

Use of Hospice and Palliative Care by People with Developmental Disabilities in New England

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Life Span of People Who Are Developmentally Disabled is Longer

- 1960s – 25 Years average
- Currently – age 62
- Reason:
 - Better management of acute health care issues
- Population of people with developmental disabilities begins to look more like general population

Does Population of People with Developmental Disabilities Use Hospice/Palliative Care?

- New Jersey study – 2003-2004
- 44% response rate (22:50)
- 18% use of hospice & palliative care
 - Could be as low as 9%
- Compare: 38% of general population uses hospice & palliative care

Social Work Perspective

- People with developmental disabilities are a vulnerable population
- This population is underserved by hospice
- Hospice & palliative care are about living well while dying
- Those who are developmentally disabled are entitled to the same consideration as the general population

Follow-up Study – Spring 2010

- New England hospice & palliative care organizations
- Used National Hospice & Palliative Care Organization website membership
 - 80% of all hospice & palliative care organizations are members
- 192 Sites/contacts

Methodology

- Re-use previous survey
- All listed members/contacts
 - Some organizations with multiple contact persons
 - Some organizations with multiple sites
- Initial survey with cover letter and tracking number
- Second survey with cover letter only

Response

- 51% (94/184) response rate
- Thirteen consistent responders to qualitative information requests
 - Little new information
- Problems with survey instrument
 - Ambiguous questions
 - Unanswered questions

Do People with Developmental Disabilities Use Hospice/Palliative Care?

- 62 of 94 institutions of respondents served at least one client with developmental disability in past year (66%)
- 278 known clients with developmental disabilities reported served in last year in New England

Has Usage of Hospice & Palliative Care Improved?

- 119,000 deaths in New England in 2007
- 1.13 % Estimated to be developmentally disabled
 - 1,345 deaths of people with developmental disabilities
- 278 known served by 79 of 94 reporting organizations
 - If non-reporting are the same 40.5% extrapolated usage
 - Vs. 38.5% general population
 - 20.7% if non-respondents represent no service
- Significant improvement from 2003-2004 NJ study
 - 18% use of hospice & palliative care

Other Results: Challenges

Very Significant

Not Significant

5

4

3

2

1



Challenges	Mean	S.D.
Communication:	3.56	.98
Need for specialized training:	3.54	.90
Lack of experience:	3.41	.87
Additional Costs:	2.30	1.16

Knowledge About Developmental Disabilities

Very Knowledgeable ← 5 4 3 2 1 → Not Knowledgeable

Knowledge	Mean	S.D.
Self	3.27	.84
Staff	3.10	.85

Possible Sources of Error?

- Non-response error – 49%
- No count provided though service provided
 - Not tracked
 - Not available
- Census ambiguity
 - 4 hospitals reporting > 100 daily census failed to report service to people with developmental disabilities
 - One hospital reported 1 person with developmental disability served
 - But daily census of 1150?
- How are specialized institutions served?
 - Southbury
 - Group Homes

Implications for Social Work

- People with developmental disabilities may still be seriously underserved compared to general population
- NASW Code of Ethics:
 - Obligation to advocate for vulnerable populations
 - We need greater awareness and better education regarding use of hospice & palliative care by people with developmental disabilities

Implications for Policy

- Professional caregivers need to be educated regarding need for use of hospice/palliative care by people with developmental disabilities
- Outreach to family/friends who are caregivers to provide better education regarding end-of-life options
- Hospice organizations report challenges:
 - Communication
 - Specialized training
 - Lack of experience

Future Research

- Who makes end-of-life decisions for people with developmental disabilities?
 - Family/friends
 - Professional appointees
- What factors influence decision choice?
 - Role
 - Education
 - Age
 - Prior exposure to hospice
 - Attitude toward hospice

Possible Dissertation

- Investigate disparity between NJ Survey (2003-2004) and New England Survey (2010)
- Revise instrument
- Conduct national survey

The End

Thank you LEND!