Supporting Sexual Health and Intimacy in Care Facilities:
Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada

Literature Search

Methodology
Bibliography
Key Informants

January 2008

Mary-Doug Wright, Principal
Apex Information
#101 – 1857 West 4th Avenue
Vancouver, BC V6J 1M4
604-731-8562
# Table of contents

Introduction ........................................................................................................... 1  
Methodology ......................................................................................................... 1  
Results .................................................................................................................. 1  
Bibliography .......................................................................................................... 3  

Appendices:  
Appendix A: Terminology Used for Searches ..................................................... 18  
Appendix B: Items Identified By Database or Resource Type ............................ 19  
Appendix C: Grey Literature Resources ............................................................. 20  
  Government and International Agencies ......................................................... 20  
  Organizations and Research Institutes ............................................................ 20  
  Library Catalogues, Specialized Databases, Internet Peer-reviewed Sites, and Internet Search Engines ................................................................. 23  

Funding for this publication was provided by:  
Sexual Health and Sexually Transmitted Infections Section  
Centre for Communicable Diseases and Infection Control  
Public Health Agency of Canada.
Introduction

A search was conducted between November 2007 and January 2008 to identify and gather both published and unpublished guidelines and policy documents to inform the development of Supporting Sexual Health and Intimacy in Care Facilities: Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada, published by Vancouver Coastal Health Authority.

Methodology

Sexual health experts and other key informants such as government officials, educators, researchers, and facility administrators and workers were identified and contacted by email or phone if no email address could be ascertained. They were asked if they knew of and could provide relevant guidelines or policy documents or if they knew of other individuals with subject expertise or of research being conducted in the area.

Initially, a systematic literature search was conducted to identify guidelines and policy documents in any language (Canadian and international), and other key published and unpublished literature discussing clinical, legal, ethical and educational issues surrounding sexual health and intimacy in adult long-term care facilities.

The search for peer-reviewed journal articles and other indexed literature was conducted in the following databases. Literature was limited to the last ten years (1997-2008), with no language or jurisdictional restrictions.

- Medline (the U.S. National Library of Medicine health database)
- PubMed (Medline plus additional literature not indexed in Medline)
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- PsycINFO (Psychological Abstracts)
- AgeLine (Social gerontology and other aging-related literature)

Database searching was followed by a search of major library catalogues, relevant organization, government, think tank, and research institute websites, grey literature repositories, and free Internet-accessible databases were also searched for grey literature such as books, reports, and unpublished material. Note: Though the secondary literature discussing legal issues was included in the search, neither statutes nor other legislation were included, as the guideline development team had references to pertinent Canadian law.

Records of documents identified and excerpts or summaries of communication with key informants were created in a Reference Manager database for the purpose of bibliographic management and bibliography production.
Tables outlining databases and other resources searched, terminology used, search results by resource type, and contact information for informants can be found in the appendices:

- Appendix A: Search terminology
- Appendix B: Items identified by database or resource type
- Appendix C: Grey literature resources
  - Government and international agencies
  - Organizations and research institutes
  - Library catalogues, specialized databases, internet peer-reviewed sites, and internet search engines

Results

In total, 303 potentially relevant documents were identified through the search process. Following examination of titles and/or abstracts by members of the guidelines development team, 214 documents were reviewed in full text by the guideline developers. Of these, 48 documents were cited in the guidelines. The remainder served as background documents.

Of 53 potential prospects, a total of 41 key informants were contacted. Of these, 29 responded and provided expert opinion and/or guidelines, policy documents, and other literature.

The remainder of this report consists of the bibliography of literature identified.
Bibliography


Bouman WP, Arcelus J, Benbow SM. Nottingham Study of Sexuality and Ageing (NoSSA II). Attitudes of care staff regarding sexuality and residents: a study in


Brick P. The heart has no wrinkles: sexuality & intimacy in the later years. [S.l.]: Peggy Brick; 2007.


Buttenschon J. Proposal to a plan for course in handicap sexuality: Markuciai Day Activity Centre. 2007.


Buttenschon J. The following types of sexuality training and help to sexuality are permitted. 2007.


de Vries N. [Sexuality and sexual assistance for people with developmental disabilities].

de Vries N. [Thoughts about sexual assistance]. 2006.

de Vries N. Excerpt from an interview with Ruth Terrinde, Orthopedagogue and Gestalt Therapist, about the sexual assistance that one of her clients (A.) is receiving from Nina de Vries.

de Vries N. Excerpts of the concept of the training to become a sexual assistant for disabled people - trainer: Nina de Vries (This training was held from January till June 2004 in Switzerland on behalf of the "Organisation for Disability and Sexuality" in Basle).

de Vries N. Something about me. 2006.

de Vries N. Something about my vision. 2006.

de Vries N. The most beautiful feeling in the world ?! Discovering the body - living sexuality: sexual assistance for people with a disability: a workshop for professional caregivers working with people with a disability.


Grossman BR, Shuttleworth RP, Prinz PM. Locating sexuality in disability experience, a report from Disability Studies: theory, policy, and practice, the


Lichtenberg P. Thinking about a resident's competence to participate in intimate relationships 1990. 1990.


Marso KJ. Sexuality and adults with mental retardation in residential facilities: services provided, perceived staff training needs, and agency policies. Dissertation Abstracts International: Section B: The Sciences and Engineering. 1997;57(10):6213.


McChesney M. Sex for disabled moves forward (Between the sheets series). Toronto star 2006 Sep 29.

McSherry B, Somerville M. Sexual activity among institutionalized persons in need of special care. Montreal: McGill Centre for Medicine, Ethics and Law; 1996.


Scarfone V. Sexual assistance policy. Sudbury, ON: ICAN - Independence Centre and Network.


Sexual assistance for people with a disability: the work of Nina de Vries on DVD.


What do you identify as problems with sexuality for patients, families, and staff in nursing homes or long-term care facilities? What type of interventions have you found useful? J Gerontol Nurs. 1997 Oct;23(10):52-5.

Appendix A: Terminology Used for Searches

<table>
<thead>
<tr>
<th>Subject Headings*</th>
<th>Text Words*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sexuality, sexual health and intimacy:</strong></td>
<td></td>
</tr>
<tr>
<td>▪ Sexual Behavior</td>
<td>▪ Sexuality</td>
</tr>
<tr>
<td>▪ (sex or sexual) education</td>
<td>▪ (sex or sexual) education</td>
</tr>
<tr>
<td>▪ sexual need*</td>
<td>▪ sexual need*</td>
</tr>
<tr>
<td>▪ sexual aggress*</td>
<td>▪ sexual aggress*</td>
</tr>
<tr>
<td>▪ sexual (aggress* or access* or activit* or behavio* or need* or right*)</td>
<td>▪ sexual (aggress* or access* or activit* or behavio* or need* or right*)</td>
</tr>
<tr>
<td>▪ (sex or sexual) surrogate*</td>
<td>▪ (sex or sexual) surrogate*</td>
</tr>
<tr>
<td>▪ intimacy</td>
<td>▪ intimacy</td>
</tr>
<tr>
<td>▪ facilitated sex</td>
<td>▪ facilitated sex</td>
</tr>
<tr>
<td>▪ sexual (expression* or disinhibit*)</td>
<td>▪ sexual (expression* or disinhibit*)</td>
</tr>
<tr>
<td>▪ hypersexual*</td>
<td>▪ hypersexual*</td>
</tr>
</tbody>
</table>

| **Long term care and population group:** | |
|  ▪ Long-Term Care |  ▪ assisted living |
|  ▪ Nursing Homes |  ▪ care facilit* |
|  ▪ Group Homes |  ▪ group home* |
|  ▪ Homes for the Aged |  ▪ nursing home* |
|  ▪ Assisted Living Facilities |  ▪ skilled nursing facility* |
|  ▪ Residential Facilities |  ▪ (homes or home) for the (aged or elderly or disabled) |
|  |  ▪ (longterm or long-term or complex or extended or institutional or residential or intermediate) care |

| **Guidelines, policies, ethical and legal issues:** | |
|  ▪ Guidelines |  ▪ guideline* |
|  ▪ policy or policies | |
|  ▪ Informed Consent |  ▪ informed consent |
|  ▪ Ethics |  ▪ ethics or ethical |
|  ▪ Ethics, Medical | |
|  ▪ Ethics, Nursing | |
|  ▪ Liability, Legal |  ▪ legal |
|  ▪ liability* |  ▪ law or laws |

* Subject headings were exploded as appropriate to include narrower terms. Examples in table are Medical Subject Headings from Medline and PubMed. For text word searching, both American and British spellings were included in the search as needed.
## Appendix B: Items Identified By Database or Resource Type

<table>
<thead>
<tr>
<th>Database/Resource*</th>
<th>Items Identified (Unique)</th>
<th>Items Included in Review**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medline</td>
<td>69</td>
<td>27 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 cited</td>
</tr>
<tr>
<td>PubMed</td>
<td>30</td>
<td>29 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23 cited</td>
</tr>
<tr>
<td>CINAHL</td>
<td>67</td>
<td>27 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 cited</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>45</td>
<td>15 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 cited</td>
</tr>
<tr>
<td>Ageline</td>
<td>13</td>
<td>0 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 cited</td>
</tr>
<tr>
<td>Google Scholar</td>
<td>3</td>
<td>3 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 cited</td>
</tr>
<tr>
<td>Grey literature resources</td>
<td>142</td>
<td>142 reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>34 cited</td>
</tr>
<tr>
<td>Total literature (excluding informants)</td>
<td>214</td>
<td>214 total reviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>48 cited</td>
</tr>
<tr>
<td>Key informants</td>
<td>41 contacted</td>
<td>29 responded</td>
</tr>
</tbody>
</table>

* Records were imported into Reference Manager database in order shown. Duplicate records across databases were eliminated. Numbers represent unique items found from each database.

**Total number of documents reviewed and cited by resource. This number is not additive due to duplication across databases. For example, none of the items identified in Ageline were unique, therefore the count for items included in the review is zero.
## Appendix C: Grey Literature Resources

<table>
<thead>
<tr>
<th>Government and International Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Australia</strong></td>
</tr>
<tr>
<td>Australia Department of Health and Ageing</td>
</tr>
<tr>
<td><strong>Canada</strong></td>
</tr>
<tr>
<td>Public Health Agency of Canada</td>
</tr>
<tr>
<td><strong>Great Britain</strong></td>
</tr>
<tr>
<td>Department of Health</td>
</tr>
<tr>
<td><strong>New Zealand</strong></td>
</tr>
<tr>
<td>Ministry of Health</td>
</tr>
<tr>
<td><strong>United States</strong></td>
</tr>
<tr>
<td>Department of Health &amp; Human Services</td>
</tr>
<tr>
<td>National Institute on Aging</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organizations and Research Institutes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Australia</strong></td>
</tr>
<tr>
<td>Australian Research Centre in Sex, Health and Society</td>
</tr>
<tr>
<td><strong>Belgium</strong></td>
</tr>
<tr>
<td>Vlaamse Vereniging voor Seksuologie [Flemish Association for Sexology]</td>
</tr>
<tr>
<td><a href="http://www.seksuologen-vlaanderen.be/">http://www.seksuologen-vlaanderen.be/</a></td>
</tr>
<tr>
<td>(No English interface – could not examine content)</td>
</tr>
<tr>
<td><strong>Canada</strong></td>
</tr>
<tr>
<td>Canadian Sex Research Forum</td>
</tr>
<tr>
<td><a href="http://www.csrf.ca/">http://www.csrf.ca/</a></td>
</tr>
<tr>
<td>Centre for Addictions and Mental Health (CAMH)</td>
</tr>
<tr>
<td><a href="http://www.camh.net/">http://www.camh.net/</a></td>
</tr>
<tr>
<td>Sex Information and Education Council of Canada (SIECCAN)</td>
</tr>
<tr>
<td><strong>Denmark</strong></td>
</tr>
<tr>
<td>Denmark. Ministry of Social Welfare</td>
</tr>
<tr>
<td><a href="http://eng.social.dk/">http://eng.social.dk/</a></td>
</tr>
<tr>
<td>Organizations and Research Institutes</td>
</tr>
<tr>
<td>---------------------------------------</td>
</tr>
<tr>
<td>National Board of Social Services</td>
</tr>
<tr>
<td><a href="http://servicestyrelsen.dk/wm142447">http://servicestyrelsen.dk/wm142447</a></td>
</tr>
</tbody>
</table>

**Finland**

- Finnish Association for Sexology  
  http://www.seksologinenseura.net/
- Finnish Association for Sexual Policy (SEXPO)  
  http://www.sexpo.fi/?julkaisut  
  (No English interface – could not examine content)
- National Association of the Disabled  
  http://www.invalidiliitto.fi/portal/en/  
  [English version]
- Väestöliitto (Family Federation)  
  http://www.vaestoliitto.fi/in_english/  
  Sexual health page  
  http://www.vaestoliitto.fi/in_english/sexual_health/

**Germany**

- Deutsche Gesellschaft für Sozialwissenschaftliche Sexualforschung (DGSS) [German Society for Social Scientific Sexuality Research]  
  http://www.sexologie.org/
- Magnus Hirschfeld Archive for Sexology, Humboldt-Universität zu Berlin  
  http://www2.hu-berlin.de/sexology/

**Great Britain**

- British Association for Sexual and Relationship Therapy (BASRT)  
  www.basrt.org.uk

**International**

- Cochrane Collaboration  
  http://www.cochrane.org/
- Disabled Peoples’ International  
- European Federation of Sexology (EFS)  
  http://www.europeansexology.com/
- International Academy of Sex Research (IASR)  
  http://www.iassr.org/
- International Committee on the Rights of Sex Workers in Europe  
  http://www.sexworkeurope.org/site/
- Nordic Association for Clinical Sexology (NACS)  
  http://www.nacs.eu/
- Society for the Scientific Study of Sexuality  
  http://www.sexscience.org/
- United Nations Population Fund (UNFPA)  
  http://www.unfpa.org/index.htm
- World Association for Sexual Health (WAS)  
  http://www.worldsexology.org/
<table>
<thead>
<tr>
<th>Countries</th>
<th>Organizations and Research Institutes</th>
</tr>
</thead>
</table>
| **World Health Organization** | World Health Organization  
Ageing and Life Course Unit  
http://www.who.int/ageing/en/  
Sexual Health  
http://www.who.int/topics/sexual_health/en/ |
| **Italy**          | Istituto di Sessuologia Clinica  
http://www.sessuologiaclinica.it  
(No English interface – could not examine content) |
| **Netherlands**    | Flekz Org  
www.flekszorg.nl  
(No English interface – could not examine content)  
Rutgers Nisso Groep  
http://www.rutgersnissogroep.nl/English  
Stichting handicap & seksualiteit (Association for Disability and Sexuality)  
www.deschildpad.nl  
(No English interface – could not examine content) |
| **Norway**         | Norwegian Society of Clinical Sexology  
http://www.klinisksexologi.no/  
http://www.klinisksexologi.no/english.php? (English interface) |
| **Spain**          | Federación Española de Sociedades de Sexología  
www.fess.org.es  
(No English interface – could not examine content)  
Instituto Espill  
www.espill.org  
(No English interface – could not examine content) |
| **United States**  | American Academy for Clinical Sexologists  
http://www.esextherapy.com/  
American Association of Sex Educators, Counselors, and Therapists (AASECT)  
http://www.aasect.org/  
Kinsey Institute for Research in Sex, Gender, and Reproduction  
http://www.indiana.edu/~kinsey/  
National Sexuality Resource Center  
http://www.nsrc.sfsu.edu/  
SexInfo, University of California at Santa Barbara  
http://www.soc.ucsb.edu/sexinfo/  
Sexual Health Network  
http://www.sexualhealth.com/  
Sexual Health Network  
http://www.sexualhealth.com/ |
<table>
<thead>
<tr>
<th>Organizations and Research Institutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexuality Information and Education Council of the United States</td>
</tr>
<tr>
<td><a href="http://www.siecus.org/">http://www.siecus.org/</a></td>
</tr>
<tr>
<td>Society for Sex Therapy and Research</td>
</tr>
<tr>
<td><a href="http://www.sstarnet.org/">http://www.sstarnet.org/</a></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Library Catalogues, Specialized Databases, Internet Peer-reviewed Sites, and Internet Search Engines</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Library catalogues</strong></td>
</tr>
<tr>
<td>WHOLIS (WHO) Library Catalogue</td>
</tr>
<tr>
<td><a href="http://dosei.who.int/">http://dosei.who.int/</a></td>
</tr>
<tr>
<td><strong>Specialized databases and resources</strong></td>
</tr>
<tr>
<td>Centre for Reviews and Dissemination databases</td>
</tr>
<tr>
<td><a href="http://www.crd.york.ac.uk/CRDWeb/">http://www.crd.york.ac.uk/CRDWeb/</a></td>
</tr>
<tr>
<td>Cochrane Library</td>
</tr>
<tr>
<td><a href="http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME">http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME</a></td>
</tr>
<tr>
<td>Intute (Health and Life Sciences Database formerly BIOME)</td>
</tr>
<tr>
<td><a href="http://www.intute.ac.uk/">http://www.intute.ac.uk/</a></td>
</tr>
<tr>
<td><strong>Internet search engines</strong></td>
</tr>
<tr>
<td>Google</td>
</tr>
<tr>
<td>Google Scholar</td>
</tr>
<tr>
<td>Vivisimo</td>
</tr>
</tbody>
</table>