Introduction: A Brief Look Backwards

In the last twenty years of inclusive community supports for people with intellectual and developmental disabilities, there has been a growing focus on aging. Improved health and human services have meant that people with intellectual and developmental disabilities are living much longer lives. That realization has recognition of the obvious fact, usually hidden in plain sight, that all people die. But now it is no longer behind institutional walls.

Death is often not welcomed, but it has added layers of complexity and problems in this evolution of services and supports. In older institutions, it was often an unseen event because relationships and connections with family and community had been cut years before. My first full-time job in the 1970s was as Protestant chaplain in one of the large, old institutions. At one of my first funerals, five people besides me showed up in the small, rather dingy chapel in the basement of the old hospital building: one staff person from the deceased person’s unit assigned to come, four other male residents at the facility gladly serving as pallbearers because it was the best paying day job on campus, the coffin, and me. If funerals are for the living and the mourning, it made no sense. This one became an act of social and theological justice.

Not long thereafter, a husband and wife came to see the grave of their daughter who had died before I arrived. We went to the small but beautiful countryside cemetery, where deep, lifelong grief and ambivalence exploded when they saw that the only marker for her grave was a round stone, level with the ground, with a number on top. That practice was fairly commonplace in older institutions. As the public exposure of institutional life grew, deaths in institutions often became one of the real markers of abuse, neglect, and even criminal actions within those walls (Janicki, 1985).

In the new world that changed the diagnosis and system to “developmental” disabilities, the bedrock principle of education and community supports was that people with intellectual and other disabilities could learn, grow and develop, with the right kinds of supports and strategies, especially in typical community settings. The ironic and paradoxical issue about death in these community-based services is that, until recently, it has not been “in the plans.” With a focus on the upward path of growth, development, inclusion and justice, aging and death led to the philosophical and spiritual quandary of recognizing and accepting the loss of capacity and ability, compounded by the fact that avoidable deaths in community-based settings, including hospitals, once again became a measure of abuse and/or inhumane, unjust care.

With the growing attention to aging and developmental disabilities, by researchers like Matt Janicki and many others, supporting aging adults has become one of the frontiers of service systems.
families and each other through typical concrete actions: sending cards and flowers, contributing to memorial funds, etc., and later, going to visit the cemetery.

With or without a community service, agencies are developing their own rituals and traditions (I am avoiding non-community words like policies and procedures, although they can be important as well). Some are hosting memorial services (or “celebrations of life”) for anyone who wants to come, with opportunities for people to talk about their friend or the person they supported. These are a way of recognizing someone’s passions, interests and gifts, like the New Jersey funeral home who arranged a graveside service for someone with no family, but did it all in the color of green, which everyone in the agency knew to be his favorite color. People being served and supported, too often known simply as “consumers,” have often touched people’s lives deeply, including peers. They need opportunities to voice, in words and behavior, their own loss and appreciation (Markell, 2008). Beyond memorial events, examples include gardens and stones with plaques at an agency, memorial trees, and more.

Draw the circle a bit wider. Has the person been involved in any other community-based activities and relationships? These may include a favorite restaurant, recreation activity, job or volunteer role where a person may have more impact on others than we recognize, simply by their presence. Caregivers need to make sure these individuals are informed and invited. Invitation and inclusion can lead to deeper relationships with others supported by that agency. If this is a death of someone living with family, then those supporting that family need to help them think about all of the possible connections their loved one has had through employment, day programs and more.

A Little Earlier: Pre-death Supports

There are new resources to help individuals voice and make their own preferences known and/or help close caregivers give voice to what they believe and know a person would want (Kingsbury, 2010).

If someone is in a hospital at the end of their life, agency and hospital staff, family, or others can work together to support that person and anyone who is present with them. Direct care staff are sometimes assigned to be present to assist the person they serve, but being in the hospital is often a new experience for them. Other staff and friends could be encouraged to visit, and, as appropriate, say their own good-byes. A trainer in New Jersey once told me that when one of their “consumers” has to go to a nursing home because of the inability of the agency to do the physical care of someone in declining health, they work to make sure their friends get to go visit. Otherwise, she said, “they will be dead in six months.” Sensitive hospital and nursing home staff can make that invitation and support their inclusion.

The danger in hospitalization near the end of life is that hospital staff will not see the person behind the labels of disability, will not recognize actions or words that are coming from them, are anxious about how to communicate and support because of their disability, or, worse, make real judgments about their quality of life because of the disability. All can lead to avoidance. I recently met a mother who is now part of an organization advocating for effective health care because of the lack of support, from all staff, including chaplains, which she received when her severely disabled son was in intensive care for six months. Friends and caregivers from outside can help hospital staff see that the number of visitors may not reflect the depths of love and commitment that may have been poured into a person’s life. This becomes an opportunity to invite others to see the person they know. One such resource is a newly developed, brief “Health Care Passport” which allows hospital staff to see the person behind long and complicated charts that focus on conditions and deficits (Perkins, 2010). An agency in New Jersey has recently started using a helium balloon, with writing on it, to tell hospital staff something personal about the person in their care. In other words, these become “teachable moments,” which can lead to more sensitive care for the individual and for the wider network of relationships mentioned above. More and more frequently, if someone has grown up and been included in community settings, there may be a huge network of people who have known or seen the individual involved; think Special Olympics, fellow employees, congregations, former teachers, and more.

Moving Earlier: Planning, Training and Mobilizing

Here is where the non-crisis, real work begins, using the best practices that are coming out of two fields of support for people with disabilities and community building. The first one is person-centered planning, a number of different yet similar strategies that focus on the unique gifts, strengths, interests and dreams of an individual, moving beyond a baseline of the services needed because of their disability (O’Brien, & O’Brien, 2006). The core question in one of those systems, Essential Lifestyle Planning, is “What is important to this person and their family/friends?” In addition to the question of “What is important for them?” The second, closely related and sometimes intertwined, is asset-based community development, in which the focus is on building community from its current strengths and capacity, rather than assuming that community development is best done by following plans devised by others that often pour in resources to fix its problems and deficits (Kretzmann, & McKnight, 1993). The core difference is believing and knowing that one builds community by focusing on gifts and strengths already present. Communities are built on gifts; service systems are built on needs (Gaventa, 2010). Resources and strategies include:

New tools, like Planning Ahead, based on Essential Lifestyle Planning, help an individual and his/her supporters and caregivers let their wishes be known and build that community that helps support someone’s death and prepare for it. That can include helping someone think about what they would like their service to look like and what they might want to “will” to others. Even earlier, when
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an agency does what is usually called “intake,” Jeff Kaufman suggests doing a “loss assessment,” finding out how the individual and their family have handled losses in the past, their cultural and religious preferences, and what kinds of support are desired. That can become a time for letting the family know what the agency tries to do when end of life approaches, so the topic is on the table, and potential family vs. agency differences can be discussed and worked through without the pressure of an acute crisis (Kauffman, 2005).

Training for agency and support staff and others on grief, loss and end-of-life issues and resources helps create a service culture where grief and loss are recognized, and support staff are encouraged to help others talk about end-of-life issues in those multiple “teaching moments” (Kauffman, 2005). Many agencies are now working with funding sources and hospices to develop ways of enabling a person to stay at home if that is their wish. This is doubly important in a time when many support staff are young and/or are from many different cultural backgrounds, where beliefs and practices surrounding both disability and death may be very different. Training for hospital staff can come in the form of following the new guidelines in the Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals (Joint Commission, 2010).

Some agencies are building grief and loss support teams and inviting community members to join, so that clergy, hospital staff, funeral home directors and hospice organizations can be prepared to help support people with intellectual and developmental disabilities as they face the end of their lives. In other words, it builds from connection and community capacity that is already in place. One of the worst things that can happen, for example, is a funeral service led by a funeral home that is brought in at the last minute and a clergy person involved who know nothing about the deceased.

New Opportunities for Building Connections as People Age

As people begin to age, the same tools of person-centered planning and community building can be used to address typical tasks of aging and build more connections at the same time they may be losing both ability and connections they have had (Gaventa, 2010). Many people, as they age, move from work to other forms of community-based activities and recreational pursuits, following interests and passions they have not been able to address for a long time. That can involve mentoring or blessing those who come behind (perhaps through a teaching role for new staff), re-connecting with places and people from one’s past, renewed connections with faith communities, writing one’s life story and more (Gaventa, 2010). Caregivers and support systems can look closely on friendship. Experiences of loss, grief and death erase labels and roles. Professionals can move toward mutuality with a recognition of the ways we have received as much as we have given, including, perhaps, our sense of call and vocation. As the people we support move towards the end of their lives, it may mean our asking for their forgiveness, but we become part of that community when we are willing to tell others how much they have meant to us. If everyone wants and needs to know that they have made a difference to others, there is the real chance of a mutual blessing and expressions of gratitude. Then, of course, they can help us with our grief just as we help them with theirs.

For example, if a person has not been connected with a faith community, it is never too late. Their interest or passion related to a chance to express their faith can be utilized to connect with a tradition of their preference, possibly leading to rites of belonging and membership that were never open to them as a child or adult. One of my favorite stories comes from Australia, where an inclusion facilitator connected a middle-aged man with severe cerebral palsy, living in a room in a nursing home covered with posters of Harley Davidsons, to the local Harley club. Relationships got established, a community formed, and when he died, the club rode behind the hearse and then carried his coffin to the graveside (Gaventa, unpublished).

Reframing and Revisioning Professionalism

As professionals and other caregivers work with people with intellectual and developmental disabilities and others to build new connections near the end of one’s life, it means shifting the focus from services meant to enable growth, development or habilitation/rehabilitation to supports that truly honor what someone wants or loves. It means recognizing the difference between services and community, and a shifting professional role from provider to community builder, i.e., being an asker, collaborator, connector, guide/coach, and celebrant, one who honors and celebrates any relationship someone has while helping build new ones (Gaventa, 2001). To do that well, a professional becomes someone who knows what they don’t know and uses ignorance to invite others into a relationship with someone out of a shared passion or gift because those others are the ones who have the expertise, or capacity, that we providers do not have.

Finally, it also means some new depths of honesty and vulnerability in our professional relationships through the recognition that we may have had long-term relationships with individuals, verging more closely on friendship. Experiences of loss, grief and death erase labels and roles. Professionals can move toward mutuality with a recognition of the ways we have received as much as we have given, including, perhaps, our sense of call and vocation. As the people we support move towards the end of their lives, it may mean our asking for their forgiveness, but we become part of that community when we are willing to tell others how much they have meant to us. If everyone wants and needs to know that they have made a difference to others, there is the real chance of a mutual blessing and expressions of gratitude. Then, of course, they can help us with our grief just as we help them with theirs.

References


1 Unpublished paper entitled “Lessons in community building from including the ‘other’” available from author at bill.gaventa@umdnj.edu.
**Maybe It’s Good to Have the Sense of a Goose**

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skills and capabilities of others. We need to recognize that each of us has a unique arrangement of gifts, talents, and resources. In truth, leadership is a group activity and each of us should be ready to take the lead in an area in which we possess particular strengths. Also, each of us should be ready to offer the support necessary to make it possible for those who do lead to accomplish what they set out to do.

Fact: “When a goose gets sick, wounded or shot down, two geese drop out of formation and follow it down to help and protect it. They stay with it until it dies or is able to fly again. Then, they launch out with another formation or catch up with the flock.” While I hope that none of us gets wounded or shot literally, it is possible for us to occasionally feel wounded by those to whom we provide care or even shot down by those with whom we provide care. It is imperative that we develop a framework of support that is activated instinctively when we, or others, are in need. Such support must remain active and intact until the one in need returns to the “formation” or finds a safe haven until they can do so.

While doing what we do as caregivers may take as much energy and focus as riding in the Tour de France, none of us will ever wear one of those special jerseys. However, each of us is special in our own way. Even without a yellow, green or polka dot jersey, we are part of the peloton of caregivers who must be as responsible for our own self-care as we are for the care we provide others. Of course, we can take such lessons to heart only if we have as much sense as a goose.

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**Reference**


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