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

Dwight Norwood, M.S.W.
LEND Fellow
A.J. Pappanikou Center for Developmental Disabilities
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
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

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Mean</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication:</td>
<td>3.56</td>
<td>.98</td>
</tr>
<tr>
<td>Need for specialized training:</td>
<td>3.54</td>
<td>.90</td>
</tr>
<tr>
<td>Lack of experience:</td>
<td>3.41</td>
<td>.87</td>
</tr>
<tr>
<td>Additional Costs:</td>
<td>2.30</td>
<td>1.16</td>
</tr>
</tbody>
</table>
Knowledge About Developmental Disabilities

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Mean</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>3.27</td>
<td>.84</td>
</tr>
<tr>
<td>Staff</td>
<td>3.10</td>
<td>.85</td>
</tr>
</tbody>
</table>
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 the 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

- Revise instrument
- Conduct national survey
The End

Thank you LEND!