'Arche. Plenary Talk by Jean Vanier Part I and II.

**Lessons from L'Arche: Wisdom for Peacemaking and Hospitality in Local Congregations** an informal presentation and conversation with Jean Vanier and Stanley Hauerwas especially planned for members of local church congregations. Jean Vanier tells the story of L'Arche, and Stanley Hauerwas speaks about what the church can learn about peacemaking and hospitality from the witness and wisdom of L'Arche. Introduction: Lessons from L'Arche

### **Monday, November 10, 2008 Keynote Lecture Living Gently in a Violent World**

In this lecture, Jean Vanier and Stanley Hauerwas address the question of how Christians are to live in a violent and wounded world. Rather than contending for privilege by wielding power and authority, they believe that Christians can witness prophetically from a position of weakness. Vanier and Hauerwas help us see how much the church has to learn from an often overlooked community - those with disabilities.

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## B'Shalom Column

By Shelly Christensen, MA

### February is Jewish Disability Awareness Month!

My *Zaide* (Yiddish for grandfather) Max used to say, "To be known, you have to be shown." These simple words of wisdom from my immigrant *Zaide* define the work of inclusion. To make meaningful inroads in our congregations, we have to raise awareness, informing congregations that people with disabilities belong in the sanctuary, the classroom and the boardroom.

The Jewish Special Education International Consortium, whose members include representatives in special education and inclusion from Jewish communities across North America met in Minneapolis in May, 2008. We decided to collectively envision an entire month dedicated to raising awareness in Jewish communities throughout North America. By working in collaboration we could help synagogues and Jewish agencies across the continent recognize the importance of inclusion. We agreed to simultaneously endeavor to raise awareness, so that people with disabilities and their families would find opportunities for meaningful participation in their own synagogues.

We organized ourselves and reached out to national Jewish organizations. The Reform, Conservative, Orthodox and Reconstructionist movements are using their websites to promote awareness and provide resources for their congregations. United Jewish Communities and Association of Jewish Family and Children's Agencies are showing their support by informing their members and encouraging action. Through a network of Jewish organizations, we have been able to get the word out to local congregations and agencies in many of communities.

Numerous activities are planned in Jewish communities. These are examples of what congregations and communities have chosen to do:

- Screen "Praying with Lior," "Autism, the

Musical," or "Including Samuel"

- Celebrate inclusion by scheduling a *Shabbat* (Sabbath) service where people with disabilities have the honor of reading *Torah*
- Invite Jewish adults with disabilities to join them for *Shabbat* services and dinner
- Host a special Inclusion *Shabbat* dinner for the entire congregation
- Create a video featuring members who have disabilities to talk about the impact that synagogue involvement has had in their lives
- Host a community-wide awards ceremony, honoring an individual who has helped engage the community in inclusion
- Provide ability awareness programming for preschools, religious schools and youth groups
- Give sermons from the *bimah* (pulpit) by the rabbi, and/or invite members who have disabilities to give the sermon
- Plan steps to take in March to capitalize on the momentum built in Jewish Disability Awareness Month.

The great *Chassidic* master *Yehudi HaKadosh* said, "Good intentions alone not accompanied by action are without value. The main thing is the action, as this is what makes the intention so profound." In February 2009 we share our intentions with our congregations. To gently rework the words of another great Jewish sage, my *Zaide* Max, "The time to be shown is now." Jewish Disability Awareness Month will provide the means to be shown. The rest of the year will be dedicated to opening our synagogues and Jewish organizations so that people with disabilities and their families can be known by their congregations. We must expect no less than that.

Shelly Christensen, MA, is the author of the Jewish Community Guide to Inclusion of People with Disabilities and is the Program Manager of the Minneapolis Jewish Community Inclusion Program for People with Disabilities at Jewish Family and Children's Service of Minneapolis. For more information on Jewish Disability Awareness Month, contact Shelly at [Schristensen@jfcsmpls.org](mailto:Schristensen@jfcsmpls.org) or log on to [www.jsped.org](http://www.jsped.org).

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## Where will we find people to care for our children?

By Don Boden, LDM Executive Director

(Editor's note: Last fall, at the Lutheran Developmental Disabilities Ministries Conference, a conversation with Don Boden led to a request to him to write this article, which formed the basis of one article for Insight, the newsletter of The Arc. Just two weeks ago, I met a Ph.D. student in special ed in Nashville whose interest in special education had been born through her work in her synagogue. The common thread...the ways in which ministries and programs by faith groups, which include high school and college students as volunteers, is a huge, unsung story of how professional call and vocation gets born. Bill Gaventa.)

This is a question asked by many, families with children who have disabilities and professionals alike. Where will the professional workers and direct care staff who will dedicate their lives in vocations that serve persons with developmental and intellectual disabilities come from?

We look to universities to generate quality young people trained in the necessary disciplines to fill the professional positions. But, what motivates young people in this day and age to choose one of these careers and invest the time and resources to equip themselves for this important field? Certainly, it's not money! These individuals may have a family member or they may have known someone in a previous chapter of their life who had a disability.

Direct care staff is another issue. The entry level pay scale makes it difficult for an individual to support a family and therefore money may be the issue. People who choose this field as just an alternative to working in other occupations that would be open to most high school students, usually don't last long. The turnover rate for direct care staff is extremely high. National turnover averages approach 40% annually. However, when someone discovers direct care as a vocation and remains in their chosen work for a long period of time, usually it's because they have experienced meaning or purpose from their work. Their work becomes a life's calling or ministry!

So how do we motivate today's young people, or even adults, to fill the professional and direct care positions that are needed? A primary source can be our churches, synagogues or temples that engage its members in relationships with persons who have developmental and intellectual disabilities. Today, there are successful ministry models that are doing this very thing with positive results as individuals from these faith communities are choosing paths towards these careers.

There are church organizations like Lutheran Disability Ministries (LDM), Friendship Ministries, Special Gathering, Special Touch Ministries, and Bethesda Lutheran Homes and Services that encourage caring individuals to get involved in the life of someone with a disability through innovative programs in faith communities. Many times, these experiences can offer the individual a sense of purpose and fulfillment that enriches their lives and in some cases, elevate a desire for this line of work.

LDM is a Christian ministry based out of Anderson Indiana whose mission is to equip the Church to minister with persons who have intellectual disabilities. This is accomplished by assisting Christian churches to develop their own congregational programs. LDM also provides overnight camp and retreat opportunities where adults with intellectual disabilities are paired one on one with volunteer companions. With the help of LDM, more than 20 congregations have begun Bible studies, respite and day programs. More than 350 volunteers are in the summer camps and retreats and church groups come from all over the United States on mission trips serving at these camps and retreats.

There are several goals for every LDM program; Christian education, community inclusion, and the formation of meaningful relationships between the person with the disability and the volunteer companion. These relationships are important to the individual who has the disability and their families, but there is a double edge to this ministry that cuts deep in the heart of the companion. These volunteers learn that their friend with an intellectual disability is a person who has value. In the context of this relationship, the pity they may have felt at first towards their new friend decreases. They begin to care about their friend with the

disability, and that friendship is quickly reciprocated. As this transition takes place and the relationship deepens, the companion's values also begin to change. They begin to value their friendship and begin to reevaluate priorities on how they use their time and resources. Some even reevaluate career choices. I know this is true because it happened to me and today I am the Executive Director of LDM.

It's also happened to many others involved with LDM. Mike was a postal carrier and he came to an LDM camp eight years ago because he wanted to bring his blended family on a mission trip. He has returned every year since with his family. Mike has served as a companion numerous times, as a cabin parent where he is responsible for an entire cabin of campers and companions, and this past summer he served as an assistant camp director. You might say we had a "service" path for him to pursue. Mike is approaching his retirement and several times we have talked about additional leadership roles he might assume as he retires.

His daughter Jana who has been coming to camp with Mike began serving as a companion at age 14. Coming to camp became a priority for Jana as well as her younger sister Krista. After Jana left for college she came back and served as a Summer Intern. As an intern, Jana's role is to lead the companions in her cabin to become better companions. Her sister, Krista, has started college this year and is also considering serving as an intern.

Jeanette came to camp as a young teenager with her youth group from St. Louis. She also returned year after year and came back to serve as an intern for three summers. She majored and graduated with a degree in social work and she is currently working on her master's degree.

After coming to camp, Jenny started a weekly Bible study in her church for some individuals who lived in a local ICFMR. While in high school, she led this group for 3 years, along with other volunteer companions from her church. While at college, she also interned with LDM for two summers. She has since graduated and works today as a special education teacher.

Prior to experiencing their first relationship with a person who had an intellectual disability, all of these people were just going on a mission trip. They wanted to do something nice for a disadvantaged person. Their trip was mainly motivated with a desire for Christian service, charity or pity. But, their value systems have changed. Their friends with disabilities have made an impact on their lives. They have a desire to spend time with their friends at more camps and retreats. They want them to be part of their faith communities or to work with them as a vocation.

The ministries and the lives shaped through LDM are just a few examples among many being shaped by churches, synagogues or temples. But many will be needed to meet the staffing needs in the future. So, what can each of us do?

We can encourage the leadership in our own faith communities to reach out to persons with intellectual disabilities in our own communities. Our faith communities need to find innovative ways to help their members form meaningful relationships with these people. We can motivate our churches to start weekly Bible studies, or respite and day programs that use inclusive models. Include them in corporate worship, small groups and other fellowship activities. Youth and adult groups can participate in mission experiences at camps and retreats that may be run by other organizations.

As more faith communities get involved in the lives of persons with developmental and intellectual disabilities, more individuals will make school and career choices that will serve them.

If you would like more information about LDM or wish to contact them, visit their website, [www.LDMinc.org](http://www.LDMinc.org).

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**Stories, Short Articles, Reflections, Moments of Revelation, Resources, Events...all welcome for the Newsletter. Send to [bill.gaventa@umdnj.edu](mailto:bill.gaventa@umdnj.edu).**

## Eulogy for Jay Turnbull by Kate Turnbull

(You can see the video of this on the website of The Beach Center)

My brother used to say to himself in times of stress, or not, "Deep breath, JT. You've gotta breathe some." So, for my sake, and in honor of Jay, let's all breathe together, shall we? In true Jay Turnbull fashion, I will count it off: a one, a two, a one two three...

(Breathe)

Thank you.

On behalf of my parents and my sister, I want to thank you all for being here with us. I want to thank those friends and family who have traveled from far and wide to honor my brother, those old house-mates, job coaches, Beach Center employees, and all of you who are here today. I know I can speak for my entire family when I say that the outpouring of love over the last couple of days has been, like JT himself, truly extraordinary. We also must thank Tom and Laura and the entire Riffel family for the love and care that you have given Jay for the last seven plus years. He was indeed a member of your family too.

The last time I saw Jay was over Thanksgiving break. He and I drove out to Wendy Parent's house to visit the animals. Wendy offered him a choice of four different pies and Jay had a slice of three of them. He cleaned up after himself. He pet the cats. He gave Wendy a soft-five and we were off. But the party, I'm sorry to say, Wendy, really started when we got in the car. I was blasting the soundtrack to Hair, which was always one of Jay's favorites, and we were singing—shouting more like it. He was doing his bounce and flapping his fingers and his eyes were crossing a little like they did when he was really having a good time. But I looked over at one point (it's hard to keep your eyes on the road when you are jamming out with Jay Turnbull) and he looked at me right in the eyes and he had this little smile of joy, of contentment, of

love. And I thought, "There is God." There is God. There is God.

Jay had a rather special relationship with the divine. I always imagined that angels talked to him throughout the day. You have all seen him, sitting quietly in his chair and he would suddenly, and without any outside prompting, giggle. "What's so funny, Jay Turnbull?" "Smiling," he would say. Who was he talking to? And what plans were they shaping up together for the rest of us?

He talked to God every night. These prayer sessions would vary in length and many of you were often included along with a few other special mentions. "God bless Mom and Dad. God bless Tom and Laura. God bless Aunt T and Uncle Will. God bless pancakes. God bless Grandma Dot and Mr. Jim. God bless Muncher's Bakery. God bless Brandon and Sarah. God bless cereal. And milk."

Cereal and milk. This is what mattered to him.

Getting a piece of chocolate from Michelle Longhurst after she lovingly trimmed behind his ears and washed his hair.

Pouring a package of M&Ms into a bowl and eating them one at a time. Mom and Dad would joke that that must be what paradise sounded like to him. And please, indulge me, for Jay. (pour M&Ms)

Paradise sounds like a package of M&Ms being poured into a bowl.

Paradise is a soft five.

Paradise is a place for everything and everything in its place.

Paradise is a chicken sandwich and a sprite.

How much we mortals have to learn from the likes of Jay Turnbull.

My parents always said he was their greatest teacher but they just wished that sometimes he had given them the course before the final exam.

He was embraced by the Lawrence community in ways I know my parents did not dream possible when they first moved here in 1980. (Chip was

saying that it seems so eerily perfect that they landed here, of all places. Jay's middle name was Lawrence. Our mascot is the Jayhawk.) But how could we not embrace him? How could we not strive to reach our highest potential as human beings when he was around? He was the best of the best. He knew no judgment, no race, no class, no sexual orientation. None of the things that we mortals see in one another, that we size up about each other.

He had no concept of shame. He would pick that nose if it needed picking, he would roll over to one side if feeling a little gassy, and when we were in a crowd of people, he would always remind me of that time-tested rule, in his very, very loud voice: "Never touch your penis in public."

How did he not see the stares around him? How did he just not care? I certainly did, especially as a child and young adult when embarrassment was the currency we all traded in.

I remember the phase when Jay Turnbull started, as my parents called it, getting a life. When he attended fraternity parties at the SAE house where, of course, a little picking and rolling would go completely unnoticed. When he moved into his own home. (It was never, ever, a house! It was always a home! How could somebody who didn't even know how to read understand that distinction?!) When Alex at Free State came to his rescue when some drunk guy was giving him a hard time in the restroom. "Don't you know who this is?" Alex said. "This is Jay Turnbull."

He never really belonged to us. He was here on borrowed time. He was an angel walking the streets of Lawrence, Kansas.

And what in the world do we do now that he is gone?

He had many songs in his life, my brother did. But one that was always a favorite was "This little light of mine." This little of mine, I'm gonna let it shine. Let it shine, let it shine, let it shine.

His light shone on you. His light changed you. Indeed, after the incredible outpouring to my family these last couple of days and seeing you all here

today, I cannot help but wonder if he was in fact closer to the divine than we all thought. Let it shine, those angels whispered in his ear. Let it shine.

And, today, this song means something even more to me. Since Jay truly knew no judgment, since he truly saw the brightest and most glorious lights in all of us, what will it take for us to live up to his example? To love ourselves with his En-compassing love. To walk through life as he did, blissfully unafraid of death. To give a soft-five of friendship to every one we meet. This is the final exam. Are we willing to be the people that Jay Turnbull had the faith that we were? Are we willing to let our light shine?

I was not done having Jay in my life. I can see him now as I did so many times over the years as I dropped him off at Haworth Hall or his home, walking away from the car, the slowest walk in the history of mankind with his feet splayed out to the sides, his shirt tucked in and, possibly, the bright, white rim of his underwear out for all to see (for what in the world did he care?). He would walk away from me and, without ever looking back, he would raise a hand in the hair and do a backwards wave. As if to say, "I've got it from here." I would often drive away at that point, knowing that as a man, and not a boy, JT didn't like his little sister watching over him. But sometimes I would watch him and just sit in gratitude, profound gratitude for the blessing he was in my life.

He never really belonged to us. And how lucky we were to have him. He would close his marathon prayer sessions each night by saying "God bless all the good people."

God bless you, Jay Turnbull, for showing us the way. For gracing us with your presence. For shedding your light on us.

We will continue to work to be worthy of it.

I would now like to invite Sarah back to lead us and, as JT would say, "You've gotta sing loud."

(sing "This Little Light of Mine.")

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## Resources

### **Spirituality, Brain Injury, Cerebral Palsy, Asperger's, and Down Syndrome**

**Brain Injury Dialogues.** A 52 minute DVD with 25 extra minutes of other resources. \$20. From [www.braininjurydialogues.org](http://www.braininjurydialogues.org)

**We are TBI.** <http://www.wearetbi.org/> A website for and about people with traumatic brain injury.

**The Heart's Alphabet: Daring to Live with Cerebral Palsy.** James Grimm. A first person account, spelled out letter by letter, by a person who uses facial gestures to tell you which letter is right. James is the son of Esther and Gordon Grimm, 200 Summit , Box 126, Center City, MN 55012. Gordon Grimm was a long time CPE supervisor at Hazelden Treatment Center in Minnesota. Available through Amazon, but also email [gordyesther@mywdo.com](mailto:gordyesther@mywdo.com).

**Asperger's Syndrome and Mindfulness, Taking Refuge in the Buddha.** Chris Mitchell. December 2008, 144 pages, paperback. Jessica Kingsley Press. ISBN: 9781843106869.

Understanding who you are can be a lonely and difficult process following the diagnosis of Asperger's Syndrome (AS). Asperger's Syndrome and Mindfulness illuminates this experience as an empowering path of discovery through the teachings of Buddhism. Chris Mitchell draws parallels between the experience of his own journey towards personhood through AS and the spiritual tenants of Theravada Buddhism, as outlined through the Eightfold Path, a guideline to personal development. Worry and anxiety, confusing desires or negative thoughts are among the everyday hindrances a person with AS faces. This book takes the reader through the key beliefs of Theravada Buddhism, such as Mindfulness and the Four Noble Truths, showing how practices such as Insight Meditation can lead to a positive resolution of these feelings.

**Spiritual Wellbeing of Adults with Down Syndrome.** Margaret Crompton and Robin Jackson .The web address is Down Syndrome Education International, <http://www.downsed.org>.

## Islam and Disability

**Islam and Disability: Perspectives in Theology and Jurisprudence.** Mohammed Ghaly. Coming in October, 2009 from the Routledge Islamic Studies Series. This book explores the position of Islamic theology and jurisprudence towards people with disabilities. It investigates how early and modern Muslim scholars tried to reconcile the existence of disabilities in life with the concept of a Merciful God. It examines also how these scholars envisage the possibilities of leading a dignified and productive life, for people with disabilities, within an Islamic context

## Congregational Adult Education Awareness Resources.

On Line and Adult Education Module, **Walking with Justice: Opening the Gates of Torah. Including People with Disabilities in the Jewish Community.** Edited by Rabbi Bradley Shavit Artson and Deborah Silver. [http://www.ajula.edu/Media/PDF/Walking\\_With\\_Justice-Opening\\_the\\_Gates\\_of\\_Torah\\_Including\\_People\\_with\\_Disabilities\\_in\\_the\\_Jewish\\_Community.pdf](http://www.ajula.edu/Media/PDF/Walking_With_Justice-Opening_the_Gates_of_Torah_Including_People_with_Disabilities_in_the_Jewish_Community.pdf)

### **How Accessible Is Your Church? Brett Webb Mitchell**

This study provides tools for learning how your church can be more welcoming to people with disabilities through both words and actions. Item #TC0309,1 Session.\$5.00 This one-session study reviews recent historical changes in the rights persons have to access buildings and programs. It points out that many churches have made substantial changes enabling all to share in the faith life of their community. Participants are encouraged to reflect on their particular community and what sorts of changes may still need to be made in order to be a hospitable community for all persons. Under Popular Culture Section of [www.thethoughtfulchristian.com](http://www.thethoughtfulchristian.com).

## Two Great Looking Religious Education Guidebooks.

**A Place for All: Ministry with Youth with Special Needs.** (2008) John Barone and The Monarch School. Winona, MN: St. Mary's Press. 128 pp. \$24.95 ISBN 978-0-88489-972-3. Creative guide for religious educators of all sorts.

**Let All the Children Come to Me. A Practical Guide to Including Children with Disabilities in Your Church Ministries.** (2006) Malesa Breeding, Dana Hood, Jerry Whitworth. NexGen, Cook Communications Ministries. 4050 Lee Vance View, Colorado Springs, CO 80918.  
[www.cookministries.com/NexGen](http://www.cookministries.com/NexGen)

## Children's Awareness Resources

**The View from Under the Pew.** Diane Johnson Illustrated storybook introduces children to the true story of Walter, a guide dog who assists Pastor Diane through her day at the church. Walter helps with visitation, attending meetings, conducting Bible studies, and worship. Abingdon Press. 2008. \$14.95

**Duncan Goes Exploring,** a coloring and activity book, is part of Mosaic's Children's Education Program,. Other items include a collection bank, a four week disability awareness calendar, a four lesson Bible Study, "Duncan's New Neighbors" video, and lessons for learning the Lord's prayer in sign language. Many are available on line and can be downloaded. Visit [www.mosaicinfo.org/duncan](http://www.mosaicinfo.org/duncan) to download or call Mosaic's Mission Advancement Department at 877-366-7242, x. 1204 for more information. Mosaic is a Lutheran agency.

## Adult Education Resource for Adults with Intellectual Disabilities

**Phillipians. Jesus, My Pride and Joy.** Simplified Bible Study Series. Written by Ardis Koeller, Illustrated by Reginald Baylor. 2008. JCM Media. [jcm@tlha.org](mailto:jcm@tlha.org) Phone: 952-873-6000. \$14.95.

**A series of spiral bound manuals, 20-35 pp. long, by Joni and Friends includes:**

**So My House Will Be Full: A Guide to Including People with Disabilities in the Church** By Paul Dicken, Jane Young, and Sheena Baird

**All Things Possible: Calling Your Church Leadership to Embrace Disability Ministry.** Stephanie Hubach.

**Practical Pathways: Reaching and Training Volunteers for Ministry with Special Needs Children.** By Pat Verbal

**Giving Them Jesus: Evangelizing Children with Special Needs.** Pat Verbal.

## Two Resources on Circles of Friends in Congregations.

These come from the annual Access Sunday materials produced by the Presbyterian Church, U.S.A. (These are in the 2008 packet) There are two three page papers by Rev. Donna Whitmore of Bridge Ministries, Seattle, and Moderator of the Presbyterians for Disability Concerns.

**Circles of Friends: Building Community with a Person who has a Disability Within the Church Community.** and **Practical Guidelines for Starting a Circle of Friends Within Your Faith Community.**

[www.pcusa.org/phewa/networks/pdc/access.htm](http://www.pcusa.org/phewa/networks/pdc/access.htm)

Add to those the classic resource from the Mennonites, now available through ADNET, Supportive Care in the Congregation, and the 11 minute DVD or VHS Believing, Belonging, Becoming, done by the DD Council of Wisconsin (available for \$10 from The Boggs Center via Bill Gaventa), and you have a great group of resources for helping start a circle. For more, go to [www.inclusionpress.com](http://www.inclusionpress.com)

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## Praying in Motion

There are a number of resources for praying with movement, not signing, but movements. **The Lord's Prayer** in motions is one I have used for years, first as a chaplain at two developmental centers, but since with "typical" congregations, teaching kids to do it, then helping kids teach adults, and finally, doing it without words. It is a powerful way to help the prayer come alive in new ways that get us out of the "heard and spoken" word. For the guidelines, email me:

[bill.gaventa@umdnj.edu](mailto:bill.gaventa@umdnj.edu)

Another are several resources from a group called **Joy Dancing**, in Texas. It is listed in Dimensions of Faith, the resource guide on our website. They have movements to accompany several Psalms.

Then, through Faith and Light, I saw their guidelines for the traditional **Irish Blessing**, one of my favorite prayers. This was in their 2008 Guidelines for Faith and Light Programs, September. It goes like this:

**May the road rise to meet you,**

*(Open arms and hold parallel in front of you to show the way)*

**May the wind be always at your back.**

*(Put hands behind your back, palms towards the back to feel the wind.)*

**May the sun shine warm upon your face,**

*(Join hands above head, make shape of large round sun)*

**May the rains fall soft upon your fields,**

*(Put hands back down by side of body, moving fingers, like falling rain)*

**And may, until we meet again,**

*(Open arms and draw a large circle, look at each person or the one to your right)*

**God keep (or hold) you in the palm of his hand..**

*(Put your hands forward, palms up, right over left)*

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## Conferences

**Only God is Able. Disability, Community, and the Church.** Western Theological Seminary. **March 9-10.** Leader, Brett Webb Mitchell. Register online at [Journey.westernsem.edu](http://Journey.westernsem.edu)

March 16. **A Day of Respect: Welcoming People with Disabilities.** Keynoter: Bill Gaventa. Connecticut DD Council and Hartford Theological Seminary. [www.hartsem.edu/events](http://www.hartsem.edu/events). Contact Yvette Law, 860-509-9555

**Opening New Worlds.** April 17-18, Smoke Rise Baptist Church, Atlanta, Georgia. Hosted by Developmental Disabilities Ministries. A great looking conference. For more information, go to [www.ddmga.org/OpeningNewWorlds](http://www.ddmga.org/OpeningNewWorlds) Or call Cathy Humphrey at 770-623-4899.

Virginia: Norfolk Area. Faith Inclusion Network of South Hampton Roads presents: "**That All May Worship**" Conference on Sat., May 30th, 2009. Tabernacle Church of Norfolk, VA. Keynote speakers are **Erik Carter and Jackie Mills-Fernald**. For information, contact Karen Jackson at [dacapomusic@cox.net](mailto:dacapomusic@cox.net).

**European Society for the Study of Theology and Disability: Bi-Annual Conference. Divine Story – Human Context.** 1st - 4th July 2009 Boldern, Switzerland in Cooperation with the Study-Center Boldern and the Theological Faculties of Aberdeen and Zürich. This is a three-day conference on theology and disability; a creative communal space in which to explore how the story of God in Christianity becomes the guiding narrative to an understanding of our humanness. In the articulation of our collective theological voice, we open ourselves to new understandings and in its energy, we move towards practices that more authentically reflect an experience of the divine story in our lives. For complete brochure, go to: [www.abdn.ac.uk/cshad/ESSTD.htm](http://www.abdn.ac.uk/cshad/ESSTD.htm)

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## A Holy Moment

I had to buy a card for my Dad's birthday. And besides I love these stores. In the UK, I find, there is a deliciously dirty sense of humour. You can pick up cards that would be considered outrageous in North America ... and as I have that sense of humour, hours can pass as I howl doubled over in my wheelchair. I had just finished with a very funny fart card and had tucked a nun with syphilis card (who doesn't need one of those) in my bag and was pushing my way down the aisle.

I waited as a young woman, who's face was obscured to me by the cut of her hair and the tilt of her head, was looking at the boxes of Christmas cards. She was with another woman who I immediately identified as a care provider. So, I waited. The care provider suddenly noticed me, grabbed hold of the arm of the woman she was with and yanked ... yanked ... her out of my way. The woman, startled looked up and I saw she had Down Syndrome. She looked over at me and saw that she had been standing in my path. Not a word had been said between the two women. All there had been was the ... yank.

'Sorry,' she said to me and began to walk away.

'Wait,' I said, and she stopped.

'It's not ok for people to grab and yank you that way,' I said. The other woman burst into words and I put my finger up. Just one finger, to indicate that I was not talking to her.

'But I was in your way,' she said.

'Well, I can wait for a moment or I can ask you to step aside, it's between me and you.'

I could see the other woman desperate to talk. I didn't engage her, wasn't interested in a conversation with her.

'Why don't you go back to looking at cards, I don't mind waiting,' I said.

She went back to the cards and picked up a box. She held it up to me and asked what I thought. It

wasn't my kind of card, it had a rustic kind of drawing of the manger and a sappy sentiment. But I asked her what she thought.

She looked at the card carefully, scanning the picture much more thoroughly than I did. 'I don't think I like it,' she said.

I was intrigued so I asked her why.

'The baby Jesus is always sleeping in these pictures, he's never crying.'

'You think he'd be crying.'

'Of course,' she said, 'he knew what was coming.'

YANK

Dave Hingsburger, Director of Clinical and Educational Services, Vita Community Living Services, 416.749.6234 x238

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## Taking Grace by the Hand!

(A New Jersey story from an email about including a girl with autism in CCD class.)

I just wanted to give you a little feedback on the first CCD class with Grace. You could tell the adults were a little uncomfortable with the new addition but they were very nice. When we entered the classroom before anyone was introduced a little boy named Frankie came to the door, took Grace by the hand, cleared a space at his table and said "She can sit next to me the rest of the year" (left me and mom standing in the back of the room). Then a little girl named Ciara moved to the other side of Grace and said "I'll help you learn your prayers". We had to go to the Church to practice reconciliation and one or the other had her hand the entire time explaining everything. God is good!

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## Join Us!! Major Activities Of The Religion & Spirituality Division Include:

### \* Annual Conference of the AAIDD:

Proposals for presentations and workshops must be submitted to the Religion & Spirituality Division President. Due dates vary, depending on the conferences.

### President (2007-2009)

Nella Uitvlugt  
Friendship Ministries  
2215 29th St., SE, Ste. B6  
Grand Rapids, MI 49508  
(888) 866-8966  
[friendship@friendship.org](mailto:friendship@friendship.org)

### \* Sites for Upcoming National AAIDD Conferences:

The 2009 Conference will be in New Orleans, June 10-12. For current information, go to [www.AAIDD.org](http://www.AAIDD.org). Calls for papers and presentations each year are on [www.AAIDD.org](http://www.AAIDD.org)

\* **A Certification Process** for chaplains and lay persons working in ministries with people with mental retardation and other developmental disabilities. For information contact:

Ron Vredevelde  
Association for Interfaith Ministries  
1400 W Pickard St  
Mt Pleasant MI 48858  
[VREDEVELDR@michigan.gov](mailto:VREDEVELDR@michigan.gov)  
989-773-7921

\* **A quarterly newsletter** with resources, educational opportunities, shared ideas and inquiries, short articles, etc. The newsletter includes resources related to ministries with people with all forms of disabilities. A subscription to the newsletter without membership is available for \$25 for three years. Published with the help of Bethesda Lutheran Homes and Services, Inc.

\* **A Cooperative Resource Exhibit** each year at the AAIDD Conference, also available for display at other workshops and conferences. A listing of the resources in the display is available free of charge.

\***Website:** [www.aaiddreigion.org](http://www.aaiddreigion.org) Webmaster: Christopher Phillips. (Members of the R/S Division are invited to share a short description of their ministry, a picture of themselves, and contact information for publication on the member list of the website. We are hoping to build a virtual community whereby

our members can engage with one another and share ideas. Send your information to our webmaster, Christopher Phillips at: [faithability@gmail.com](mailto:faithability@gmail.com))

\* A 180-page **Resource Listing** (2005 Edition) entitled *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families*, published by The Boggs Center, New Jersey. \$15 includes shipping and handling. **(Now On Line) Other resources and publications for sale:** Write the AAIDD Religion & Spirituality Division for a listing of resources for sale or see website: [AAIDDreligion.org](http://AAIDDreligion.org). To order the newsletter, send a request with check payable to "Religion & Spirituality Division, AAIDD" to:

Religion & Spirituality Division, AAIDD  
c/o The Boggs Center  
P. O. Box 2688  
New Brunswick, NJ 08903

Rev. Bill Gaventa, Executive Secretary  
(732) 235-9304 [gaventwi@umdnj.edu](mailto:gaventwi@umdnj.edu)

\* **The Religion & Spirituality Division of the AAIDD networks with:**

National Apostolate for Inclusion Ministry (formerly NAPMR); the Religion and Disability Program of the National Organization on Disability (NOD); the National Council of Churches Committee on Disabilities; the Christian Council for Persons with Disabilities; the *Journal of Religion, Disability and Health* published by the Haworth Press; the Congress on Ministries in Specialized Settings (COMISS); and other national and regional organizations involved in religion and disabilities.

### Advertising Rates

This newsletter goes to approximately 600 people and organizations. Advertisements are welcome. The cost for members is \$25 for 1/8 page, \$50 for 1/4 page, \$75 for 1/2 page and \$100 for one full page. Non-members: \$25 more on each rate. The ad runs in one issue. Ads need to be fully designed and sent to the editor as hard copy or by e-mail. The Division reserves the right to refuse ads that do not meet the purposes of the newsletter and its mission. Acceptance of an ad does not necessarily mean endorsement of a product or event. Information about new resources and conferences will continue to be included, per editorial decision, in the newsletter at no charge. Deadline dates for Quarterly Newsletters are the first of day of March, June, September, and December.

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### Mission and Goals

The Religion & Spirituality Division of the AAIDD (formerly American Association on Mental Retardation) is an interfaith, interdisciplinary association of professional ordained and lay people who journey with persons with developmental disabilities and their families.

*Our Mission* : Providing interfaith, interdisciplinary leadership in religious participation and spiritual growth with people with intellectual and developmental disabilities.

### *Our Goals:*

1. To foster inclusion of persons with developmental disabilities and the sharing of their gifts and graces in the total life of the congregation and community.
2. To provide a forum for dialogue to creatively foster religious education programs that are life long and age appropriate.
3. To work cooperatively with all divisions of the AAIDD to enhance the spiritual supports available to persons with developmental disabilities and their families.

### Membership

The Religion & Spirituality Division is one of thirteen professional divisions within the AAIDD, which has approximately 6,000 total members. Religion & Spirituality Division members include chaplains, clergy, religious educators, coordinators of ministries with people with disabilities, residential ministries, and staff from a variety of disciplines and settings who share a common commitment to the role of faith and spirituality in services with people with developmental disabilities.

Membership is at various, differentiated by a sliding scale based on annual adjusted gross income. Active membership benefits include two AAIDD journals, the Religion & Spirituality Division Quarterly Newsletter, and membership rate on conferences and resources. Associate members receive on journal plus the newsletters. **To become a member, write the AAIDD office in Washington, DC (see address above), call AAIDD Membership at 1-800-424-3688, or do so through [www.AAIDD.org](http://www.AAIDD.org).** Editor: Bill Gaventa, Deadline for articles is March 1, July 1, October 1, and January 1. Email submission preferred to [Bill.Gaventa@umdnj.edu](mailto:Bill.Gaventa@umdnj.edu)