

Marquette University

e-Publications@Marquette

College of Nursing Faculty Research and
Publications

Nursing, College of

9-2008

Supporting a Community of Individuals with Intellectual and Developmental Disabilities in Grieving

Sarah Ailey

Marilyn O'Rourke

Susan Breakwell

Anna Murphy

Follow this and additional works at: https://epublications.marquette.edu/nursing_fac



Part of the [Nursing Commons](#)

Marquette University

e-Publications@Marquette

Nursing Faculty Research and Publications/College of Nursing

This paper is NOT THE PUBLISHED VERSION; but the author's final, peer-reviewed manuscript. The published version may be accessed by following the link in the citation below.

Journal of Hospice & Palliative Nursing, Vol. 10, No. 5 (September-October 2008): 285-292. [DOI](#). This article is © The Hospice and Palliative Nurses Association and permission has been granted for this version to appear in [e-Publications@Marquette](#). The Hospice and Palliative Nurses Association does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from The Hospice and Palliative Nurses Association.

Supporting a Community of Individuals with Intellectual and Developmental Disabilities in Grieving

Sarah Ailey

Assistant Professor, Department of Community and Mental Health, Rush University College of Nursing, Chicago, IL

Marilyn O'Rourke

Assistant Professor, Department of Community and Mental Health, Rush University College of Nursing, Chicago, IL

Susan Breakwell

Assistant Professor, Department of Community and Mental Health, Rush University College of Nursing, Chicago, IL

Anna Murphy

Adjunct Faculty, Department of Community and Mental Health, Rush University College of Nursing, Chicago, IL

Abstract

Individuals with intellectual and developmental disabilities are living longer and experiencing deaths among their family and peers, yet their grieving is not well recognized. Staff members who provide care for these individuals witness the aging and death of their clients, yet they also receive little preparation to work through issues surrounding bereavement for their clients and themselves. The End of Life Nursing Education Consortium developed a national initiative to improve end-of-life and bereavement care education. Recommendations from the End of Life Nursing Education Consortium were incorporated into a home care/hospice/community health course and practicum for second-degree BSN students. The following reports on an innovative clinical experience in which students developed a program to address the bereavement needs of individuals with intellectual and developmental disabilities and their staff.

BACKGROUND: THE COMMUNITY AND CLIENTS

Nurses are increasingly confronted with issues of chronic and life-limiting illness in vulnerable groups and populations. Considering the aging of the population, undergraduate students need didactic and clinical experiences in the issues of end-of-life (EOL) care, palliative care, and bereavement care adequate to prepare them as beginning professional nurses. To address this need, the End of Life Nursing Education Consortium (ELNEC) developed a national initiative to improve EOL and bereavement care education for undergraduate nursing students.¹ Through the ELNEC initiative, more than 19,000 nursing students and 460 institutions across the United States have participated in the improvement of nursing education in EOL and bereavement care.² Furthermore, because 40% of healthcare is delivered outside hospital settings,³ nurses must also be prepared to care for both individuals and groups or populations who are based in community settings.

The terminal objectives of the American Association of Colleges of Nursing⁴ also indicate the need to educate nurses in the care of vulnerable populations. A vulnerable group that has received little recognition as needing EOL and bereavement care and has received little recognition in nursing education programs is that of individuals with intellectual and developmental disabilities (I/DD). With improved medical care, individuals with I/DD are living longer, and significant numbers of individuals are aging. The American Association on Intellectual and Developmental Disabilities estimates that there are anywhere from 600,000 to 1.6 million individuals with I/DD aged 60 years and older in the United States.⁵ In 2003, more than 400,000 individuals with I/DD were in community residential placement, an increase of more than 30% from a decade earlier.⁶ As individuals with I/DD and their caregivers age, this number is expected to increase in the years ahead. Although some specialized services providing care to individuals with I/DD, the healthcare needs of this aging population are usually addressed in the mainstream healthcare system.

The reality is that many individuals with I/DD are experiencing the deaths of their parents, family, and peers. A recent literature review regarding the responses to grief and bereavement by individuals with I/DD noted that current literature often first discusses the ability of individuals with I/DD to grieve,

followed by the effects of grief on this population.⁷ Individuals and agencies supporting individuals with I/DD are only beginning to grapple with this phenomenon of grief and bereavement. As with the general population, there is a growing need for nursing care that effectively addresses issues surrounding grief and bereavement in this population. Despite these trends, nursing students may receive limited observational experience with individuals with I/DD, but most schools do not devote specific didactic content nor in-depth clinical experiences concerning working with this population.

Given the time and resource constraints of nursing education programs, experiences that facilitate synthesis of more than one area of nursing are important. A program for senior-level, prelicensure, second-degree nursing students undertook such an endeavor as part of a 10-week clinical practicum at an agency providing residential, developmental, vocational, and other services to adults and children with I/DD. The clinical practicum was part of a community health, home health, and hospice course. Faculty worked with students as they applied emerging knowledge and skills in community/public health nursing, palliative care, hospice, and EOL care. As their required community project, the students at this agency developed a bereavement support program for this community of individuals with I/DD and agency staff. Although this article describes one project, it is hoped that it will spark similar nursing school or community-based programs to address the emerging needs of individuals with I/DD and support personnel to deal with issues of grief, loss, and bereavement.

DESCRIPTION OF THE COURSE

Second-degree nursing students were enrolled in an accelerated 1-year BSN program. During their final quarter, they took a course over 10 weeks entitled "NSG 411 Community Health/Home Health and Hospice Nursing." The didactic course included three main content areas: population-focused public health, community-based home health, and palliative care/hospice.

Population-Focused Care

The Association of Community Health Nurse Educators indicates that community assessment and care of populations are basic community health nursing skills learned by baccalaureate students.⁸ Students received lecture material on community assessment, epidemiology, program planning, nursing interventions for groups, and program evaluation. They learned how to conduct a "windshield survey" and key informant interviews, how to evaluate community resources, and how to use epidemiological data and relevant health literature and research to identify and explore health issues. Students also received instruction on program planning techniques, including prioritizing community problems or strengths, partnering with key stakeholders in the community, and developing culturally relevant, ethical, legal, and sustainable intervention plans (see Table 1).

Table 1: NSG 411 Community Health/Home Health, and Hospice Nursing Course Objectives

1. Analyze historical perspectives and current healthcare trends that impact nursing care in community settings.
2. Synthesize and apply nursing and other appropriate theories, models, and standards to nursing care of individuals, families, and aggregates in the community.
3. Analyze strategies for program planning, implementation, and evaluation in community settings.
4. Describe nursing interventions to address the healthcare needs of individuals, families, and

aggregates in the community.

5. Discuss the challenges in improving the health of vulnerable individuals, families, and aggregates in an increasingly diverse society and along the continuum of care.

6. Demonstrate understanding of the impact of the healthcare system on the provision of community nursing services.

Palliative Care/Hospice Course Content

As part of the palliative care/hospice content, important concepts from the ELNEC were incorporated into the course as a means of preparing the students with beginning-level skill to support complex needs and lessen distress experienced by patients, families, and communities confronting EOL and bereavement issues.¹ Prior to this course, students had coursework on loss, grief, bereavement, spirituality, and working with the patient in pain. In this final-quarter course and clinical practicum, the differentiation between palliative, EOL, and hospice care was addressed, with an emphasis on care and resources available during end of life and bereavement. Students dealt with more complex pain and symptom management issues as well as care in the final hours of life. Content on grief, complicated grief, and grief and bereavement support was presented. Underpinning this content were ELNEC elements of the advocacy role of nursing, the needs of special populations in EOL care, the impact of EOL issues across care settings (home and institution), and the essential roles that various disciplines play in quality care at end of life and bereavement.

Clinical Practicum

In addition to the didactic course, students met at their assigned clinical site 12 hours per week over a 10 week period in fulfillment of their 3 credit hour practicum. To meet the multiple clinical objectives of the combined content areas (see Table 2), faculty selected clinical sites that provided the opportunity to make visits to individuals in their "homes" and that afforded students the opportunity to put into practice concepts of palliative care. The sites also needed to provide access to a defined population and for whom the students could develop a population-focused healthcare program. Congregate living sites, community service centers, and organizations housing homeless individuals were among the sites that met the criteria needed.

Table 2: NSG 411 Community Health/Home Health, and Hospice Nursing Clinical Objectives

1. Perform a community assessment and use the data to diagnose, deliver, and evaluate quality care.
2. Foster/investigate collaborative action for community health promotion/disease prevention.
3. Integrate appropriate levels of prevention in community-focused activities.
4. Incorporate appropriate processes and tools into patient care activities in the clinical setting.
5. Demonstrate effective communication and clinical decision making with diverse individuals, families, and groups in community and home settings.
6. Collaborate effectively with team members and groups in working toward achieving goals in the clinical setting.
7. Analyze environmental, financial, psychosocial, and healthcare delivery system factors that potentially impact individual, family, and aggregate responses and the degree of participation in their care.

8. Demonstrate application of the nursing process along the continuum of care from wellness to end of life.

One such ideal site was an agency providing residential, vocational, and other services to approximately 450 adults and children with I/DD. Students were guided in the project by a clinical faculty member with experience in community health nursing, psychiatric nursing, and care of people with I/DD. Although the agency was recognized to provide opportunities to meet the clinical objectives, the faculty members were initially not fully aware of how ideal the agency was for combining and integrating both the population-focused and the palliative care and hospice content in the course. For their required community assessment and program planning project, students developed a grief and bereavement support program for this community of individuals with I/DD and their staff. At the conclusion of the course, students made a formal presentation of the project as part of the capstone requirement for graduation. The presentation demonstrated their integration of knowledge from previous coursework, including leadership and management coursework, in addition to the current course.

DESCRIPTION OF THE STUDENT PROJECT

Community Assessment

The students chose the Community-as-Partner framework⁹ to guide their community assessment and program planning. The Community-as-Partner model provides a framework for conducting a community assessment, identifying health problems or disparities, identifying strengths of communities, partnering with communities to address identified problems, and evaluating health interventions. The framework for assessment incorporates a community assessment wheel. Within the middle of the wheel is a "core" that represents the people who make up the community, including their demographics, values, beliefs, and history. Surrounding the core are eight subsystems that compose and affect the community. These eight subsystems are physical environment, education, communication, safety and transportation, politics and government, health and social services, economics, and recreation.⁹

The students began their community assessment with a "windshield survey" and concentrated their observations on physical environment, education, health and social services, economics, and recreation. In the physical environment, the students noted the pleasant landscaping, the brightness and cleanliness of the facilities, and the small-town atmosphere with the multiple houses, restaurant, bowling alley, swimming pool, a mock post office, and other facilities on the grounds of the agency. Under education, the students noted that the agency had a developmental training program for clients. Posters and pictures regarding the organization and health issues were clearly visible. Regarding health, nursing services were available 24 hours a day. Most personal care was provided by direct support professionals (DSPs). The agency was responsible for most aspects of daily healthcare, with the involvement of clients and guardians in health decision making. Under economics, the students noted the variety of work experiences available to clients on the grounds of the facilities. The agency relied on public and private financing. Evidence of extensive private fund raising was noticeable. Under recreation, the students noted the exercise and leisure activities available to the clients. Crossing physical environment, economics, and recreation was the art program at the agency.

The art program was part of the organization's developmental and vocational training. The clients developed art both for sale and to decorate the agency. Overall, the students noted a culture of celebration of the lives of the clients, and the art program was a clear part of this culture.

In addition to observing the community through a "windshield survey," students were directed to interview key informants to obtain information about the core issues of demographics, values, beliefs, and history. Key informants were also interviewed about what they considered to be key health issues for the organization, about the strengths of the organization, and about resources available to address identified issues. Key informants included a chaplain, a nurse practitioner, staff nurses, managers, DSPs, and clients.

It should be noted that besides the community assessment and program planning aspect of the clinical practicum, students also participated in the care delivery of the clients by administering medications and treatments, which provided multiple benefits. Students were involved in providing care to the clients of the agency in their homes. The care provided by the students meant that they entered the community as an asset rather than another challenge with which to deal. More importantly, they could begin to establish trust with the clients and staff of the agency. In the process of delivering care, they could also conduct primary informant interviews of the clients, to learn about the organization from their viewpoint. Overall, the windshield survey, key informant interviews, and participation in the care of the clients provided students with the tools to identify health problems facing the community as well as to develop some understanding of the strengths of the community and the forces for change in the community.

Analysis of the data revealed several issues. Two health problems seemed the most salient: issues around bereavement and loss related to recent deaths at the agency and the prevalence of diabetes accompanied by a need for education regarding its management.

The demographic investigation revealed that there had been recent deaths among clients of the agency prior to the students' practicum. Other individuals were receiving EOL care (some specifically related to end-stage Alzheimer disease). A client receiving EOL care died during the students' time at the agency. Furthermore, approximately 30% of the clients were older than 40 years. About 30% of the clients had Down syndrome, and 25% had cerebral palsy; these groups are at higher risk of early aging. Individuals with Down syndrome have increased risk of early-onset Alzheimer disease. Based on the demographics of the agency, the clients were expected to need EOL care in increasing numbers over the next several years. The agency also had approximately 600 staff, including DSPs, professional staff, and staff in maintenance, secretarial support, and other services. Many staff were long-term employees who had known and cared for the residents over many years (A. Murphy, oral personal communication, October 2004).

Values, Beliefs, and History

A number of key informants noted that the organization was all about celebrating the lives of their clients and staff. Although the agency accepts individuals of all ethnic and religious backgrounds, the agency was founded by a specific religious organization that remains its sponsor. Key informants also noted the religious convictions of many staff who believe in "the worth of every individual as being

created in the image and likeness of God." Many staff stated that they felt that their clients were often devalued and that there was a strong sense of protectiveness toward clients by the organization. The staff also noted the general sense of pride in the services provided by the organization. Some staff indicated that they felt they had more contact with clients of the organization than with their own children. The culture of the organization was one of celebrating the existence and capacity of the clients rather than disability. However, a resistance to recognizing loss, deterioration, and death was also noted as a cultural aspect of the organization.

Problem Identification and Prioritization

The syllabus directed students to develop a process for identifying and prioritizing health problems facing their identified community. Using all of the data collected through the assessment process, the students evaluated the potential projects against four criteria: importance of the problem to the community, community interest in solving the problem, resources to address the problem, and the time constraints of a 10-week clinical. After scoring the two main problems against these criteria, the need to support clients and staff in grief and bereavement was determined to be the more important issue.

Importance of Bereavement Support and Community Interest

Key informants noted the aging of the clients and their family members. The recent deaths had traumatized both clients and staff. The lack of programming to assist clients and staff with dealing with grief and bereavement was consistently mentioned. Key informants pointed out the difficulty in dealing with death, especially in the context of the very positive culture of celebrating the lives of the clients. As the student project progressed, there was growing internal support for a grief and bereavement program from the organization's nurse practitioner, chaplain, and art therapy program director. Various clients expressed interest in participating in the program.

Community Resource Evaluation

Students evaluated the potential resources available to carry out a program of bereavement support at the agency. The students had access to consultation with faculty with expertise working in community settings and with expertise in working with individuals with I/DD. Furthermore, students were able to consult with an oncology unit-based psychiatric clinical nurse specialist, and an ELNEC trainer. Students also partnered with a local hospice organization in the planning and delivery of a program for the organization's clients and staff. At the agency, the students were able to work with a nurse practitioner who had given professional presentations on EOL care for individuals with I/DD. They also were able to work with a chaplain who was very interested in the project and with the art therapy director, who was also a graduate student working on using art in grief support. The remaining challenge was to design something that could be accomplished in the remaining 5 weeks, implement and evaluate it, and structure it in a way that would facilitate sustainability.

Cultural Relevance

Cultural competence was a concept covered in various contexts from the beginning of the students' nursing courses. Students were also expected to demonstrate an understanding of cultural relevance in population-based healthcare. Some key informants pointed out that it was more possible for the students as outsiders to develop a program on bereavement. One person noted, "We're all about

celebrating life here, and it is hard to deal with death," and pointed out that sometimes it takes outsiders who have a fresh perspective to deal with issues. Respecting the organizational culture of celebrating life, respect for the clients, and protectiveness of the clients, the students designed a grief and bereavement project for the clients that had a celebratory tone. This is consistent with what is done in many cultures, such as Hispanic and Hindu, in which death is seen as an extension of life and a reward for a life well lived. The date chosen was also close to the Day of the Dead, a celebration based on Mexican indigenous and Catholic traditions that celebrates the lives of those who have died. Furthermore, the students were careful to involve clients in a way that was incorporated into their usual daily activities.

INTEGRATION OF SCIENTIFIC LITERATURE

The course objectives called for students to integrate knowledge from the scientific literature into their health programs. The literature indicated that the right and the ability of individuals with I/DD to grieve were not well recognized. As so eloquently stated by Lavin,¹⁰ "Individuals with developmental disabilities live, laugh, love, and eventually must cope with illness and death, whether their own or that of those they love. Their disability is simply one of their attributes." However, Hollins¹¹ stated, "Staff turnover, the discharge of roommates to community care, the end of weekly visits by a devoted parent-now dead-and the death of people one has lived with for many years all go unremarked." Very limited literature indicated that individuals with I/DD might experience increased depression because of bereavement.¹² A small study with 21 clients indicated that individuals with I/DD who participated in a bereavement group had lower depression scores after participation.¹³

Staff members who work with individuals with I/DD are also witnessing the deaths of their clients. The number of personnel working with individuals with I/DD is unknown because current labor statistics do not adequately define and count these positions, but there may be more than 500,000 full-time equivalent positions for DSPs. This group, composed of nonprofessional caregivers, provides most of the hands-on care in residential and vocational settings.¹⁴ Staff serving individuals with I/DD may have long-term relationships with individuals who age and die. Knowing and working with their clients over such a span of time, staff may come to view them more as family than clients. Nevertheless, training for support staff about working with their clients' issues of aging, loss, grief, and bereavement is limited. There are no such federal training requirements, and while some states have training requirements, many states do not. Furthermore, the current skill standards suggested for support staff do not specifically include discussion or skill building for supporting individuals in grief and bereavement.¹⁵ Therefore, there is a great need to support and educate staff on how to deal with their own grief and bereavement and that of their vulnerable clients.

The students attempted to integrate their understanding of the need for grief and bereavement support among clients and staff of the agency with their understanding of the culture of the agency. Students used concepts learned in class, ELNEC recommendations, and the expertise of faculty, the psychiatric clinical consultant, the local hospice agency, and key stakeholders at the agency to design the program.

DESCRIPTION OF THE PROJECT

Students designed a bereavement support project with two main elements. The first was an in-service for the DSPs, who are the unlicensed personnel most in contact with the clients. The in-service was facilitated by hospice personnel and included an explanation of hospice services, a sharing by the DSPs of their feelings and issues around their own grief, ways to support each other in grief, and ways to support clients who are grieving. The hospice facilitator did not dominate the session but helped the DSPs discuss the issues and identify coping and management strategies. For instance, DSPs talked about how painful it is to witness the rapid emptying and cleaning of a deceased client's room to prepare it for the next tenant. For years, they have shared experiences with that individual, and the quick emptying of the room seemed to have erased that person from their lives. Some of the DSPs discussed how they felt closer to the residents than to their own children because so many of their waking hours were devoted to their work at the facility. Some residents had been there since childhood, and staff had participated in major events in their lives, like birthday celebrations and fun outings in the community. Their sense of loss was profound, and it was happening at an increasingly frequent rate. They talked about the need to have their grief recognized and to be able to talk about their grief. At the conclusion, the facilitator summarized the key ideas to crystallize the experience for the participants.

To prepare for the celebratory event for the clients, the art therapy director suggested involving the clients in the creation of a quilt square memorializing someone they had lost who was important in their lives. They were encouraged to recall fond memories. A quilt square memorializing a grandfather who loved fishing incorporated a large fish, whereas a square memorializing a grandmother who "loved to party" featured a woman dressed in colorful clothing and "granny" shoes. The quilt squares were made over a 2-week period, so clients were afforded ample opportunities to reminisce about their loved ones. The activity was incorporated into the usual daily schedule of developmental and vocational programming for the clients. The nursing students assisted the clients in making the squares, allowing the students the opportunity to provide bereavement support. Twenty-five squares were made. On the day of the event, the squares were combined into a large quilt and prominently displayed. The quilt continues to hang at the agency and affords further opportunity to discuss the memories of deceased friends and family in the lives of the residents.

The students also obtained from the agency a list of names of people who had died in the previous 2 years. The list included staff, clients, and family members of either staff or clients. Each deceased person's name was written on a paper balloon, and a display of more than 100 rising balloons was developed and displayed at the celebratory event. The Day of Remembrance celebratory event lasted for 1.5 hours and included singing by a client choir, music, and singing and readings from volunteers, clients, and students. A student assisted a client to read a poem of remembrance. The students continued to use available resources, such as the organizational volunteers who coordinated the musical portions of the program.

Project Evaluation

Evaluation of the project included an output evaluation of the attendance at both events, an informal survey of the DSPs following the in-service, and an informal survey of the staff and clients after the celebratory event. The in-service was attended by 15 DSPs. More than 40 clients and staff participated

at the Day of Remembrance event by contributing to the remembrance quilt, relaying stories of loved ones they remembered, and singing in the event choir. Both clients and staff expressed that the events opened up much-needed dialogue about their needs regarding grief and bereavement. The agency holds ongoing in-service meetings for staff about how to support residents and themselves in grieving. Agency staff advocate for the grieving needs of clients and that clients be involved in funeral services for family and friends.

All of the clinical objectives of the course were met by this project. Students were able to foster collaborative action through partnering with multiple staff in the organization (nurse practitioner, chaplain, art therapist, volunteers), in the college (faculty consultants), and in the community (hospice organization). They designed an intervention that combined primary, secondary, and tertiary prevention depending on the specific needs of the person involved and whether their need was anticipatory, immediate, or chronic. Students used management concepts and skills to work with a variety of staff and volunteers of the agency to design and implement the program. Because it was a team project and needed to be carefully designed to fit the community and its organizational culture within a tight time frame, the students learned how to work effectively as a team and within the constraints of a culture different than their own. The students were also expected to display professional behaviors in their attendance, timeliness, dress, communication, and therapeutic interactions. Both the project and the setting proved to be a rich learning experience for the students and a benefit for the agency, which plans to continue it on an annual basis.

CONCLUSION AND DISCUSSION

Since the time that the students carried out this project, scholarly works promoting the development of grief support services, education for staff in supporting individuals in grieving, and standards of care for grieving in the I/DD population have been published.¹⁶ Although progress has been made in recognizing the care needs of individuals with I/DD at EOL, few evidence-based standards of care or model programs address the needs of individuals with I/DD who are grieving or have experienced a loss. Experience with the project also highlights the bereavement needs of staff working with individuals with I/DD, both professional staff and direct care staff. Staff have a need for education on how to provide EOL and bereavement care for their clients with I/DD, but they also often have long-term close relations with their clients and are in need of bereavement support themselves. This is an area needing better attention by nurses interested in developing bereavement care.

The project shows how a well-designed student clinical project can benefit organizations serving individuals with I/DD and their staff. As the literature and the experience of this project indicate, there is a need for agencies serving aging individuals with I/DD to develop programs-both for clients and staff-around support of grieving. The project also highlights the rich learning opportunities for students working with vulnerable populations such as individuals with I/DD in congregate living facilities. While the project described in this article was undertaken by nursing students, much opportunity remains. Community-based projects such as this can be developed, implemented, and evaluated toward addressing issues of death, grief, loss, and bereavement for individuals with I/DD and those who work with them.

Acknowledgments

The authors would like to acknowledge the advice and assistance of Mary Virginia Casey, MS, RN, instructor in the Department of Adult Health Nursing and Psychiatric Liaison Nurse at Rush University Medical Center and of the Midwest Palliative and Hospice Care Center in developing this project.

References

1. End of Life Nursing Education Consortium. ELNEC Training Program, Faculty Guide. Washington, DC: American Association of Colleges of Nursing and City of Hope; 2003.
2. Ferrell BR, Virani R, Grant M, et al. Evaluation of the End-of-Life Nursing Education Consortium undergraduate faculty training program. *J Palliat Med.* 2005;8:107-114.
3. Inglis T. Nursing the trends: nurses have more employment options than ever. *Am J Nurs.* 2004;104:25-32.
4. American Association of Colleges of Nursing. The Essentials of Baccalaureate Education for Professional Nursing Practice. Washington, DC: AACN; 1998.
5. American Association on Intellectual and Developmental Disability. Fact sheet: aging older adults and their aging caregivers. Washington, DC. http://www.aaid.org/Policies/faq_aging.shtml. Accessed May 2, 2007.
6. Lakin KC, Prouty R, Coucouvanis K. U.S. residential support recipients with ID/DD now exceed 400,000 after 30% increase in past decade: increases evident in all states. *Ment Retard.* 2004;42:490-493.
7. Dodd P, Dowling S, Hollins S. A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *J Intellect Disabil Res.* 2005;49:537-543.
8. Association of Community Health Nursing Educators. Essentials of Baccalaureate Nursing Education for Entry Level Community/Public Health Nursing. Pensacola, FL: ACHNE; 2000.
9. Anderson ET, McFarlane J. Community as Partner: Theory and Practice in Nursing. Philadelphia, PA: Lippincott Williams & Wilkins; 2004.
10. Lavin C. Helping individuals with developmental disabilities. In: Doka KJ, Davidson JD, eds. *Living With Grief: Who We Are, How We Grieve.* Washington DC: Hospice Foundation of America (HFA); 1998:161-180. <http://www.hospicefoundation.org/teleconference/books/lwg1998/lavin.pdf>. Accessed July 25, 2008.
11. Hollins S. Managing grief better: People with developmental disabilities [electronic version]. http://www.intellectualdisability.info/mental_phys_health/P_grief_sh.html. Accessed July 25, 2008.
12. Hollins S, Esterhuyzen A. Bereavement and grief in adults with learning disabilities. *Br J Psychol.* 1997;170:497-501.
13. Stoddart KP, Burke L, Temple V. Outcome evaluation of bereavement groups for adults with intellectual disabilities. *J Appl Res Intellect Disabil.* 2002;15:28-35.
14. Larson SA, Lakin KC, Hewitt AS. Direct-service professionals: 1975-2000. In: Schalock RL, Baker PC, Croser MD, eds. *Embarking on a New Century: Mental Retardation at the End of the 20th Century.* Washington, DC: American Association on Mental Retardation; 2002:202-219.
15. National Alliance for Direct Support Professionals. Community support skill standards. <http://www.nadsp.org/training/csss.asp>. Accessed May 2, 2007.

16. Kauffman J. Guidebook on Helping Persons With Mental Retardation Mourn. Amityville, NY: Baywood Publishing Co; 2005.