



104

**Guidelines for  
Library Services to Persons with Dementia**

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## TABLE OF CONTENT

Introduction	3
Acknowledgements	3
What is dementia?	4
The most common variations of dementia	4
The stages of dementia	5
A short history of dementia	6
A challenge for public libraries	7
Serving persons with dementia	8
Communicating with persons with dementia	8
Library materials for persons with dementia	9
Library services to the homebound	11
Library services to persons in long-term care facilities and day care centers	11
Cooperation with staff	11
Models for library services	12
Reading representatives	12
Ethnic and cultural minority groups	13
Marketing the library services	13
Conclusion	13
Bibliography	14
Web sites	15
Additional resources	16



## **Introduction**

Over the last decade many countries have paid increasing attention to dementia related diseases, primarily due to the rapid growth of the elderly population. Although dementia is generally considered as an age-related disease, younger people may also suffer from dementia.

A person with dementia will gradually lose his/her memory, the personality may undergo profound changes, physical limitations develop, and the patient will require help with many or most of daily activities. In spite of such mental and physical limitations, a person with dementia can benefit greatly from many types of library services.

The purpose of this guidelines publication is to raise awareness in libraries, among library professionals, care givers, public policy makers, as well as among families and friends of persons suffering from dementia, that many types of library services and materials can help stimulate the memory while providing pleasure and entertainment.

Experience shows that even persons with a middle-stage dementia can benefit from reading literature and obtaining information. These guidelines give practical recommendations on how to provide mental stimulation with books and other library materials. The publication also includes suggestions for library staff on how to tailor such services to the target population. The examples included are mostly taken from public libraries in Denmark.

This publication is part of a series of guidelines publications from the IFLA Standing Committee Libraries Serving Disadvantaged Persons (LSDP) focusing on persons with specific disabilities or special needs. A full list of the LSDP guidelines can be found at the end of this publication.

The authors of "Library Services to Persons with Dementia" will be pleased to answer questions from international colleagues. Please find their contact information at the end of this document.

## **Acknowledgements**

The authors are grateful to the many persons and institutions who contributed to this publication, in particular, the members of the Standing Committee of the IFLA Section of Libraries Serving Disadvantaged Persons, Bror Tronbacke, Director of the Centre for Easy-to-Read in Sweden, The Danish Knowledge Centre on Ageing, The Danish Reminiscence Centre and The Dementia Services Development Centre, Stirling. The authors also thank Vibeke Lehmann, LSDP, for her stylistic and grammatical text editing.

## What is dementia?

According to the [World Health Organization](#)<sup>1</sup> dementia is the result of a disease process. When a person is diagnosed with a form of dementia, e.g., Alzheimer's disease or a related disorder, he/she exhibits clear symptoms of impaired memory, thinking processes, and behavior. Early signs include problems in remembering recent events and difficulty performing routine and familiar tasks. The person may also experience confusion, personality change, behavior change, impaired judgement, difficulties finding words, finishing thoughts, or following directions.

Dementia is not a normal part of ageing. It knows no social, economic, ethnic or geographical boundaries. Although each person will experience dementia in his or her own way, eventually those affected are unable to care for themselves and need help with all aspects of daily life. There is currently no cure for dementia, but medical treatment may postpone the progression of the disease. Dementia is irreversible when caused by disease or injury. It may be reversible if caused by drugs, alcohol, hormonal or vitamin imbalances, or by depression.<sup>2</sup>

## The most common dementia diseases

### Alzheimer's disease (AD)

Alzheimer's disease is the most common cause of dementia. It is estimated that about 60 % of all cases of dementia are related to AD.<sup>2</sup> Alzheimer's disease attacks the parts of the brain that control thought, memory and language.

During the course of AD, nerve cells die in particular regions of the brain and the brain shrinks. This affects people's ability to remember, speak, think and make decisions. The onset of the disease is gradual and the person's decline is usually slow. Currently, the cause of the disease is unknown. AD affects all groups in society and is not related to social class, gender, ethnic group or geographical location. Although AD is more common among elderly persons, younger persons can also be affected.

Alzheimer's Disease affects each person in a different way. Its impact depends largely on what the person was like before the onset of the disease, i.e., personality, physical condition and life style. The symptoms of AD can be best understood in the context of three stages of its development – early, middle and late. As stated before, not all persons with AD will display all these symptoms and the symptoms vary from individual to individual.

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<sup>1</sup> [www.alz.co.uk/adi/pdf/helpforcaregivers](http://www.alz.co.uk/adi/pdf/helpforcaregivers)

<sup>2</sup> [www.alz.co.uk](http://www.alz.co.uk)

## Vascular Dementia

*Vascular dementia accounts for about 20% of all cases of dementia.*

*Vascular disease occurs where blood vessels are damaged and the supply of oxygen is at risk. If oxygen supply fails in the brain, brain cells are likely to die, leading to a series of mini strokes (infarcts) and possible vascular dementia. Cited from: [Alzheimer's Disease International \(ADI\)](#)<sup>1</sup>*

*Some people with vascular dementia find that symptoms remain steady for a time and then suddenly decline as the result of another stroke. This contrasts with the gradual decline many people with Alzheimer's disease experience. It is sometimes difficult to determine whether people have Alzheimer's or vascular dementia. It is also possible to be affected by both. Cited from:*

*[Alzheimer's Disease: help for caregivers. WHO](#)<sup>2</sup>*

## Dementia with Lewy Bodies

*Dementia with Lewy bodies is the third most common cause of dementia and occurs in up to 20% of cases. Dementia with Lewy bodies is similar to Alzheimer's disease in that it is caused by the degeneration and death of nerve cells in the brain. It takes its name from the abnormal collections of protein, known as Lewy bodies, which occur in the nerve cells of the brain.*

*Half or more of people with Lewy body disease also develop symptoms of Parkinson's disease.*

*Cited from: [Alzheimer's Disease International \(ADI\)](#)<sup>1</sup>*

## The stages of dementia

*In **the early stage** the person may*

- *show difficulties with language*
- *experience significant memory loss – especially short-term*
- *be disoriented in time*
- *become lost in familiar places*
- *display difficulty in making decisions*
- *lack initiative and motivation*
- *show signs of depression and aggression*
- *show a loss of interest in hobbies and activities*

*In **the middle stage** the person may:*

- *get very forgetful - especially of recent events and people's names.*
- *can no longer manage to live alone without assistance*
- *be unable to cook, clean and shop*
- *become extremely dependent*
- *need assistance with personal hygiene*
- *have increased difficulty with speech*
- *show problems with wandering and other behavioral abnormalities*

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<sup>1</sup> [www.alz.co.uk](http://www.alz.co.uk)

<sup>2</sup> [www.alz.co.uk/adi/pdf/helpforcaregivers](http://www.alz.co.uk/adi/pdf/helpforcaregivers)

- *become lost at home and in the community*
- *experience hallucinations*

In **the late stage** the person may:

- *have difficulty eating*
- *do not recognize relatives, friends, and familiar objects*
- *have difficulties understanding and interpreting events*
- *be unable to find their way around in the home*
- *have difficulties walking*
- *display inappropriate behavior in public*
- *be confined to a wheel chair or bed*

Cited from: [Alzheimer's disease: help for caregivers. WHO](#)<sup>1</sup>

## A short history of dementia

Dementia, derived from the Latin word *de* = out from + *mens* = the mind means loss or impairment of mental powers due to a disease.

**The Egyptians and Greeks** of the period 2000 - 1000 BC were well aware that advancing years and old age were associated with disorders of the memory.

**The Chinese** used the words *Zhi Dai Zheng* for dementia and *Lao Ren Zhi Dai Zheng* for senile dementia, which was described basically as a disease of old people characterized by muteness, lack of response and craziness.

**The Romans**, i.e. Aulus Cornelius Celsus and Claudius Galen of the first and second centuries AD, referred to chronic mental disorders known to produce an irreversible impairment of higher intellectual functions. Cited from: [WHO. What is dementia? What is Alzheimer's disease?](#)<sup>2</sup>

**Dr. Philippe Pinel** (1745-1826), the French founder of modern psychiatry, first used the word "dementia" in 1797.

In 1906 **Dr. Alois Alzheimer** (1864-1915), a famous German pathologist, described a 55-year old woman who had died from an unusual mental illness causing memory loss, disorientation and hallucinations. Since Dr. Alzheimer first described the characteristic abnormal brain changes, the disease has been known as "**Alzheimer's Disease**".

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<sup>1</sup> [www.alz.co.uk/adi/pdf/helpforcaregivers](http://www.alz.co.uk/adi/pdf/helpforcaregivers)

<sup>2</sup> [www.searo.who.int/en/Section1174/Section1199/Section1567/Section1823.htm](http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1823.htm)

## A challenge for public libraries

*The world's population is ageing. Currently there are an estimated 24 million people worldwide with dementia. Two thirds of these live in developing countries. This figure is set to increase to more than 81 million people by 2040. Much of this increase will be in rapidly developing and heavily populated regions such as China, India, and their south Asian and western pacific neighbors. Cited from: [Alzheimer's Disease International](#)<sup>1</sup>*

In spite of this large number of persons with dementia, it does not appear that public, health, and social services in most countries are sufficiently prioritized to meet their growing needs. With the rate of dementia related diseases growing, it would benefit all segments of society to respond in a more responsible manner to the needs of persons with dementia.

Until now, librarians have not generally been included in the circle of professionals caring for persons with dementia. Frequently, the treatment focuses more on physical care than on mental stimulation.

Most public libraries do not have special services for persons with dementia, although their services are supposed to meet the informational and recreational needs of **all** population groups. In a democratic society, the right of access to culture, literature and information extends to all, including persons with disabilities. Quality of life is an important factor, and everybody is entitled to participate fully in society as long as possible.

Different cultures have different ways of accepting and dealing with persons with dementia, whether these persons live at home or in an institution. Regardless of cultural differences, public libraries can lead the way in tailoring certain services and collections to those with dementia. In the Scandinavian and other Western countries there is a growing understanding and acceptance of this challenge.

Reading materials and music can help stimulate memory, as well as provide enjoyment and entertainment. Reading and listening to music, in particular, stimulate several brain functions. The popular saying **“if you don't use it, you loose it”** has been found to be true. Calm music and meditative chants have also been shown to decrease nervousness and anxiety.

It is important to emphasize that common sense and a warm heart alone cannot cope with dementia – professional insight and expertise are also important parts of the solution. In other words, a solid knowledge of dementia is essential.

The following sections will show how appropriately tailored library services and specific materials can have positive effects on persons with dementia.

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<sup>1</sup> [www.alz.co.uk](http://www.alz.co.uk)

## Serving persons with dementia

Library staff providing services to persons with dementia must be knowledgeable of dementia related diseases and how these patrons may react. There is a large amount of literature available (see Bibliography), and it is strongly recommended that library staff consult with professionals in the field, participate in relevant courses and conferences and, if possible, spend some time with a mentor observing dementia patients in a care facility. If the service project is to be successful, multi-professional cooperation is important.

**Patience and caring** are also required for a successful outcome, as well as close cooperation with the family and caregivers of the patient.

## Communicating with persons with dementia

- **Make eye contact** so the person knows you are talking *to* and not *about* him/her
- **Make sure to get the person's attention** before speaking
- **Speak clearly and slowly.** Make eye contact
- **Pay attention to the body language** of the person with dementia as well as your own, since non-verbal communication is very important for persons with language impairments
- **Use simple language**, short sentences, and avoid foreign words
- **Use repetitions and consistent phrasing** to avoid confusion
- **Be a creative listener** and show understanding, tolerance, and respect
- **Give the person with dementia enough time to answer** and ask questions that can be answered with a simple "yes" or "no." Avoid open-ended questions.
- **Include everyday topics in your conversation**, e.g., the weather, and references to familiar objects that may trigger the memory
- **Be calm and supportive and use comforting gestures**

## Library materials for persons with dementia

Books and audiovisual materials can contribute to the quality of institutional life. By evoking pleasant memories you help the patrons regain their feeling of identity. These persons may have had specific hobbies and interests during their lifetime. Books and music may remind the patrons of these interests and stir memories of childhood, youth, working life and family.

- **Illustrated books**

Persons with dementia usually like books with big and clear illustrations, particularly photos. Popular subjects are animals, flowers, fashion, children, countries, old cars, etc. Children's picture books with big and clear illustrations are appropriate.

- **Books for reading aloud**

Persons with dementia usually enjoy hearing somebody read aloud. The text, however, should be short and have a simple story line. Easy-to-read books for persons with reading difficulties are also appropriate as they are written in short sentences and have an uncomplicated plot. **Essays, fairytales and short stories** are recommended. Books with **jokes, rhymes and jingles from old times and very easy quizzes** have also proven popular. Some persons with dementia enjoy listening to familiar **poems and songs**. They often join the singing and show an amazing ability in remembering the text. Children's materials may also be incorporated into these activities as they can be finished in a single sitting.

- **Thematic books for the staff**

Certain books can be helpful for care staff in their daily contact with the person with dementia. In connection with holiday celebrations, e.g. Christmas and Easter, theme books may be used as conversation starters about old traditions, holiday meals, decorations, etc. It can be very rewarding to experiment with various subjects, using illustrated "**coffee table books**" from different countries.

- **Local history** is popular and so are **biographies of famous persons** written in an easy-to-understand language. **Books about the past** are very suitable for reminiscing and for conversation groups.

- **Audio books for persons with aphasia** are read at a slow speed and can also be used for persons with dementia.

- **Music** is an important medium in the interaction with persons with dementia. Verbal communication is often difficult, but singing, dancing and listening to music are good alternatives. Music gives the person with dementia an opportunity to

- express feelings
- interact with other persons
- remember the past
- express his/her personality
- reduce anxiety and restlessness

Music can be used in small groups or with individuals. The music should be popular and familiar. Examples:

- **Calm classical music** – e.g., special editions for persons with dementia. [Music for the Mozart Effect. Spring Hill Music](#)<sup>1</sup>
- **Music and songs with a special theme** – e.g., the seasons, flowers, love or loss
- **Meditative music** - for relaxation
- **Video and DVDs**  
Everybody likes to watch a good movie. Persons with dementia enjoy watching **old movies** in their native language and from their own country. These movies bring back memories from “the good old days”. Films about **local history** and **nature** are also popular.
- **Other media**  
Other new electronic media, e.g., **computer games**, will be of interest to the new generation of persons with dementia. Many elderly are already familiar with computers. They may enjoy searching on the Internet with help from caregivers, relatives or library staff. The pictures on the computer screen may be used to stimulate conversation and illustrate certain subjects. Library staff can introduce relevant sites to care givers.

- **“Reminiscence kits”**  
Reminiscence kits are very helpful in stimulating memories. In Denmark, libraries and institutions for the elderly can borrow or buy these kits from the Danish Reminiscence Centre.<sup>2</sup> The kits are theme defined and may contain old cooking utensils, old toilet articles for ladies or gentlemen, schools books and supplies, craft items and tools, gardening items, etc. Open the kit and the conversation will start immediately!

In some countries, such reminiscence kits are sold by publishers, e.g., Bi-Folkal Productions in the United States<sup>3</sup>, and Winslow in the UK.<sup>4</sup>

In the Nordic countries there is a growing trend for libraries to develop their own reminiscence kits, sometimes in co-operation with caregivers and local historical societies.

- **Materials on dementia for staff and caregivers**  
A selection of books and other information materials about dementia should also be available to library staff and patient care givers. It is recommended that public libraries offer a broad selection of books and other materials on dementia as part of their general collection.

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<sup>1</sup>[www.springhillmedia.com/b.php?i=8520](http://www.springhillmedia.com/b.php?i=8520)

<sup>2</sup>[www.reminiscens.dk](http://www.reminiscens.dk)

<sup>3</sup>[www.bifolkal.org](http://www.bifolkal.org)

<sup>4</sup>[www.winslow-cat.com](http://www.winslow-cat.com)

## Library services to the homebound

Persons with dementia living in their own homes can be served through the library's home delivery service or via Books-by-Mail. Persons with dementia should be an obvious target population for these library outreach services.

It is important to **visit a new patron at home** in order to identify the specific needs of that person. Many homebound persons in the early stage of dementia live with a spouse or relatives. It is important that these caregivers are present at the initial visit by library staff and that a family member acts as a contact person for continuing services. Outreach services to homebound dementia patients require understanding of the patient's individual situation. It is difficult to cope with the daily care and needs of a person with dementia, but providing the right book, music, or information can add vastly to the quality of life for both patient and caregiver. Homecare aides and other outside support staff should also be familiar with the services from the library and should be encouraged to contact the library on behalf of their client.

## Library services to persons in long-term care facilities and day care centers

### Long-term care facilities

In long-term care facilities an increasing number of the residents suffer from dementia related diseases. In some countries, special facilities for persons with dementia are now being established. These facilities will have some staff members with special education in dementia.

### Day care centers

In some countries, community day care centers for persons with dementia have been established. Here the visitors spend half or whole days occupied with various hobbies, excursions and other entertaining activities. Books and other materials from the library are much appreciated by the users of the day care centers.

## Cooperation with staff

Offering library services to persons with dementia has turned out to be very successful. It is important that the library staff that makes regular visits to the care facilities, interacts closely with the facility staff. If possible, library staff should participate in facility staff meetings.

As persons with dementia cope better when certain routines are incorporated into their daily life, it is preferable that the visiting library staff remain the same over a period of time.

**Ask questions** and **involve** the facility staff in the planning of library services. Keep in mind that it may take some time for the care staff to realize how much your services can contribute to the quality of life of the residents.

## **The important dialogue**

Before delivering library materials, let your designated contact person know what materials you intend to bring. Ask that person to recommend topics of interest.

Take care to nurture your contact with both residents and staff each time you visit. Offer to bring books to the staff for their professional and private use.

If the institution has a group for relatives and friends of the residents, you can attend a group meeting and discuss your library services.

## **Models for library services**

Library services can be provided in different ways, including:

### **1. Library services by a librarian on a regular basis (e.g. once a month)**

The librarian visits all departments of the institution bringing books, music, and other materials for those residents who are interested.

This service should be supplemented by a **small collection of books and music** in the living or activities room. This collection should be changed at each visit.

### **2. A selection of books, music recordings, and other materials at various locations in the institution**

Replace the collection every three months. When exchanging collections, ask staff and residents for suggestions and recommendations.

### **3. Visitors to day care centers**

Persons with dementia coming to day care centers should be given the opportunity to join the library's home delivery service.

## **Special programs and events in the institution**

Some librarians serving persons with dementia have very positive experiences with arranging special programs and events in the institutions. These arrangements can be reading aloud, showing movies or playing music. Arrangements can be made in co-operation with institution staff or perhaps a music therapist. Book talks by the librarian can be an enjoyable activity and may lead to a joint discussion.

## **Reading representatives**

Some years ago the Swedish Centre for Easy-to-Read started a new project: "Läs Ombud" (Reading Representatives). The representatives are primarily recruited among the staff in long-term care-facilities and day care centers. Similar services could be provided for persons with dementia. The purpose of the Reading Representatives is to stimulate interest in reading and to arrange read aloud sessions (primarily with easy-to-read books,

short essays, and news stories) and visits to libraries. The Reading Representatives are trained by and maintain close contact with the local public library.<sup>1</sup>

## **Ethnic and cultural minority groups**

Libraries should make sure that the needs and interests of all ethnic and cultural minority groups in the community are considered when planning services to persons with dementia. This means selecting library materials that reflect the history and experience of these groups. Some members of these groups may be illiterate or weak readers and for these individuals videos and music from their native country will be popular.

Many bilingual persons with dementia may at some point forget their “new” language. In such cases, library staff may have to rely on family members or other staff speaking the language in question to establish a co-operation.

## **Marketing the library services**

The library should produce a brochure about the services offered to persons with dementia. The brochure should inform about services to homebound persons with dementia, as well as services to institutions. The brochure should be displayed in the library and should also be distributed to doctors, nurses, social workers, public information centers and other places where the elderly and their relatives meet. Equally important is the electronic marketing of the library services and the brochure content should also be posted on the library's webpage.

## **Conclusion**

The authors hope that this publication will inspire colleagues around the world to meet the challenge of serving persons with dementia.

The ultimate goal should be to make library services to this population group a part of the library's basic services. Persons with dementia have just as diverse tastes and preferences as other library patrons but have additional needs, which the library is in a unique position to meet jointly with other service providers. Working with persons with dementia is certainly challenging and requires special insight and knowledge. The rewards, however, are gratifying when the patient clearly exhibits signs of both physical and mental stimulation as the result of such efforts.

These guidelines provide basic information on different dementia related diseases, suggest various ways to establish library services to persons with dementia, and recommend appropriate materials and resources for such services. Library staff in countries around the world may adapt these guidelines to their local circumstances and may want to add additional elements.

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<sup>1</sup> [www.lattlast.se/?page=162](http://www.lattlast.se/?page=162)

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The Art of Dementia Care. By Daniel Kuhn and Jane Verity. Thomas Delmar Learning, 2008. Publish Date 07/20/2007. ISBN: 140189951X

Kitwood, Tom: Dementia Reconsidered: the Person Comes First. Buckingham: Open University Press, 1997. Reprinted 1998, 2000, 2001

Larsen, Jeannette: Library Service in the Year 2007 – With Yesterday's Objects. LSDP Newsletter, 64, June 2007

Verity, Jane: Joyful Activities for People with Dementia. Dementia Care Australia, 1997

## Web sites

### **Alzheimer's Disease International (ADI)**

Umbrella organization of Alzheimer associations (with addresses on associations worldwide)

[www.alz.co.uk](http://www.alz.co.uk) [Accessed 01/05/2007]

### **The Alzheimer's Association**

USA

[www.alz.org](http://www.alz.org) [Accessed 01/05/2007]

### **Alzheimer's & Related Disorders Society of India**

[www.alzheimer-india.org](http://www.alzheimer-india.org) [Accessed 01/05/2007]

### **Alzheimer Europe**

UK (except Scotland)

[www.alzheimers.org.uk](http://www.alzheimers.org.uk) [Accessed 01/05/2007]

### **Alzheimer Iberoamerica**

Latin America

[aib.alzheimer-online.org](http://aib.alzheimer-online.org) [Accessed 01/05/2007]

### **Bifolkal Productions**

USA

[www.bifolkal.org](http://www.bifolkal.org) [Accessed 01/05/2007]

### **Chinese Association of Alzheimer's Disease and Related Disorders**

[www.adc.org.cn](http://www.adc.org.cn) [Accessed 01/05/2007]

### **The Danish Reminiscence Centre**

[www.reminiscens.dk](http://www.reminiscens.dk) [Accessed 01/05/2007]

### **Dementia Care Australia**

[www.dementiacareaustralia.com](http://www.dementiacareaustralia.com) [Accessed 01/05/2007]

### **The Dementia Services Centre**

[www.dementia.stir.ac.uk/about.htm](http://www.dementia.stir.ac.uk/about.htm) [Accessed 01/05/2007]

### **Glasgow Museums Resource Centre**

[www.glasgowmuseums.com/venue/index.cfm?venueid=14](http://www.glasgowmuseums.com/venue/index.cfm?venueid=14) [Accessed 01/05/2007]

### **The Reminiscence Centre, London**

[www.age-exchange.org.uk](http://www.age-exchange.org.uk) [Accessed 01/05/2007]

### **Winslow**

[www.winslow-cat.com](http://www.winslow-cat.com) [Accessed 01/05/2007]

### **World Health Organizations (WHO)**

[www.who.int/en](http://www.who.int/en) [Accessed 01/05/2007]

## Additional resources

### IFLA Guidelines

Bror Tronbacke: Guidelines for Easy-to-Read Materials. 1997. (IFLA Professional Report No. 54)

[www.ifla.org](http://www.ifla.org)

Nancy Mary Panella: Guidelines for Libraries Serving Hospital Patients and the Elderly and Disabled in Long-Term Care Facilities. 2000. (IFLA Professional Report No. 61)

[www.ifla.org](http://www.ifla.org)

Guidelines for Library Services to Persons with Dyslexia. By Gyda Skat Nielsen and Birgitta Irvall. 2001. (IFLA Professional Report No. 70)

[www.ifla.org](http://www.ifla.org)

International Resource Book for Libraries Serving Disadvantaged Persons. By Joanne Locke and Nancy Mary Panella (Eds.). 2001. (IFLA Professional Report No. 96)

[www.ifla.org](http://www.ifla.org)

Guidelines for Libraries Service to Prisoners. By Vibeke Lehmann and Joanne Locke. 2005. (IFLA Professional Report No.46)

[www.ifla.org](http://www.ifla.org)

Access to Library for Persons with Disabilities. CHECKLIST. By Birgitta Irvall and Gyda Skat Nielsen. 2005. (IFLA Professional Report No. 89)

[www.ifla.org](http://www.ifla.org)

### The authors

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**Gyda Skat Nielsen** was the head of the Department of Outreach Services at the Sollerod Public Libraries until the end of 2005. She has been a member of IFLA's Standing Committee for Libraries Serving Disadvantaged Persons (LSDP) from 1997 to 2005. From 2005 she is a Correspondent Member of the LSDP. Gyda Skat Nielsen has several years' of experience in serving persons with dementia both in their homes and in institutions. She is now a freelance library consultant.  
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