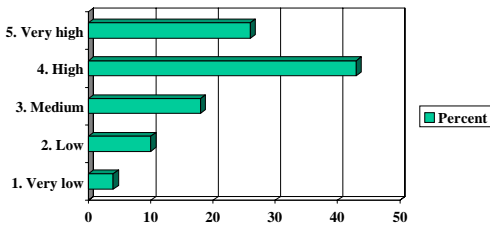
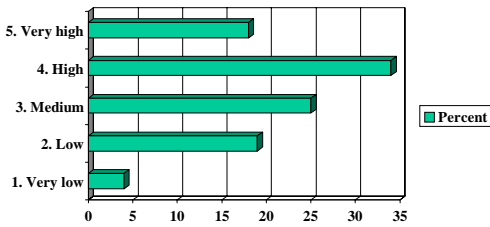


End Of Life Care

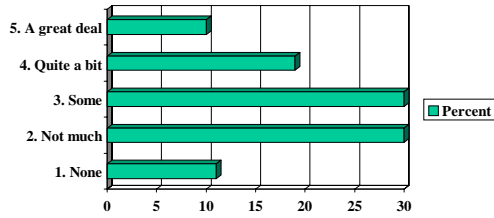
Considering clients, families and employees, how would you rate the current need for end of life care services in your organization?



How would you rate end of life care as a priority in your organization?



How would you rate the extent of resources allocated to end of life care in your organization?



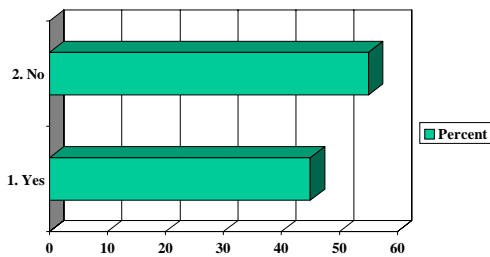
I would not be surprised if ___% percent of the consumers in the organization die in the next year.

Death %	Frequency	Percent of Answers
0	2	2.1978%
1	17	18.6813%
1.5	3	3.2967%
2	26	28.5714%
3	7	7.6923%
4	2	2.1978%
5	19	20.8791%
10	9	9.8901%
15	2	2.1978%
20	1	1.0989%
25	1	1.0989%
98	1	1.0989%
100	1	1.0989%

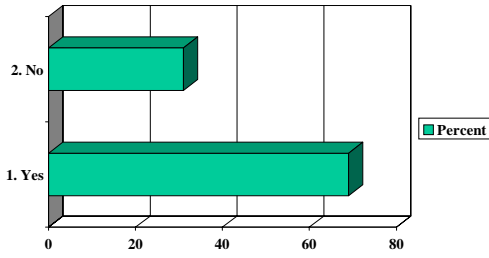
(Not Answered) 23 25.2747%
 (Total) 91+23=114 100.0%

Sample Answering: 91 responses.

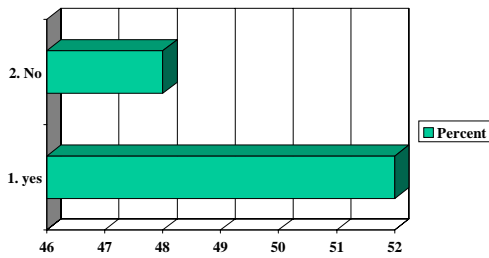
Out Patient Services:



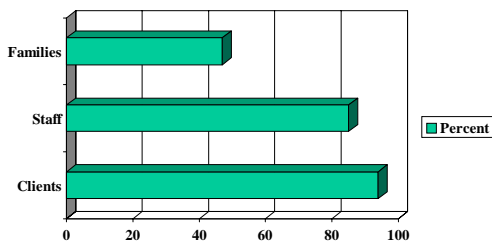
Home care:



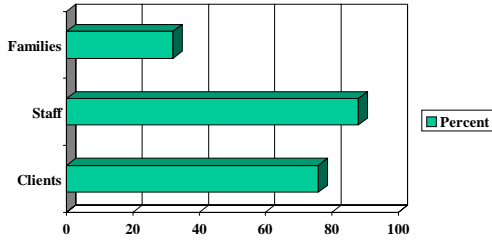
Hospice care:



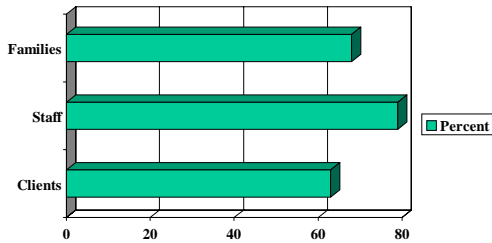
Bereavement support :



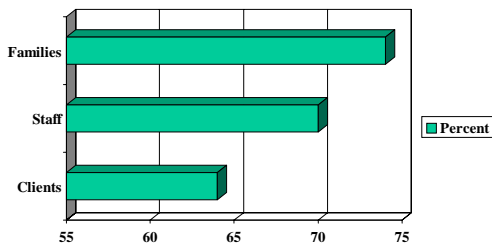
Education about end of life issues
(Dying, Death, Mourning):



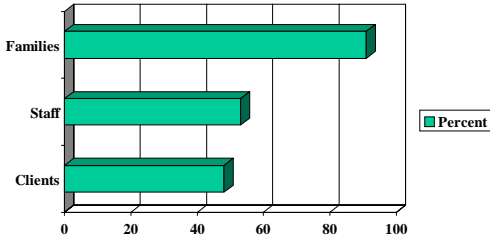
Education about advance
directives(Health Care Proxy, DNR):



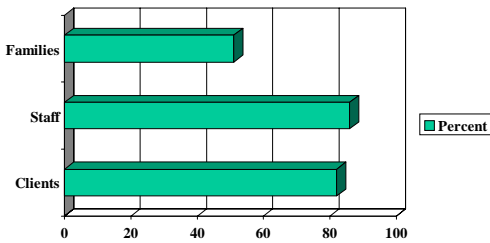
Education about planning funeral,
funeral, funeral service, obituary



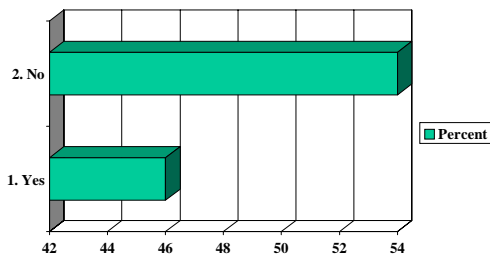
Education about legal issues (Special needs trusts, Guardianship)



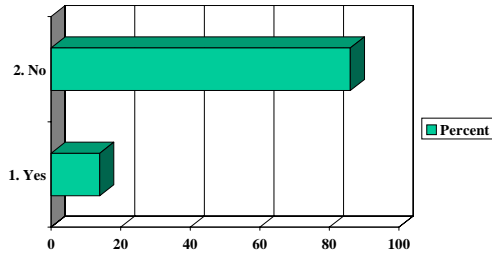
Education about psychosocial, spiritual issues at end of life



End of life care training for staff



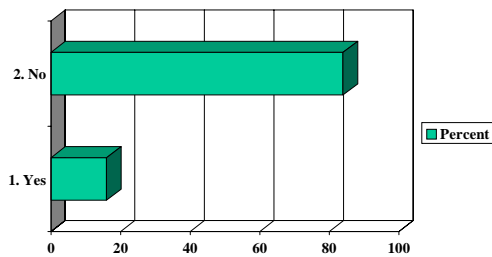
Inclusion of end of life care in annual staff orientation



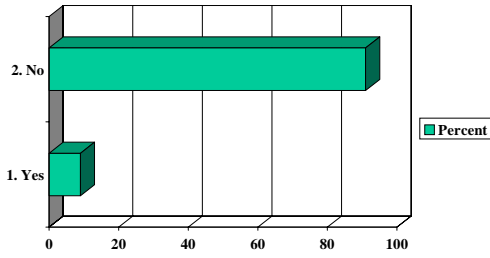
End of Life Care Survey

Ways in which organizations monitor the ongoing care of consumers at the end of life

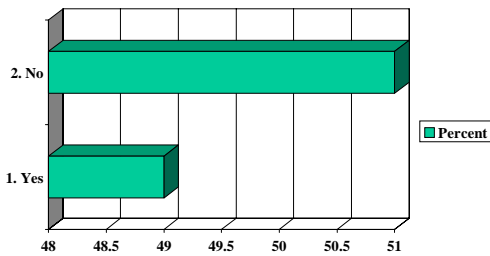
Ethics Committee



End of life care Committee



Quality Improvement Committee



Other Committee(s) that monitor(s) end of life care.

- State Long Term Care Work Group
- Special Review Committee, Incident Review
- incident review
- Human Rights Committee
- None
- Healthcare Team
- none
- Human Rights Committee
- none
- 0
- N/A
- Human Rights
- Pastoral Ministry Team & Nursing Staff
- none
- Pikes Peak Forum on Health Care Ethics

Sampling 40 responses.

Other Committee(s) that monitor(s) end of life care.

Continued....

- special review committee
- Health Care
- bereavement dept.
- treatment team
- human rights
- HUMAN RIGHTS COMMITTEE
- INCIDENT REVIEW COMMITTEE
- Health & Safety
- incident review
- Human Rights Committee
- AGING COMMITTEE
- Committee on Aging, Human Rights Committee
- IP team
- not as proactive as need to be. Board has a Program Services Committee that discusses this issue as it arises, not really monitoring.

Sampling 40 responses.

Other Committee(s) that monitor(s) end of life care.

Continued....

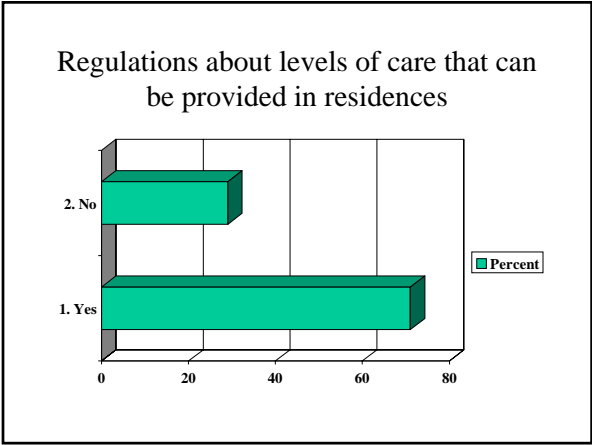
- no
- Community Resident Committee, & Incident Review Committee
- 0
- None
- None
- Human Rights
- nurses meetings
- House/individuals team (staff)
- bereavement-community memorial service, staff retreats
- special review committee
- Individual Support Teams

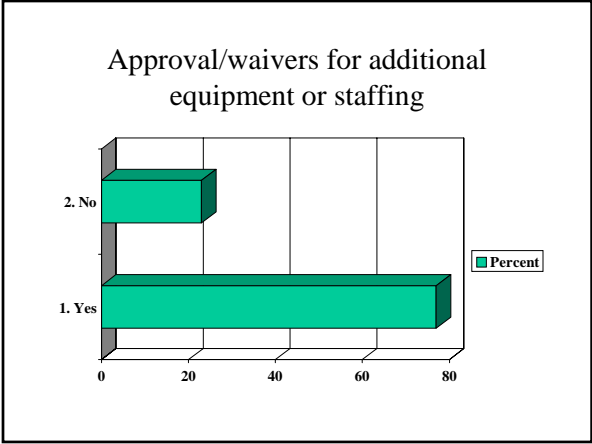
Sampling 40 responses.

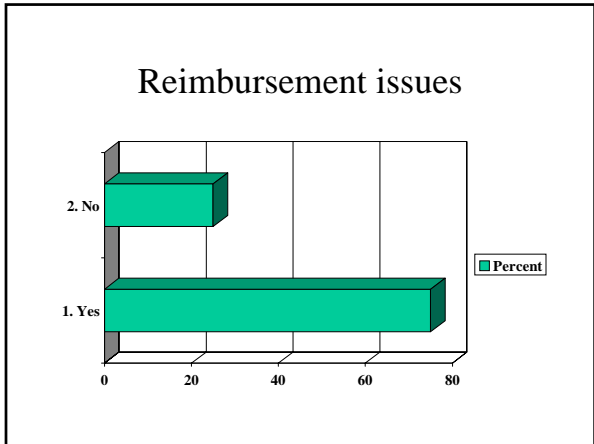
End of Life Care

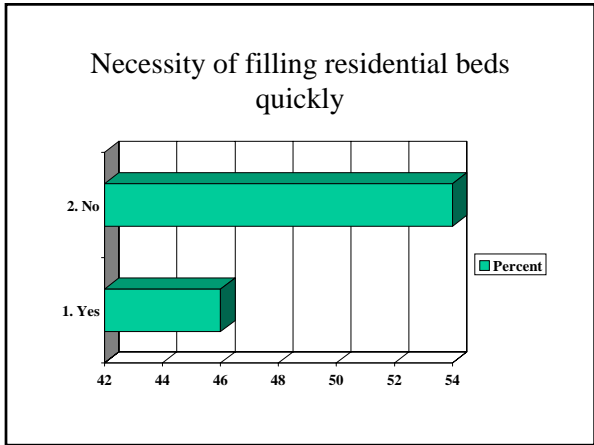
Obstacles to providing end of life care to consumers in organizations

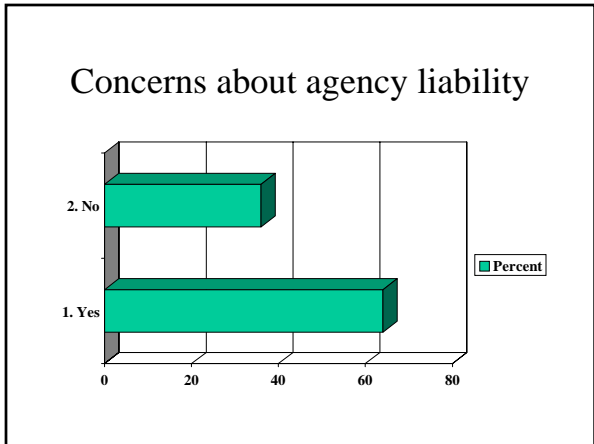
End of Life Care
Administrative Concerns











Other administrative issues

- No matter how we handle it, staff or someone feels it was handled in the wrong way.
- lack of RN's/LPN's to provide medical care
- Need to comply with regulations that do not provide of special circumstances such as an individual that may require PRN morphine for pain at the end stages of their disease.
- covering the cost of the funeral
- Providing the support needed to the staff in the field in as timely a manner as they need it.
- as above
- We have had no trouble with system issues for the deaths/terminal illness that involve hospitalizations or transfers to nursing homes, or unexpected deaths. However, I doubt seriously that hospice services and extended professional counseling would be available to DD clients in the event we had a protracted illness and death and a consumer wished to stay in their paid residential placement during this time.
- Having the system we work within embrace the concept
- there simply is no money in the budget to provide for additional training/assistance for staff/consumers/families
- conflict between guardianship statutes and DNR statutes on whether guardian can consent to a DNR for an adult with DD

Other administrative issues (Continued)

- We are a group home facility, but not really a nursing care facility. Our current population is aging and I have found that some clients need more specialized care i.e. Alzheimers and Parkinson's Disease which might be better served in a nursing home facility where there is more expertise and better nursing care
- lack of RN's/LPN's to provide medical care
- Communication between staff, family members and clients regarding needs of the person dying.
- Human rights protection of consumers and camera in residential homes.
- Our community has developed end of life guidelines. The medical society and The Arc have developed a working relationship for a number of years now.
- appropriate staffing trained staff
- enormous amount of paperwork that must be done perfectly in order to file claims with medicare
- if services are needed beyond our capacity to provide
- Long term behavioral medications have an affect on illnesses, etc. in the senior years. Resistance by the state to allow people to live at home until the end, yet not willing to support nursing homes
- We utilize hospice and they are directly reimbursed. It has been extremely helpful. There are challenges in filling nursing positions so while the service is available there are problems with delivering the service-not extensively, at this time. I see it as a much larger problem in the future due to shortage of nurses, the diminution of nursing students and the increasing number of aging consumers.

Other administrative issues (Continued)

- As the state DD Council, we do not provide direct services but have the capacity to model new approaches and promote policy and best practices. This issue has not been identified as a priority by our Council, but as an individual staff, I believe it merits attention.
- Population we serve in still young
- Having the knowledge of what to do, best ways to support, legal issues, available resources.
- Home of Guiding Hands tries to deal on an individual basis, looking at the needs of the person, staff, family, etc. We do not do all we could be doing, so yes/no question/answer is tough, we are not where we would like to be, but we do respond to the needs as we see someone entering those end states without over-reacting.
- News stories in area sensationalize deaths as poor care.
- lack of outside agencies that provide organizational programs for individuals
- We are legally obligated to provide life sustaining measures and this can be in conflict with family/consumer wishes and obtaining hospice care in their home.
- Money is the biggest issue. Funding stays stagnant while the need for staff/time dramatically increases. Funding agencies expect people to die in their homes without any additional expense. At times medical concerns demand that nursing care be provided but funding agencies think the clients should stay at home which is not the norm in the community.

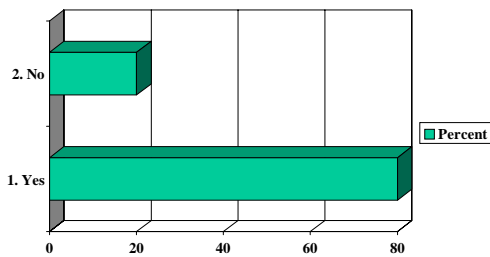
Other administrative issues (Continued)

- Licensure issues - agency is starting a residential program for aging consumers - it will be necessary to address these issues as we have not had to in the past
- concerns with surveying entities/ agency liability
- housemate, females, privacy, support of treatment teams

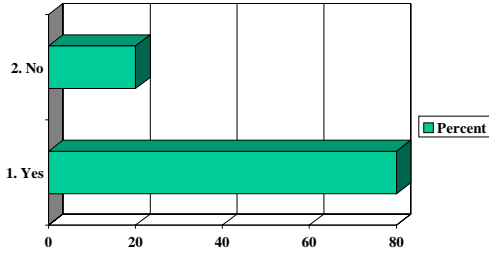
End of Life Care

Staff Concerns

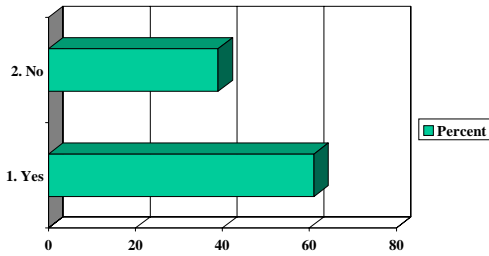
Availability of nursing/medical staff



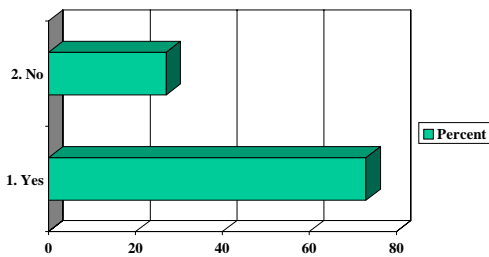
Availability of direct care staff



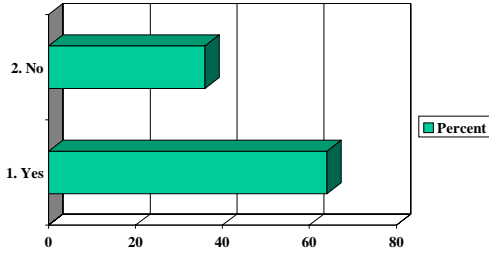
Staff concerns about their liability



Staff not trained in end of life issues



Concerns about how to respond to families



Other Staff Concerns

- Educating families about tube feeding in late stage Alzheimer's
- They are not supported enough. They are the only ones who loved or care for the person...
- welfare of co-residents, peers with the person terminally ill
- I manage a group home of elderly disabled adults. We had a lady pass away a year and a half ago. As staff and consumers in the home we got help from several agencies and within our corporation that was very supportive.
- individuals with DNR orders
- Some of our staff have never dealt closely with someone who is dying. This often results in a need for that staff person to explore their feelings regarding death and this can be very difficult. We also have staff from different cultures who do not deal with death in their country the same way that we deal with it here and it is difficult for them to understand why we do certain things. For example, one woman from Africa told me that in her country it is very wrong to discuss a person's death, even when it is imminent. She had to struggle with her feelings in order to participate in the many discussions that were held regarding a consumer that she was working with who was dying.
- unknown
- ability to carry on with their job and continuing to care for other consumers

Other Staff Concerns (Continued)

- Our agency doesn't recognize DNR. This is a great concern when a family has one in place.
- Group homes are not really funded to provide total nursing care (I realize some are). None of my staff are PCA's and we have a nurse on a consulting basis. When one of these issues arise we try as best we can to get the funding etc. to move in place services. Sometimes the disease progresses faster than the services can be put in place.
- individuals with DNR orders
- family conflicts about end of life care and planning for an individual
- Many staff have become close to clients, seeing them as almost family. Their death becomes an issue for them on a personal level.
- Various levels of emotional responses to death. Also, at our organization, staff know the clients very well and are also often good friends with the person dying.
- Staff have been educated and continue to educate themselves about the different issues around end of life care.
- lifting and personal injury personal liability for on the spot decision making in crisis
increased pay for increased work. requirement to increase their skills/training without increased pay.

Other Staff Concerns (Continued)

- burnout of direct care staff boundary issues of direct care staff
- dealing with staff emotional level, preparing them for pending loss
- welfare of other consumers who are co-residents, peers of the person terminally ill
- We have a regional ethics committee and a health care ethicist available for assistance. They have been very helpful. Additionally, there is a regional bereavement counselor and specific trainings available.
- AFRAID OF GHOSTS- CULTURAL ISSUES, ETC.
- Some staff are comfortable with allowing a client to die at home where other staff are not emotionally able to handle it.
- Some are able to deal with end of life issues/matters. How to face these matters and keep things happening for the rest of persons in the home/program. Cannot talk about this matter too much.
- Many believe other residents should not be 'exposed' to death of roommate. Person in end of life should be moved out.
- cultural & religious values
- Not having any training. This issue has come up many times in the last two years and no one knew what to do.

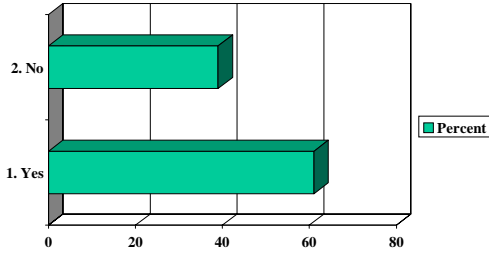
Other Staff Concerns (Continued)

- Being comfortable with the dying process as a natural part of life and death.
- Emotional issue for young staff who have never experienced death.
- Emotionally very hard on direct care staff.

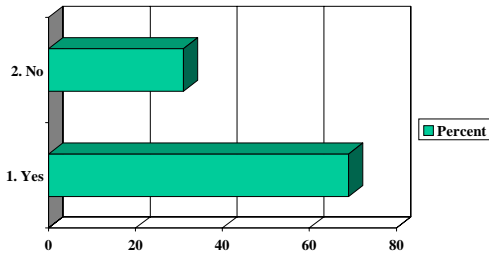
End of Life Care

Community Resources

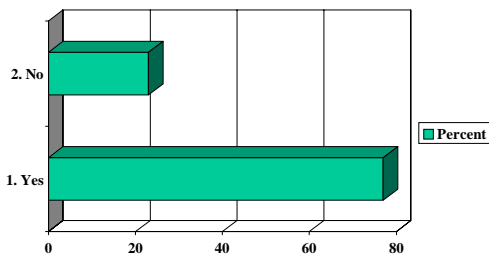
Reluctance of other providers to serve consumers



Problems in coordination of end of life care with other providers (hospital, home care, hospice, funeral home, nursing home)



Gaps in community resources



Other community issues

- Fear lack of understanding
- education about the intelligence and awareness of issues by consumers
- unknown
- See comment in item 25 please.
- lack of knowledge of health care providers in caring for people with developmental disabilities
- Persons with medical disabilities not being taken seriously.
- the local medical society has been a great deal of support
- intolerance of neighbors with the noise of ambulance/medics etc.
- differences in philosophy between medical professionals
- education about the intelligence and awareness of issues by consumers
- Medical supplies are being denied so payment is a problem. Hospitals are often overwhelmed and do poor discharge planning. We have a regional committee, which I chair, developed specifically to improve coordination around medical concerns for our consumers with the general health care system. We have published a manual on Supporting People During Hospitalization which has helped the various systems communicate more effectively. And, we've maintained our committee because these concerns require continuing effort.

Other community issues (Continued)

- Hospitals and hospices see a person with a disability with a terminal condition and assume the problem doesn't belong to them, it belongs to the dd system. Some rare examples of these systems struggling to provide reasonable accommodations pop up but overall people with disabilities don't register on their radar.
- provides failing to perform required training under patient self-determination act and state law
- Our state does not have any funding for a proper burial. They don't allow a service, they will bury a person.
- Good linkages and relationships have to be established ahead, not at the time the support/service is needed. Most resources have been very responsive to supporting our residents. We have difficulty with who is going to pay the difference between what SSI will cover and the actual costs of burial.
- Hospitals seldom are interested in working with end of life issues for people with developmental disabilities. The clients are too much work.
- physicians concerned with liabilities
- Conflicts between funders on who supports what services.

Other issues?

- unknown
- inability of family to act as health care proxy for the cognitively impaired - end of life care issues as hydration and nutrition, dialysis, etc. (issues not covered by DNR)
- A basic fear of death that pervades our culture.
- Hospitals reluctance to serve the elderly population since they do not have legal guardians. They have accepted their choices in the past, but tend to not accept them as they age.
- I was the guardian for a man with severe disabilities who died this year. I was alert for hospital pressures to do less for him to keep him alive. I was surprised to find the opposite. There was actually an odd pressure to prolong his life even though it was futile and very uncomfortable for him because of a legal understanding that end of life decisions to withhold extraordinary measures to keep one alive can only be made by a competent person for him or herself. Substitute decision making by a guardian or someone with power of attorney didn't extend to end of life decisions unless the person clearly and formally communicated this desire at a point when he or she was competent. Since this man was never competent in this sense, this option was precluded for him.
- Hospice has been excellent in the San Diego, CA area. Intensive care unit staff have worked well with staff, families, to meet the needs of the person. EAP's and other consultants are very helpful with employees. Trainings and discussions need to occur often to increase everyone's comfort level with the topic.

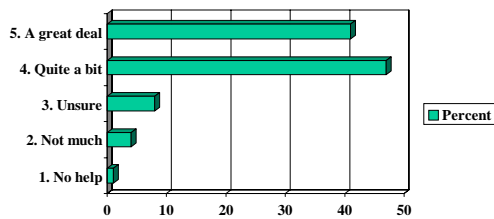
Other issues? (Continued)

- Education of community resources regarding needs of people with developmental disabilities.
- funding
- residents with no legal guardian who are unable to consent or deny consent for medical treatment

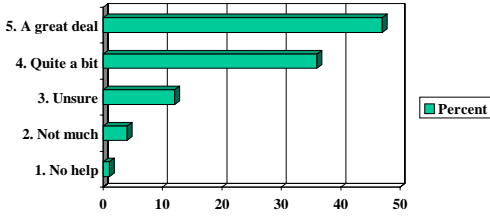
End of Life Care

Opinions on strategies that would improve the quality of the end of life care in organizations

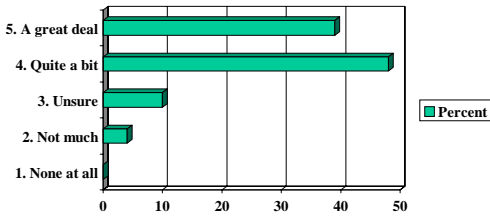
Training staff in end of life care issues



Developing system of end of life care with other community providers, such as hospices, hospitals, home care agencies and nursing homes.

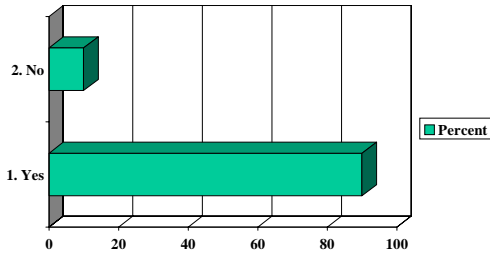


On-line information about effective programs and services in other organizations.

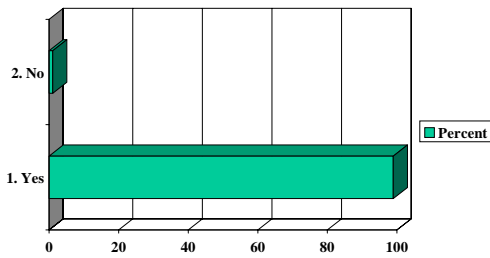


Organizations
develop educational programs regarding
End of Life Care for ...

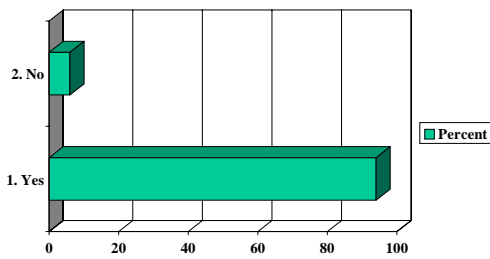
Consumers



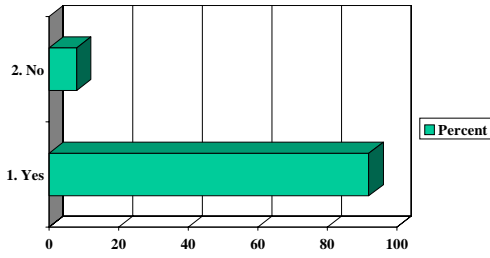
Staff



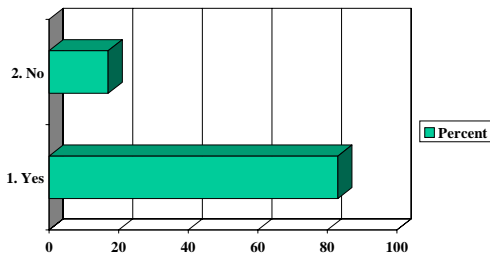
Families



Other providers



The community



Please add your suggestions for ways of improving end of life care for people with a developmental disability

- Adding Aging in Place components to ICF/MR regulations
- System change in how they react to death. It is always a result of something someone did wrong. Lots of fear because every death is handled like a protective service issue. Just very punishing. Then the system pushes to fill the bed. No time staff or roommates to grieve.
- public service advertisements, films, books re: issue
- having the state address issues of mandatory tube feeding
- Public Awareness
- Having enough staffing to provide adequate care. In our city we don't have enough workforce to fill all of our positions when things are going well. It is that much more difficult when there is a person present that is at the end of their life. Regular staff pitched in a great deal in our situation.
- for people who incapable of self preservation, it is often difficult to
- In my experience, the most difficult part of providing end of life care for our consumers was trying to coordinate the care so that we remained compliant with the regulations that we function under. I have felt that the county/state provide very little guidance in how to manage a situation where someone requires hospice care in their home. I have been very fearful of putting our agency license in jeopardy in order to provide end of life care for one of our consumers.

Please add your suggestions for ways of improving end of life care for people with a developmental disability (Continued)

- Addressing the issue early on...immediately with consumers of all ages, so it is a continuum of care, rather than something that is only addressed AT the end of life. This also would allow people to become more comfortable with the idea of death & dying, providing for better planning, and ongoing training that would hopefully improve the quality of life during the last period of one's life.
- support with resources for agencies to respond and or be proactive in relation to a persons changing life circumstance. State will pay for someone to be participating in a vocational placement but will not reimburse a residential provider to provide services designed to support that person in their home (ICF-MR).
- HONESTY IN DEALINGS MAKE THEM COMFORTABLE AS POSSIBLE
- education, means to augment staff (cover financially), ways to overcome the issue of Medicaid not paying for Hospice and Day Treatment concurrently
- Have all supports in place before it becomes a need.
- I agree a plan needs to be developed and implemented by the Interdisciplinary Team.
- for people who are incapable of self preservation, it is often difficult to
- This was not an issue in the past. However, clients just like to general population is living longer. The geriatric diseases are now occurring to the clients. The agency's need to educate staff on a regular bases about the end of life issues through training with community hospice program.

Please add your suggestions for ways of improving end of life care for people with a developmental disability (Continued)

- Spiritual education regarding beliefs about death and life after death helps individuals face death with much less fear and hysterics. Those individuals who have a sense of faith deal with death as more of a process of the life cycle and have a positive vision of afterlife. Very important.
- communicating with physicians about the needs of people with developmental disabilities
- dealing with licensure barriers within Adult Family Homes
- keep them in a familiar setting and maintain as much continuity in their lives as possible.
- greater understanding among all constituents in the process regarding MR/DD population and their needs
- STATE AND FEDERAL. GOVT'S TO HELP WITH DYING IN COMFORT AND DIGNITY AT HOME
- My staff is very supportive of taking care of our consumers till the end. The frustration comes with funding, and the medical supports.
- public service advertisements / film and book issues
- Education and support on end of life care issues is relatively foreign to the DD field in that our focus was more typically on helping people to reach self actualization. It has been hard for staff to recognize that these two ideas are simultaneously possible; in fact, necessary. So, initially there needs to be a recognition of staff's personal experiences with end of life care and death.

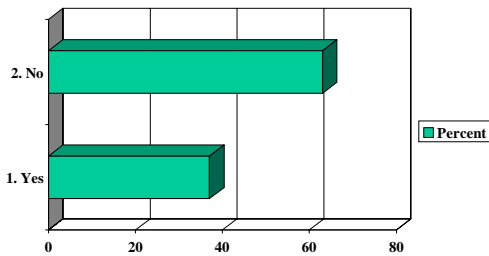
Please add your suggestions for ways of improving end of life care for people with a developmental disability (Continued)

- IMPROVING FUNDING STREAM AND MODEL- TO ALLOW HOSPICE AND OTHER SERVICES IN RESIDENCES
- Information and forums for discussion and learnings will assist a great deal. There cannot be too much discussion on this topic. The desires and wishes of the family and the consumer are very important. Written Instructions to staff about preferences and desires need to be in the person's record so that all parties know what is requested/desired. It needs to be reviewed periodically, so that everyone is still in agreement. The sources of funding support for burial and services is needed.
- Recognize the need to have a family member move in the residence if possible.
- bereavement counseling and sensitivity training for all staff
- Funding can be a concern if services are required by more than one provider and both providers use medicade as their funding source.
- MORE STAFF AT THAT TIME
- Impressing upon funding agencies the need for reasonable staff increases.
- have them stay in their place of residence as long as absolutely possible
- I believe the regulations should be revised to address end of life care and recognize the importance of this in the resident's life

Please add your suggestions for ways of improving end of life care for people with a developmental disability (Continued)

- Provide information on best practices across the country to give states new ideas to explore to improve the quality of end of life care. Address creative ways these services have been funded and coordinated among different providers.

People who have or know someone have expertise and special interest in end of life care for people with a developmental disability and their families.



Name and Phone numbers of people who have expertise and special interest in end of life care for people with a developmental disability and their families. we might contact them as a possible resource for a National Advisory Council

- Marc Gold Director-Long Term Care Policy Texas Department of Human Services 512-438-3161
- Don Thomson 503-838-2403 x 300 Deb Lindsey same as above.
- Marcia Richman Dir. of res. Services AHRC 200 Park Ave. NY,NY 10003
- Gayle Stende 3937 15th Ave. So. Great Falls, MT 59405
- Dan Thompson 219 - 884-1138 ex. 6338
- Vicki Baldwin SW 954-3368
- Georgia Swank RN, BS 260-490-9453 Ext. 14
- Jeffery Kauffman 610 789.7707 Suite 304 8600 West Chester Pike Upper Darby, Pa 19082
- David Ross 507-387-8281
- The Reverend Jim De Hoog Chaplain 210-924-9265
- Margaret Palmer, RN, BSN, MHSA Director of Habilitative Services Jefferson Rehabilitative Center mmp@imcnet.net
- Linda N. Ward 401-942-9044 ext. 11

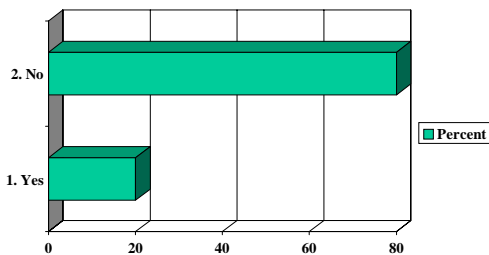
Name and Phone numbers of people who have expertise and special interest in end of life care for people with a developmental disability and their families. we might contact them as a possible resource for a National Advisory Council
(Continued)

- Joseph Anastasio, Director of Residential Services, The Arc of Baltimore, 410-296-5520, extension 5013
- Nancy Bareis, Agency Nurse, The Arc of Baltimore, 410-296-2272, extension 5041
- Marcelle Bailey c/o EDCSPIN 241 37th Street Suite 604 Bklyn, NY 11232 718-965-1998 ext.16
- BEVERLY KAUFMAN NEW HORIZONS RESOURCES 473-3000 X 318
BKAUFMAN@NHRNY.ORG
- Steve Zwettler: 920-674-8213 Jane Clare Ishiguro: 920-674-8355
- Teddi Roberts 719-633-4601
- Sue Closser, 425-347-3149
- I have special interest but no expertise except experience with end of life for two clients
- we have interest and skills to handle such situations as they arise, but not specific expertise
- Gene Keeler Dir. of Advocacy and Legal Services COARC 518-672-4451
- Sharon Krevor-Weisbaum, Esq. skw@browngold.com
- Susan Holton- CEO- Community Living, Inc. 301-663-8811
- Marcia Richardson Director of Res. Services AHRC 200 Park Ave. S NY, NY 10003

Name and Phone numbers of people who have expertise and special interest in end of life care for people with a developmental disability and their families. we might contact them as a possible resource for a National Advisory Council
(Continued)

- Patrica Padllano Saratoga ARC 2902 RT 9 Ballston Spa, NY 12020
- Barbara Pilarcik, RN, Director The Association for Community Living 41-732-4715
- Jason Squires, Administrator Cedar Lake Lodge 502-222-7157
- Laurie Catron, Atty, 1-619-291-7865, Carol Fitzgibbons, 619--448-3700, ext. 318. Both of us are in San Diego, CA
- Mary Maicontonio 518-793-4204
- There are several folks at our agency. The folks have an interest but do not have any expertise at this time.
- Cindee Kakac 763-689-0343
- Linda Raker, MPH 336-227-1011 ext. 50 or linda@rsli.org
- michele monroy, r.n. (315) 393-3072 ext.250
- Pastor Bill Van Dyken, Religious Services Coordinator Hope Haven, Inc. 712-476-2737
- Liz Symonds, 503-666-4186
- susan mattern 845-225-5650
- Nancy Murray President of The Arc of Greater Pittsburgh 412-995-5000 x414

Does your organization provide effective end of life programs, services or practices that you want to share as examples for other organizations?



Description of effective end of life care programs, services or practices followed by organizations.

- They have not yet been developed
- we have in the past provided in home hospice
- Nothing that I know of.
- see packet
- I have recently coordinated an End of Life Stages Task Force in our organization that has developed and just begun implementing an End of Life Policy & Procedure for/with our consumers. I also have an Out of Hospital DNR Policy that accompanies this. An End of Life Needs Assessment is the initial step in our implementation process, which was developed to identify a realm of needs and gather information from the consumer and involved family/friends/guardians about their wishes or vision for how they would like their end of life to proceed. Options are addressed. All is documented as apart of the IDT process, and addressed a minimum of annually. Legal issues (HCR, guardianship, DPOA, DNR, etc.) are addressed as a part of this process also. Needs are addressed as identified, as early in the process as possible, so that when an end of life situation occurs, all of our ducks are in a row. This, of course, benefits the consumer, the family, the staff, the organization, and the community.
- Same as above

Description of effective end of life care programs, services or practices followed by organizations: (Continued)

- We have created services that support individuals in such a way that they have been able to stay at home (ICF-MR) until they passed away. These services included recreation, medical, spiritual, dietary, family and staff training and support, and funeral planning.
- We treat people like we'd want our parents to be treated, and try to keep people at home as long as we can, hoping people can die at home. One time we were successful with a very old man who had congestive heart failure, but received lots of negative attention regarding the fact that we did not put him in the hospital, even though the doctor had not recommended it, and the person was seen by the doctor the day he died. We are required by regs to call the ambulance, and did so. They managed to get him breathing, and kept him on machines til family arrived to tell them to turn them off, even though we had a DNR. We're doing it anyway, but it's hard!
- We have been able to work quite well with community hospice care programs, both in-home and conventional residential hospice care programs.
- 1. Whenever there is a death of a client or staff member, we meet with all clients affected and offer a Listening/Prayer Service. People share their thoughts, concerns and feelings about the death of the person. We offer guidance, support and prayer. 2. Before each funeral of a client, we read a scripture reading pertaining to the person, and then open the microphone up for 25 minutes for storytelling and sharing. It gives the individuals we support the opportunity to grieve and to support each other. 3. We do a training once a year with staff, using videos on What do say when a person has suffered a severe loss or death.

Description of effective end of life care programs, services or practices followed by organizations: (Continued)

- WILL UTILIZE HOSPICE
- End of life guidelines, and a policy about medical and dental care for the developmentally disabled.
- as a free-standing hospice, we provide all care required for terminally ill consumers. this includes nursing, social work, chaplains, home health aides, medications, volunteer services (gerry reichel, RN 405-848-3779)
- We are struggling with this. We have started a retirement program, have had four consumers live with us through their last stages and currently have three in the same situation. Our population is aging rapidly and it is an ongoing issue that we are dealing with.
- Our work has been done in collaboration with community agencies. Our most effective project has been on hospitalization as described earlier
- William Schwab MD, 608/263-7947 Char Luchterhand (Arc USA published her paper on this topic)
- same contact person
- Richard Ingham, State Legal Services Developer, OK okdhs.org/aging 405-522-3069
- I don't think I would call our resource, effective. It is a guide for families to use when trying to think ahead about end of life issues and needs with work sheets for families. Several agencies were involved in developing this guidebook. Trainings for parents have been conducted, but there needs to be ongoing offerings. San Diego also has a Special Needs Trust Fnd, started with 4 founding organizations and has 9 members, now. Seminars are conducted at very nominal costs on Estate Planning, including the Special Needs Trust and then one on SSI.

Description of effective end of life care programs, services or practices followed by organizations: (Continued)

- being printed currently- we submit in a month or so end of life planning for consumers, advoc directives, living will training
- Grief and Loss Team A group of employees that provides immediate assistance when someone in the home dies. We provide understanding life and death training to the people who live in the homes (classroom style) We have developed a grief and loss manual and checklist for people to use to train employees, the people who live in the home, and to use as a resource when someone dies, or when communicating with loved ones. Brenda Mohrland Brendam@dakcom.org
- not at this time but will be working on this as a part of the Aging program currently being developed
- we have a 14 bed ICF that is primarily for people with terminal illnesses (315) 393-3072 ext 250 Michele Montroy R.N.
- We have dealt with each situation individually - assessing the type and level of services that were needed and then periodic reviews with the team to assure that services/supports were continuing to meet the needs.
- Dave Kahr, Res. Director, Liz Symonds, Res. Admin. oversee our group home for seniors and have unfortunately gained much experience with end of life issues
- live alone program, bereavement program

Demographics

Current Job Title

Total of 102 responses

- Director of Employment Services
- Program Specialist
- assistant executive director
- Director
- Dir. of Nsg. Res. Services
- medical director for ARC
- Program Director
- Resource Coordinator
- CEO
- Business Manager
- director, residential services
- Health and Safety Dir.
- Assc. Executive Dir.
- Director of Healthcare Coordination Services
- residential coordinator

Current Job Title (Continued)

- Director of Nursing
- Vice President of Mission Effectiveness
- associate executive director
- program director
- State Director
- President/CEO
- Executive Director
- President
- Executive Director
- PROG. DIR.
- Program Manager
- retired
- director of habilitative services
- trainer/resource liaison
- program administrator

Current Job Title (Continued)

- Team Leader/Trainer
- Resident director
- Director
- executive director
- Director of Residential Services
- social worker
- director, residential services
- program director
- Director of operations
- Nursing Services Coordinator
- Program Services Director
- Director of Mission Effectiveness
- DIR. OF CLINICAL SERVICES
- Director
- program director

Current Job Title (Continued)

- Administrator
- Director of Quality Assurance
- Executive Director
- clinical director
- director of social service
- Dir. of Program Operations
- Director of Clinical Services
- ceo
- EXC. DIR.
- Executive Director
- DIR. OF COMM. RES.
- CEO
- Executive Director
- Executive Director
- Director of Employment Services

Current Job Title (Continued)

- dir. of res. services
- Director, Family Support Services
- Executive Director
- Executive Director
- Director
- Director of Residential Services
- Program and policy advisor
- Administrator
- Exec. Director
- legal skills developer
- Vice President
- executive director
- Exec Director
- director of services
- executive director

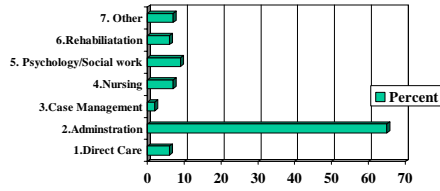
Current Job Title (Continued)

- CEO
- social services director
- District Manager
- Associate Executive Director
- Program Manager
- PROG. DIR.RES. SERV.
- Training and Development Coordinator
- Executive Director
- Program Director
- asst. exec. director
- Director of Senior Consumer Services
- Executive Director
- director of nursing
- CEO
- COO

Current Job Title (Continued)

- CEO
- Executive Director
- exc. dir.
- Director, Resident Services
- exec. director
- executive director
- clinic psychotherapist, article 16 clinic
- Director
- social Work/Advocacy Director
- Program Director
- Executive Director
- President

Is your professional background primarily



Professional Background

45 Responses

- Administrative Social Work
- Master in Rehab Administration
- Nurse, Geriatrics, Health Educator
- Licensed Counselor
- group home management
- MSW
- Registered Nurse for 19 years.
- BA Goshen College, MPA Penn State, Seminary Training . 50hrs
- social work
- 20 years administration of DD services in community. Previous experience as Behaviorist, QMRP, direct care.
- Health Care Admin
- PROG. DIR.
- parent
- RN BSN, Master in Health Administration

Professional Background (Continued)

- special education as well
- social work
- Human services
- BA in Human Services
- CSW
- Pastoral Ministry & Spirituality
- Business
- direct care and casemanagement
- msw
- Administration
- MSW
- Behavioral Supports, Individual and Group Therapies for Individuals with Sexual Issues
- EDUCATION
- 20 +yrs. residential
- nurse, geriatrics, MRDD, health educator

Professional Background (Continued)

- working with families
- Provider Association
- I've been the exec here for 22 years
- Registered Nurse
- Program development and policy advocacy; prior experience in starting and running supported living agency; personal commitments as guardian, circle member, friend.
- don understand ?
- attorney
- Quite a background in direct care
- Special Education
- 22 years in field of intellectual disabilities
- MSW
- 20 years social service direct care and administration
- Direct Services, Case Management, Habilitation, and Administration
- I have worked for our organization for 19 years - I started as an overnight staff and worked my way to the Executive Director position.

Professional Background (Continued)

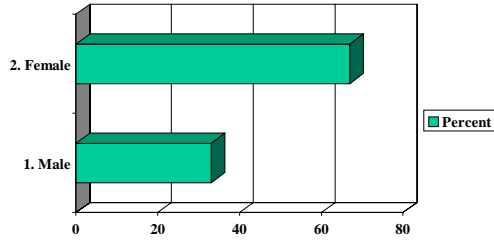
- registered nurse
- RN,MBA

Age in years

Age in Yrs.	Frequency	Percent	Age in Yrs.	Frequency	Percent
26	1	1.0204%	47	2	2.0408%
27	2	2.0408%	48	5	5.1020%
29	1	1.0204%	49	7	7.1428%
32	1	1.0204%	50	11	11.2245%
33	1	1.0204%	51	5	5.1020%
34	1	1.0204%	52	5	5.1020%
35	3	3.0612%	53	3	3.0612%
36	2	2.0408%	54	8	8.1632%
37	1	1.0204%	55	2	2.0408%
38	2	2.0408%	56	1	1.0204%
39	1	1.0204%	57	4	4.0816%
40	4	4.0816%	58	1	1.0204%
41	3	3.0612%	59	3	3.0612%
42	2	2.0408%	60	1	1.0204%
43	1	1.0204%	62	1	1.0204%
44	8	8.1632%	63	1	1.0204%
45	3	3.0612%	68	1	1.0204%

Sample Answering: 98 responses

Please indicate your gender

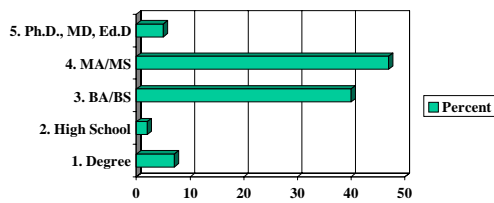


Years of full-time (or full-time equivalent) work experience you have with people with a developmental disability

Exp. In Yrs	Frequency	Percent
0-4	24	21.428
5-9	5	4.464
10-14	14	12.5
15-19	12	10.714
20-24	20	17.857
25-29	26	23.214
30-34	11	7.143
35-39	3	2.678

Sample Answering: 112 responses

Please indicate your educational background:



COMMENTS : If you have suggestions about designing an end of life care database, model and resources, please feel free to write them in the space below. In addition, if you are willing to share your comments with us on the phone, please write your name and phone number (or email address) below and we will contact you. A report on the findings of the survey will be reported and made available for distribution by the end of the summer of 2002.

- Rose Rossman ICF/MR Program Specialist Texas Department of Human Services
512-438-3750 rose.rossman@dhs.state.tx.us
- Marcia Richman AHRC 200 Park Ave. S NY, NY 10003 marica@ahrcnyc.org
212-780-4455
- Wouldn't allow me to submit number of consumers (%) I wouldn't be surprised at dying.
- Gayle Stende Quality Life Concepts Box 2605 Great Falls, MT 59403
- We are not an end of life provider, but serve 650 developmentally disabled adults in our day programs. We see effects of aging on the population we serve and have an interest in learning more about end of life care. Of our aging clients over 50% are in group homes, most are not conversed.
- Joanne Parke jparke@ciinc.org 610.328.9008 x 122
- Send results to me; jlandis@deltaweb.org
- Peggy Terlune pterlune@arcofstanlyn.org We'd love to be involved, to get people the supports they need!
- Great study, really needed. I especially see a need out there for end of life stuff with the Down Syndrome population. As they are living longer. This population is seeing Alzheimer's disease in their 50's and it is not really appropriate for them to be in a nursing home setting. Maybe it is but nursing homes aren't really prepared for our population.

COMMENTS : If you have suggestions about designing an end of life care database, model and resources, please feel free to write them in the space below. In addition, if you are willing to share your comments with us on the phone, please write your name and phone number (or email address) below and we will contact you. A report on the findings of the survey will be reported and made available for distribution by the end of the summer of 2002. (Continued)

- Joseph Anastasio 410-296-5520, extension 5013
- Thank you for the opportunity to participate. This is a much needed project.
- I am available to consult with you about these issues. We have many physicians who have taken on end of life issues for all adults at risk
- I would like to receive a copy of the results. We are currently exploring possible expansion of our services to the elderly so this information is very timely. Please E-mail me at lynn_snow@newhopeservices.org. Thanks, Lynn
- Marcia Richman AHRC 200 Park Ave. S NY, NY 10003 Marcia@ahrcnyc.org
212-780-4455
- Utilize hospice program data, pastoral counselor association in addition to the usual sources. 413-732-4715 pilarcib@theassn.org
- suggest training, research in the pros and cons of surrogate (unappointed) decision makers (they provide disposition of an end of life matter, but they bring their own agenda, religion, and needs to the process
- Carol Fitzgibbons, 619-448-3700, ext 318
- cindeck@bdri.org

COMMENTS : If you have suggestions about designing an end of life care database, model and resources, please feel free to write them in the space below. In addition, if you are willing to share your comments with us on the phone, please write your name and phone number (or email address) below and we will contact you. A report on the findings of the survey will be reported and made available for distribution by the end of the summer of 2002. (Continued)

- Michele Montroy RN 315-393-3072 ext.250
- David R. VanNingen, dvanning@hopehaven.org
- cdccristo@oslp.org
- VivianZ@mtolivetrollingacres.org
