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TO SELF-DETERMINATION

APRIL 2013

Research to Practice in
Self-Determination

Issue 5:
Self-Determination
and Aging

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The Life Stories of Older
Self Advocates

Using Social Media to
Support Families

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Health Care

Personal Thoughts on
Growing Older

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Research to Practice in Self-Determination Series

Introduction

People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives.

The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. Each issue is prepared with a social-ecological framework in mind. This framework calls for strategies for intervention and support to take into account both the capacities of the person and the demands of the environment. Interventions to promote self-determination should focus on enhancing personal capacity, improving opportunity, and modifying the environment. A series of seven issues will be produced, each focusing on a specific topic: self-advocacy, health, employment, community services, aging, family support, and siblings. The format for these issues will include definitions, a brief review of the literature, promising practices, applied examples, and targeted recommendations for



Arthur Campbell is an Advocate Advisor to the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function. Arthur received the 2012 Ed Roberts Lifetime Advocacy Award from the Center for Accessible Living in Louisville, KY.

scaling-up efforts. This series is intended for use by people with developmental disabilities, family members, professionals, state and federal agencies, and academic programs. By collaborating with and enabling each of these entities, the goal of full inclusion for people with developmental disabilities can be realized.



NATIONAL GATEWAY

TO SELF-DETERMINATION

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Editors

Tamar Heller, PhD
Alan R. Factor, PhD

Layout

Crystal Pariseau

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The National Gateway to Self-Determination Leadership Consortium Includes:

Carl F. Calkins, PhD, Co-PI; Institute for Human Development, University of Missouri-Kansas City
Michael Wehmeyer, PhD, Co-PI; Lifespan Institute, University of Kansas
Ansley Bacon, PhD; Westchester Institute for Human Development, New York Medical College
Tamar Heller, PhD; Institute on Disability and Human Development, University of Illinois, Chicago
Hill Walker, PhD; Center on Human Development, University of Oregon



Self-Determination and Aging

Tamar Heller, PhD

While this Research to Practice Guide focuses on aging and self-determination for adults with developmental disabilities and their families, a life course approach to self-determination recognizes that self-determination is important throughout one's life. The process begins early in life and is characterized by different issues at different life periods. Much of the difference results from changes in age-related abilities and in societal and cultural expectations at different ages. Throughout life the expression of self-determination is shaped not only by one's abilities and motivations, but also by supports and opportunities provided in one's environments. Families, friends, and staff in home, work, and other community environments play a role in setting expectations, providing support, and enabling opportunities. In addition, public policies and practices can contribute to supporting self-determined lives for people with developmental disabilities (Heller et al., 2011). The Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, funded by the National Institute on Disability and

Rehabilitation Research, incorporated these factors into the *Support-Outcomes Model of Aging Well*. This model builds on the gerontological concept of successful aging (Baltes & Baltes, 1990) and the American Association on Intellectual and Developmental Disabilities' most recent definitions of intellectual disability (AAIDD, 2010). The key outcomes of aging well for people with developmental disabilities are maintaining maximum health and function and remaining actively engaged with life. Their capacity to age well is shaped by the supports and opportunities for self-determination provided by their environments over the life course.

A growing number of adults with developmental disabilities are living to older age. There are an estimated 850,600 people with developmental disabilities age 60 and older living in the community (Larson, S.A., Lakin, K.C., Anderson, L. Nohoon, K., Lee, J.H., & Anderson, D., 2001; US Census, 2010). Due to their increasing life expectancy their numbers will likely increase to 1.4 million by 2030 (US Census, 2008). Several studies have shown dramatic increases in age of death

for people with intellectual disabilities from an average age of death at age 33 in the 1930s to 66 in 1993 (Janicki et al., 1999) and for those with mild to moderate intellectual disability that age is in the 70s (Bittles et al., 2002).

With age there can be greater opportunities for personal growth, skill development, and life experience.

An important element of aging well is living a self-determined life. However, many people with developmental disabilities have few opportunities for self-determination throughout their lives. In addition they often face further discrimination as a function of "ageism." The majority of these adults have lived either with parents throughout their lives or in residential settings that tend to have restrictive policies that can undermine personal autonomy.

However, with age there can also be greater opportunities for personal growth, skill development, and life experience. In this research to practice issue, we provide examples of issues faced by adults with developmental disabilities as they age and of ways to promote their self-determination. Hence we address the issues through examples of training and skill development, peer mentoring, provision of environmental supports, and changes in public policies. First, it is important to understand the beliefs, values, and motivations of these adults as they age. One example is the extensive in-home surveys conducted in Indiana as reported by Stafford. This led to development of the Hoosier TYZE Project which uses social media



Daphne Ron, sister of Tamar Heller, smiles in front of her PATH plan, created during a teaching demonstration for students.



to support families and adults with developmental disabilities. Life stories are another way to better understand the experiences, self-identity and desires of individuals. Caldwell provides insight into the experiences that shaped the development of leaders in the self-advocacy movement for people with developmental disabilities. He also points to the important role that older advocates can and want to play in mentoring younger advocates. Van Heumen's interview provides a view of what growing older means to one woman and how she finds happiness in her daily life.

A key issue with aging is the development of age-related chronic health conditions and illnesses. Often people with developmental disabilities have difficulty accessing adequate health care due to lack of knowledge of health professionals and their own capacity to communicate their health needs. *My Health Passport* is one tool that is useful in helping adults with developmental disabilities advocate for improved communication and better health care access, as noted by Perkins' article.

Person-centered planning by individuals with developmental disabilities and their families is an important tool in providing opportunities for individual choice-making and planning that fit with their wishes and preferences. Within the family context siblings are playing an increasingly important role as older parents are less able to provide supports. Redman provides an example of an application of the evidence-based *The Future is Now* (Factor, DeBrine, Caldwell, Arnold, Kramer, Nelis, & Heller, 2010) and its use in a sibling support project in Wisconsin.

One transition that is important as one ages is retirement. Many adults with developmental disabilities have little knowledge of the concept of retirement or of options in the community. Recognizing that choice and control are key dimensions of successful retirement, Standcliffe and his colleagues in Australia developed the *Transition to Retirement* model that supports persons aging with developmental disabilities to transition to volunteer work with community groups through active mentoring.

Furthermore, person-centered approaches provide a dignified, self-

determined approach in planning for end of life supports as noted by Kingsbury. These person-centered strategies provide a way to recognize the heterogeneity of adults as they age and to counter negative attitudes toward these older adults.

With transformations in health and long-term supports, including the move to managed care, adults with developmental disabilities, their families, and their providers need to make sure that their voices are heard. Cooper and Brent provide tips for advocates in this rapidly changing service environment.

Throughout this publication we provide examples highlighting the importance of hearing the voices of adults aging with developmental disabilities and providing them adequate supports and opportunities for them to age well and to live self-determined lives.

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Tamar Heller, PhD, Professor, is Head of the Department of Disability and Human Development, University of Illinois at Chicago (UIC) and director of the UCEDD for the State of Illinois. She also directs the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function.

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The key outcomes of aging well for people with developmental disabilities are maintaining maximum health and function and remaining actively engaged with life. Their capacity to age well is shaped by the supports and opportunities for self-determination provided by their environments over the life course.



Hoosier TYZE Project: Using Social Media to Support Families

Philip B. Stafford

Across the U.S., adults with developmental disabilities are benefiting from the “longevity revolution,” living longer than ever before (Fujiura, G. (1998). In Indiana, it is estimated that there are more than 15,250 adults with intellectual and developmental disabilities living with parents or siblings over the age of 60 (Braddock & Hemp 2008). In that same study, the researchers estimated that there are nearly 14,000 individuals with disabilities on waitlists for Medicaid waiver services.

This scenario has changed the landscape of services that have been developed to support individuals and families as well. Because of the changing demographics and increasing pressures on the service system, the Indiana Division of Disability and Rehabilitative Services contracted with the Indiana Institute on Disability and Community in 2008 to conduct an in-depth study of the everyday life, the strengths, and the support needs of families in which one of the members is an adult with a developmental disability (Stafford, Pappas, Hyten-LaFontaine 2009; Stafford 2009, 2010). Rather than approaching the issue with a broad



Phil Stafford collaborates with Muncie, Indiana author Jody Powers at an ArtsWORK Indiana strategic planning session.

survey, it was felt that a qualitative study, seeking depth before breadth, would be most appropriate. Developing a deeper understanding of the individual experiences of families would, it was felt, help identify key issues that, later, could be explored to answer questions of scale and scope. A series of 21 in-depth, in-home interviews with a diverse group of family caregivers from across Indiana and focus groups with service providers and self-advocates provided rich data across multiple perspectives. A grounded analysis of interviews revealed some key themes relevant to this article:

1. Attention needs to be given to the **support of future planning**, particularly within the context of Person-Centered Planning processes.
2. As with other studies of families with children with developmental disabilities, many of the families in the study were **not aware of resources or even possibilities** for support. For others, there was simply too much information, and

multiple and confusing sources. For most families, attention needs to be given to providing just-in-time information—the right kind of information, the right amount of information, at the appropriate time.

3. Currently, many families, especially those in rural areas, have limited access to training opportunities. Families are often unclear about where to receive help, and unsure about where and how to seek support as they become less able to care for their adult child. Development of a family support system should **support education and training for both family caregivers and consumers** to help them prepare for healthy, self-directed futures (Heller T, & Factor, A 1991).

The Climate for Expanding Formal Family Supports

Many Indiana families are desperate for an expansion of the formal system of supports, especially Medicaid waivers

A new system of family supports benefiting adults with IDD should enable families and communities to tap their “indigenous” strengths that complement, supplement, and bridge informal and formal systems of care.

The Wheel of Family Functioning



and residential supports for community living. However, this desire meets the hard reality of declining and, in the best case, flat funding. Here, Indiana is not alone and may even be faring better than other hard-hit states. Clearly, a new “social capital” paradigm that enables families to better tap existing and new community resources is needed.

If it is unlikely that a major expansion of formal family supports is possible, clearly we need to assess the role that government can play in sustaining, and even expanding, the role of informal supports in caregiving families. Our recent research reflected wide variation in families’ access to information and informal social supports in their communities. In some families, primary caregivers made wide and effective use of supports; in others, primary caregivers were relatively isolated from other informal supports. In some families, the primary caregiver was a savvy consumer of formal services; in others, the primary caregiver was significantly “in the dark.” Interviewers commented on the significant level of isolation and stress experienced by family caregivers, and how greatly their situations are affected by their ability or inability to develop

informal supports across the spectrum from family to friends to community. A conceptual model we labeled the “wheel of family functioning” visualizes the contributions of a number of factors that, beyond simple formal care systems, define effective functioning of family systems.

What is important to acknowledge is that many factors contribute to successful family functioning, but these can also change over time, even day to day. An “annual” plan may not adequately reflect the day to day vicissitudes of family support.

A New Approach To Intervention

Several observations and assumptions provide the logic for a proposed intervention.

- The increased longevity of adults with developmental disabilities is putting new strains on the formal system of supports nationwide.
- State governments, the primary formal provider of support for adults with developmental disabilities, cannot alone meet the increasing demand for services.

- Family and community are the primary pillars of care and support, even for emancipated adults with developmental disabilities (Griffiths, D. L., & Unger, D. G. (1994), Heller, T. (2000), Heller, T., & Caldwell, J. (2006).
- The formal provider system is not aligned with the total ecology of family and community systems of support.

Therefore:

- A new system of family supports benefiting adults with developmental disabilities should enable families and communities to tap their “indigenous” strengths—to provide appropriate and equitable access to formal services, while making best use of internal and external informal systems of support.
- A new system of family supports should complement, supplement, and bridge informal and formal systems of care.

This new system will be demonstrated through the development and support of family and community networks of care organized around a proven web-based social media platform created by the PLAN Institute in Vancouver, British Columbia and known as “TYZE.” TYZE evolved from PLAN’s 25 years of experience in developing personal networks of natural community supports for people with disabilities and reduce their reliance on formal services. The Indiana project is called ‘Hoosier TYZE.’

Project Objectives

As an innovative and expandable family support program based on a social media platform, Hoosier TYZE addresses the following two objectives:

For most families, attention needs to be given to providing just-in-time information—the right kind of information, the right amount of information, at the appropriate time.

1. Through developing and participating in facilitated, web-based networks of information and support, families caring for adults with disabilities will increase their capacity to tap and bridge formal and informal systems of assistance and better plan for the future welfare of all family members.
2. Through the research associated with the Hoosier TYZE project, state program and policy makers and public and private funders will understand the differential capabilities of community-based organizations, including non-disability organizations, to serve as local, sustainable network sponsors.

The Indiana project, Hoosier TYZE, was initiated in August of 2012, so reports on outcomes are premature. For the pilot project, 18 “site administrators,” typically adult and older adult caregivers, will be selected and followed for a period of 10 months as they build their web-based circle of support around themselves and an adult child or other relative with a developmental disability. Site administrators receive technical assistance from community builders (“networkers”) being trained by the TYZE Canadian professionals. Networks will grow beyond their virtual reality and connect with face to face relationships within the neighborhood and informal and professional community. The user-friendly, private nature of the social media platform provides a vehicle for multiple tasks: arranging respite, transportation and other forms of instrumental assistance; sharing individual and network stories; accessing information sources; circulating written records (with secure and private storage); giving and receiving emotional support.

A research to practice agenda associated with the pilot will assess the growth of technology-assisted helping networks and the potential relevance for state agencies to extend supports to un- or underserved families in a significant but extremely cost-effective manner.

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The hard reality of declining or level funding warrants a new “social capital” paradigm that enables families to better tap existing and new community resources.

Phil Stafford, PhD, is the Director of the Center on Aging and Community at the Indiana Institute on Disability and Community, Indiana University's Center of Excellence in Developmental Disabilities. A cultural anthropologist, Stafford oversees Center projects on livable communities, oral history, leadership for self-advocacy and careers in the arts for people with disabilities.

Additional resources on aging and self-determination of adults with developmental disabilities

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function (RRTCADD)



The RRTCADD seeks to enhance the health, function, and full community participation of adults with

intellectual and developmental disabilities (I/DD) across the lifespan and bolster family caregiving capacity through a coordinated set of research, training in evidence-based practice, and dissemination activities. RRTC activities promote a society that involves people with I/DD within the fabric of their community, enables them to access the supports and resources they require throughout their lifespan, and helps them attain a socially relevant, personally meaningful, and healthy life. www.rrtcadd.org

The National Gateway to Self-Determination



The National Gateway to Self-Determination is a consortium of University Centers for Excellence in Developmental Disabilities in partnership with a national self-determination alliance. Its website has a variety of publications on self-determination across the lifespan, including aging. www.ngsd.org

Learning from the Life Stories of Older Self-Advocates

Joe Caldwell

Life story research has a long tradition in the field of intellectual and developmental disabilities. In recent years there has been resurgence of life story research. The field of disability studies has opened doors to new knowledge and insights from self-advocates (Goodley, 2000). Advances in technology (such as smartphones, social media, and self-publishing) have also made it easier than ever before for individuals to share their stories in creative ways.

With support from a Switzer Research Fellowship from the National Institute for Rehabilitation Research (NIDRR), I had the opportunity to work on a life story project with thirteen leaders in the self-advocacy movement. While I knew some of the individuals I interviewed well, what amazed me was what I didn't know about them—the central stories of their lives that formed the basis of their identities, leadership development, passions, and beliefs. Even more impressive was their strong desire to share these stories, particularly with younger generations.



Tia Nelis is a Self-Advocacy Specialist at the Illinois UCEDD.

History of the Self-Advocacy Movement

The history of the self-advocacy movement remains one of the great untold stories in our field. Only a handful of works have explored its rich history, culture, and meaning. Perhaps the most significant, *New Voices: Self-Advocacy by People with Disabilities* (Dybwad & Bersani, 1996) was published shortly after formation of the national self-advocacy organization, Self-Advocates Becoming Empowered (SABE). It traced the history of the movement up to that historical marker. However, there remains much more to uncover and chronicle as the movement has evolved in subsequent decades.

Through the life stories of self-advocates in our project, we documented additional history of the movement. We learned details about the early days of forming state organizations in a number of states. For example, Nancy Ward retold the memorable story of delivering newspapers so she could hitch rides across Nebraska to get to the chapters. As she said, “Now that is what I call being resourceful!” We learned about the importance of key conferences and the historical significance of figures like Justin Dart to the movement. From the voices of self-advocates, we learned more about the role of the key advisors, mentors, and leaders who helped spread the movement. We also learned about the ongoing struggles the movement has faced for funding and control of funding.

As a whole, the collection of stories also documents progress. The collection spanned a time period of more than six decades. The oldest leader, Marvin Moss, was born in 1946, a time well before any organized self-advocacy movement. At that time, institutions were the only option for many families and there was no right to public education. His role model was

his mother, Dorothy Moss, one of the original founders of The Arc of the United States. In contrast, Max Barrows, the youngest leader in the collection, was born in 1986. He experienced full inclusion in school. At the time of the interview, he had never seen a sheltered workshop, never seen an institution, and aspired to

The enthusiasm expressed by older self-advocates to work with the younger generation reflected a core value of the self-advocacy movement: interdependence.

be a national leader in the self-advocacy movement like his many role models. Yet, while differences in environmental barriers and challenges could be seen across the decades, similarities in the root elements of oppression surfaced.

All the leaders interviewed wanted their stories to be archived and made available publicly, particularly for younger self-advocates. We worked with the Bancroft Library at the University of California at Berkeley to add the complete interview transcripts to its archive of the history of the disability rights movement. In addition, in order to make the information more accessible to individuals with limited reading abilities, we posted short video excerpts from the interviews on YouTube. These archives can be accessed at: <http://bancroft.berkeley.edu/collections/driilm/index.html>.

Intergenerational Leadership Development

In addition to preserving history, the life stories allowed us to explore factors that contribute to leadership development of self-advocates (Caldwell, 2010). We identified a framework with four major areas: 1) disability oppression and resistance; 2) environmental supports and relationships; 3) leadership skills; and 4) advance leadership opportunities. Involvement in the self-advocacy movement played critical roles. It provided self-advocates with community and connection with peers. This allowed for personal and collective resistance to oppression and formation of a positive disability identity (Caldwell, 2010). The movement provided trusted environments and supports to practice leadership. Family supports, key advisors and mentors, and community-based services also played key environmental roles. Volunteer opportunities, leadership positions within the movement, service on boards and committees, leadership workshops and trainings, and mentoring were among factors that contributed to building leadership skills.

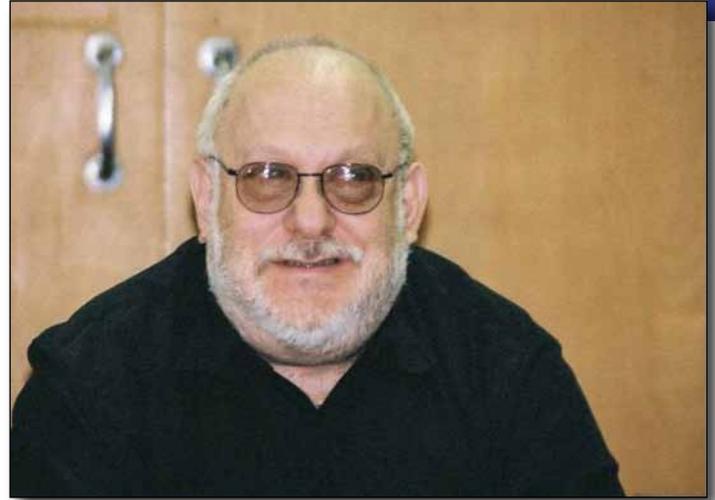
One area of difficulty expressed by many leaders was lack of advanced, paid leadership opportunities. The older leaders interviewed were among some of the early founders of local, state, and national levels of the movement. Some were also pioneers in being among the first hired by disability organizations, such as chapters of The Arc, Protection and Advocacy Associations, and University Centers for Excellence in Developmental Disabilities. Another leader was one of the first self-advocates to assume an executive director position of a self-advocacy organization. They frequently described these positions as their “dream jobs.” However, these positions were few and far between and

Leadership development of the younger generation was not viewed as a one-way street. Connections with youth brought great joy and sense of purpose.

often very tenuous. In addition, leaders expressed needs for peer-led advanced leadership trainings to assist with transitioning from positions within the movement to other advanced leadership opportunities and paid positions.

Finally, many of the older leaders expressed both concern and excitement about future leadership of the movement. Some expressed worry that many of today’s youth don’t have connections with peers with disabilities or exposure to the movement. They expressed needs for youth to learn about disability history—such as the history of eugenics, institutionalization, and the disability rights movement. While many of the older leaders were actively involved in outreach to youth and mentoring, they expressed great desire and enthusiasm to do even more. Needs for additional outreach, mentoring, and youth leadership development were also strongly heard across states and territories that participated in the regional self-advocacy summits convened by the Administration on Intellectual and Developmental Disabilities (Caldwell, Arnold, & Rizzolo, 2012).

Important themes emerged from the life story project, which can help guide future interventions and efforts to support intergenerational leadership. The enthusiasm expressed by older self-advocates to work with the younger generation reflected a core value of the self-advocacy movement: interdependence. For example, older leaders shared stories of consciously giving up positions to provide others with opportunities to grow and lead. Leadership development of the younger generation was not viewed as a one-way street. There was an equally strong desire among the older generation to learn from younger self-advocates. Many expressed that the younger generation grew up with opportunities and expectations which they never had. They expressed



Marvin Moss is an advocate advisor to the RRTCADD. He has conducted training using RRTCADD curricula teaching people with disabilities how they can play leadership roles and make contributions to community and professional organizations.

great “awe” and optimism from their interactions with the younger generation. Connections with youth brought great joy and sense of purpose: older self-advocates had paved the way. However, there was great hesitancy to speak for the younger generation. There was desire to pass on history and lessons they had learned to younger self-advocates. Yet, there was acknowledgement that the movement “will soon be theirs,” and that younger generation needs the space to pave their own path forward. This intergenerational philosophy embraced by self-advocate leaders is empowering. Indeed, it lies at the very heart and meaning of self-advocacy.

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Joe Caldwell, PhD, received his doctorate at the Illinois UCEDD and is Director of Long-Term Services and Supports Policy at the National Council on Aging.

What Does Growing Older Mean?

Lieke van Heumen

Growing old means that you are settled and know what you are doing. I am more kinder, I get along a lot better. I have friends I am happy with and that I do things with.

Sharon Lambert is a friendly older woman who works at the Country Inn restaurant at Lambs Farm in Libertyville, Illinois. Lambs Farm is where I met with Sharon on a Friday afternoon at the restaurant after lunch. Sharon will turn 65 in a couple of weeks, and has firsthand experience of what it means to grow older with an intellectual disability. She lives with her sister and for her upcoming birthday they are planning to go out for dinner.

Asking Sharon how she feels about turning 65, she says: "I don't feel older. I won't retire for a while, I don't think so." Sharon tells me about her work at the restaurant. There she sets and cleans up the tables. She serves the bread and

brings water to the guests. She also gets the guests a box for their leftovers if they want one. Sharon seems to enjoy her work and is also very active socially: "I like to do a lot of activities. We do bowling. There is a whole bunch of us. We go exercise and use the machines. I have a lot of friends in the restaurant. We play games, we play ball. We do that for fun."

When I ask Sharon what growing older means to her, she tells me that she feels more mature and that when you are older "you are settled and know what you are doing." She feels different now that her age is different: "I am more kinder, I get along a lot better. I have friends. Friends I am happy with and that I do things with." Sharon explains to me how her life changed after her parents passed away: "I didn't have many friends when I was growing up. I was a home person. I didn't go out very much. I am happy now; I get to go out more. What I want to do, I can."

Sharon tells me enthusiastically about her upcoming trip to Tennessee with a group of women. She will be staying in a nice hotel and is planning to do lots of sightseeing. This summer she went camping in Wisconsin and had quite an adventure there: "We played games, we went swimming, and we were cooking. We had three tents. There was a big storm. A

bad storm. We got our shoes and ran to the van. We went to a hotel in our pajamas. It was very scary. The next day we went back and one tent was destroyed. We stayed in a hotel until Friday. I had a good time."

When asking Sharon what she wishes for the future, she says: "I wish that I keep going happy and that I don't feel old and that I am not in a wheelchair. My dad walked with a cane and so did my mother." She says the changes in her life are the hardest aspect about growing older. She tells me it was difficult when a personal support worker she was very close to

For the future I wish that I keep going happy and that I don't feel old and that I am not in a wheelchair.

stopped working for her and her sister.

When her sister is travelling, Sharon stays in a group home in Wisconsin so that she is not home alone. She tells me: "I was scared at first there, but then I met nice people. The church is very nice. We have church on Wednesdays and Fridays." Sharon tells me that she will stay with her sister as long as her sister's health is holding up but that she could not live by herself: "I can't be by myself. I know my disability because I can't read or write. Certain things I can do, certain things I can't do. I would have to go in a home. I don't mind as long as it is a nice home. My sister wants me to be in a place where I am happy, where I can do things."

As we conclude our talk I ask Sharon what advice she would give me, being a person almost 40 years younger than her. Her answer: "Be happy." She assures me: "Be with your friends."

Lieke van Heumen, MSc is a doctoral candidate in the Disability Studies Program at the University of Illinois at Chicago. Her background is in gerontology and her research interests focus on the intersection of aging and disability, and intellectual disability in particular.



Sharon's advice on growing older: "Be happy. Be with your friends."



My Health Passport: A Journey to Better Healthcare

Elizabeth Perkins

In an ideal world, everyone would enjoy the gift of perfect health. The reality is people do get sick and are unhealthy for a variety of reasons. People with disabilities, especially those with intellectual and developmental disabilities (IDD), all too often experience poorer health compared to those without disabilities. People with IDD are more likely to live with complex health conditions associated with their disability, and they often have poorly managed chronic conditions (e.g. epilepsy). Further complicating matters, they often experience limited access to quality healthcare and health prevention/promotion programs (CDC, 2009). Another major factor to consider is the role of aging. As people age there are unavoidable physical changes that occur (Saxon, Etten, & Perkins, 2010). Increasing age itself becomes a risk factor in the development of serious health conditions such as heart disease, arthritis, osteoporosis, and cancer. Furthermore, individuals with specific types of IDD can also have a greater risk than the general population for developing certain diseases. Not surprisingly, as people with IDD age, their health must be more closely monitored to detect changes in function and mobility and the onset of age-related health issues along with the continued management of lifelong chronic health

People with IDD often have difficulty accessing quality healthcare because many professionals do not receive any instruction regarding their unique needs.

concerns. As a result, older adults with IDD will likely be frequent visitors to many types of healthcare settings.

People with IDD often have difficulty accessing quality healthcare because many healthcare professionals do not receive any instruction or education whatsoever regarding their unique healthcare needs. Physicians admit to feeling ill-prepared and lacking resources and specific knowledge about people with disabilities (Morrison, George, & Mosqueda, 2008). People with disabilities may experience unsatisfactory care during hospital visits due to communication limitations and nurses' negative attitudes (Smeltzer, Avery, & Haynor, 2012).

While there are many dedicated healthcare workers who provide high quality care to people with IDD, health care research and clinical training have traditionally focused on children and adolescents with IDD. The increasing life expectancy of people with IDD has created a growing need for more healthcare professionals who focus on adults and older adults and have better knowledge of lifespan health concerns (Perkins & Moran, 2010). To meet this need, there are increasing numbers of training initiatives educating both future and current health professionals. The University of South Florida (USF) Morsani College of Medicine in collaboration with the USF-Florida Center on Inclusive Communities (FCIC) is a notable example for having a mandatory module in adult health and disabilities that all their medical students must successfully complete. Medical students have reported significant benefits including increased knowledge, improved comfort in providing care, and better attitudes (Woodard et al., 2012). Another notable project is the Physician Education in Developmental Disabilities project by American Academy on Developmental Medicine and Dentistry (in collaboration with FCIC) and funded by the Florida Developmental Disabilities Council. It is

currently offering family physicians free continuing education on developmental disabilities in a 12-part webinar series that is available nationwide for the next two years. More education and training experiences, however brief, are obviously desirable. Realistically though, unless mandates that insist upon coverage of disability-related health in general medical and nursing curricula nationwide are forthcoming in the near future, a sizeable proportion of healthcare professionals will never receive formal training about people with IDD. So what can we do to remedy health professionals' lack of knowledge and experience in treating adults with IDD?

This is where a self-determined approach can be extremely effective. The individual with IDD can truly become the person that trains the healthcare provider by sharing crucial knowledge about their health and support needs. Self-determination is accomplished by the development of self-advocacy skills. Important self-advocacy skills include leadership (guiding the actions of others), assertiveness, having knowledge of one's rights and responsibilities, and good communication (Wehmeyer et al., 2007). By being assertive, by providing helpful information and communicating their unique support needs, an individual can indeed help guide the actions of their healthcare professional to mutual benefit. Sometimes, a simple but effective tool can assist in this process. FCIC's *My Health Passport* (Perkins, 2011) is an example of such a tool that can help initiate a self-determined journey to demand better healthcare.

Introducing *My Health Passport*

The concept of a health passport to note useful health information is nothing new. They come in all shapes and sizes but rarely have they addressed the special supports that may be required to assist people with IDD. *My Health Passport* is a

four-page document, primarily designed to be read by healthcare professionals who work in hospitals and clinics. Think of it as a ‘cheat sheet’ of knowledge that would ordinarily take someone months or even years of insight and observation of the individual to acquire. Healthcare professionals often do not have the luxury of time to become fully acquainted with the individual, so anything that can speed up the ‘getting to know you’ process is always welcomed. It is very user-friendly for individuals with IDD (and their caregivers) to fill in the information while being visually appealing and concise for those who will read it. Furthermore, *My Health Passport* is equally relevant and appropriate for use by people with IDD whatever their age.

Inside *My Health Passport*

The four pages of *My Health Passport* can seem brief, but the knowledge shared can be quite substantial. The first page includes general contact information, space for a photograph (useful to see how the person looks when well and healthy), and a vital description about how the individual communicates (e.g. verbal/non-verbal, uses communication device etc.). The second page includes medical history, current medications and how they are best taken, and a list of those all-important allergies. It also describes how the individual might express if they are in pain (or if they have high/low pain threshold), or how they could be helped if they get upset or distressed (e.g. play favorite music). The third page describes how an individual copes with medical procedures, and can highlight if they have never had a particular procedure or whether it has been sometime since they have (e.g. has not had an x-ray for 10 years). The supports that may be required with respect to eating and drinking, mobility, and personal hygiene are also noted. The final page includes details about favorite foods and drinks, as well as those that are disliked. Any sensitivity to different sights, sounds, odors, textures etc., can also be documented. Examples of activities that the individual likes to do to help pass the time are noted, which is especially useful for those who might have a lengthy hospital stay. The last section describes how future appointments or follow-ups could be made easier (e.g. early morning

appointments, visiting a new clinic before the treatment, allowing extra time).

My Health Passport was designed to be an evolving document that can be easily modified and updated. Healthcare professionals can add other useful information and note experiences gleaned from the current visit (e.g. copes well with chest x-ray). Adults with IDD (and their caregivers) who complete *My Health Passport* to report and communicate their unique needs can take the lead in guiding professionals on the best way to provide assistance. Healthcare professionals are glad to receive this information because it reduces their uncertainty and discomfort and it enhances rapport with the patient. An added benefit is that each individual who uses *My Health Passport* will be an advocate for better care for others with disabilities! Their healthcare professional will have an increased awareness on how to better support future patients.

Since it was released in April 2011, *My Health Passport* has proved very popular nationwide. It has also proved to be very versatile. Some agencies are even using it for emergency disaster management preparation and as an orientation tool for respite workers or new staff.

Self-determination above all requires communication, and the importance of effective communication regarding health needs and supports is unquestionable. The ability to enjoy all that life has to offer is so much easier to achieve when we are in good health. Maintaining good health

with increasing age can be a challenge, but challenging interactions with healthcare professionals is an unnecessary barrier that *My Health Passport* can help remove!

My Health Passport can be downloaded from the following web addresses (case-sensitive):

English version:
<http://bit.ly/VJ3rtG>

Spanish version:
<http://bit.ly/15eV6ko>

Elizabeth Perkins, PhD, RNMH, is Research Assistant Professor and Health Coordinator at the Florida Center for Inclusive Communities UCEDD, University of South Florida. Her work focuses on training future and current health professionals and research on later life health issues of adults with IDD and their family caregivers.

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Using “The Future is Now” in the Fox Valley Sibling Support Group

Harriet Redman

Whether voiced or held quietly inside, children, and adults who have siblings with special needs have many concerns that often take a back seat to the immediate necessities of caring for their siblings. That’s why, with the help of a small group of school psychologists and teachers, I established the Fox Valley Sibling Support Network (FVSSN) in Wisconsin in 1998. From the beginning, its mission has been to create the opportunity for individuals who have brothers and sisters with special need to understand, accept and thrive in their unique family and community throughout their sibling journey.

For the first couple years, FVSSN offered the award-winning Sibshop program created by Don Meyer, director of the Sibling Support Project. Very quickly, the organization expanded to also offer sibling summer programs and teen activities. Once the organization was financially able to hire a part-time Executive Director, it focused on expanding to adult siblings by gathering information through focus groups of adult siblings; focus groups of care providers and other professionals; visiting other siblings

groups offering adult sibling conferences in Ohio, Illinois, and New York; and evaluating available research data.

Clearly, adults were looking for help in connecting with area resources to help support a quality life for their vulnerable siblings. While they recognized that their parents would soon be unable to care for their siblings, or perhaps already were gone or unable to provide care, they felt very unprepared and lost. Most had not participated in learning how the social service and funding systems worked that were needed for their sibling’s support, or their parents’—for many, many reasons. Parents often didn’t allow them to participate in the process, saying something like, “Oh, we’ve taken care of everything. You don’t need to worry.” But worry is exactly what most adult siblings were doing because they had little or no information, parents weren’t talking about it, and most siblings didn’t know anyone else dealing with the same circumstances. Even worse in many cases, those plans that parents rarely mentioned didn’t really exist.

Besides the worry about the future, siblings did not want to become their siblings’ parents. They told us they wanted to be brothers or sisters, not parents. They enjoyed their sibling relationship and feared that when it was necessary to take responsibility for care, they’d lose that special sibling bond. The fun and playfulness they shared as siblings would give way to managing their lives as perhaps

they had seen their parents do for so many years. For many, the opportunity to voice all this out loud for the first time to someone listening was an emotional recognition of their deepest fears.

With lots of information, in 2003-2004 the FVSSN formed a committee of professionals and siblings to design an adult sibling program model. It would begin with hosting annual Wisconsin Adult Sibling Conferences to help

Besides the worry about the future, siblings did not want to become their sibling’s parents.



Three brothers work together on future planning in a FVSSN *The Future is Now* workshop as another participant looks on.

siblings network and find information. While sibling focus groups indicated that conferences were NOT their most desirable method of getting information, conference events would be necessary to start building a database of participants. Throughout the year, shorter, local mini-sessions that were more preferred by siblings would continue to offer networking and information sharing. A mini-session would include social time, a 30-45 minute conversation/presentation with a professional, followed by a meal and discussion. Topics included: Housing Options, Loss and Grief, Employment and Leisure, Special Needs Trusts, and many others.

To encourage healthy sibling relationships, reduce isolation, and make memories for siblings, the model included fun social events several times a year to appeal to the general public and was designed so that siblings (both with and without disabilities) would be comfortable in the setting and would have complete access to the activities rather

Most adult siblings had not participated in learning how the social service and funding systems that provide support for their sibling with a disability worked and were clearly looking for help.

than being observers. Many siblings were already participating in Special Olympics as coaches and spectators and other organizations that were doing a good job of providing those events. FVSSN social events have included:

- Miniature golf outings at public, accessible courses.
- Potlucks and gift exchanges that were very simple and very fun.
- A Holiday Social, which was held in a restaurant followed either by local artists helping the group make Christmas ornaments or a limousine bus ride to see local holiday lights displays
- Casino Night, which was open to the public and featured well trained, fun-loving volunteer dealers prepared to

teach ANYONE how to play the games, a quieter Bingo area for a fun and more serene retreat, dancing, a cash cube, raffle and a cake walk.

- Sibs Night Out, which included such activities as cosmetic experts who engaged sisters (and even brothers) in fun with make-up and with learning skin care tips or bakers who involved siblings in baking and decorating cookies.

However, the most intense and comprehensive program offered by the FVSSN for adult siblings is *The Future Is Now* training, originally created by the University of Illinois at Chicago for parents of adults with disabilities (Factor, DeBrine, Caldwell, J., Kramer, Nelis, & Heller, 2010; Heller & Caldwell, 2006). The goals of *The Future is Now* training are to equip families and their adult relative with a disability with the communication skills and information to jointly plan for the future. Participants learn how to overcome the emotional and systematic barriers to planning with the support of peer mentors who have made plans. They prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality.

Research conducted by Heller and Caldwell (2006) found that families who attended *The Future Is Now* sessions had the following results:

- 24% developed a special needs trust
- 64% who had not previously taken action in planning for the future, took action
- families reported relief and encouragement from getting to know other siblings experiencing similar joys and concerns

In addition, compared to groups not attending *The Future is Now* participants reported:

- significantly less feelings of caregiving burden
- greater daily choice making by their relatives with developmental disabilities
- More discussions about future plans with their relatives with developmental disabilities

This 5-session future planning series was introduced to FVSSN by sibling John Kramer, a doctoral student at UIC participating in research on how *The Future is Now* training could engage adults with disabilities and their nondisabled siblings in future planning. In 2008, FVSSN invited John Kramer to include adult siblings from the Fox Valley area in this research and facilitate the first *The Future is Now* with FVSSN siblings. The program involved 7 adult siblings at the first session. By the second month, most were bringing their siblings with disabilities as well. Over the next three monthly sessions, the group had grown to 30—made up of the original 7 adults, their siblings with disabilities, a couple of their other siblings, some parents, and spouses.

Along the way, FVSSN interjected peer-support activities, social activities (this first group loved potlucks) and correspondence to keep the group



Siblings with and without disabilities working on an activity that promotes discussion about the future.



Adult siblings take advantage of discussion time for adult sibling peer support.



connected and focused over the six-months to complete a Letter of Intent that reflected their sibling's dreams, needs, and action steps for the future. Besides getting information on topics such as housing, legal issues, work and leisure, etc., the program helped families understand person-centered planning and how to overcome barriers to planning. The training resulted in families moving forward with future planning that involved the sibling with disabilities more than before the program and in most cases, got discussions going between parents and their adult children.



FVSSN Future is Now workshop with parents, siblings and other family members.

Since that first *The Future is Now* program in 2008, we have offered the program several times. Each time we've edited, added, and reorganized content to better suit the interest and needs of adult siblings and make the content more sibling-focused. The participation of individuals with disabilities is even more significant as we've added more activities suited to their needs and interests

and collaborated with other agencies in presenting the program. This past year, FVSSN introduced a new format taking it from a 5-session series to a 2-session workshop format which has allowed more family members to participate. The goal is still to work on their Letter of Intent, but siblings are taking the lead and involving their parents in this homework assignment. It may be a simple concept

that we've learned along the way, but still significant. Parents can't resist helping their children with their homework.

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Harriet Redman, MS, is Executive Director and founder of the Fox Valley Sibling Support Network, which is dedicated to the interests of children and adults who have siblings with disabilities or long-term illnesses in Northeast Wisconsin. She has a 20 year old son with developmental disabilities and a 23 year old daughter without disabilities.

Policy Corner

Over the past 35 years there have been several federal efforts to bridge the aging and developmental disabilities service systems to more effectively address the needs of the growing numbers of adults with developmental disabilities who are surviving into old age and their families. The U.S. Department of Health and Human Services established the Administration for Community Living (ACL) in March 2012 as the umbrella federal agency for the Administration on Aging, the Administration on Developmental Disabilities, and the Office on Disability. The ACL now supports cross-cutting initiatives and targeted efforts to increase access to community supports and community participation for people with disabilities and seniors.

Although it is too early to assess the ACL's effectiveness in enhancing collaboration between the aging and developmental disabilities service networks, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function (RRTCADD) recently examined the Aging and Disability Resource Centers' (ADRC) role in bridging these networks. ADRCs are a joint initiative of the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) to establish a national network of local "one-stop shops" that facilitate access to long term services and supports including private pay resources for people of all ages with disabilities. Core functions include information and referral, streamlined eligibility determination, and person-centered options counseling so people with disabilities and their families can make informed choices that reflect their individual needs and preferences.

ADRCs serve all people age 60+ and younger individuals with either physical, developmental, or psychiatric disabilities. First established in 2003, there are now 467 local ADRCs in 54 states and territories that are available to nearly 70% of the population. Although ADRCs in 36 states were serving individuals with I/DD in March 2011, only Georgia and Wisconsin successfully used the ADRCs to bridge their aging and I/DD service networks. Their ADRCs were entry points for 25,865 individuals with I/DD, which accounted for 77% of people with I/DD served by ADRCs in these 36 states over the preceding five years.

The RRTCADD report *Bridging the Aging and Developmental Disabilities Service Networks: Challenges and Best Practices* also examines other federal bridging initiatives, the implications of current federal health and long term supports and services reforms, and UCEDD collaboration with ADRCs, and provides recommendations for sustaining collaboration across service networks. The report can be downloaded at www.rtcadd.org.



Self-Determination and Transition to Retirement

Roger J. Stancliffe, Nathan J. Wilson, Christine Bigby, Nicolette Gambin, Susan Balandin, and Diane Craig

Background

Retirement is a major life transition that offers many opportunities for self-determination. In Australia, there is no compulsory retirement age, so workers need to make an active decision to retire. Retirement research in the general community shows that choice and control over retirement decisions is very important to wellbeing in retirement (Quine, Wells, de Vaus, & Kendig, 2007).

In this article we describe aspects of our *Transition to Retirement* (TTR) project (Wilson et al., 2010) and give examples of what individuals with lifelong disability did to begin to build a retirement lifestyle. We focus on participants who worked in sheltered employment.

We began the TTR project with a series of focus groups with older workers with (intellectual) disability, family members, and disability service staff. We found that many people with disability did not fully understand retirement and avoided the issue. As one participant said, “No-one thinks of retiring.” Participants had great difficulty imagining a retirement lifestyle and feared that they would lose contact with friends and be bored, “You’re sitting at home and you’ve nothing to do,” (see Bigby et al., 2011).

The life-course approach helps identify interest and hobbies from earlier in life that older adults with disabilities may want to explore again.

In response to this concern we looked at what other Australians do in retirement and found that many volunteer or join a community group. Many such groups exist within Australian communities and offer an inclusive opportunity for meaningful activity and friendship in retirement.

The Transition to Retirement Model

The TTR model involves supporting the person to begin their transition to retirement by attending a mainstream community group or volunteering opportunity of their choice one day per week instead of working on that day (Wilson et al., 2010). Only *one* person with a disability is supported to go to any particular group. At the group, the person receives support from group members who volunteer as *mentors*. Disability staff are not present. To ensure that the person is included socially and is an active group participant, mentors are trained to provide effective support (social support and support for participation in activities) and to ensure activities are available.

Much highly skilled work is needed to engage with community groups, train and support mentors, teach the person with a disability relevant skills (e.g., independent use of public transportation), and provide ongoing episodic support to the group and mentors to help deal with issues that arise and to keep things on track. Full details of the TTR model are set out in Bigby et al. (2012).

Overall, 90% of TTR participants joined a community group and attended weekly for at least 6 months. According to their interests, people joined a wide variety of groups that included a seniors’ group, the Cat Protection Society, a walking and knitting group, a seniors’ choir, a community garden, and an aviation museum. Most people continued

to attend their group long term. As one man said: “I’ll keep on doing it for the rest of my life.” A few people chose to return to work, or were unable to continue attending the group for health reasons.

Self-determination and Transition to Retirement

We used a range of strategies to support self-determination. These were:

- *Opting in* – participants chose to join the TTR project
- *Individual retirement planning meetings*
- *Initial visits* – the person visited their new group several times with support from project staff
- *Opting out* – people could leave the project at any time, including returning to work (there was a guaranteed right of return to work)
- *Choice of activities* at the community group
- *Choice of companions* among group members (people in the TTR project were free to choose who they spent time with at the group)
- *Ongoing support from mentors* – some people needed support to participate and if unsupported had no real choice about taking part

We will describe some of these strategies in more detail and give examples of people who made different decisions about continuing to go to their community group.

Individual Retirement Planning Meetings

Meetings were held involving the person with disability, a close family member, a key worker, and significant others. Discussion focused on the person’s past, present, and future. This life-course approach helped identify interests or hobbies from earlier in their life that they



Jeff hanging out at the men's shed.

might want to explore again. Examples often stimulated discussion, such as, "When I retire, I will get back into golf. I used to play when I was younger and really liked it." Often, the person with disability would

struggle to articulate preferences, so others at the meeting assisted them to identify their likes and interests.

For example, Jeff (aged 60) had only one stated interest - watching TV sports. Through discussing his younger life we discovered that he enjoyed cycling and tinkering with bikes. This led to a local "men's shed" that converted old bicycles into wheelchairs for developing countries. In Australia, men's sheds are community organizations that provide a space for older men to participate in meaningful occupation together such as woodwork. Jeff no longer goes that that shed, but continues to attend a different men's shed and loves the tinkering and mechanical activities, even though they don't involve bikes.

Daryl Takes Up Lawn Bowls

Daryl, now in his late 40s, had to move into residential accommodation when his mother became ill and moved to an aged-care facility. Daryl's new accommodation was far away and involved changing to a new sheltered employment factory. After



Daryl rolls a winning bowl.

moving he lost many skills, including independent use of public transportation.

Daryl joined the TTR project and said he wanted to play lawn bowls as he had seen it on TV. He was supported to join the local bowls club and reduced his work time by half a day. With support from TTR staff, Daryl spent three months learning a new travel route to the club. At the club his mentor, Bob, would spend an hour coaching Daryl. Afterwards, Daryl enjoyed a few beers with Bob and other club members. Daryl now independently also goes to bowls from home each Saturday. Daryl says "I like coming to lawn bowls 'cos I have fun down here. I have some beers (I don't have too many!) and have a good time here with my friends." Daryl also adds independent shopping to this trip each week - something that he had not done since moving into residential accommodation.

Bob told us, "I've realized that Daryl has got a great sense of humor... as you talk to the man you get a little bit... his sense of humor and cheekiness... he's got a lot broader range of abilities than people give him credit for."

I've come to realize that Daryl has got a lot broader range of abilities than people give him credit for.

Sandra Decides to Return to Work

For over 15 years, Sandra has worked in the kitchen of a supported accommodation facility for people with disability. At age 53, Sandra joined the TTR program as she wanted to, in her words, "help" the elderly. Sandra was assisted to volunteer one day per week at her local senior citizens centre to support members of a frail-aged social and activity group with meal preparations, making cups of tea and setting-up games such as bingo. Although Sandra enjoyed her time at the centre, losing a day's wages had a significant effect on her life and Sandra chose to return to full time work at the kitchen. "They're a nice bunch of ladies down there [senior citizens' centre] but I've come back 'cos I'm

happy here." Experiencing volunteering has provided Sandra with a tangible option for the future, "I'm thinking of going back... I'm not sure when yet."

Contributing to the Group

In volunteering and community groups it is usually easy to be self-determined about which activities to join. Unlike employment, there is no requirement to be "working" constantly (it is okay to chat or chill out), and there are very few required activities. Even so, for many TTR participants, one important part of going was contributing positively to the group. With help from mentors, participants often chose to take responsibility for a particular role within the group, drawing on their existing skills. Several examples are shown in the *Transition to Retirement* DVD. These include:

Judy, aged 64, who enjoys domestic activities, took on the role (with a mentor) of setting the lunch tables for the 30-40 group members who attend each week.

Graeme, 60, who volunteers at a community plant nursery, learned how to mix a wheelbarrow load of potting mix and fertilizer for use by other volunteers when potting seedlings. This task is recognized as Graeme's special role and he does it well.

Transition to Retirement DVD

Many people did not fully understand retirement and had difficulty seeing beyond their current work routine and activities, so we made a DVD to show enjoyable alternatives to work. The *Transition to Retirement* DVD shows the stories of six TTR participants. Each story lasts 6-8 minutes and shows the experiences of the participant, their family, caregivers, and mentors from their community group.

We hope the DVD will give people with a disability, family members, and disability staff a range of concrete examples of inclusive activities to help them plan their transition to retirement.

The DVD can be streamed from: <http://www.afford.com.au/employment/transition-to-retirement>

To obtain a copy of the DVD please contact Nicolette Gambin (TTR Coordinator) nicolette.gambin@afford.com.au Note that the DVD uses the PAL format.

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Roger J. Stancliffe is Professor of Intellectual Disability at The University of Sydney, Sydney, Australia.

Nathan J. Wilson is a lecturer at The University of Sydney.

Christine Bigby is Professor of Social Work & Social Policy at La Trobe University, Melbourne, Australia.

Nicolette Gambin is Transition to Retirement Coordinator at The Australian Foundation for Disability (AFFORD), Sydney, Australia.

Susan Balandin is Professor and Director of the Jessie Hetherington Educational Research Centre at Victoria University of Wellington, Wellington, New Zealand.

Diane Craig is a doctoral student at La Trobe University

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Planning for the Future: Using Person Centered Practices to Plan for the Future and Support People with Critical and/or Life- Ending Illnesses

Leigh Ann Creaney Kingsbury

Many of us who are part of the services system for people with intellectual and/or developmental disabilities (IDD) are accustomed to planning. For providers of services, much of the required planning revolves around life goals and outcomes; and most often those goals and outcomes are seen through the lens of "within the next year," or maybe "a few years." We participate in annual plans, we have quarterly updates, we may participate in vocational and/or day services plans. Rarely however, do we think very far forward and consider what plans a person will need as he/she gets older and is at greater risk of developing chronic health problems or a terminal illness. Yet, families and service providers will more

frequently need to address these situations because adults with IDD are living longer and states are shifting long-term care from institutional settings to home and community-based services. The dilemma service providers will increasingly face is how to care for individuals with chronic and terminal health conditions that honors their personal values, preferences, and choices, especially if the person is unable to express his/her wishes.

Person centered practices, specifically the skills and tools of Person Centered Thinking (www.learningcommunity.us), work well whether the need is immediate or in the future. *People Planning Ahead* (Kingsbury, 2009; AAIDD) uses the skills and tools of person centered thinking to develop a person centered plan inclusive of healthcare and, if need be, end of life wishes.

Once family, friends, and staff have been taught and supported to use these skills and tools, this approach can be used when the individual is unable to communicate. We need to ask, "How do we think the person with disabilities would respond in this situation?" and, "What do we know about the person that we can use to better understand his/her interests and desires?" The answers can come from others who know and love the person or by spending time with the person. Let's look at Sarah's example.

We were planning with Sarah, her mother, and several members of her

Person Centered Thinking requires us to differentiate between what is important to the person and what is important for the person and create balance between the two.



clinical team. Sarah is a woman in her 50's. She has a bright smile ("lights up the room" is how others describe her) and a wonderfully contagious laugh. Sarah likes peace and quiet, enjoys reading magazines with bright pictures, and can be a bit shy until she warms up to people she has just met. Sarah communicates without using words and needs support with almost all activities in her life. Sadly, in addition, Sarah has been treated for pancreatic cancer but at this point has no more treatment options available, and has been told she will likely die within the next year. Sarah's team knows a lot about her, but the thought of her dying frightens them. They want to support Sarah to the best of their ability and in a way that makes the most sense for her until the end of her life. I asked Sarah's team to tell me about a typical day, and then I asked some specific questions about things Sarah really enjoys and wants to have present in her life. I also inquired about things she does not like, is uncomfortable with, or fears. We quickly learned several things about Sarah that were very important to her which could help us understand how to better support her as her illness progressed. First, we learned that Sarah was not a morning person and really didn't like getting up much before 9 AM. Secondly, we learned

The dilemma service providers will increasingly face is how to care for individuals with chronic and terminal conditions that honors their personal values, preferences, and choices, especially if the person is unable to express his/her wishes.

that Sarah's need for personal space was much more than the average person's 3-4 feet requirement. Sarah is very shy when she first meets new people, and she doesn't like it when people get too close to her. If someone does get too close Sarah will protect herself by attempting to pinch and scratch the person. Third, we learned that Sarah really doesn't like doctors, and most critically, she hates having her blood drawn. Last, we learned that Sarah prefers quiet spaces without a lot of people. Sarah attends a traditional day program which presented challenges for her even before her illness. But she does have a favorite place where she can sit in a favorite comfortable chair and spend time without a lot of commotion around her. Sarah enjoys this retreat even more if she has a glass of cold chocolate milk! We learned much more about Sarah, but will use these specific examples to show how they can help with future planning.

One way to help service providers plan for the future includes building a scenario for them, such as:

Given what we know is important to Sarah, imagine supporting her as her illness progresses. Imagine that while she is receiving palliative care services she develops a serious infection (for example, pneumonia) and needs to be hospitalized. Think for a moment about hospitals: bright lights, often noisy with overhead paging systems, alarms, etc., busy and lots of commotion, lots of people the patient doesn't know coming and going, and frequently getting in the patient's personal space (albeit for good reason). How would Sarah handle an aide coming in at 6 AM, waking her up to take her vital signs? How would Sarah handle a group of unfamiliar doctors standing closely around her and touching her? How would Sarah feel about an IV?

Sarah's team reported that she would very likely be quite upset and anxious, she would probably try to pull her IV's out, and would definitely try to pinch anyone who came too close. From the hospital's perspective, it is likely Sarah would be seen as an "aggressive and non-compliant patient." How would they handle her pulling on the IV's and attempting to pinch or scratch

Although we participate in annual plans and interim updates rarely do we think very far forward and consider what a person will need as he/she grows older and is at greater risk of developing chronic health problems or a terminal illness.

staff? Simply put, they would likely restrain her and/or medicate her.

From her agency's perspective however, Sarah is not aggressive or non-compliant. She is simply communicating her preferences and wishes in the only way she knows how and in the only way others can comprehend. Understanding her communication gives us great insight into her wishes and the supports she will need. When we explored Sarah's behaviors further with her team, we also learned what makes for a good day and what makes for a bad day. Because it is likely that Sarah will only live another year or so, we can use this information to plan with her, her family, and her team. We already know that being with familiar people and spending her time in quiet places are very important to Sarah. The core concept of Person Centered Thinking requires us to differentiate between *what is important to* and *what is important for the person and create balance between the two*. We can generate a list of expectations and qualities that must be present in Sarah's life in order for her to be happy and safe. Using this information and additional insights provided by her team, a condensed version of the core concepts might look something like the following for Sarah:



Important To Sarah	Important For Sarah
<ul style="list-style-type: none"> • Sleeping until she naturally wakes up (not getting up early) • Strangers staying at least 4 feet away; and introducing themselves before they approach her or touch her • Having quiet places throughout her day to spend her time alone • Having magazines to roll up and hang onto • Being in her bare feet; no socks or shoes inside • Really cold chocolate milk with a flexi-straw at least once a day • Having the chance to spend time with animals frequently (favorites are cats, small dogs, and bunnies) 	<ul style="list-style-type: none"> • Being pain-free as much as possible • Not hurting herself (by pulling on IV's or other equipment) • Not being perceived as an aggressive and non-compliant patient: <ul style="list-style-type: none"> • Having strangers approach her slowly and only with her or staff's permission • Having familiar and favorite supports around at all times, especially when she is someplace unfamiliar • Having someone she knows hold her hands and reassure her when she has to have her blood drawn or other medical procedures done • Learning other alternatives to express her displeasure other than pinching and scratching people who are trying to help her • Maintaining a reasonably safe weight • Nutrition that gives her "the best bang for her buck"

Once we have distinguished between what is "important to" and "important for" Sarah, the following example describes strategies and methods to incorporate these elements in her life.

To Achieve A Balance Between "Important To" and "Important For," We Need To:

- Always keep a stash of magazines available for Sarah to hold onto, roll up, and keep with her
- With support from her physician, keep Sarah pain free (or at a tolerable minimum) and arrange her medication schedule so she doesn't have to wake up early to take her first dose.
- When taking Sarah to the doctor, always make sure that whomever takes her is someone she knows well, and ensure that person can stay with Sarah for any and all medical procedures.
- Try to schedule all appointments after 10:00 AM.
- When doing something where strangers will need to approach Sarah, explain to them that Sarah needs time to warm up. Explain that they MUST take their time, and let them know she may reach out and grab them as a way of guarding and/or introducing herself. If they

approach too quickly however, she may not just grab, but she may pinch or scratch. If this happens, it means Sarah is frightened and the stranger should back off and give Sarah a few minutes to become more reassured.

- Make sure to take time every day to ensure Sarah can have some quiet time alone and enjoy a big glass of chocolate milk (she will need a flexible straw)

Whether someone can tell us with words what their hopes and dreams are for the future; whether the person uses very few or no words to communicate; whether the person is in good health or as in Sarah's situation, has a life ending illness, good person-centered practices, starting with Person Centered Thinking, can guide us in planning. The Person Centered Thinking process enables staff, family, and friends to provide end of life care that is consistent with the person's own values and preferences.

Leigh Ann Creaney Kingsbury has worked with people with disabilities for more than 30 years and has been using person-centered practices for healthcare decisions and care at end of life for over a decade. She is a consultant in planning and healthcare decision making; and has written extensively about the subject.

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Self-Determination within Managed Long Term Supports and Services: Tips for Advocates

Robin E. Cooper and Barbara Brent

According to a recent survey by the Kaiser Family Foundation, all but three states operate comprehensive managed *health care* for individuals enrolled in the Medicaid program¹. Much like the private insurance market, Medicaid financed health care has moved to managed care models². What is new is the emerging use of managed care approaches in the arena of long term supports and services (LTSS) for seniors and individuals with disabilities. Newer still is the inclusion of people with intellectual and developmental disabilities (IDD) into these systems. It is important to recognize that moving long-term developmental disabilities support systems to managed care is largely uncharted territory. To date, only Arizona, Michigan, and Vermont have fully moved their systems of LTSS for individuals with IDD to managed care. Wisconsin's transition is almost statewide and North Carolina is embarking on expanding to the entire state. Several states are beginning the process of shifting their systems to include individuals with IDD³.

1 *Medicaid Managed Care: Key Data, Trends, and Issues*, KCMU, February 2012 found at: <http://www.kff.org/medicaid/upload/8046-02.pdf>

2 By 2002, KFF reported: "...virtually all private health coverage now involves some aspect of managed care." Claxton, Gary, *"How Private Insurance Works: A Primer"*, Institution for Health Care Research and Policy, Georgetown University, April 2002 found at: <http://www.kff.org/insurance/upload/How-Private-Insurance-Works-A-Primer-Report.pdf>

3 Arizona, Michigan and Vermont have statewide managed care, Wisconsin Family Care is in most of the state and North Carolina has managed care in one area and is moving the rest of the system

Why the shift to managed care?

States are facing increasing demands for services at the same time there are significant budgetary limitations. This situation requires that states assess every opportunity to improve the productivity and sustainability of the services systems, including looking to managed care as a possible method to assure limited resources are used in the most efficient and cost-effective ways. The central question is not whether to just substitute managed care for current system wide management strategies but rather which managed care technologies will improve the quality, access to services, and effectiveness of existing systems while affirming the values upon which those systems are based and the essential need to keep them intimately tied to communities.

What is Managed LTSS?

Managed care is grounded in the idea that coordinated care will result in better outcomes at less cost. For seniors, this may mean home care instead of nursing facilities. For individuals with IDD this may mean investing in robust family supports, reducing reliance on congregate settings, focusing on employment, or all of these strategies. The specific aims of managed care will vary from state to state—but the following characteristics are common to this service delivery model⁴:

into a managed approach. Kansas, Iowa and New York are actively planning to move their I/DD systems into managed care.

4 A lot of good materials on managed long term supports can be found at: http://www.chcs.org/info-url_nocat5108/info-url_nocat.htm?type_id=1051

1. **Managed Care Organizations (MCOs)** are responsible for managing the system, coordinating care, and developing the provider networks. They can be public or private entities and for profit or non-profit, depending on how the state designs the system.
2. **Capitation** means that MCOs receive a predetermined standard payment amount for each plan member regardless of their varying service and support needs. The capitation rate may be just for long term supports and services—or may include health and medical services as well. The MCO then reimburses each provider at the established payment rates for the different services authorized in the person's individual support plan. This fixed pool of funds creates an incentive.
3. **Care coordination** assists individuals to choose their preferred service and support options while also making sure they are the "best fit" and most cost effective approach for producing the desired outcomes. When an MCO is experienced in developmental disabilities services in which community based services and IDD values are embedded in the system, coordination across acute health services and long term care can trigger innovations that increase care quality and improve individual outcomes. For example, improving collaboration among health professionals, community agencies, and/or family caregivers can enhance home and community-based services (HCBS) and increase access to outpatient care to improve health and reduce emergency room use and hospitalizations.



Few states currently provide managed care long-term services and supports for people with intellectual and developmental disabilities. However, many states plan to include individuals with IDD in managed care programs and 25 states are developing managed health care plans for people who are dually eligible for Medicare and Medicaid, which includes people with IDD. In some states the move to managed care is happening quickly, so it is important that families and advocates engage policy makers and state agencies before the train leaves the station.

What can families and individuals with disabilities do to influence managed care development in their state?

1. **Become an involved, knowledgeable participant at the proverbial “table.”** States are well aware that robust stakeholder involvement from individuals with disabilities, their families, and other advocates is essential in assuring that managed care delivers desired outcomes for individuals with IDD. It is helpful to include stakeholders who are knowledgeable about managed care—who can speak the “lingo”—along with others who can give input on the outcomes and values that the managed system needs to uphold. Self-advocates must have the individual supports they require to meaningfully participate in system design.
2. **Families and self-advocates will want to get clarity from decision-makers on why the state is pursuing managed long term care for individuals with IDD. Understanding the intent of managed care, including its effect on those currently receiving services and those unserved, is essential to having an impact on planning.** Stakeholders must ask what problems managed care will solve and how it will improve service delivery. If managed care will facilitate system “rebalancing” from institutional to community care, stakeholders can specify the supports, services, and safeguards necessary to achieve this outcome. If managed care is a response to

- budget constraints, stakeholders must know how the growth in LTSS expenditures will be contained. In Arizona, Michigan, and Wisconsin, managed care reduced waiting lists and made access to services an entitlement. New services, robust home and community based systems, and family and consumer engagement were all foundational components of systems design. Arizona also integrated health and long term services and supports, and Vermont expanded access to coordinated healthcare for people with IDD.
3. **The development of managed care should be based on an agreed-upon set of values and outcomes that uphold those values.** While certainly managed care is about using financial resources effectively, managed care—like all approaches to supporting individuals with disabilities—should be based on a set of principles that inform the system design and outcomes. The National Council on Disability has developed a clear set of values and principles for managed care at <http://www.ncd.gov/publications/2012/Feb272012/>. Addressing such critical issues as personal choice and control, stakeholder involvement, a cross-disability lifespan focus, competency and expertise in developing service delivery and financing strategies, operational responsibility and oversight, and quality management provide a framework for system design.
 4. **System structure matters.** We tend to focus on who will be served and what services will be covered. While positive individual and system outcomes are foremost, how those services and supports are coordinated and delivered (system structure) also is important. How much will the new system incorporate positive practices from the existing system? Will the new system assure that disability-specific knowledge and programs are retained in the new managed care system? Do state statutes and policies specify the executive authorities that oversee managed care, and are there sufficient staff to undertake this? What is the track record and

expertise of the entities selected to become MCOs? Are valued outcomes for people with disabilities, stakeholder engagement, and expectations of expertise and network development specific to community based services in addition to health care for people with IDD in service provider contracts? These are essential questions to ensure the managed care system has the competency and capacity to deliver appropriate outcomes for the individuals served.

5. **Managed care should include policies and practices that increase self-determination, self-advocacy, and self-direction.**

The central question is not whether to just substitute managed care for the fee-for service model; rather, will managed care improve service access, quality, and effectiveness while also affirming the values and progressive service paradigms that underlie services for people with developmental disabilities.

These concepts are core elements of progressive services delivered by “traditional” or managed care models.

- **Exercising self-determination.** Managed care environments can incorporate several practices to support self-determination by individuals with disabilities and their families. Wisconsin’s managed LTSS program, Family Care, developed specific guidelines for promoting their involvement, providing opportunities for meaningful participation, and making planning and implementation transparent. Wisconsin’s guidelines are at <http://www.dhs.wisconsin.gov>



gov/managedltc/grantees/pdf/info1stakeholder.pdf. Opportunities to engage stakeholders include having significant consumer and family representation on boards and internal committees and involving them in designing and implementing quality management systems like Pennsylvania’s IM4Q approach⁵.

- **Person-centered planning and service delivery.** Person-center planning—and person-centered services delivery—are the cornerstones of any good system of support. Care coordination is an essential element of managed care and is not incompatible with person-centered practices. But it is important that person-centered practices and expectations are embedded into the managed care contract and are required to be implemented by managed care organization care coordinators and by service providers.
- **Self-directed services.** Another way to promote opportunity for self-determination is through the inclusion of self-directed options in the managed system. Self-directed services do not have to be incompatible with managed care approaches. North Carolina’s current managed care program, PBH, includes options for self-direction and uses individual resource allocation (individual budgets). Wisconsin’s Family Care also includes options for self-direction⁶. Under Family Care individuals have the ability to self-direct whatever resources would have been made available to them through the MCO—and can hire, train, and fire their own workers, including family members. In Arizona, people with IDD can have an agency provide their approved services and supports,

recruit, train, and supervise their own workers who are paid by a fiscal intermediary, or use both of these options. In designing self-directed options—whether managed care or not—it is important to establish the basis for individual budgets and assure individuals have the supports they need to engage in self-direction.

- **Services array.** Self-determination is also enhanced by the types of opportunities afforded individuals to work, live, and play in their communities. Managed care LTSS need to include opportunities to live independently, work in real jobs for real pay, and to develop self-advocacy skills by providing customized employment options, supported living, and opportunities to learn self-advocacy skills which are critical paths to self-determination and a full citizenship.

In parting...

Managed care is neither good nor evil in and of itself. What matters is understanding what managed care might solve in terms of systems issues and embedding core values, principles, practices, and services within the managed care system that uphold self-determined lives for individuals with IDD. And, critically important, getting stakeholders at the table with an effective voice is vital to uphold what really matters.

Robin E. Cooper, MSSW, is Director of Technical Assistance at the National Association of State Directors of Developmental Disabilities Services. She has 18 years of experience using her expertise in systems design and financing options with government agencies, providers, consumers, and families to promote consumer choice and control.

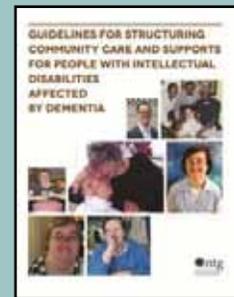
Barbara Brent, MS, is Director of State Policy at the National Association of State Directors of Developmental Disabilities Services and previously was state director for the Arizona Division of Developmental Disabilities Services. Barbara has worked in various roles in the public and private disability sectors for over 30 years.

5 Information on IM4Q (Independent Monitoring for Quality) is found at: <http://www.dpw.state.pa.us/foradults/intellectualdisabilitieservices/independentmonitoringforquality/index.htm> (Scroll down page to see materials.)

6 Self-directed services in Family Care found at: <http://www.dhs.wisconsin.gov/publications/P0/p000881.pdf>

Best Practices for the Community Support of Individuals with Dementia

The National Task Group on Intellectual Disabilities and Dementia Practices has released *Guidelines for Structuring Community*



Care and Supports for People with Intellectual Disabilities Affected by Dementia. These guidelines were drawn from research, clinical experiences, and demonstrated best practices to assist community agencies and families in supporting individuals with intellectual disabilities in the community over the progressive course of Alzheimer’s disease and related dementias. They also address related issues of assessment, environmental modification, potential abuse, care costs, supporting choice, medications, and nutrition. These guidelines can be downloaded at no cost from the National Task Group website at www.aadmd.org/NTG and the RRTC on Aging with Developmental Disabilities: Lifespan Health and Function website at www.rrtcadd.org.

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UMKC
Institute for Human Development
215 W. Pershing Rd., 6th Floor
Kansas City, MO 64108
aucd.org/ngsd

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To establish a sustainable,
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system that enhances self-
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that lead to quality of life
outcomes for individuals with
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