

Impact

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At age 51, Myrta Rosa, president of the NJ/Woodbridge Self-Advocacy Group, and recipient of the 2004 Hero Award from the New Jersey Self-Advocacy Project, is looking forward to a new life adventure – moving into her own home in the community. See story below.

Make Your Voice Heard Until the Very End

by Myrta Rosa

My name is Myrta. I'm a 51-year-old Hispanic woman, born in Puerto Rico, brought up by my grandmother. I immigrated to the U.S. at the age of 5 and lived in Perth Amboy, New Jersey, where I later attended the vocational training at Perth Amboy High School. I lived with my parents until they died and then was admitted to the Woodbridge Developmental Center in October 1998.

Over the years, I've become very involved in the self-advocacy groups! Being the president of the NJ/Woodbridge Self-Advocacy Group keeps me occupied with several meetings and seminars that occasionally I have traveled the nation to attend. I think my life has changed now to a point where I can truly believe that one day I can have a place of my own. Learning about community living fascinates me, and I am really looking forward to being in a home setting more personally designed for me.

Growing older for sure brings on more responsibility! Making sure I am healthy is a large part about the aging process. Blood pressure and diabetes problems arose and now keeping up with medications and diet changes takes up a lot more of my time than in the past years. With age, I realize I need to exercise and watch my diet because the excess weight doesn't fall off as easily.

[Myrta, continued on page 32]

From the Editors

"What can be done today to support people with intellectual and developmental disabilities who are aging?" That's the focus of this issue of Impact. The articles in these pages give a variety of responses to the question. From self-advocates we hear of the importance of having opportunities to be active participants in their communities, to be listened to as they speak up for themselves, and to continue to pursue their own goals and dreams for their lives. From siblings we hear about the necessity to respond to the concerns that keep them awake at night as they deal with the aging of all their family members, including parents who may have been primary caregivers for their brothers or sisters with disabilities. From researchers we hear of the policy and service issues that need to be addressed as the number of adults with intellectual and developmental disabilities over 60 years of age is projected to grow to 1.2 million in the next 20 years. And we hear from practitioners as they describe some of the promising approaches to ensuring quality service and supports that address the physical, social, emotional, and spiritual dimensions of aging with intellectual and developmental disabilities. Our hope is that readers of this issue will find some fresh perspectives and information that will be useful to them as they journey with the aging adults with disabilities who are in their lives.

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People with Intellectual and Developmental Disabilities Growing Old: An Overview

by Tamar Heller

Most people with intellectual and developmental disabilities (I/DD) have a need for support throughout their lives. With their growing life expectancy the numbers of older adults with I/DD continues to expand, and community agencies and families now face the challenge of providing supports as these adults experience age-related changes. In comparison with adults without long-term disabilities, adults with I/DD are more likely to experience earlier age-related health changes, limited access to quality

The number of adults with I/DD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030.

health care, and fewer financial resources. In addition, they are more likely to be living with parents into adulthood and have more limited social supports and friendships outside the family.

As they age, people with I/DD seek the same outcomes as other people without I/DD, including (a) maintaining their physical and mental health and ability to function as independently as possible; and (b) actively engaging with life through friendships, contributing to society, and meaningfully participating in community life. However, older adults with I/DD are often more vulnerable to conditions that will make their old age potentially more difficult.

A Growing Need to Address This Group

Several demographic trends point to the need to focus greater attention on the population of people with I/DD who are

aging. These trends include their growing numbers, the aging of their caregivers, changes in public policies, and technological advances.

As with the general population, whose average lifespan has grown from 66 years in 1950 to 78 years in 2007 (Miniño, 2009), the life expectancy for adults with I/DD has also grown over the last few decades due to medical advances and improved living conditions. The life expectancy for people with I/DD is similar to that of the general population, with the mean age at death ranging from the mid-50s (for those with more severe disabilities or Down syndrome) to the early 70s for adults with mild/moderate I/DD (Bittles et al., 2002; Janicki, Dalton, Henderson &, Davidson, 1999). The number of adults with I/DD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030.

Over 75% of people with I/DD live with families, and more than 25% of family care providers are over the age of 60 years and another 38% are between 41-59 years (Braddock, Hemp & Rizzolo, 2008). Without a mandate for support to adults with I/DD and their families, most of these families receive few support services and face long residential services waiting lists, estimated at roughly 115,000 families nationally (Lakin, Larson, Salmi & Scott, 2009). An urgent need exists for aging adults with I/DD and their families to have access to quality supports that address their age-related health and social changes.

Key Challenges

Public policies have increasingly supported the rights of people with disabilities to live in communities of their choice. Making this relevant to people with I/DD requires a corresponding

increase in environmental supports to allow their full community participation. Until the age of 21 years, persons with I/DD are eligible to receive support services (i.e., education, training, health promotion) through the Individuals with Disabilities Education Act (IDEA, PL 101-476). When eligibility for these services ends, the task of securing support shifts from the educational system to the individual and family or other caregivers. This task becomes more challenging over the lifespan as aging-related changes impact both the person with I/DD and supporting family members. Key challenges that must be addressed by communities, families, and adults aging with I/DD include the following: (a) improving the health and function of adults aging with I/DD and their families, (b) enhancing consumer directed and family-based care, and (c) reducing barriers to health and community participation.

Improving Health and Function

Adults with I/DD are more likely to develop chronic health conditions at younger ages than other adults due to biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, and lifestyle and environmental issues. These adults have higher rates of obesity, sedentary behaviors, and poor nutritional habits compared to the general population (Yamaki, 2005). Many health care providers, people with disabilities, and families are unfamiliar with the latest information about the age-related health issues for people with I/DD. A need exists not only for more research in this area, but also for getting the information out there and for improved preventive and surveillance strategies across the lifespan for adults with I/DD. These strategies include targeted

health education programs, appropriate screening, and community health promotion programs.

Enhancing Consumer-Directed and Family-Based Care

Although most adults with I/DD live with family, only about 5% of I/DD funding is directed for family support (Braddock et al., 2008). This gap between need and public resources is likely to increase with the “graying of America,” and the trends over the last 50 years in the U.S. of more dual-income families, lower fertility rates, and more families living in poverty. Other important trends include the increased number of minority families. The percentage of non-Hispanic Caucasians is estimated to drop from 66% in 2008 to 46% of the population in 2050

While this generation of older adults with I/DD had restricted options regarding supports in the community as they were growing up, the next generation of adults with I/DD and their families has grown to expect more options.

(U.S. Census Bureau, 2008). Cultural caregiving norms and language barriers, along with poverty, affect access to services and well-being of individuals with I/DD and their families.

Models of consumer-directed supports (e.g., personal assistance, supported living, and cash subsidies) have grown, stimulated by the Real Choice Systems Change grants of the 2000 New Freedom Initiative, and the Robert Wood Johnson Self-Determination Initiatives. Outcomes of consumer-directed supports for families of individuals with I/DD have included greater

service satisfaction, fewer unmet needs, better access to health care, fewer out-of-pocket disability expenses, reduced feelings of stress and burden, greater self-efficacy, more opportunities for employment (both caregivers and individuals with I/DD), and improved social and leisure opportunities and community participation (Caldwell, 2006; Heller & Caldwell, 2005). However, in many of these programs the other family members often make the decisions rather than the person with disabilities. Also, in many cases funds are used to pay other family members, which can include a parent. We know little about the impact of using consumer-directed funds to pay family members to provide care, and how this affects the quality of life and self-determination of adults with I/DD.

Reducing Environmental Barriers to Health and Community Participation

The concepts of “livable communities” and “healthy homes” have been promoted for persons who are aging and persons with disabilities. As people age and require more supports for their activities of daily living, work or recreation they may require modifications to their homes and communities that allow them to remain in their current settings. Environmental interventions (EI) to adapt or modify home/living environments, and assistive technologies (AT), have shown positive effects on function and reduced mortality for persons with Alzheimer’s disease and decreased stress for their caregivers (Gitlin et al., 2006). Hammel, Lai and Heller (2002) also found that EI and AT maintained and/or increased function for adults with I/DD. For older adults with I/DD, families and service providers have the challenge of adapting the environments so that persons can maintain function and continue desired activities as long as possible.

Conclusion

While this generation of older adults with I/DD has generally had few opportunities to make their own choices

regarding their daily lives, and have had restricted options regarding supports in the community as they were growing up, the next generation of adults with I/DD and their families is likely to have higher expectations from the service system. Years ago the major options offered to families were institutionalized residential services or no services. The generation that has received mandated school services has grown to expect more options in the community, more consumer-direction in services, and more support for aging in one’s home setting.

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What Does Growing Older Mean to Me? Some Thoughts From Adults with Disabilities

compiled by Jane Harlan-Simmons and Maribeth Mooney

We recently asked a dozen adults with intellectual and developmental disabilities what they think about growing older. Below are some of their thoughts on the question.

Independence

- “My Mom’s not around anymore, my Dad’s not. If I don’t do it, I want to learn. I’m riding the bus. People out here thought I couldn’t get my apartment. I’ve gotten out and bought my own groceries, I’ve done my own laundry, dried my clothes, cleaned my own apartment.” – *Clarence, age 43*
- “[Aging] means a lot to me because if my Mom and Dad die I’m going to be able to go live with my sister and hopefully be able to work somewhere out there. It’s not good my mom and dad dying, but you know what I mean, it’s hard to explain.” – *Christy, age 46*
- “I have white hair. It took me 10 years to be my own guardian. I worked awful hard for that.” – *Craig, age 60*
- “[The staff where I live] help me go to the bathroom and take showers so I won’t fall down again. I don’t want to go in the nursing home. You never know when something’s going to happen.” – *Joy, age 70*

Work

- “I’m not old. [I want to keep working so I can] get some bucks to buy something.” – *Marcella, age 84*
- “You don’t retire from this place [the workshop]. I may someday. Not right now, I need the money. I ain’t going to retire from this place for a long time. I’d get bored. I don’t want to do that.” – *Gary, age 71*

- “[When you’re retired] you got nothing to do except stay home and watch TV. You just get bored.” – *Rosemary, age 52*
- “I don’t want to retire. I like coming in to work, seeing people. I work at the canteen.” – *Dollie, age 61*
- “[When you stop working] you can do pretty much what you want to do. You don’t have to be bored.” – *Joy, age 70*

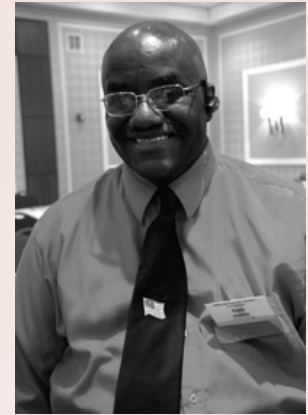
Change

- [Any fears about aging?] “Nothing you can do about it.” – *Dollie, age 61*
- “[Getting older] isn’t easy. I need to be busy. I want to use my mind more.” – *George, age 60*

Losses

- “It’s been hard on me [his mother’s passing earlier this year]. But I still got Mom’s pictures to hang on. I still love my Mom in my heart.” – *David, age 42*
- “My sister’s got sugar diabetes and high blood pressure and strokes. That’s why they’ve got her in the nursing home, so they can watch her. She can’t get up out of bed. Yes [I’m afraid of falling]. I stepped off the curb and bang, I broke my hip.” – *Paul, age 85*

Compiled and edited by Jane Harlan-Simmons and Maribeth Mooney, Research Associates, Indiana Institute on Disability and Community, Bloomington. They can be reached at 812/855-6508, 812/855-9396 (TT) or by e-mail at jeharlan@indiana.edu and mfmooney@indiana.edu. Most responses came from longer conversations within the context of in-person discussion groups.



My Thoughts About Being 50: Samuel O. Jenkins

As a person with a disability I get around the state, and travel to conferences, and learn, and make the right choices. As a 50-year-old person with a disability, I feel I can do all the things a young person can do, but better.

I work for The New Jersey Self-Advocacy Project in North Brunswick as an Information/Referral Coordinator. I have worked for the project for over six years. My role as the Information/Referral Coordinator involves giving resources and information, plus providing training to self-advocates on how to speak-up for themselves and others. I assist self-advocacy groups with setting up projects such as testifying before legislators, writing letters to the media, and facilitating discussions between self-advocates, staff and administrators of provider organizations.

My interests are listening to music, educating others, learning new things, and, most of all, enjoying life. I feel people 50 years and older have the same chances as younger people have – and more! Especially people with disabilities. Finally, I feel older people with disabilities shouldn’t let their age or disability stop them from getting the job of their dreams or having fun.

Contributed by Samuel O. Jenkins, Plainfield, New Jersey

An Elder Among Self-Advocates: Cliff Poetz

interviewed by Vicki Gaylord

In this interview, 61-year-old Cliff Poetz talks about some of his life experiences as a self-advocate, and reflects on what's important to him now that he's an "elder."

Q: I think of you as an "elder." I use "elder" as a term of respect for an older person who has not only lived a long time, but who has also lived their life in a way that provides leadership



and inspiration to others. Is it okay that I think of you as an "elder"?

A: Yes, that's okay with me.

Q: I'm wondering if there are other "elders" who have inspired and guided you during your life?

A: Gloria Steinbring has been one of those. We both lived at Portland Residence [an intermediate care facility] at the same time. She now lives independently in her own apartment with supports. Given the problems she faced earlier in her life, that's remarkable. She has been a good leader for people with developmental disabilities. [Gloria is a well-known Minnesota self-advocate].

Also, Charlie Lakin [director of the Research and Training Center on Community Living, University of Minnesota]. He's well-respected and knows what he's talking about, and has advanced the idea

of closing state hospitals. People trust what he says in the courts and the communities, which tends to move mountains that people may resist moving.

Gloria is very sensible and knows what she wants, and Charlie I think is the same way, but he uses facts and data to prove his point, which is good when dealing with Congress or the legislature. If they don't see the numbers they won't fund it.

Q: When you think back over your own life, what are some of your accomplishments that you're most proud of?

A: A few years ago we got the legislature to pass the Remembering with Dignity bill which asked to put names on the graves of the people who died in Minnesota's institutions. Their graves only have a number, and no grave marker with their names. And we've asked for a simple apology from the State for treatment of people with disabilities kept in institutions, and for burying them without markers. We were successful and got the money to start putting markers on some of the graves. There's a bill now to get money to mark more of them [5,000 now have markers, 7,000 are still

unmarked; see www.selfadvocacy.org/programs/rwd]. But we didn't get the apology. The legislature gave a public apology for the people who were committed to camps in WWII who were Japanese. They have not done the same for the people with disabilities in institutions. I want to know why not? I'm trying to get a hearing again on a bill for an apology. We've been working on this since 1994.

Q: How did you get started in self-advocacy?

A: I've been active as a self-advocate since the 1970s. I was living at Portland Residence and served on their client council, became president, and along the way we started giving presentations for Arcs and DD Councils around the region and nation. I also used to serve on the Arc-Hennepin board of directors, then served two terms on the state Arc board, and then the national board. Irving Martin was the first self-advocate on the national board, which was a big step for them. I came after Irving. There are three self-advocates on that national board now, which is good.

[Cliff, continued on page 32]

There Was a Day

There was a day,
A dark and dank and dreary day.
It challenged all my skills,
It was a very painful day.
Even so, I faced it and embraced it
And as that day dissolved into memory
My skills gained greater ability.

There was a day,
A bright and shiny, joyful day.
It was a very peaceful day,
A day of blessed rest.
As that day dissolved into memory,
My spirit was strengthened with love.

This is a life
Made up of many days -
All different and apart,
Yet dissolving into a balanced blend.
I face and embrace all these days,
The dreary and the shiny,
The painful and the joyful.
They are the gifts of this life.

By Teddie-Joy Remhild, Founder of Disability and Aging Advocacy, educator, and advocate who has lived independently as a blind woman for the last 42 years. Reprinted with permission from <http://www.disabilityandagingadvocacy.com/poetry.html>. She may be reached at teddiejoy@att.net.

Supporting Community Inclusion of Aging Adults with Developmental Disabilities

by Philip B. Stafford

Community membership is not only being in, but being of the fabric of daily life in society. It is recognizable in the presence of satisfying relationships and meaningful participation (Harlan, Todd & Holtz, 1998, p. 4).

For adults with developmental disabilities who are aging, the later decades of their lives can be a time to pursue new interests and contributions to their communities alongside other “seniors” and neighborhood members. To make it happen, however, takes work. It starts with a community commitment to inclusion in the myriad of social, recreational, and educational programs available for senior

adult programs and settings. OASIS is a national education organization dedicated to enriching the lives of adults age 50 and older through lifelong learning and service. Offering programs in the arts, humanities, health, technology and volunteer service, OASIS brings people together to learn, lead and contribute in their communities. Sharon Hales, the founder of the OASIS FRIENDS program, was at first surprised by the prejudices encountered by adults with developmental disabilities as she referred them to community-based senior programs. Then she realized that the seniors in those programs, for their entire lives, had not had opportunities to be in contact with age peers with disabilities. Exclusion practices in school, in work, in life prompted seniors at OASIS to ask, “Who are these people?” Of course it would take some work and some “getting used to” to overcome these barriers. Sharon realized that “it’s not just access.”

So, 15 years ago, she started a small pilot project. She identified 12 individuals with developmental disabilities and helped them express their interests and select classes at the OASIS senior program. Similarly, she hand-picked a small number of regular OASIS members who would volunteer as peers to accompany adults with developmental disabilities and, through joining activities with them, help integrate them into the regular programs. She intentionally invited as volunteers OASIS members who themselves were leaders and role models within the program. Drawing on the work of LaPore & Janicki (1991), Sharon developed a sensitivity training program for the volunteers to address concerns they had about the task they were taking on. Soon, pairs of buddies were taking dance classes, art classes, and attending a myriad of community events totally outside of the disability services system. A survey at the

end of the first year demonstrated real changes in attitudes and the modeling of new behaviors not only on the part of general program participants but also on the part of the aging adults with disabilities, who were becoming accustomed to a new, less stigmatized stage of life.

Today, the FRIENDS program includes 50 aging adults with developmental disabilities attending OASIS programs in several locations in the St. Louis area. A solid core of 25-30 volunteers keeps the community integration effort alive, with Sharon’s continued support and leadership. Challenges remain. There is, after all, the question of access and Sharon notes that there is another system – transportation – that needs to be transformed around the value of inclusion. And, after 15 years of inclusion, adults with developmental disabilities themselves are encountering new issues around physical health and function that complicate their participation and highlight the need for more inclusive educational programs in healthy aging, fall prevention, chronic disease management, and others.

Throughout the 15-year evolution of the program, Sharon attributes its success to the ongoing commitment to two core values expressed in posters on her wall: “Allow abilities to bloom” and “In the heart of each community, everyone belongs.”

Involving All Neighbors in Seattle

Involving All Neighbors offers another comprehensive approach to including aging adults with disabilities in the community. Developed by the Department of Neighborhoods in Seattle, Washington, the program, which operated from 1995-2008, started from a simple question asked in a city-sponsored meeting of neighborhood activists: “What does the Department of Neighborhoods

Sharon was at first surprised by the prejudices encountered by adults with developmental disabilities in community-based senior programs. Then she realized that the seniors in those programs had never had opportunities to be in contact with age peers with disabilities.

citizens and others, and an investment in an infrastructure of support. Two programs that have made it work demonstrate this point.

The FRIENDS Program in St. Louis

The FRIENDS Program of the St. Louis Regional OASIS Center was inspired by the insight that aging adults with developmental disabilities should be able to take advantage of typical senior

do to encourage persons with developmental disabilities to get involved in neighborhood life?" Such a question is inspired. It reverses the normal presumption that people with disabilities have needs, not gifts to offer their neighborhoods. In Seattle, it initiated a serious investment of personnel and creativity in responding.

Often facilitating action through funding from its Small Sparks program,

A self-advocate named Larry was active in disability advocacy, and an insightful friend introduced Larry to the president of the neighborhood council. It wasn't long before Larry was elected vice president of the council.

the Department of Neighborhoods encouraged neighborhood-based solutions to the challenge of involving adults with disabilities. It realized there was no wholesale solution, rather, that each neighborhood would innovate on its own. In some instances, a person who was already a leader in the disability arena, such as People First, would be drawn into more generic neighborhood leadership roles. A self-advocate named Larry was active in disability advocacy and an insightful friend introduced Larry to the president of the neighborhood council. A staff member of the department helped Larry create a presentation to the council on accessibility issues and it wasn't long before Larry was elected vice president of the council. Archie, the president of another People First chapter, was an avid gardener, often found helping with neighborhood clean-up projects. With the assistance of the chapter advisor, the West Seattle People First group applied for and received a small

grant to design and implement a plan for a new neighborhood park.

In many cases, the simple bringing together of people who would not otherwise interact results in unanticipated relationships and wonderful benefits to the neighborhood. A workshop called "Get Involved in Your Neighborhood" was developed by the department and brought together two women who had known each other since childhood, but were spurred on to double-up and offer Saturday volunteer services in tandem to young patients in the local hospital.

Though Involving All Neighbors may have ceased as a program, the spirit of inclusion continues. For instance, the Department of Neighborhoods has brought on board Public Outreach Liaisons to work on culturally relevant outreach to many different communities, including people with disabilities.

Getting Started

A few years ago the Center on Aging and Community at the Indiana Institute on Disability and Community published *The Guide to Building Community Membership for Older Adults with Disabilities*, which provides some compelling insights into the work of the prospective community builder who can open up opportunities for older adults with developmental disabilities to be engaged in their communities. It provides several community-building tools for the individual or organization seeking to help integrate older adults with disabilities into senior centers, neighborhood organizations, and other community groups. It includes worksheets, capacity inventories, relationship maps, and a community presence questionnaire that helps the community builder evaluate his or her efforts. And, it provides practical advice about what might be the critical starting point for any attempt to build community membership: active and deep listening. It cites Pat Beeman's (1995) Ten "Points to Listening":

1. Listen with the belief a person has something to give and is of value.

2. Listen to help people discover their gifts, which they may not see.
3. Listen with an open mind.
4. Listen to dreams or visions, not only to what is in the present.
5. Listen without hurrying.
6. Listen to fears and pain.
7. Listen with no intent to fix or control anyone.
8. Listen for words that actions may not reveal.
9. Listen to recognize opportunities.
10. Listen knowing that things take time.

By listening and not dominating the conversation with too many questions, we can achieve the kind of conversational equality from which a relationship can grow. From one "unpaid" relationship, others can grow. When the balance of paid to unpaid relationships tips in favor of the latter, then we know that the adult with a developmental disability has achieved authentic membership in a real community.

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Aging and End of Life: Helping the Spiritual Tasks of People with Disabilities Come Alive

by Bill Gaventa

Dealing with aging, death, grief, and end of life issues with people with intellectual disabilities is a growing challenge in services and supports. It is a challenge brought on, in some ways, by success in terms of effective health supports in that people with intellectual disabilities are living longer into old age. But the challenges are many:

- Dealing with decline and death seems like the antithesis to the values of growth and development (i.e., independence, productivity, inclusion and self-determination) that are at the core of so many services and supports.

Many cultures see the elderly as those to be honored, in stark contrast to some modern culture that sees aging as curse. As people with intellectual disabilities age, how might professionals and caregivers honor them?

- Loss of ability and decline to death may seem to staff and caregivers like a “double injustice,” adding the “Why?” of death to the “Why?” of disability in the first place. For younger staff without personal life experience with death and loss, this can be even harder; and for all staff and carers, it may feel like “failure” in their responsibility. That can be compounded in systems where normal deaths get investigated as if they were a “critical incident” or evidence of abuse or neglect.

- As in any relational system, intense feelings about responsibility and care can be part of the mix between people with disabilities, their friends, their families or relatives, and professional caregivers.
- Until recently, there has been little attention to the ways that people with intellectual disabilities experience and process grief and loss, a paradox given the amount of loss that they have to deal with in so many areas of their life, including staff and caregiver turnover. People worry about their capacity “to understand,” yet rather than taking more time and attention to help that happen, the pressure is to move on quickly. There is pressure in agencies to fill the empty beds, to get back to the programs and plans, rather than recognizing the power of relationships.

Those same challenges can present opportunities to do the following:

- Re-vision the end of life not as decline but as journey, and to give people as much choice and control as possible in the final stages of life.
- Focus on the importance of relationships, and remember connections to the past, present, and future relationships. “Remember” is about connections with important relationships, and “re-membering” can be about helping people get connected again to relationships and communities of which they have been members.
- Build new communities of caregiving and meaning around a person in the latter stages of life.
- Pay attention to the importance of spirituality in people’s lives, what is most important to them, the cultural and religious rituals that are part of old age and death, and the opportunities to participate in and practice spiritual connections.

- Re-vision the core values of independence, moving from “Who am I?” to “Who have I been?”; of productivity, moving from “Why am I” to “What difference have I made with my life?”; and of inclusion, moving from “Whose am I?” to “Whose have I been? Who will remember me, and how will I be remembered?”.

In a resource manual called, *The Challenges of Aging: Retrieving Spiritual Traditions in the Long-Term Care of the Elderly*, the Park Ridge Center in Chicago identified five tasks of aging common to all major spiritual traditions (Park Ridge Center, 1999):

- Reaffirm covenant obligations to community.
- Blessing...how have you been a blessing and given your blessing?
- Honor, respect and appreciation for aging and the elder.
- Maintaining and growing faith in face of loss.
- Reconciliation of discordant experiences (e.g., letting go, reunion, forgiving).

As we think about adapting those tasks to and with adults with intellectual disabilities, the remainder of this article outlines some ways we might do so.

Reaffirming Covenant Obligations to Community

Of what communities has someone been a part? What has been important to them about those communities? What might they want to do in those communities? So, for example, would people like to revisit places they have lived in their lives? Would they find it meaningful to make a photo album of places and people that have been important to them? Would they like to volunteer somewhere? If they have never

had the chance to join a desired faith community, could this now happen? For example, there are powerful stories in the state where I live, New Jersey, of people with intellectual disabilities being able to have the bar or bat mitzvah they never had, or having the chance to be confirmed or baptized. Those relationships also need to be built to avoid

Can we help people participate in rituals of loss and mourning, or develop new rituals in service systems where grief and loss have often been unacknowledged and unrecognized?

the crisis of “who to call?” when someone in residential services is suddenly hospitalized with life-threatening illnesses or dies. Clergy and spiritual communities can respond, but that response is so much better if a person is known to a given faith community.

Giving and Receiving Blessing

Service providers have gotten better at identifying the key strengths and gifts of individuals with intellectual disabilities as well as their needs or deficits. This is a time to focus on those gifts and strengths. How can we celebrate and honor them for those gifts? Could they give them to others, such as by writing or telling their life stories to younger professionals or others? Could we help individuals think about what they want others to have when they die (i.e., make a will, and think about who would like valued possessions as a keepsake, something to remember them by)? One chaplain at a small residential facility started a practice of identifying key strengths in each person, and then developing

a “Certificate of Appreciation” for that person and their gifts that was presented to each individual and their family at the annual plan review. Not only did those certificates start ending up in frames and on their walls, but they changed the ways that others saw the people with whom they worked.

Restoring Honor to Aging

Many cultures see the elderly as those to be honored, in stark contrast to some modern culture that sees aging as curse. As people with intellectual disabilities age, how might professionals and caregivers honor them? We could ask for their blessing, in a variety of ways. We can help turn records and charts into life stories. One agency is doing just that with Power Point presentations and scrapbooks that are turning a team of consumers into speakers and presenters at workshops. We can re-vision “consumers” as “survivors and veterans” of endlessly changing service systems, and honor them as we would any veterans. We can also do so by restoring mutual-ity to the relationship between professional and “client” by finding ways to tell and thank them for what “they” have meant to us, and how they have helped us. Professionals all know people with intellectual disabilities who touch deep parts of their own lives and values, and have provided part of their own sense of calling and vocation. We need to share that appreciation with others as they age, as we would with other elders who have been our teachers or mentors.

Maintaining Faith in the Face of Loss

How do we help people prepare for and deal with the losses they have – losses of relationships and losses of their own health or vitality? Can we help people participate in rituals of loss and mourning, or develop new ones in service systems where grief and loss have often been unacknowledged and unrecognized? Many elderly people get more involved with religious communities. Can we help that happen, and build supports

that will be there at the end of life? And, can we find new and creative ways to help people express their own grief and develop their own form of understanding; for example, the book *Am I Going to Die?* in the *Books Beyond Words* series (www.rcpsych.ac.uk/bbw) is one creative way to help people understand both facts and feelings, loss and mourning.

Reconciliation

Are there old relationships that need to be renewed as people get older? Or connections with families, old friends, or former staff that need to be “re-membered?” For the rest of us, “reunions” become more important in old age. Can we work with people with intellectual disabilities to see if there are people they want to see, or need to see? Many old institutions where people lived were terrible places and times; so is war. But people who have survived and gone their separate ways to better lives often choose and seek the opportunity to have reunions, or to re-visit those places and relationships that shaped their lives.

Summary

Support and service agencies, families and other caregivers, and individuals can develop their own creative ways to address these tasks of aging and end of life planning with people who have intellectual disabilities. The challenges can indeed become opportunities.

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Futures Planning for Families Supporting Adults with Life-Long Disabilities

by Theresa M. Varnet

As a parent of a 42-year-old daughter challenged with intellectual disabilities, I used to lie awake at night worrying about who is going to look after Jennifer when my husband and I die. Parents often worry about unknowns such as where their adult child with life-long disabilities will live; who will advocate for their child; and what kind of vocational, recreation, residential and support services will their child need and receive. Parents will gain great peace of mind if they take the time to plan for their child's future while they still have the health, time and energy to do so.

Planning is more than just having a will and perhaps a special needs trust in place. It is working with the agencies

Within the so-called typical population, few parents plan for their own aging or discuss issues related to aging with their adult children. It is therefore no surprise that so few families supporting adults with life-long disabilities have had meaningful discussions concerning viable long-term plans for their son or daughter who will need lifetime supports. Aging parents owe it to themselves, to their typical adult children, and especially to the adult child with life-long disabilities to begin the process of making plans that address the long-term care needs for themselves as they age as well as for the family member in need of long-term supports.

Planning as an Ongoing Process

While opening a dialogue with other family members about long-term care plans is important, it is impossible to resolve this issue in a single talk. Planning for one's old age and the future of a family member is an ongoing process. The one thing we all know is that life is filled with the unexpected. The plan made must be reviewed every few years to be sure it still reflects everyone's needs – not just the needs of the adult child with a disability. The needs and circumstances of siblings and other family members who may be called upon to play a role as advocate, caregiver, guardian, trustee or in some other meaningful support role must be reviewed as their life situations may have changed since “the plan” was first put into place.

My advice to families when developing a life care plan for the family member needing life-long care is to “hope for the best, but prepare for the worst.” Parents will often say, “I’m not worried because I know my daughter will take her brother in and care for him.” They may assume this without ever discussing it with their typical child. Perhaps they

have shared their expectations with their typical child, but the typical child does not express his or her concern about making a lifetime commitment for fear of angering or upsetting the parent(s). Relying on adult siblings to fill-in as caregivers is often not realistic nor is it often in the best interest of the adult who may desire independence from his or her family, but may need help in gaining independence. It is important for adult children to be honest with their parents about what they are prepared to do for their sibling. Even for those families whose adult child prefers to live with a sibling, and the typical sibling is willing to assume responsibility for lifetime care, parents need to plan for an alternate living arrangement.

Situations change and as a result a life care plan may need to be adjusted. In one family, it was decided that the daughter with an intellectual disability was to live with her younger sibling. The sibling and her husband and three children were all in agreement that the best place for “Julie” was to live with them when the parents died or were not able to provide for her. Unfortunately, the younger sibling was diagnosed with breast cancer in her early 40s. Following her diagnosis and treatment, she felt her own future was uncertain and she was no longer able to commit to caring for her sister's life-long needs. “Julie” has since moved into a supported living program with two women with similar disabilities. She is still very close to her sister and visits often, but her sister no longer has to worry about what will happen to “Julie” if her cancer returns. “Julie’s” parents changed their estate plan to provide her share of the inheritance be distributed to a special needs trust, which will provide funds for supplemental needs and a higher quality care in her state-funded program.

Aging parents owe it to themselves, to their typical adult children, and especially to their adult child with life-long disabilities to begin making plans that address long-term care needs for themselves as they age, and for the family member in need of long-term supports.

within the community where the family anticipates the adult child will be living when the parent(s) die to ensure that proper supports are in place. This type of planning often requires the involvement of significant others, including siblings, other family members, family friends, and professionals such as a financial planner, attorney, and social worker.

In another family, two of the siblings agreed to share in the responsibility of caring for their adult brother with Down syndrome. “Brian” was a young man with a wonderful sense of humor and ability to self-care for all of his personal needs. Shortly after his parents died, he developed Alzheimer’s disease at the early age of 50 and regressed very quickly to the point that he needed help with bathing, toileting, and other personal hygiene. It soon became difficult for the two siblings to care for him and he was eventually placed in a nursing

Parents will gain great peace of mind if they plan for their child’s future while they still have the health, time and energy to do so.

home. Fortunately “Brian’s” parents had provided for him with a special needs trust, which meant his inheritance did not have to be spent down on nursing home care. These two cases illustrate the need to always plan for the worst in case the unexpected occurs.

Considerations in Planning

In talking with my clients about aging, theirs and their child’s, I recommend that they begin a discussion with their children. Where possible, the discussion should include the child with life-long planning needs. Self-advocates have a saying, “Nothing about me without me.” How can parents plan for their child’s future without gaining input from their child as to what his or her preferences are? Parents need to ask their children and other family members for their advice and wishes regarding future roles and responsibilities. A plan made in the absence of input from all of the key players is doomed to failure.

Parents need to meet with an attorney who is well-versed in special

needs planning to draft the legal documents one will need in the future. Finding such an attorney is difficult. Families may want to contact the National Academy of Elder Law Attorneys (www.NAELA.org, 703/942-5711) or the Academy of Special Needs Planners (www.specialneedsplanners.com, 866/296-5509) for a list of attorneys who concentrate in special needs law in their area. An attorney who is a member of one or both of these two professional organizations will be familiar with special needs planning. Parents may also want to meet with a financial planner who can advise them on how to best fund the special needs trust. A financial planner can also assist parents in changing the beneficiary designations on non-probate assets such as IRAs, retirement funds, and life insurance policies so that the share for the family member with life-long disabilities is directed to a special needs trust.

Legal documents should, at a minimum, include the following:

- Pour-over will, which provides for the share of the child with long-term needs to “pour over” into a properly worded special needs trust.
- Properly worded special needs or supplemental needs trust.
- Powers of attorney for health care and property for the parents. The power of attorney for property should include Medicaid gifting powers so that if the elderly parent enters a nursing home, the parent’s assets can be preserved for the benefit of a child with a disability as defined by the Social Security Act. (Note: There is no five-year look back period for transfers to a qualified trust for a special needs child. This enables the elderly parent to qualify for Medicaid to pay for his or her long-term nursing home and preserves the net worth of the parent for the benefit of the adult child with disabilities).
- Guardianship documents if needed. If the adult child does not need a guardian, it is recommended that he or she should sign durable

powers of attorney for health care and property designating a family member or friend as agent. This is important for all persons over the age of 18, but especially critical for persons with life-long care needs who often need an advocate to assist them with navigating the health and human services care systems. I have created a customized form that I call a Power of Attorney for Advocacy which designates an agent to review records, release records, attend meetings, apply for benefits, and so forth. This form enables a trusted friend or family member to formally advocate on behalf of the family member with a disability. The POA for Advocacy overcomes the confidentiality shield that often prevents friends and relatives from being effective advocates due to the restrictions of the Health Insurance Portability and Accountability Act.

In addition to the above documents, it is helpful for a parent of a child who is non-verbal or unable to communicate his or her wishes due to disabilities, to write a letter of direction. The letter of direction is an informal document that provides future caregivers and significant others with important information that provides continuity for the subject of the letter of direction. A letter of direction should be reviewed no less than once per year to be sure it adequately reflects the current needs and wishes. A typical letter of direction will include important information such as:

- The names, addresses, phone numbers, and relationships of all significant family members.
- A list of significant others such as respite care workers, social worker, job coach, neighbors who may be of assistance, as well as how to contact these individuals.
- The location of important documents such as wills, trusts, birth certificates, guardianship order or POA’s, insurance policies, deeds and titles to properties, and burial plans.

[Varnet, continued on page 33]

“I’m Constantly Thinking About Bev and Her Future”: Siblings Speak About Aging

by Don Meyer

No single topic is more worrisome for siblings than the future well-being of their brothers and sisters who have disabilities. Their concerns are obvious for anyone who cares to listen: Their brothers and sisters with disabilities are now routinely outliving their parents, many of their parents are reluctant to plan for the future, and waitlists for Home and Community-Based Services are as commonplace as they are obscene.

In May of 2009, I invited adult siblings – ages 50 and older – to be a part of an informal online survey about the concerns they have about their siblings who are also aging and the roles they play. The results, I am sorry to report, are not optimistic. However, I hope they will serve as a wake-up call for parents, policymakers, and service providers who are concerned about older Americans with disabilities and their families. Below are excerpts from the survey:

- **Q: My guess is that you have given some thought to the days to come for you and your sibling who has a disability. When you look into the crystal ball and imagine the not-too-distant future, what do you see?**
- About five years ago, Beverly was showing changes in her behavior, mood and memory. I had her evaluated for Alzheimer’s disease. I was shocked and saddened when we received the diagnosis. I was not aware that people with Down syndrome are more likely to get early-onset Alzheimer’s than not. It was something that I was not prepared for. From that point on we were on a new road in Bev’s life journey. Knowing that Bev has Alzheimer’s and seeing the changes that have occurred already, I know that the road ahead is going to be very rough.

- Fear. I am also aging and am tired of watching for red flags in his life. My three children have offered to help, but we all know that is not realistic. They all work and have their own families. I do not want to leave to them what was left to me.
- If I stay healthy, Tom will always have a home if he should decline in his ability to take care of himself. If not, others will have to step up. Who that will be, I do not know.
- I see me leading my own life without the restrictions of Mary’s care. But doing so means that Mary might live in a facility where her care needs may not be met, and her life wouldn’t be as full as it is now. It’s sad to think of her not being active and getting the attention she does now.
- I see us going from crisis to crisis and possibly having to move all three of our brothers again.
- I think that she will be living out a longer life than people with Down syndrome used to have, and for that I am very glad indeed!
- I’m hoping to find a stable, safe, and stimulating place for him to live with others who have similar interests so we both can get on with “living our best lives.”
- **Q: Are there issues regarding your and your sib’s future that you find yourself thinking about as you cut the lawn or drive to work?**
- I think about the fairness to my husband after all these years of raising children to still have an adult/child living with us – and my own children. They’re starting their adult lives with the possibility of having their aunt to take care of.
- I worry that I am going to die and there will be no one to look after him, and that the responsibility will

fall on my husband or children, who don’t deserve the added responsibility (but then again, neither do I!).

- What worries me most is if something happens to my sister and I would have to take over the care for our three brothers. I just don’t know how I could take care of all of them by myself. I don’t know that my marriage would survive that. Hell, I don’t know if I would survive that.

Brothers and sisters will be in the lives of family members who have disabilities longer than anyone. They desperately need parents and service providers who understand their unique concerns.

- I wonder why so many people seem to think that Tom is so wonderfully independent that they never need to do anything, offer help, take him to a ball game, or even ask. Where is everybody?
- Other family members (nieces, etc.) disapprove of my sister’s and my decision to place Patty in a group home. I worry that Patty will outlive us as longevity runs in the family and she is seven years younger than I am.
- I have been overwhelmed this past year and am seeing a social worker to help me deal with letting go of being the perfect sister. I do not want to be the first-responder any more.
- I would like to leave the area for the opposite coast but I am concerned

about her not having an advocate. I am also concerned about the grief – hers and mine – that would ensue and her inability to deal with my absence.

- Yes, I fear his being alive when I am gone, needing all kinds of care, and his resisting because that is what he does when he is scared or in pain.
- I am constantly thinking of Bev and her future. My first concern is making sure she is happy and that all of her needs are being met. But at the same time I know that I have long-range planning to do, which involves possible long-term health care and eventually her death. This is so hard for me to fathom and difficult to do without much family input.
- I worry that he's not getting enough stimulating and interesting things to do outside of his part-time job. I worry that he's bothering the neighbors too much. I'm concerned that he might be depressed, although he insists he's a "happy person" by nature.
- I wish we could count on our needs being met by appropriate funding and how nice it would be if services were there when you need them, not so difficult to find and easy to take advantage of. It's sad to have to worry about money when it comes to her care.

• **Q: Are there "hopeful signs" as you think about your sibling's future?**

- The most hopeful sign I have is my sister's behavior: As years go by living with me, she's more comfortable and more secure. She shows that with more smiles and attempting to use her voice more often. I hope that her life is happier as she ages and forgets the hard times in her past when she was in a bad group home.
- He loves people and seems to adapt to new activities quite well. When things change in the future, as life goes on, I think he'll manage to adapt and latch on to whatever is new for him.

- "Hopeful signs" are his financial cushion that was afforded by my mother's thoughtful planning that allowed his trust to be funded at the time of her death.
- The hopeful sign is that my other sibs and I work well as a team in a time of crisis or need.
- My sister is in a terrific group home right now. She can get around by herself on public transportation, she has wonderful, caring friends and housemates, and the staff is great with her. I can't imagine a better living situation, and it gives me hope that, if we need to find another place for her down the line, there are other good places out there.
- Tom has been a trailblazer his whole life: He was among the first with Down syndrome to receive early intervention, go to a public school, be employed in the community and live independently. Will we be first

with Alzheimer's, too, teaching the community about the needs of those who are aging?? It makes me tired to think about it.

• **Q: What should service providers know about your thoughts regarding life with an aging sibling who has a disability?**

- My relationship with Tom is birth to death. He tells me everything. He never lies. And I am never, ever going to rest until you are doing your job properly and he is safe, healthy, and not lonely.
- I would like them to know that most siblings will have to take over the parent's job – but they won't have the authority of a parent in the disabled sibling's eyes as well as the eyes of many providers. This is both frustrating and scary.

[Meyer, continued on page 33]



Sibling Support Project

Meeting Sibling Needs: The Sibling Support Project

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental or mental health concerns. Because disabilities, illness, and mental health issues affect the lives of all family members, the Sibling Support Project seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs, and to increase parents' and providers' understanding of sibling issues.

Since 1990 its mission has been accomplished through the following activities:

- Training local service providers on how to create community-based Sibshops, which are lively peer support and education programs for school-age brothers and sisters.
- Increasing parents' and providers' awareness of siblings' unique, lifelong, and ever-changing concerns through workshops on sibling issues.
- Hosting Yahoogroups for adult sibs (SibNet), young sibs (SibKids), parents (SibParent), and Sibshop providers (SibGroup).
- Publishing written materials, including its latest book, "Thicker than Water: Essays by Adult Siblings of People with Disabilities" (2009, Woodbine House).

For more information about the Sibling Support Project visit its Web site at www.siblingsupport.org or call 206/297-6368.

Contributed by Don Meyer, Sibling Support Project, Seattle.

The Age Wave: What It Means for Families

by Philip B. Stafford

The longevity revolution, sometimes called the “age wave,” has certainly been in the news lately, and with good reason. Never before in our history have so many people lived such long lives. There are certainly important public policy implications surrounding the aging of the population worldwide. One implication is, unfortunately, off the radar: Adults with developmental disabilities are also part of the age wave! They are living longer than ever before.

For adults with developmental disabilities, the longevity revolution provides the opportunity for a full and meaningful life course equivalent to their peers and their siblings. For elderly parents this can, however, be a surprise. Many elderly parents of children with developmental disabilities were told early on, and have lived their lives under

A recent study of aging families in Indiana provides some insights, lessons and “take aways” in seven areas for families trying to remain strong over the long haul (Stafford & Pappas, 2009). Below are each of the areas, common types of responses from aging families, and what might be learned from their experiences:

- **It’s not just about the family.**

It’s about the community. “I gave up my social life at night; she’s my life, she’s my project I guess. I feel that (she) is my responsibility, our responsibility, until we can no longer take care of her. That’s just the way I feel.” As laudable as this sentiment might be, it’s perhaps useful to expand our notion of family to include neighborhood and community. It’s important to start “cultivating” community early on so when that day comes the broader family can play a role. Here’s a take away provided by another parent pursuing that very strategy: “He volunteers at the fire station...Being such a public place, everybody knows him and [he has] ‘joined’ all the families that have a connection with fire and police...He is so well known in the community, it makes a huge difference in my sense that he will be fine after we are gone.” And there’s a “take away” for policymakers too: Public policy and programs that determine eligibility solely on the “functional capacity” of the adult with a disability miss the point. It is the overall relationship between the family and community that determines successful family functioning.

- **You have to learn how to use formal services and systems, and expect frustrations.** As one family noted, “[We’ve] had these services for a year or more. The girls [from the agency] don’t stay too long. That’s the only problem, the frequency of turnover. I assume the pay is not that great and they find something

better and quit. Everyone...has been nice, except the first one or two were inexperienced.” The take away: Don’t expect formal services to solve every problem. But don’t be a patsy, either. Learn to be assertive. As one parent said, “Dealing with the state can be frustrating... but I also talk a lot and get myself in the door if I have to.”

- **Don’t assume you’ll live forever.**

“When the time comes that our health starts to fail, then that’s when we’re going to have to start looking outside of our family or for services so that we make sure that she’s taken care of. Until that happens we haven’t worried about it too much,” observed a parent. The take away: Don’t forget to consider the role your adult child might want to play in helping you as you age. From one family we heard regarding their daughter with a disability, “She stays home doing chores, dishwasher and laundry since I have been laid up...”

- **Assess your support system realistically.** The experience of this family is not all that unusual: “We have a very nuclear family. It is just the three of us, and our daughter is in Illinois. I have friends but no one would know what to do. It’s pretty much the three of us and we are trying to manage as best we can... My husband went to the emergency room at midnight and I took [my son] with me. I think I could ask someone working with him to stay with him or take him home in an emergency, but that would involve money or something...” The take away: If your support system is thin, give the community a chance to care. One family has done the following: “Making sure everyone [in town] knows him – that’s my protection when I’m dead. They’ve got to know, they’ve got to care.”
- **Isolation is not healthy for either party.** This family knows the stressors of isolation: “[I] sometimes worry

A recent study of aging families in Indiana provides some insights, lessons and “take aways” in seven areas for families trying to remain strong over the long haul.

the assumption that, they would outlive their child with a disability. As a consequence, far too few parents of a child aging with a disability have engaged in “futures planning.” Without planning, the death or frailty of an elder parent can lead to a less-than-smooth transition for an adult child with dependencies. Emergency admissions to nursing homes and group homes are not only expensive, they put an extreme burden on an adult with a disability who has been living comfortably, securely, and even independently.

that everything for [my daughter] is work and in her room. I wish she had more social life outside of the workshop. Basically all she has is pretty much church and bowling related. She needs a friendship outside the house... Everything that she does Momma and Daddy has to do it. She gets sick of Momma and Daddy sometimes. We go to every party that she goes to..." The take away: Think creatively about blending formal and informal sources of help, as one family did: "Our sitter is our daughter's mother-in-law, and they have been family friends for a long time... We certainly trust her. At that point when we needed somebody she was raising dogs and she went through and got certification so she could sit with [our daughter] and she has been doing it for six or seven years. It means a lot to have somebody. We call her directly [and don't have to go through the system]."

- **Be future oriented, and don't assume the other children will step up.** One parent observed when thinking about future supports, "I've not really thought about it. They have all said that they don't want him to go to a group home." The takeaway: Don't assume. Have a conversation as this family did: "The issue came up especially when we went through the legal guardian process. There was a lot of things we took for granted. Until we asked the boys we didn't know how they felt about it. We assumed that they would be ready to take her in, but they said no, with their family life it would be more difficult for them than what we anticipated it would be.... That was kind of upsetting to begin with, but when you think about responsibilities these days, you can't really... It could be when the time comes it may change."
- **Accept that there are risks in life.** "He does his own showering, but I lay clothes out for him because he would wear shorts in November." It is true that adults with developmental disabilities will make errors in judgment (as we all do at times), but it's

worthwhile to focus "risk reduction" on those issues that are serious ones. Allowing people to make decisions and receive feedback from a caring community can lead to greater independence, which can, ironically, be scary for a parent – any parent! The take away: If you have developed effective community ties, go ahead and rely on the community when you can, as the following quote demonstrates: "If there is a ball game I will take him out there and he will find a ride home 'cause he can't ride his bike out there. He knows everybody and pretty much everybody knows him."

It's true, aging ain't for sissies. Keeping the family strong, however small it may be, can be a challenge over many decades. Sticking with it is hard, but brings its own share of rewards. Strong family ties, even in small families, play a critical role. But extending ties, especially in small families, is an important part of the formula for success in the face of overwhelming stress. As one family member said, "All of the sudden some things just aren't as important anymore. I don't need to be quite so controlling. You've got to trust. In the long run, [he has his] brother and they have always been very close. [Jane and Joe, community members] have demonstrated they like [my son] – they consider him in their family."

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Strengthening Sibling Voices: The Sibling Leadership Network

The importance of supportive sibling relationships between adults with and without disabilities often increases as parents age and can no longer provide care. The Sibling Leadership Network (SLN) is a national network whose mission is to provide siblings of individuals with disabilities the information, support, and tools they need to advocate with their brothers and sisters, and to promote the issues important to them and their entire families. Founded in 2006, the SLN connects siblings nationally to be the leading voice on policy, research, services, and supports for siblings. Made up predominately of siblings of people with disabilities, it also includes other family members and people with disabilities, as well as professionals who support the mission. Among its activities are:

- *Providing resources for siblings through its Web site (<http://sibleadership.blogspot.com>) that include networking opportunities; publications such as its "white paper" containing recommendations for research, advocacy, and supports for siblings; and links to resources for siblings and families.*
- *Meeting with members of Congress to discuss policies that affect adults with disabilities and their families.*
- *Collaborating with organizations including Self-Advocates Becoming Empowered, The Arc, The Sibling Support Project, and the National Alliance for Caregiving to reach and support siblings of people with disabilities.*
- *Supporting the development of state and local sibling chapters. Current state chapters are in Illinois, New York, Ohio, Tennessee, and Wisconsin.*

For more information visit <http://sibleadership.blogspot.com> or contact network leaders Katie Arnold at kkeiling@uic.edu or 312/996-1002; and John Kramer at john.kramer@sibleadership.com or 312/436-1839.

Preparing for the Future: The Lifetime Assistance Program of Arc Greater Twin Cities

by Anne Roehl and Lori Sedlezky

Preparing for retirement and later life years is a natural part of growing older. Most people make financial plans, complete legal documents, consider their health care plans, and share wishes with loved ones. But this planning process can be more complex for people who have intellectual or developmental disabilities

The Lifelong Support Plan is a comprehensive, individualized, future-oriented document that provides a framework for future services and supports based on the needs, wishes, and dreams of the individual and his or her family.

and their families. The Lifetime Assistance Program of Arc Greater Twin Cities was developed in response to this very concern, and it provides an example of an innovative planning process.

Responding to a Need

A few years ago Arc saw a growing number of older adults with disabilities who were being impacted by inadequate planning. While each situation was unique, the outcome experienced was often the same – crisis that could have been avoided with proper comprehensive planning. In partnership with the Research and Training Center on Community Living at the University of Minnesota, Arc collected information from family members and service providers in Minnesota to identify the needs of families as they

prepared for the future of their adult member with a disability, and to determine how they could best be supported in this process. The information was collected through focus groups and surveys with parents of adults age 40 and older who have intellectual or developmental disabilities. Eighty-two percent of the families surveyed indicated a need for help with financial planning, and only 22% were satisfied with current case management. The families wanted long-term help for consistent, quality services. Based on these findings Arc Greater Twin Cities launched the Lifetime Assistance Program in 2006.

Program Overview

The Lifetime Assistance Program is designed to help people with disabilities and their families plan for their later life years. It offers a new approach that combines future life planning and ongoing caregiving support. The program uses a person-centered process that results in increased understanding of the future needs of the individual with a disability, assists with legal and financial preparations, and plans for the social supports that contribute to quality of life.

The program is offered in the Twin Cities metropolitan area to individuals and families at many different stages of life – from toddlers to aging adults with disabilities. While each family and individual brings unique concerns, they are able to create a solid plan for what they want and need in the future. The process takes 12 months to complete, and throughout that time participants receive assistance with developing a Lifelong Support Plan for their family member with a disability; access to financial, legal and estate planning for a sound, secure future; and the support of a Quality of Life specialist.

Quality of Life Planning

A good person-centered planning process is one of discovery and exploration. Arc staff facilitate conversations that identify and uncover the details that define a good life for the individual with a disability. It is often the only time the individual and his or her support network have sat down to discuss, dream, and create a plan for a fulfilling future. That plan includes identifying who will take over the responsibility of overseeing support services, and prepares family members for that responsibility.

In the event that there are no family members to assume this responsibility, or when the family would like additional support, a Quality of Life Specialist can be hired. The Quality of Life Specialist becomes a substitute advocate who provides much of the same type of monitoring of supports and services that parents or family members provide. The family and individual with a disability decide the degree of oversight the specialist will have and how this will take place. Quality of Life Specialist services are fee-based services that can begin whenever the family feels they are no longer able to provide the support they would like to provide. Many families choose this service as a way to assist a sibling or other relative to take on the role of overseeing services to their family member with a disability.

Legal and Financial Planning Assistance

The Lifetime Assistance Program works with qualified attorneys and financial planners who understand the unique needs of families who have members with disabilities. Education and assistance is provided to the family members to ensure that the legal documents and financial plans are in place to safeguard an individual's future and support the goals identified in the person-centered

plan. The team develops the wills, trusts, health care directives and financial plans needed to provide for the future security and happiness of the family member with a disability.

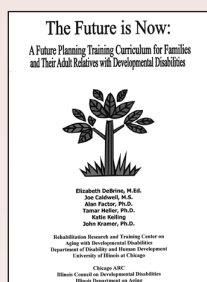
Pulling It All Together

The results of these components are personal plans, legal documents, and financial preparations that are coordinated and complement one another in an overall Lifetime Support Plan. The Lifelong Support Plan is a comprehensive, individualized, future-oriented document that provides a framework for future services and supports based on the needs, wishes, and dreams of the person with a disability and his or her family. In addition to identifying a vision for the future, the Lifelong Support Plan provides information about existing

formal and informal supports; identifies what supports are needed above and beyond what is offered through the existing service system, including requested Quality of Life Specialist services; and the timeline for providing these services. The services outlined in the plan help families cover the gaps that will exist when primary caregivers are no longer able to oversee quality of life; it integrates existing documents and works in concert with guardians to help ensure the person is well supported. This proactive planning process is designed to strengthen the person's safety net, ensure continuity of care, and as a living document recognize and respond to the changing needs of the person as he or she ages. The plan is adjusted as needed, and is formally reviewed and updated at least annually.

The Lifetime Assistance Program provides a great sense of relief to aging family members who can now be comforted that they have made the plans and taken action to prepare as much as possible for the life of their adult member with a disability. For the 60 families who are currently engaged in the process at various stages, it ensures a solid framework for future supports and services, and can lead to increased satisfaction in later life years.

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“The Future is Now”: Training Individuals with Disabilities and Families in Future Planning

The Rehabilitation Research and Training Center on Aging with Developmental

Disabilities (RRTCADD) at the University of Illinois at Chicago has developed an innovative planning resource: “The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities” (DeBrine, Caldwell, Factor, Heller, Keiling & Kramer, 2009). This curriculum equips individuals with developmental disabilities and their families with the communication skills and information needed to jointly plan for the future. The goal of the training – which is designed to be delivered by disability and aging organizations – is to have families prepare a letter of intent that describes their relative's desired future living arrangement, community role, and lifestyle preferences, and specifies the available resources, needed supports, and action steps to achieve these outcomes.

“The Future is Now” is unique because it was the first such curriculum to include people with disabilities in the planning process, and to empirically test its outcomes. It received the National Alliance for Caregiving 2008 innovative program award. Research revealed that, when compared to non-participating families, families who participated in the training were more involved in future planning activities and were more likely to prepare a special needs trust and to initiate planning for future living arrangements. The training also significantly reduced caregivers' feelings of burden and increased the daily choice-making of individuals with disabilities (Heller & Caldwell, 2006).

The curriculum consists of five 2.5-hour sessions that incorporate breakout training segments for families and individuals with developmental disabilities. Each group is co-facilitated by a professional and a peer mentor. Content addresses the family's and individual's dreams for the

future; expanding support networks; future living arrangements; work, education, and retirement; and safeguards to ensure their future plan will be implemented.

“The Future is Now” training manual, updated in 2009, contains instructions for planning the training, facilitator's guides, workbooks for families and people with disabilities, and assessment tools along with a CD-ROM.

For more information about “The Future is Now” curriculum manual and train-the-trainer workshops, contact the RRTCADD at rrtcadd@uic.edu or call 800/996-8845.

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We Can Do More to Help One Another! Creating Networks and Cooperatives

by John Agosta, Holly Bohling, and Reena Wagle

Over the past three decades, we have made significant progress to establish comprehensive systems to support citizens with developmental disabilities. Presently, however, this trend is facing formidable economic and structural challenges. What can we do? Part of the answer rests within us.

One of the strongest assets any community has is its people. People volunteer daily to do any number of tasks for others through structured groups or individual initiative. In addition, beyond individual efforts, any community also has an array of community serving entities, such as faith communities, schools, and clubs. Future systems must seek to

supports within communities. Here, participants unite voluntarily to address common needs. Such networks can be composed of individuals with disabilities, family members or both. A coordinator is needed to advise and organize the network, though it should ultimately be shaped by the needs and preferences of its members.

One aim of such networks is to assist participants to help one another by offering mutual support and sharing resources. In Stuttgart, Arkansas, families organized to provide one another temporary relief and other supports (Daignault, 2006). For instance, they organized a “Parents Night Out” where a few parents volunteer to manage activities and provide oversight at a central location (e.g., a church recreation room) for individuals with disabilities while their parents take time to see a movie, shop or just take a break.

Families with older support-givers find the Network to be a great source of information and support. Older participants note, too, that they appreciate the social events that give them and their family member things to do. They also like that they can lend a helping hand to others and receive help back. One older parent commented, however, that it is important to have younger families involved, too, so that they can work together for change. “We are getting tired,” she says, “and it’s time for younger families to take our place.”

Peer support may also be organized more formally through a “time bank.” A time bank organizes participants within an exchange network where everyone’s contributions are valued and tracked. For instance, at the Lynn Time Bank in Massachusetts (see <http://www.lynnertimebank.org>) an hour of help offered equals “one service credit.” The hours of time a participant gives to others are credited to his or her “account”

by computer, and hours of help the person receives are “debited” from the account. Participants e-mail each other with service exchange information, such as placing an ad for services (“I can provide transportation”), placing service requests (“I need a ride to my doctor Wednesday), and confirming that the service took place. In this fashion, individuals reach out to others across an area to provide mutual support without heavy public agency investment.

Cooperatives

Individuals may also develop more formal cooperatives or companies where participants work together to manage the services they receive. In the current system, families may have lots to do to manage the services provided to the family member with disabilities. Working on their own, such responsibilities can prove burdensome over time. If families and individuals work together, however, many of the associated responsibilities taken on by families may be more easily managed. This can be accomplished by promoting partnerships within the public and private sectors – for example by forming a certified Human Services Cooperative (HSC®) company. HSC® companies are directed by families and individuals who use human services; they provide a range of services that benefit the needs of the membership. The company itself may function as a provider agency, performing any number of jobs collectively for its members. This can include: (a) recruiting direct support staff; (b) acting as an “employer of record” for support staff in each household; (c) managing support staff and assuring that supports are properly delivered and accounted for; (d) purchasing services, equipment or other supports; and (e) acting as a fiscal intermediary to ensure that providers are

One aim of Peer Connection Networks is to assist participants to help one another by offering mutual support and sharing resources.

forge alliances between individuals with disabilities, family members, and the array of community assets available to find additional means of support. To do so, we can develop lightly structured Peer Connection Networks where individuals offer one another mutual support. We may also go further to establish formal Human Services Cooperative (HSC®) companies where participants work together to manage the services that they receive.

Peer Connection Networks

Peer Connection Networks are not meant to take the place of public services. They are intended to generate complementary

paid, but also to offer providers worker's compensation and other benefits.

Some HSC® companies find a blend of older parents, younger parents, and self-advocates brings a healthy balance and perspective. Older members bring history and experience, though they often benefit from the energy younger members bring. All benefit from the social networking opportunities that develop across all ages. Finally, as younger members gain experience and take the leadership baton, older members can feel secure the next generation will carry on with their same common legacy, guiding philosophies, and principles that frame the companies they have formed.

People may also develop more formal cooperatives or companies in which they work together to manage the services they receive. Human Services Cooperative® companies are directed by families and individuals who use human services.

HSC® companies are recognized by the Federated Human Service Cooperative, an organization whose goal is to “assist in the creation of Human Services Cooperatives” (www.federatedhsc.coop/). This national entity certifies the local companies directed by individuals and families who use disability services to provide supports that benefit the membership. Once certified, an HSC® company operates as a provider agency, delivering services based on policies formulated by member owners. Several local HSC® companies have been successfully implemented in Arizona, California, Illinois and Tennessee.

Managing Risk

Overall, Peer Support Networks or HSC® companies require that people work together to achieve common goals. The idea of people working together freely, however, raises concerns for the well-being of the participants, especially when people with significant disabilities are involved. What happens if a participant cheats another? Or if the help offered is unsatisfactory? Or someone is injured while providing assistance? These are good questions pertaining to the well-being of participants.

Concerns like these can be addressed in the same way as any volunteer program. Individuals can be screened to assure that eventual participants satisfy safety criteria. The program may also help participants get to know one another better before they exchange support, match individuals according to their needs and what they can offer, and provide means for participants to rate the help they receive. Certain members may also act as mentors to others to help them through the exchange process and monitor its outcomes. Further, staff or members in leadership roles may monitor activities across the exchange network. For instance, the nationally based Federated HSC® community and its members are comprised of a self-directed leadership that monitors its members. The idea is to build trust and reciprocity, but in ways that make the process transparent. Finally, Peer Support Networks and HSC® companies can obtain liability insurance to cover those offering their time. The insurance covers problems that can occur during a service exchange.

Conclusion

We cannot successfully confront the challenges we face by continuing to do business as usual. Times have changed and the systems that we put into place decades ago are not up to the challenge. Accepting the new reality, however, does not mean that we should become its victims. Change, after all, offers choice

– to either adapt and accommodate or to seize the opportunity to move the system forward.

States increasingly want to keep individuals home with their families for as long as possible. One reason is that providing supports to individuals while they live at home costs less than other alternatives. An unfortunate outcome, however, is that family households, including ones with aging support-givers, can become isolated, and so more vulnerable to sporadic crises.

In response, we can establish communities of association by working together to offer each other mutual support. We can build alliances with others to provide us enormous opportunity for reshaping future support systems. Several organizations nationally are already positioned to establish Peer Connection Networks or HSC® companies. Examples include self-advocacy groups, local Arc chapters, and other family advocacy groups. While these organizations may not be particularly charged with establishing networks or cooperatives, they may provide a useful local structure where such work can begin.

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The Role of DSPs in the Lives of Aging Adults with Intellectual and Developmental Disabilities

by Lori Sedlezky

As more people with intellectual and developmental disabilities are living longer, Direct Support Professionals (DSPs) need to have the knowledge and skills to support them as they age. The guiding principles of person-centered services, individual empowerment, and valuing natural connections and relationships in the community reflect DSP best practices. These principles should continue to guide DSPs as they respond to the unique needs of individuals with disabilities in later life years. Within this framework, DSPs will need to be knowledgeable about the following five aging-related areas: (1) awareness of physical and mental health changes, (2) supporting aging in place, (3) retirement and later-life social networking, (4) grieving and loss, and (5) end-of-life planning. While each of these critical areas could be the subject of an entire article, below is a brief description of each and suggested steps DSPs can take to improve the quality of support they provide to older adults.

Changes in Physical and Mental Health

As individuals with intellectual and developmental disabilities age, increasing health problems and functional limitations occur. Changes in physical health and mental functioning that are part of the normal aging process begin in the mid-50s for the general population. However, people with intellectual and developmental disabilities often experience those changes earlier than people without disabilities. It is important for DSPs to learn about the aging process in relation to the individuals they support, and actively assist their healthy aging. This includes identifying early signs of physical or mental decline, and facilitating access to health care services. Some specific support strategies for DSPs to use include the following:

- Assist the person receiving support to remain as physically and mentally active as possible. Inactivity can contribute to increased health complications. Many people with intellectual disabilities are at a greater risk than the general population for degenerative diseases. Direct Support Professionals can help slow the decline caused by these diseases and general aging by supporting individuals to maintain active lifestyles. Ways to do this include involving the person as much as possible in everyday living tasks such as shopping, cleaning activities, and setting the table; and assist the person to be involved in community activities that promote healthy aging, such as walking groups, low-impact exercise classes, gardening, and other physical and social activities of a person's choice.
- Educate the person you support about maintaining his or her health. Share information in a way that the person understands. Explain why it is important to stay active, and remember, keep it fun to be active!
- Identify early signs of physical or mental decline. Is the person you are supporting acting differently than usual? Is he or she reacting to specific stimuli differently than in the past? These can be indicators of changes in physical or mental functioning. Keep detailed records of the changes you notice, as well as any changes in support you are providing. Share this information with the appropriate health care professionals.
- Learn the signs and symptoms of depression, and be aware of other types of mental health concerns for which a person may be at increased risk due to health history, hereditary factors or medication. Grief and loss can also be contributing factors in mental health of aging individuals.

- Support healthy eating. Understand changes in diet that may be needed as a person grows older. Be observant! Changes in a person's preferences may indicate difficulty in chewing and digesting food, sensory changes affecting the sense of smell and taste, or other health related concerns. Being responsive and encouraging person-centered planning to adapt to these changes is essential.

Supporting Aging in Place

Growing old in one's own home as independently as possible is a common goal of most people. This goal is often difficult to attain for people with disabilities. Both people living with their families and those who live in congregate settings can face barriers to remaining in their homes in their later life years, including service structures, policies, and funding. As a person becomes older and experiences decreased functional skills, he or she may be moved to a home with other people who have similar functional support needs. This is often a more restrictive environment. DSPs can play an important role in helping people to live in their own homes as long as possible through these strategies:

- Make environmental adaptations to reduce the risk of falls and accidents, and make the environment more user friendly. Can handrails or guardrails be installed? Have area rugs been removed? Does the person need additional lighting to see well? Would it be helpful to have phones and clocks with larger displays and buttons? Do they need dishes, clothes and other items moved to lower shelves? There are many ways to make a person's environment safer and more accessible.
- Be an advocate for the person you support and continue to support his

or her self-advocacy needs. How can you help the person to remain in his or her own home? Communicate additional support or environmental needs to the service provider agency and help plan ahead.

- Learn about fall/accident prevention strategies. Check with your employer or local senior service center to learn more about fall prevention programs. You can also go to www.stopfalls.org. Many providers will already have this information, but if not, you can do this research.

Retirement and Social Networking

Retirement is a normal part of the aging process for many people. It is a time in life that people often view as an opportunity to try new activities, learn new hobbies, and meet new people. Remember, retirement does not need to be determined by chronological age. Rather, it should be determined by the needs and desires of the person being supported as they are aging.

For those who do retire, it can be a way to become engaged in their community in new ways. Some may have worked the majority of their lives in a segregated setting or workshop. This next stage of life can offer time to become more involved in a wider community and other areas of interest. Formal retirement programs are currently more limited for people with disabilities than for those without, but the numbers are growing. There is also increased awareness and options for people to participate in integrated community settings.

Staying active during retirement can help to minimize the loss of existing skills. Maintaining physical, social, and intellectual skills helps keep a person feeling young, enjoying life, and staying healthier longer. Some support strategies for DSPs in this area are:

- Educate the person you support about what retirement can mean. Give the person opportunities to experience activities he or she might choose to do in retirement, and

support their decision-making regarding how and when to retire.

- Support the transition from work to retirement. This is a process and should naturally occur over time as the interests and abilities of the person you support change.
- Identify and gather information about recreational and social opportunities in the community. Assist the person to choose activities they like, respect their choices, and facilitate their participation in these activities.

Loss and Grieving

Many different types of loss commonly occur as people age, such as losses related to leaving friends at work, losing the skills or ability to participate in activities, and loss of friends and family to death. Friends and family become ill and may not be able to be as involved in the person's life. Oftentimes, people with intellectual and developmental disabilities have smaller groups of friends and family, or support networks, than people without disabilities. People with disabilities are often more isolated than those without disabilities, and may not have been part of a formal grieving process before. Anecdotal information suggests that often a DSP may want to "protect" a person from loss and grieving by not sharing information or supporting the person to participate in typical grieving processes. It is important that people with disabilities have the same opportunities as those without disabilities to grieve and experience rites of passage, such as wakes, funerals and other events. The DSP has an important role in supporting a person to cope with loss and grieving. Some strategies include:

- Share information about death in a way that the person you support can understand and process it. Do not hide information.
- Let the person you support talk to you about losing loved ones. You don't need to be a therapist. Listen without judging and give the person a sympathetic place to talk about

their feelings. Being friendly and supportive is part of the DSP role.

- Support the person to attend wakes, funerals or other public functions of mourning. Ask the person how he or she would like to participate. Discuss with other family members or friends how to best support the person at the event. Be respectful of the wishes of the individual and the family of the deceased.
- Consider the person's faith. Involve clergy or other spiritual leaders as appropriate. Many religious leaders will provide guidance and consolation during times of grief.

End of Life Planning

End of life planning is another area in which a DSP may have a role. Learning about a person's wishes for their end of life care, including preferences about health care, establishing a living will, health care power of attorney, and other legal documents can all be considered end of life planning. End of life planning should be a thoughtful person-centered support process that includes people who are important in the life of the person you support. There are many models and programs available to support the end of life planning process. As a DSP you will want to learn more about end of life planning and understand your role in the process.

Conclusion

Aging holds opportunities and challenges for people with intellectual and developmental disabilities. There are many resources available for DSPs to use to learn more about their needs and how to apply the information to practice. This article is just a start.

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Caregiver: A New Paradigm in Connecticut

by Peter Carbine, Daniela Buri-Kurtz and Tina Varick

A few years ago the Kennedy Center Inc. in Trumbull, Connecticut, needed a way to help serve our aging parents. Some of our families have been receiving services from us for decades, and we had to find a way to help the parents who, because of their own aging-related issues, were now in need of receiving caregiving assistance for themselves. Our Caring for the Caregiver program was developed to creatively meet that need.

Unlike traditional caregiver programs, this caregiver is the adult son or daughter with intellectual disabilities who provides assistance for an elder family member.

The Kennedy Center Inc. is a community-based rehabilitation organization that provides vocational, residential, educational, therapeutic and recreational services to more than 1,400 people with disabilities and special needs annually. The Caring for the Caregiver program, which has been funded by the Southwestern Connecticut Agency on Aging since 2003, is a truly innovative approach to the caregiving concept. Unlike traditional caregiver programs, where the caregiver is the parent who looks after a child with disabilities, this caregiver is the adult son or daughter with intellectual disabilities who provides assistance for an elder family member. The program was created to address the problems of parents over the age of 60 who continue to support their sons and daughters with intellectual disabilities as they deal with their own aging issues.

When a family is referred for service and support from the program, the

Family Support Coordinator completes an intake process that identifies the critical caregiving issues. From there a plan of service is developed, along with a task analysis of the skills to be learned by the adult family member with disabilities. It is essential that the caregiving son or daughter with disabilities is taught to complete household tasks in the way that their parents have done in the past. This ensures a level of comfort for both the caregiver and the senior parent.

During the ensuing home visits, the Family Support Coordinator and the Caregiver Facilitator work with the caregiver on various skills such as cooking, laundering, money management, home safety, housecleaning, learning to use a phone, and shopping. The caregiver with disabilities repeats each identified task with the encouragement of both the elder family members and program staff. The program staff understands that the best way to learn is through active participation in a safe environment that allows individuals to try new things. Through task repetition, the caregiver is allowed to internalize and actively process the new skills. As a result of his or her personal perseverance, the caregiver is then rewarded with the achievement of a highly valued caregiving skill. The son or daughter with a disability is able to provide practical support for their older parent and other family members.

The most successful strategy for supporting new caregivers is through the frequent validation of their importance in the support of their elder parent. Nothing compares to watching the son or daughter assume new caregiver responsibilities that support the household as a unit, a process that develops the self-esteem of the individual with disabilities and provides peace of mind for the elder parent. With each new skill learned, the family is better able to provide for itself.

The Family Support Coordinator position serves as a vital link in network-

ing caregivers to program supports, and seniors to important respite services. Overall, coordination of services is achieved through regular home visits and personal phone contacts. Concurrently, both the Family Support Coordinator and the Caregiver Facilitator address the needs of the elder adult and the caregiver by providing applicable service assistance. Program services include, but are not limited to, case management, information sharing, functional skill development, respite planning, monitoring, regular family support and education meetings, and follow-up. Also, family and caregiver surveys are conducted on a regular basis to elicit feedback on the impact of the program and to ensure continuous quality improvements.

Nothing compares to watching the son or daughter with a disability assume new caregiver responsibilities that support the household and provide peace of mind for the elder parent.

The role of the new caregiver is dramatically different from that which existed in the previous parent-dependent relationship. The new caregiver role must be nurtured in order to establish a new relationship model based on mutual reliance within the family unit. In support of this newly developing relationship model, program staff journal the skill achievements and collect photographs that illustrate the ongoing progress of the new caregiver. The journal also contains favorable comments

made by family members during this learning process. These journals are shared with the family, and occasionally potential funders, to record each family's journey in the Caring for the Caregiver program.

An illustration from one family demonstrates the impact of our caregiver program. Andrea continued to live with her parents as an adult. Her mother Joanne, had been experiencing some normal health issues associated with increased age and needed additional help around the house. Andrea already had some household skills, like helping with the laundry and setting the table, but was uncomfortable with taking on more housework. The Caregiver Facilitator was able to expand Andrea's skills by teaching her tasks like changing

the sheets, making the bed, and doing some light cooking. Over time she developed the new skills and experienced an enriched sense of self-esteem as she contributed to the family in a new way. Today, Andrea's mother is both grateful for and proud of her daughter's accomplishments. "Andrea has made great progress," Joanne explains. "Now she shows a real interest in cooking, and prepares meals without hesitation. Andrea has grown to be more independent, and has taken on the responsibility of helping her family."

The Caring for the Caregiver model is a relatively new concept, but it has practical and cost-effective applications that are really needed as our population ages and fiscal resources continue to dwindle. The journals kept by the families really

demonstrate the amount of progress that is being made in households with aging caregivers that participate in the program. We think this model holds great possibilities, and look forward to expanding our program, as well as seeing the model replicated all over the country.

Peter Carbine is Vice President of Residential Programs, Daniela Buri-Kurtz is Family Support Coordinator, and Tina Varick is Grants and Project Manager, all with the Kennedy Center Inc., Caring for the Caregiver program, Trumbull, Connecticut. For more information about the program model, contact Daniela at 203/365-8522, ext. 233, or dkurtz@kennedyctr.org; and Peter at 203/365-8522, ext. 204, or pcarbine@kennedyctr.org. Or visit their Web site at www.thekennedycenterinc.org.

Ways of Thinking About Aging with Disabilities: Select Resources

The following resources may be of interest to the readers of this Impact issue:

- **Caresharing: A Reciprocal Approach to Caregiving and Care Receiving in the Complexities of Aging, Illness and Disability.** By Marty Richards. The word "caregiver" typically suggests someone doing all the giving for another who is doing all the receiving. This book proposes a rebalanced approach of "caresharing." From this perspective, the "cared for" and the "carer" share a deep sense of connection. Each has strengths and resources. Each can teach the other. Each can share in grief, hope, love and wisdom. Available spring 2010 from Skylight Paths Publishing, www.skylightpaths.com, 800/962-4544.
- **Creativity Matters: The Arts and Aging Toolkit.** This guide for arts, healthcare and aging services organizations explains why and how older adults benefit from participating in professionally conducted community arts programs, and offers detailed advice and examples on program design, implementation

and evaluation. Published jointly by the National Center for Creative Aging, the National Guild of Community Schools of the Arts, and the New Jersey Performing Arts Center. It is a companion to the monograph **Creativity Matters: Arts and Aging in America** by Gay Hanna and Susan Perlstein, which is intended to begin a dialog about the role of artistic expression in the lives of older adults. It presents a paradigm that sees older people for their creative potential. Though not specifically addressing persons with developmental disabilities, both these publications present ideas that may be applied to programs and services for aging individuals with disabilities. Available at no cost online from the Center for Creative Aging at <http://www.creativeaging.org/publications/>.

- **Elderburbia: Aging with a Sense of Place in America.** By Philip B. Stafford. This new book argues that aging is not about time and the body, but about place and relationships. Drawing on the multidisciplinary field of

ethnography, it gives readers a deeper understanding of how the aging experience for all adults is shaped by where people call home, as well as a look at what makes a place well-suited for post-retirement living. The author is director of the Center on Aging and Community, Indiana Institute on Disability and Community, Indiana University. Published by Praeger Publishers. For more information go to www.praeger.com/catalog/C36436.aspx.

- **Remembering with Dignity (www.selfadvocacy.org/programs/rwd).** Remembering With Dignity is a coalition of disability rights organizations working to honor people who lived and died in Minnesota's state institutions. Since 1994 it has been putting personal markers on the graves in institution cemeteries previously marked by only a numbered cement block, or nothing at all. It is also gathering life stories of people with disabilities who have lived in institutions, and organizing to prevent a return to institutionalization.

Age-Related Health Changes for Adults with Developmental Disabilities

by Beth Marks and Jasmina Sisirak

Individuals with developmental disabilities living in community settings are increasingly enjoying similar lifespans as the general population. However, life expectancies are lower for individuals with a variety of syndromes and conditions (e.g., Down syndrome, severe intellectual disability, cerebral palsy, multiple disabilities). While many of the

the general population for a number of health conditions, such as difficulty eating or swallowing, dental disease, gastroesophageal reflux, esophagitis, respiratory disease and infections (leading cause of death), and constipation (White-Scott, 2007). Several chronic conditions seem to be more prevalent among individuals with disabilities than in the general population, including non-atherosclerotic heart disease, hypertension, hypercholesterolemia, diabetes, obesity, reduced mobility, bone demineralization, and osteoporosis. Also, thyroid disease, effects of taking multiple psychotropic drugs, and deaths due to pneumonia, bowel obstruction, and intestinal perforation have a higher prevalence among groups of people with various disabilities.

Individuals with disabilities have a higher risk of developing chronic health conditions at younger ages than other adults, due to biological factors related to syndromes and associated developmental disabilities, problems with access to adequate health care, and lifestyle and environmental issues. Although people aging with developmental disabilities can now expect to live late into life along with their peers without disabilities, many experience major changes in health, function, and psychosocial status at much earlier ages. The new problems they report as early as in their 20s and 30s include the onset of age-related chronic health conditions, pain, and loss of energy and endurance. These changes, suggestive of premature aging, have a major impact on their ability to engage in community activities.

Persons with developmental disabilities who have syndrome-related conditions and certain health conditions (e.g., Down syndrome, Fragile X, Prader-Willi, cerebral palsy, epilepsy) are predisposed to certain health conditions based on their type of disability. For

example, adults with Down syndrome have a higher prevalence (15% to 40%) of early-onset Alzheimer's disease occurring 15-20 years earlier compared to the general population, and may experience hypothyroidism and sleep apnea more frequently (McCarron, Gill, McCallion, & Begley, 2005). Adults with Fragile X may have more issues with heart problems (mitral valve prolapse), musculoskeletal disorder, earlier menopause, epilepsy, and visual problems. Persons with Prader-Willi have high rates of cardiovascular disease and diabetes (Prasher & Janicki, 2002). As persons with cerebral palsy age, they have an increased likelihood of having reduced mobility, bone demineralization, fractures, decreased muscle tone and increased pain, difficulty eating or swallowing, and bowel and bladder concerns (White-Scott, 2007). People aging with cerebral palsy and epilepsy who use psychotropic and anti-seizure medications on a long-term basis also have a higher risk of developing osteoporosis (brittle bone disease) and tardive dyskinesia (repetitive, involuntary, purposeless movements caused by the long-term use of certain drugs). This risk is often compounded by limited physical activity and diets low in calcium and vitamin D. Anti-epileptic medications are also frequently given long-term to individuals with developmental disabilities. Studies suggest that osteoporosis and osteomalacia (softening of the bones) are potential side effects of certain antiepileptic medication, and vitamin D may be reduced, leading to possible loss of bone mass.

Understanding "Confusion"

As people age, "confusion" is used as a broad and imprecise term to describe behavior changes. Common causes of confusion consist of the following: drug intoxication, circulatory disturbances,

Although people aging with developmental disabilities can now expect to live late into life along with their peers without disabilities, many experience major changes in health, function, and psychosocial status at much earlier ages.

health concerns are similar to their peers without disabilities, they also often have health concerns related to their disability and the combination of aging with a life-long disability.

Health Issues for People with Developmental Disabilities

Health issues related to disability are often not stable across a lifespan. Many people with disabilities show signs of earlier medical, functional, and psychosocial changes that are customarily not experienced by persons without disabilities until much later in life. For example, recent studies have documented higher rates of disease and death for adults aging with disabilities in comparison with

metabolic and fluid imbalances (e.g., thyroid and kidney problems), major medical and surgical treatments, neurologic disorders, infectious processes, nutritional deficiencies, abrupt loss of significant person, multiple losses in a short span of time, and moves to radically different environments (Ebersole et al., 2004). To provide appropriate care, it is important to understand distinctions between three conditions that can manifest as “confusion”: delirium, dementia, and depression (Edwards, 2003).

Delirium (used synonymously with “Acute Confusional State”) is severe confusion with hyperactivity. It is characterized by a rapid impairment of intellectual function resulting from a widespread disturbance of brain metabolism. Characteristics include clouding of consciousness, mental incoherence, and impaired concentration and attention; it may also be reversible (Edwards, 2003).

Dementia is broadly defined as an observable decline in mental abilities (APA, 2000). In general, its onset is insidious and memory impairment is often a prominent early symptom. People with dementia have difficulty learning new material. Short-term memory problems commonly result in losing valuables such as wallets and keys, or forgetting about food that is being cooked on the stove. In more severe dementia, people may forget previously learned material, such as the names of loved ones.

The World Health Organization defines depression as a “common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration” (WHO, 2010). It may coincide with major life changes and is typically worse in the morning. A person with depression has minimal impairment in attention, although they are easily distracted. Depression is more prevalent among people with developmental disabilities compared to their general population peers (Stavarakaki, 1999) and is frequently under-assessed, under-diagnosed and untreated. Several conditions may mimic depression, such

as metabolic and endocrine disorders (e.g., serum glucose abnormalities, pernicious anemia, hypothyroidism, or hyperthyroidism) (Edwards, 2003; Sutherland & Sklar, 1999).

Resources to Address Aging Issues

Age-related changes in health and functioning and psychosocial losses necessitate accessing an array of potential supportive services. As people with developmental disabilities age and have more difficulties with activities of daily living (ADLs), maintaining a household or employment may become more difficult. Also, they often have greater needs for family and social support, assistive technologies, environmental accommodations, therapeutic and nursing services, and respite and other housing and vocational supports.

Families and professional caregivers have a pivotal role in meeting the increased needs for support of people with developmental disabilities as they age. As people with life-long disabilities live longer, parents may experience extended caregiving responsibilities at a time in life when they are experiencing their own health care issues and are potentially in need of caregiver support for themselves. Many service delivery systems and communities are not prepared to meet the needs of adults with developmental disabilities who will likely need day and residential services as they age, and no longer have parents to provide care for them.

Assistive Technology and Environmental Interventions

As individuals with long-term disabilities and other older adults face declines in health and function, a greater need exists for assistive technology and environmental interventions to help them maintain their independence and community participation. New and highly personalized devices and technological advances can now aid aging individuals with disabilities in maintaining or increasing independence, productivity,

and quality of life. Innovations in assistive technology and environmental interventions reduce their dependencies on others for assistance, lower their risk of secondary conditions, allow caregivers to provide assistance more easily, and forestall the need for nursing home care. Advances in microelectronics, computer science, communications, bioengineering, and health and rehabilitation sciences have led to the development of a host of physical and cognitive aids. These aids can help older adults function in work, home, recreational, and other community settings as they encounter age-related changes. Examples of the uses of such technologies include the following:

- Helping with planning, execution, attention, and memory (cognitive prosthetics and orthotics).
- Monitoring health and safety (telecare, tele-health, alert systems).
- Assisting with ADLs (robotics, personal digital assistants, adapted eating devices, handrails).
- Controlling the physical environment at home (environmental controls, ramps).
- Facilitating greater community participation (navigational systems, recreational aids, communication devices for social interaction).
- Improving mobility (wheelchairs).
- Providing communication and learning aids for educational and employment settings (augmentative communication devices).
- Using information technology (Internet, computers, adapted Web browsers).
- Helping to improve vision (glasses) and hearing (hearing aids).

While many older individuals and their caregivers could benefit from such advances, often they are unaware or unable to access or pay for them. This is particularly true for individuals with developmental disabilities who lag behind other disability groups in their use of technology. Barriers to use include lack

[Marks, continued on page 34]

Alzheimer's and Individuals with Intellectual and Developmental Disabilities

by Marsha Berry

There are an estimated 5.3 million people in the U.S. with Alzheimer's disease. By the year 2030, that number is expected to increase to 7.7 million. Alzheimer's disease is the most common form of dementia, a group of symptoms characterized by loss in memory and at least one other cognitive skill. Sixty to 80% of people with dementia have Alzheimer's disease (Alzheimer's Association, 2009). The most significant risk factor for Alzheimer's is age. For most

between ages 40-49, 20-50% of individuals between ages 50-59, and 60-75% of individuals with Down syndrome older than age 60 have Alzheimer's disease (Alvarez, 2008). Because people with Down syndrome experience accelerated aging, they are at greater risk for this disease of the aging brain. Additionally, the amyloid precursor protein gene sits on chromosome 21; most people with Down syndrome have two copies of this chromosome in every cell and therefore double the risk of having one of the genes implicated in the brain degeneration associated with Alzheimer's. Clinical studies have also noted that the volume of the hippocampus, the area of the brain responsible for beginning the process of memory storage, is reduced in people with Down syndrome (Piner, et al., 2001).

Signs of Alzheimer's Disease

For years, the Alzheimer's Association has provided the public with a list of the "10 Warning Signs" of Alzheimer's disease. These include memory changes significant enough to impact daily life, challenges in planning or problem solving, difficulty completing familiar tasks and confusion with time or place. (For a complete list of the warning signs see www.alz.org). The warning signs for people with intellectual and developmental disabilities focus on functional capabilities (see Figure 1). Most often, the first change that family members or professionals notice is a change in activity of daily living skills. For example, if an individual has worked independently in a restaurant for many years she may begin to lose attention for the task, make many errors or become frustrated with the task. A man who has enjoyed going out with others in his group home may seem reluctant to do this and want to stay home. Families and staff will most

often notice that the individual loses the ability to perform skills he or she has been able to do for many years.

They may notice other changes as well. She may ask the same question repeatedly. An individual who has been outgoing may seem more withdrawn. She may seem less alert and move more slowly. He may cry easily and appear frustrated when completing tasks that have been part of his daily routine in the past. He may be confused and get lost in familiar places. These changes will not happen quickly, but will be noticeable when compared to previous abilities.

With individuals who have severe developmental disabilities it may be more difficult to identify changes in behavior. However, among those changes that may appear are becoming more socially withdrawn, being less responsive to others, seeming easily frustrated even in familiar surroundings, appearing much less interested in activities that engaged them in the past, and having shortened attention.

Having a clear and specific understanding of the individual's skills, abilities, and interests is important for comparing current behaviors to those from the past and noticing changes. A baseline evaluation of skills at work, abilities at home, and interests will help caregivers to notice possible signs of Alzheimer's disease, and share changes with medical professionals.

Diagnosing Alzheimer's Disease

There is no one test for the diagnosis of Alzheimer's disease. Physicians may suggest several tests as a way to rule out other issues. There are many reasons why an individual may experience difficulties with activities of daily living or show changes in his or her personality. If caregivers notice changes and losses in skills, it is important to seek a

People with intellectual and developmental disabilities develop Alzheimer's disease at rates similar to older adults in the general population. However, adults with Down syndrome develop Alzheimer's disease at greater rates.

people the disease begins with difficulty remembering new or current information, and other cognitive abilities such as the ability to plan, use language, and understand time and spatial relations deteriorate as the disease progresses.

Alzheimer's Disease and Intellectual/Developmental Disabilities

People with intellectual and developmental disabilities develop Alzheimer's disease at rates similar to older adults in the general population. However, adults with Down syndrome develop Alzheimer's disease at greater rates. Recent studies for adults with Down syndrome show that 10-25% of individuals

medical evaluation. A medical professional will want to rule out issues which can be corrected such as thyroid disorders, depression, physical health problems, and medication side effects. Clear documentation as to current abilities is important so that staff and medical professionals can compare current abilities to past.

Progression

Alzheimer's is a progressive disease, and while it does not progress at the same rate in every person, there are some general stages of the disease. For individuals with mild to moderate developmental disabilities the changes first noticed in the early stages of Alzheimer's disease include loss of activity of daily living skills, personality changes, and disorientation to time and place.

As the disease progresses the symptoms seen in the early stage increase. Individuals become increasingly confused and their frustration may increase. Many individuals will experience disruptions in their sleep schedule and become very confused about day and night. Some individuals may attempt to leave their residence and become lost.

Late in the disease process individuals are very disoriented to time and place and exhibit physical issues. They may have difficulty swallowing, be incontinent, and have difficulty walking. They will need total care for survival.

Medications for Treating Cognitive Symptoms

The FDA has approved four medications for treating the cognitive symptoms of Alzheimer's disease. The approved medications are three cholinesterase inhibitors – donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne) – and memantine (Namenda), a glutamate receptor antagonist. While these have been tested in older adults without intellectual or developmental disabilities, there have been no large randomized controlled studies in adults with intellectual or developmental

Figure 1: Warning Signs of Alzheimer's Disease for Adults with Intellectual and Developmental Disabilities

- *Loss of activity of daily living skills, difficulty with well-learned abilities*
- *Changes in personality; more withdrawn, frustration*
- *Periods of inactivity or apathy, disinterest in activities the individual previously enjoyed*
- *Development of seizures not previously seen*
- *Disorientation to time and place*
- *Increase in stereotyped behaviors*
- *Hyperactive reflexes*
- *Visual retention deficits*
- *Speech difficulties, not able to use words or speech that is not clear*

disabilities. It is important for caregivers to seek advice from a medical professional about the use of these medications.

Care Principles

The University of Stirling (Scotland), the University at Albany, and the University of Illinois at Chicago called a group of international experts together in 2001 to define internationally applicable working practices for the community supports of adults with intellectual and developmental disabilities who have Alzheimer's disease. Known as "The Edinburgh Principles," these guidelines focus on quality of life and promote care management. The group proposed that "governments, organizations, and providers adopt these and promote their use in aiding those adults with intellectual disabilities affected by Alzheimer's disease and other similar conditions resulting in dementia" (http://www.rrtcadd.org/TA/Dementia_Care/Resources/Edinburgh_Principle/Info.html). The Principles are as follows:

1. Adopt an operational philosophy that promotes the utmost quality of life of persons with intellectual disabilities affected by dementia and, whenever possible, base services and support practices on a person-centred approach.
2. Affirm that individual strengths, capabilities, skills, and wishes should be the overriding consideration in

any decision-making for and by persons with intellectual disabilities affected by dementia.

3. Involve the individual, her or his family, and other close supports in all phases of assessment and services planning and provision for the person with an intellectual disability affected with dementia.
4. Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs, and support healthy ageing of persons with intellectual disabilities affected by dementia.
5. Plan and provide supports and services that optimize remaining in the chosen home and community of adults with intellectual disabilities affected by dementia.
6. Ensure that persons with intellectual disabilities affected by dementia have the same access to appropriate services and supports as afforded to other persons in the general population affected by dementia.
7. Ensure that generic, cooperative, and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with intellectual disabilities affected by dementia.

The Edinburgh Principles are the foundation of the caregiving suggestions in the following section.

[Berry, continued on page 35]

Aging with Developmental Disabilities: Women's Health Issues

by Allison A. Brown and Leone Murphy

Women generally live longer than men, so a larger number of the growing population of older people with developmental disabilities will be women. More research is needed to understand all the specific health issues of aging women with developmental disabilities and the ways to support a healthier lifestyle. However, it is important that older women with developmental disabilities receive the health-related information that is presently available in order to promote well-being and prevent health problems.

- **What effect does menopause have on women with developmental disabilities?**

Menopause is unique for every woman, including women with developmental disabilities. Menopause is typically thought of as the time when women stop menstruating. A woman is considered to have reached menopause if she has not had a menstrual period in one year. Menopause varies considerably from woman to woman, but it usually occurs around age 50-52. The transition to menopause is a process that begins as a woman's body produces less and less estrogen and eventually menstrual periods stop permanently. Near the time of menopause, periods become less frequent and bleeding decreases. Since this natural drop in estrogen may be inconsistent, women who are in their mid to late forties should keep a calendar of their menstruation to help note any irregularities in their periods. For most women, reaching menopause is a gradual transition. However, some women may experience menopause abruptly through surgical removal of both ovaries, radiation treatment, or by taking certain medications. Some women barely notice any changes related to menopause. Others may experience hot flashes, sweating,

insomnia, heart palpitations, itchy skin, backaches, joint pain, headaches, bloating, weight gain, thinning hair and the growth of facial hair. Depression or other mental health changes may be associated with menopause for some women. However, the above changes may also have other causes not related to menopause, so a blood test for hormone levels may be necessary to determine if these changes are due to menopause.

There is little research in the area of menopause and older women with developmental disabilities. However, several studies suggest that women with Down syndrome and women with epilepsy may reach menopause at an earlier age than women in the general population. For some women, seizure patterns change, for better or worse, around the time of menopause. It is unclear if this is from the effects of hormones or changes in anti-seizure drug levels.

Women with developmental disabilities typically have not received information about the nature of menstrual periods and menopause. Therefore, it is important to inform women about menopause and to arrange for periodic evaluations by a health care professional with expertise in women's health.

- **What is osteoporosis and how does it affect women with developmental disabilities?**

Osteoporosis is a disease in which bones become fragile and are more likely to break. Unfortunately, many older women become aware that they have osteoporosis only after they break or fracture a bone. Estrogen helps maintain bone density. The natural drop in estrogen because of menopause increases a woman's risk

for osteoporosis. Other risk factors include: advanced age, family history of osteoporosis, Caucasian or Asian ethnicity, very thin or small stature, physical inactivity, a condition which limits movement, early menopause, a diet low in calcium or vitamin D, high alcohol and/or coffee intake, over-dieting, excessive weight loss, and smoking. The more risk factors a woman has, the higher her chances are for getting osteoporosis. Women who have several of these risk factors should have a special bone x-ray to determine if osteoporosis is present and the rate of bone loss.

Women with developmental disabilities may be at greater risk for osteoporosis and related bone fractures due to amenorrhea (absence of periods), earlier menopause, the use of certain medications (anticonvulsants, excessive thyroid hormones, steroids), and because they are more likely to be inactive or experience falls. Recent studies suggest that people with certain conditions like Prader-Willi or Klinefelter's syndromes may be at increased risk for osteoporosis. Women with cerebral palsy may be at greater risk for developing a number of other bone, muscle, and joint-related diseases as they age, such as scoliosis (abnormal curvature of the spine) and spinal stenosis (neurologic problems associated with narrowing of the spinal canal).

- **Is heart disease a concern for women with developmental disabilities?**

Heart disease accounts for half of all deaths of women over age 50. Preliminary research suggests that it may be a leading cause of death for women with developmental disabilities as well. Generally, women are not diagnosed as early as men are, so their

heart condition is not treated until it is much more serious. Major risk factors for developing heart disease include family history, hypertension, diabetes, lack of cardiovascular fitness, and smoking. Menopause also can increase the cholesterol levels in a woman's blood, which can lead to a greater risk of heart disease or stroke.

• Are women with developmental disabilities at risk for cancer?

Like heart disease, cancer is one of the leading causes of death for women, including women with developmental disabilities. Older women should receive regular screenings and examinations for early detection of breast, ovarian, cervical, and uterine cancer, especially if they are sexually active or postmenopausal. Women with developmental disabilities often do not receive these services. Frequently, families are unaware of this need and many health care professionals are inexperienced and/or untrained in working with women who have disabilities. In addition, many clinics and offices lack adaptive equipment to accommodate women with physical disabilities.

• How is urinary incontinence related to aging?

Around the time of menopause, some women may have difficulty in controlling their urination, leading to urinary "accidents." This is known as urinary incontinence. Women with a prior history of urinary incontinence may experience increased difficulty in controlling their bladder. For older women with cerebral palsy or other neuromuscular conditions, urinary incontinence may be related to both aging and their physical disability. As women age, changes in the urinary tract can also increase the risk of urinary tract infections (UTI). Frequent symptoms of a UTI include an increased need to urinate and a burning sensation or discomfort during urination. If left untreated,

this can contribute to urinary incontinence and lead to more serious health problems.

• What health-related supports and accommodations should women with developmental disabilities receive?

Older women with developmental disabilities are generally uninformed about many of the changes that their bodies are, or will be, going through. Family, staff and close friends can play an important role in the health and well-being of women with developmental disabilities by:

- (a) Watching for behavioral changes that may indicate an underlying health problem, especially for women who have communication difficulties.
- (b) Ensuring access to appropriate health information and to health professionals who are experienced in diagnosing and treating age-related health problems for women with disabilities.
- (c) Ensuring that health professionals have accessible examination rooms and the proper equipment to examine women with disabilities appropriately.
- (d) Providing the necessary supports to address health concerns, including alleviating their fears and helping them feel comfortable with the health care professional and the examinations/procedures.
- e) Ensuring that health information is available, understandable and explained in a way that is respectful.

Adapted and excerpted with permission from "Aging with Developmental Disabilities: Women's Health Issues" (1999) published by The Arc of the United States, and the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago. The full document is available at http://www.rttcadd.org/Resource/Publications/HP/Brief/assets/500015_womenshealth.pdf.

Prostate Cancer: Information for Men with Intellectual and Developmental Disabilities

- Prostate cancer is the most commonly diagnosed cancer in men, and most cases of prostate cancer occur in men over age 50.
- The prostate is a walnut-sized gland, found only in men, that is located below the bladder and in front of the rectum. Prostate cancer occurs when cells within the prostate grow uncontrollably, creating small growths called tumors.
- In most cases of early prostate cancer, men do not have symptoms. But some men may have one or more of the following symptoms: Difficulty urinating; a weak urine flow; more frequent urination, especially at night; pain during urination (like a "burning" or "stinging" feeling); blood in the urine; or pain in the back, hips or pelvis that doesn't go away.
- These can also be symptoms of other conditions that are not cancer, so it is very important to call your doctor right away if you are having any of these symptoms.
- There are two screening procedures (tests) that check for prostate cancer. You should begin having these screenings at age 50 (or sometimes earlier if you and your doctor determine that you are at a higher risk for prostate cancer). They are the Prostate-Specific Antigen (PSA) test, and the digital rectal exam. Having these tests is a simple way to find prostate cancer early.
- Prostate cancer grows very, very slowly, if found early, it can be successfully treated and stopped from spreading.

Excerpted with permission from *Health Screenings That Detect Prostate Cancer and Lifestyle Choices That May Help Reduce the Risk of Developing It: A Comprehensive Guide for Men with Intellectual and Developmental Disabilities and Their Caregivers*. Published by The Arc of New Jersey and available online at www.arcnj.org/information/issues.html; scroll down to "Let's Talk About Health."

Elder Abuse Programs and Elders with Intellectual and Developmental Disabilities

by Nora Baladerian

Adults with intellectual, developmental, and other disabilities are at greater risk of abuse, neglect, and other violence against them than the general population. Annually, approximately 5 million adults with disabilities experience substantiated cases of abuse and neglect. As increasing numbers of adults with disabilities are becoming “elders,” the need is growing for programs that prevent and respond to elder abuse to get good at outreach to this group and their families and caregivers, and become skilled at responding to their needs. The need is also growing for disability advocates and service providers, persons with disabilities, and their families to help elder abuse programs for the broader aging population create and deliver services and resources for persons with intellectual and developmental disabilities.

What Elder Abuse Programs Can Do

The best outreach models engage in interdisciplinary collaboration, involving people with disabilities and disability specialists in the planning, design, and ongoing implementation of education, prevention, intervention, advocacy, and other services by elder abuse programs. Below are seven realistic, cost-effective activities that any elder abuse agency can employ to collaborate with community disability organizations, individuals with disabilities, and families in increasing knowledge, skills, and effectiveness in working with elders with intellectual, developmental and other disabilities:

1. Be guided by the “Nothing about us without us” principle. This principle means that you involve people with disabilities in all phases of service delivery, including planning for the physical site; development of service delivery procedures, protocols and policies; board membership; and training activities.

2. Practice inclusion in all phases and phrases. Include people with disabilities in all phases of service delivery, and in the phrases and images in all your materials stating who you serve and employ.

3. Follow the spirit and the letter of ADA. Ensure that your program has full Americans with Disabilities Act (ADA)-guided accessibility that complies with both the spirit and letter of the law.

4. Deliver disability awareness and sensitivity training to all staff. Prior to employment or within six weeks, ensure that all staff complete disability awareness and sensitivity training. Hold monthly meetings with disability service agencies to provide ongoing staff development for both organizations, rotating meetings between different disability related agencies during the year.

5. Use “CREDO” as your operating philosophy:
C - Compassion
R - Respect
E - Empathy
D - Dignity
O - Open-minded to needs of the individual

6. Recognize when you don’t know something and ask for help. Be aware when you run into a situation in which you “feel” you are in unknown territory. It is okay to not know information and to not have skills yet! It is not okay to generate new “techniques” without regard to how these may affect the individuals to whom you’re providing services. Seek guidance from those more knowledgeable about elders with disabilities when you need it.

7. Use the Web/listservs. Make sure your Web site is accessible to elders with intellectual, developmental and

other disabilities (see the W3C accessibility guidelines at www.w3.org/WAI). Also make sure it has information addressing their needs, and is promoted in disability-related newspapers, newsletters, and Web sites. Join listservs (such as that of the CAN DO project at <http://disability-abuse.com>) to stay up to date and get help with elder and disability issues.

What Disability Organizations, Self-Advocates, and Families Can Do

It is also important that elders with disabilities, their families, service providers, and advocates engage with elder abuse programs to learn more about preventing and responding to potential abuse, and to assist the elder abuse programs to effectively reach individuals with disabilities. Collaboration is the key. Disability services agencies, as well as advocacy and self-advocacy organizations, can close the gap by inviting elder abuse response/prevention providers to their “inner circle.” They can develop specialized service linkages with elder abuse organizations, invite victim advocates to their inservice trainings, place links to elder abuse services on their Web sites, co-host events, and participate in elder abuse efforts at the community and State levels. In addition, they can help develop or support professionals who bridge the gap, and request their consultation in linking agencies. They can also generate other ideas to strengthen the connections between elder abuse programs and people with disabilities through checking out resources such as the National Center on Elder Abuse at www.ncea.aoa.gov.

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Resources on Aging and Individuals with Disabilities

The following resources from around the country may be of interest to readers of this Impact.

- **Aging and End of Life Webinar Series** (http://www.aaidd.org/content_276.cfm). Information about upcoming Webinars as well as archives of materials and presentations from past Webinars in this series are available on the Web site of the American Association on Intellectual and Developmental Disabilities (AAIDD). This series, sponsored by AAIDD, the Association of University Centers on Disability, The Arc of the United States, ANCOR, and the RRTC on Aging with Developmental Disabilities (University of Illinois at Chicago) has included the following presentations, among others: “Dementia Among Adults with Down Syndrome: Individual Differences in Risk and Progression”; “Aging and End of Life: Crisis or Opportunity for Individuals and Service Providers?”; “Key Issues in Healthcare Decision Making and Care at End of Life: How to Use Person-Centered Practices to Support Quality Planning with People with Critical, Chronic and/or Terminal Illnesses;” and “End of Life Through a Cultural Lens.”
- **AbleData** (www.abledata.com). This Web site provides objective information on assistive technology and rehabilitation equipment available to consumers, organizations, professionals, and caregivers in the United States. It includes a database of information on more than 22,000 assistive products of use to individuals with disabilities and persons who are aging, and for each provides a detailed description of the product’s functions and features, price (when available), and contact information for the product’s manufacturer and/or distributors. It also offers information on non-commercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs. AbleData is sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.
- **Health Disparities Among Latinas Aging with Disabilities (Family & Community Health, 2009, 32 (1))**. Latinas with disabilities report greater levels of disablement than non-Hispanic White women with disabilities. Latinas experience increased numbers of functional limitations, more difficulties with activities of daily living, and more unemployment due to impairments. The reasons for this disparity are unclear. This journal article explores the empirical evidence surrounding health disparities in disablement among Mexican American women and makes recommendations for responding. See http://journals.lww.com/familyandcommunityhealth/fulltext/2009/01001/Health_Disparities_Among_Latinas_Aging-With.6.aspx.
- **RRTCADD Clearinghouse on Aging and Developmental Disabilities** (<http://www.rrtcadd.org/Resource/Home.html>). In this clearinghouse are publications, products, and bibliographies on topics pertaining to aging with developmental disabilities. Major topics include health, caregiving, self-advocacy, policy, service delivery, and assistive technology. Special topics of interest include women’s health, dementia care, end of life care, and bridging the aging and disability networks. It is operated by the RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago.
- **A Guide to Building Community Membership**. By Jane Harlan, Jennie Todd, & Peggy Holtz. This guide outlines methods for finding positively valued roles and relationships that will bring adults with disabilities into the web of community life. It discusses the special challenges and opportunities of community building with aging persons. The text interweaves information, strategies, training activities, and tools for community builders. Published by the Center on Aging and Community at Indiana University’s Institute on Disability and Community. Available from Training Resources Network Inc. at <http://www.trninc.com/pdfs/TRNCatalog10.pdf> or 904/823-9800.
- **Journeys in Progress: Stories From the Community**. In this DVD the viewer will meet four older adults with disabilities and follow their journeys as they discover valued roles in community. By working on a one-to-one basis with a community builder, they have been introduced to a variety of community activities. The viewer will hear from many of the people in these individuals’ lives as they describe the gifts these four bring to their communities. A second DVD, **Cultivating Community: Landmarks of the Journey**, is a sequel and further describes the community building process as six older adults with disabilities discover their interests and abilities, get connected to activities and organizations in the community, take on valued roles, and explore social relationships. Published by the Center on Aging and Community at Indiana University’s Institute on Disability and Community. Available from Training Resources Network Inc. at <http://www.trninc.com/pdfs/TRNCatalog10.pdf> or 904/823-9800.

[Myrta, continued from page 1]

One thing that I am proud of is that over the years I've learned to use a cash register and deal with money transactions, which landed me in a job at the boutique at Woodbridge Developmental Center. Also, I am more active in the Special Olympics and have improved my skills in bowling and swimming and have medals to show for it!

As time has flown by, I have learned to tolerate my peers' behaviors and habits in order to live cordially. I have also learned to control my frustrations by talking to the people who can help me. I feel lucky to be able to speak up for myself because I realize that no one defends you as much as yourself, so it is vital to be heard, and respected the way you want to be respected. By advocating for myself, I have let other people know to treat me the same way just as they would treat an individual with no disabilities.

I look forward to the future very much, to pursue my personal and career goals, and also to spend time with my sister and spend some time in the warm weather in Florida.

If there's one message I have for others it would be to always speak up for yourself. Growing older is part of life's journey and till the very end make your voice heard.

Myrta Rosa lives in Woodbridge, New Jersey.

[Cliff, continued from page 5]

Through all that I got invited to testify before Senator Kennedy's subcommittee on health and human services in 1973. What's remarkable about that was that my father was very over-protective and didn't want me to do it. Then my mother said, "He's living in the city now, and he's going to do it anyway." So they signed the permission form. We spent three days in DC and most of the staff couldn't believe I went to a movie by myself in DC. The night before I was to testify I wrote out three pages of testimony about the state hospitals, and about the need for greater involvement by self-advocates and parents in policymaking organizations such as DD Councils.

Two weeks ago we had 300 self-advocates and staff at the Day at the Capitol in St. Paul. We've come a long way and providers are now putting in their job descriptions that staff are to be advisors to People First groups in their facilities. And part of their job descriptions is also to spend time at the legislature with their self-advocates. We've come a long way in terms of being over-protected.

Q: Did you ever think it would happen?

A: No. And I never dreamed that as of this year the legislature would get a grant to hire people with disabilities to work in their offices as interns. Now that will educate the legislature on how well people with disabilities can work.

Q: Do you have certain beliefs or values that you've tried to live by?

A: Being able to live as independently as possible and be able to do what other people do, whether that's going to church or Twins games or a movie. All we've ever said is we want to be treated as equals. We're getting there. I would have never believed we would have a governor of a state who's blind; David Paterson, governor of New York, is blind.

Q: I understand that at this time of year you're over at the state legislature a lot. What is it that you're working on there?

A: We're worried about General Assistance Medical Care, and we're also worried about what else the budget cuts will mean. We've been advocating to improve the system and give people the right to choose their own services, and hire and fire their own staff if they want to. That requires money to be allocated for that. Some budget cuts may mean people may not be able to pay for DSPs and may have to go back into nursing homes. About two weeks ago I did a speech at the day at the legislature to remind legislators they had to raise taxes to fund the programs that are serving us. It went very well. We won't know until the end of the session how this works out.

In the early 90s everybody finally found out that self-advocates could speak

for themselves and begin to advocate for their needs themselves. And that's what I do.

Q: When you look to the future, what are some of the things you still want to accomplish?

A: If we have the money I want to see the State restore the budget cuts so people can continue to live independently, because God forbid they should have to go back to larger institutions again. Also, hopefully when they complete the light rail they're working on it's accessible. And if the legislature builds new buildings they should build them to be accessible.

Q: When you think of younger people with disabilities today, are there any lessons you've learned in your life that you want to pass along to them?

A: I think we haven't done a good job of educating young people in school about what services are out there for them. Back when I was growing up, after age 18 or 22 they would send you to a group home or a sheltered workshop. Under state law now planning for everyone with a disability kicks in at 14. Sometimes that planning goes on without parents or self-advocates being involved. I'd like to see parents and self-advocates say, "Tell me what my options are" when they're a junior in high school; that would give them 18 months to find out what options they have and make plans.

I think we have come a long way, but we have a long way to go. I think we have to be patient sometimes because some of the stuff may take years to work through at the federal or the state level. It takes the legislature a long time to feel comfortable on how they spend money and why. If you build good solid relationships with legislators that will help move the process. What will happen with the budget shortfall will be another problem. It's going to cost less money in the long run to support people to live independently.

Cliff Poetz is Community Liaison at the Research and Training Center on Community Living, University of Minnesota. Vicki Gaylord is Managing Editor of Impact.

[Varnet, continued from page 11]

- Updated information about your and your child's medical history including a list of names, addresses, phone numbers, hospital ID numbers for all the doctors and other therapists who treat your child may also be helpful.

A letter of direction (also known as a letter of intent) also enables parents to memorialize their hopes, dreams and wishes for their child. This last section often provides guidance for the persons who assume the caregiving role or who are trustees of a special needs trust. An excellent resource with more information about letters of intent is the MetLife Center for Special Needs Planning at www.metlife.com/specialneeds.

It is also wise to leave written information regarding your financial assets, Social Security numbers, and other confidential matters in a place of safe keeping so that assets are not lost when you die. Often times, pension benefits, insurance policies, and other assets are not claimed because the parent did not inform their future executor or successor trustee of the existence of these assets.

Conclusion

Making sure their financial documents are in order and that their adult child is receiving all the benefits to which he or she is entitled, applying to the relevant social service agencies for life-time supports, working with agencies and family members to develop a plan for future care and supports, and memorializing the family's wishes in a current letter of direction will enable parents and persons with long-term disabilities to sleep better at night. A parent who has completed the above steps has the peace of mind of knowing they have done what they could for their son or daughter with a life-long disability.

Jennifer, by the way, moved into a shared living arrangement with a woman who is a teacher's aid in the public school. This woman enables Jen to live independently and for Jen, this is a terrific arrangement. My husband and I purchased a home in our neighborhood

where Jen and her housemate live. Jen receives a Section 8 voucher for rent and funding under a Title XIX Medicaid waiver program which provides the supports and services she needs to live independent of her parents. Oh, and yes, I do sleep a lot better these days.

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[Meyer, continued from page 13]

- Many of us live in fear: Fear of doing "right" for our siblings and by our parents who expect that we will follow their example and wishes despite our inability to do so. Fear about how further involvement with one's sibling will constrict one's own life and that of one's family. Fear of wondering whether our siblings will recover from the loss of a caring parent – and who will take over if we no longer can. For some siblings, the whole service system is daunting and they worry that they won't be able to navigate it to assure that their siblings get the services they need.
- They should know that we need as much support as parents. We need info and resources. We are usually coming into this without the years of experience about the system. Many sibs are taking on the responsibilities of supporting our sibs at the same time we are helping our aging parents and raising our own kids.
- I've always been Loren's second mom as I'm ten years older than he is. Our mother had serious mental and health issues so I tried to parent him and provide perspective and stability for him. I guess what service providers should know, or remember, is that many people with disabilities come from widely divergent situations and there are many complex backgrounds interwoven into the

mix. The person is not just definable by their disability; they are also defined by the environment they were lucky or unlucky enough to land into in the first place.

- In general, service providers should understand some sibling-guardians will be as involved as parents in caring for their siblings – but some may not because of commitments to their own families or professional lives. This isn't necessarily a bad thing for the siblings who have the disability because many times typical siblings will give them more responsibility and autonomy than parents will.
- Service providers should understand that having a sib with a disability is a life-altering event. They should know that although many of us are preoccupied with that consequence, we are still people who want to achieve, prosper and try to be happy. Even though we are not parents, we tend to be very responsible. But we need help from agencies who can provide high quality, trustworthy, uninterrupted services for our brothers and sisters.

Brothers and sisters will be in the lives of family members who have disabilities longer than anyone. Theirs is a relationship easily in excess of 65 years. They will likely be the primary advocates for siblings who have disabilities when their parents are no longer around. And as these responses eloquently attest, these brothers and sisters desperately need parents and service providers who understand their unique concerns – as well as information and support to help their sibs have dignified lives living and working in the community.

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[Marks, continued from page 25]

of proper equipment, poor fit of mobility devices, lack of training in use of equipment, poor communication of needs, and reluctance to accept the necessity for the devices. In the United States, the Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988, and 1994 amendments) provides financial assistance to the states to support programs of technology-related assistance for individuals with disabilities of all ages. These programs provide technical assistance, information, training, and public awareness activities relating to the provision of assistive technology and environmental intervention devices and services. They also promote initiatives to increase the availability of funding for, access to, and provision of such devices and services.

Providing Care

Now that people are living longer with a disability, health promotion and disease prevention increase in importance. Key components of health promotion include adequate health care, diet and nutrition, and physical activities. Although persons with developmental disabilities have a significant need for routine primary care screenings as they age, in general, for them surveillance and early detection of chronic health conditions are poor. Screening activities such as breast, pelvic, and prostate examinations; blood pressure and cholesterol checks; urinalysis; and bowel analysis can lead to enhanced functioning, prevention of conditions, and an increased quality of life.

Physical barriers often constitute a chronic problem for many persons with disabilities. Health care facilities often are not accessible to individuals who may have physical and sensory impairments. In addition, persons with disabilities often experience difficulties with examinations and procedures. For many people, the most important barrier to effective medical care is case complexity. They encounter a variety of medical subspecialists, dentists, mental health providers, and other health care professionals, often without sufficient guidance.

With the scant attention given to health promotion strategies for people with disabilities, a need exists for community organizations to provide health promotion services (e.g., health education and fitness activities) for persons with disabilities to address age-related and disability-related conditions and decrease the risk of acquiring new health conditions. For example, for people with cerebral palsy, exercise prescriptions need to consider the potential for muscle overuse resulting in pain, injury, and fatigue. Adults with Down syndrome are more prone to osteoporosis and are more likely than other people to require calcium and vitamin D supplements as they age. Although specific guidelines pertaining to the types of exercises, nutritional requirements, and use of medications for individualized care are limited, in the past decade health promotion programs developed for adults with developmental disabilities have demonstrated positive psychosocial and physical health outcomes (Heller, Hsieh, & Rimmer, 2004; Rimmer, Heller, Wang, & Valerio, 2004).

The coordination of care between persons with disabilities, various health care providers, and families is critical for provision of health-related activities. Many primary care providers have received little education in disability or geriatrics, and they often lack training in dealing with multiple conditions, interacting medicines, and unique aspects of various disabilities. Increasing the understanding of ways that exercise and nutrition influence health, and of ways to promote more positive lifestyle behaviors among individuals with developmental disabilities and their supports is critical to improving health status and participation in community life.

Conclusion

The aging and disability service systems will need to build greater capacity to provide services to a growing number of persons with lifelong disabilities who are aging, and to other older individuals with disabilities who will increasingly

need more services and supports to maintain their health and independence. Communities will need to make adaptations for this population by designing environments that accommodate elders of diverse abilities and functional limits. This includes developing more accessible transportation, recreational facilities, and businesses. In addition, there is a need for better and more training of health care professionals on age-related changes in people with disabilities. Finally, family caregivers, who provide the greatest amount of care physically, emotionally, psychologically, and financially, will need supportive services.

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Caregiving Suggestions

There are a number of things caregivers can do to support quality of life, as well as safety and well-being of individuals with intellectual or developmental disabilities who have Alzheimer's disease. Among them are the following:

- Caregivers can support adults with intellectual and developmental disabilities who have Alzheimer's disease by helping the person to feel safe and secure, emphasizing maintaining abilities rather than teaching new skills, and simplifying routines and reducing choices.

As people with intellectual and developmental disabilities continue to age more successfully and live longer, the numbers with Alzheimer's disease and other dementias will increase.

- Early in the disease process, make minimal changes to the home or work environment or schedule, maintain the routine and familiar, and continue regular activities with structure and added supervision. Respond to confusion and repeated questions with patience. Because of changes to the brain, he may not recognize familiar places or caregivers and will not know he has asked when lunch is multiple times. Simplify directions and offer several clues so that the individual knows exactly what you mean.
- As the disease progresses, it is important for caregivers to anticipate the individual's physical and emotional needs. To prevent bathroom accidents, use a scheduled toileting time. Continue to offer nutritious food and

adequate fluids; she may not ask for either. Respond to the feelings behind the confusion. If she insists it is time to go home in the middle of the day, spend some time talking with her, look at familiar photographs or just sit together with a glass of juice. Create a calm environment, allow for rest, and simplify tasks.

- Modify work and home environments as the disease progresses. Attend to his physical needs and support with gentle comfort. Allow the person to "age in place" as he is no longer able to be active and needs longer rest times. Consider palliative/comfort care and hospice care to support his physical needs.

Conclusion

As people with intellectual and developmental disabilities continue to age more successfully and live longer, the numbers with Alzheimer's disease and other dementias will increase. To promote quality of life it is important that caregivers understand the early warning signs of dementia. Being aware of changes individuals experience will allow individuals and their caregivers to seek an evaluation by a medical professional to diagnose dementia or treat another medical condition. Having a diagnosis and understanding the progress of dementia will allow caregivers to adjust supports and services to meet the new and changing needs of the individual.

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Resources Promoting Healthy Living for Adults with Disabilities

• **Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program.**

By Beth Marks, Jasmina Sisirak, & Tamar Heller, RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago. Adults with developmental disabilities are at significant risk for health problems. Effective health promotion can improve outcomes. This book shows administrators and service providers within adult day and residential agencies, schools, and other organizations how to increase supports for health education, exercise and nutrition by implementing their own successful program. Available May 2010 from Brookes Publishing (see www.brookespublishing.com).

• **Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities.**

By Beth Marks, Jasmina Sisirak & Tamar Heller, RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago. This research-based, field-tested curriculum shows professionals how to help adults with disabilities live healthy lifestyles and make the best choices about health, exercise, and nutrition. Available March 2010 from Brookes Publishing (see www.brookespublishing.com).

- **Let's Talk About Health Series.** *The Arc of New Jersey has published three booklets in this series written for individuals with intellectual and developmental disabilities, and their caregivers, about health screenings and prevention for three types of cancer: breast cancer, colon cancer, and prostate cancer. The booklets are available online at www.arcnj.org/information/issues.html; scroll down to "Let's Talk About Health."*

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