

Supporting Dementia Self Advocates: A Directory of Resources



Foreword

I'm very pleased to have been involved in the development of this resource and very happy to see the advocacy knowledge and activity happening around the world being pulled together.

Back in 2012, I somewhat reluctantly 'fell' into advocacy and my participation grew from there. My initial worries and fears would have been reduced had I had access to this directory of resources. Six years on, I still find this information helpful, not only for its content but it is always good to know what to expect, what is good practice and that your thoughts are generally in tune with those doing similar work.

I hope you find it as useful as I have. I hope it enables you to go to places you never thought possible. I hope you feel proud of your achievements because everyone who speaks out makes a difference.

I'm looking forward to hearing new voices

A handwritten signature in blue ink that reads "Hilary" with a stylized flourish underneath.

Hilary Doxford

3 Nations Dementia Working Group

This project was initiated with the goal of capacity building and highlighting inspiration to people with dementia to become self-advocates. What is unique about it is that people with dementia are theoretically losing capacity, and yet, with strategies and disability supports, so many will find ways to continue to live meaningful lives in their own communities, or as advocates, locally, nationally and globally. What dementia advocates have shown for more than two decades, is that with the right support, it is possible to continue to contribute significantly to society, and to live a more positive life than expected with dementia. The vision of Dementia Alliance International is “a world where people with dementia are valued and included.” The partners of this project and the many contributors all share these goals, and hope this directory and video resource increase the inclusion and participation of many more self-advocates. Together, we are stronger.

Kate Swaffer

Chair, CEO & co-founding member
Dementia Alliance International

About this directory:

Dementia Alliance International (DAI), 3 Nations Dementia Working Group (3NDWG) and Alzheimer's Society (via its International and Dementia Voice teams) worked as partners to deliver a small capacity building project for self-advocacy and inclusion in the dementia arena. The project aimed to identify the barriers as well as tools to support inclusion of people impacted by dementia in campaign activity and self-advocacy.

This directory is one of the project outputs. It collates relevant existing resources that support inclusive working, including tools to support self-advocacy and resources to help organisations work more inclusively.

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Disclaimer

DAI, 3NDWG and Alzheimer's Society are committed to the highest standards of information quality and every attempt has been made to provide up to date and accurate information at the time of publishing.

However, DAI, 3NDWG and Alzheimer's Society give no warranty, either expressed or implied, as to the accuracy of the information in this resource and accepts no liability for any loss, damage or inconvenience caused as a result of reliance on such information.

External links are provided in this material to provide users with relevant information. DAI, 3NDWG and Alzheimer's Society cannot guarantee that such links will always work, and make no representations as to the quality or accuracy of the sites linked to. DAI, 3NDWG and Alzheimer's Society do not endorse any external sites and are not responsible for their content.

New resources and adaptations will be made for future versions of this directory. However as new resources emerge the list below may no longer represent the views or the current preferred language of dementia advocates.

How to use the directory

This resource was created to signpost to existing dementia and non-dementia specific resources to support people impacted by dementia to engage in campaign activity. The resource can also be used by those working with people impacted by dementia.

Resources are categorised into dementia-specific and non-dementia specific and then classified under the nine themes below.

Each resource is specified by type (toolkit, practical tip, factsheet or video) and also includes the barrier to inclusion it addresses.

Resource themes

- Dementia inclusive/ friendly/ accessible events
- Inclusive language
- Engaging and consulting with people with dementia
- Self-advocacy on dementia
- Human rights
- Co-production, access and participation
- Campaigning- strategy and tips
- General self-advocacy
- Safeguarding

Resource types

- Toolkit ✨
- Practical tips ♦ (often within the body of a report/document)
- Factsheet □
- Video ★

Barriers resources address:

- General accessibility (physical and social)
- Dementia-specific accessibility (physical and social)
- Discriminatory language (based on condition)
- Stigma (based on condition, age or gender)
- Engagement & representation (identifying, engaging and participating)
- Confidence & skills development (to participate in campaign and self-advocacy work)
- Protection (of at risk groups)

Table of Contents

Foreword	1
About this directory:	1
Disclaimer	1
How to use the directory	2
Resource themes	2
Resource types	2
Barriers resources address:	2
Dementia specific resources	6
1. Dementia inclusive/friendly/ accessible events	7
1.1. Supporting and Accommodating People with Dementia at Professional Conferences and other Events	7
1.2. Involving People with Dementia as Members of Steering or Advisory Groups.....	7
1.3. Setting up an Influencing Group	7
2. Inclusive language	8
2.1. Person Centred Language Guideline.....	8
2.2. How to spot (and challenge) negative language in the media.....	8
2.3. Dementia Friendly Language.....	8
2.4. Dementia Language Guidelines	9
2.5. Dementia Words Matter: Guidelines on Language about Dementia.....	9
2.6. Guide for journalists	9
3. Engaging and consulting with people with dementia	10
3.1. How to Include People with Dementia in the Activities of Alzheimer Associations	10
3.2. Meaningful Engagement & Representation of People with Dementia.....	10
3.3. Strengthening the Involvement of People with Dementia	11
3.4. From Seldom Heard to Seen & Heard.....	11
3.5. Collecting the Views of People with Dementia.....	11
3.6. Listen to Us: Involving People with Dementia in Planning and Developing Services.....	11
3.7. Devising a Dementia Toolkit for Effective Communication	12
3.8. Core Principles for Involving People with Dementia in Research.....	12

3.9. Involving People with Dementia: Making Involvement Count.....	12
4. Self-advocacy on dementia	13
4.1. I Can! I Will! Idea library: Raising public awareness	13
4.2. Self-advocacy strategies- library of resources for people affected by dementia.....	13
4.3. Self-advocate video stories	13
4.4. Speaking up about Dementia: a Simple Guide to Raising your Voice	14
4.5. Hello Our Voices Matter.....	14
4.6. The Many Voices of Dementia Advocacy	14
4.7. Hear What I Say: Developing Dementia Advocacy Services.....	14
4.8. Making an Impact Together	15
4.9. Independent Advocacy for People Living with Dementia and Unpaid Carers	15
4.10. Sound Bytes After Diagnosis.....	15
4.11. Collection of videos by Ontario Dementia Advisory Group (ODAG) on Facebook group page.....	15
5. Human rights	16
5.1. Brief for Alzheimer Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People living with Dementia.....	16
5.2. Extending Community-based Rehabilitation (CBR) to Older Persons: a Global Imperative.....	16
5.3. The Human Rights of People Living with Dementia: from Rhetoric to Reality	17
5.4 Our Dementia Our Rights.....	17
5.5 By Us for Us Guides- Library of resource files and links	17
5.6 PANEL and the Charter of Rights	17
5.7 The Rights of Persons with Dementia.....	18
Non-dementia specific resources	19
6. Co-production, access and participation.....	20
6.1. Towards Inclusion: a Guide for Organisations and Practitioners (2017).....	20
6.2. Digital accessibility Toolkit – Tools and Guidance for Producing Accessible Content (2018)	20
6.3. Inclusion Made Easy - a Quick Program Guide to Disability in Development	21
6.4. 6 ways to make your sessions more inclusive.....	21

6.5. Report on Good Practice in E-inclusion, Ethical Guidance and Designing a Roadmap (2009)	21
6.6. Disability Inclusion Toolkit Enabling Inclusive Youth Work (2016).....	21
6.7. Lived experience influence participation toolkit – library of resources	22
6.8. Framework for Patient and Public Participation in Primary Care Commissioning	22
6.9. Inclusion: Making it Happen - Key Elements for Disability Organisations to Facilitate Inclusion.....	22
6.10. Co-production in social care: What it is and how to do it.....	22
6.11. Co-production with different groups	23
6.12. The Co-production Commitment.....	23
7. Campaigning - strategy and tips	24
7.1. Guidance Note: Good Practice Approaches for Engaging with Social Movements for Women's Rights	24
7.2. NCVO Knowledge Bank: campaigns and awareness.....	24
7.3. Your guide to campaigning with Oxfam	24
7.4. Seeds for Change Knowledge Bank: campaigns, co-ops or projects.....	25
8. General self-advocacy	26
8.1. Being Heard: a Self-advocacy Guide for Carers	26
8.2. Campaigning and advocacy factsheets and guides	26
8.3. Self-advocacy for Inclusion: a Global Report.....	27
8.4. The Advocacy Charter	27
8.5. Empowerment - a Guide to Influencing your Local Services	27
8.6. Celebrating 10 years of the CRPD	27
8.7. Advocacy Toolkit.....	28
8.8. Advocacy skill building toolkit.....	28
8.9. Voiceability advocacy resources	28
8.10. Advocacy Toolkit Skills for Effective Self and Peer Advocacy.....	29
9. Safeguarding.....	30
9.1. Safeguarding Adults Policy May 2018.....	30
9.2. Safeguarding Adults at Risk of Harm Toolkit – library of resources	30
9.3. Guidelines for working with vulnerable groups.....	31
9.4. Young People and Legal Consent Sheet 1: Background to Consent.....	31
Barriers index	32
Contact information for additional support:.....	39

Dementia specific resources

1. Dementia inclusive/friendly/ accessible events

Contents:

- 1.1. Supporting and Accommodating People with Dementia at Professional Conferences and Other Events
- 1.2. Involving People with Dementia as Members of Steering or Advisory Groups
- 1.3. Setting up an Influencing Group

Number and name of resource	1.1. Supporting and Accommodating People with Dementia at Professional Conferences and other Events
Summary of content	Practical recommendations when inviting people living with dementia to conferences and creating accessible and inclusive venues, e.g. tips for using language, time event, accessible presentations etc.
Source	Dementia Alliance International (DAI)
Resource type	Practical tips ◆
Barriers addressing	Dementia-specific accessibility
URL	https://www.dementiaallianceinternational.org/wp-content/uploads/2016/10/Supporting-and-Accommodating-People-with-Dementia-at-Conferences-and-Other-Events_2016.pdf

Number and name of resource	1.2. Involving People with Dementia as Members of Steering or Advisory Groups
Summary of content	Resource provides guidance to make adjustments to support people with dementia to take an active role in steering/advisory groups.
Source	Dementia Engagement and Empowerment Project (DEEP)
Resource type	Toolkit ✨
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	http://dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf

Number and name of resource	1.3. Setting up an Influencing Group
Summary of content	Resource with principles, practical and inclusion pointers, dementia friendly meetings and groups
Source	Dementia Engagement and Empowerment Project (DEEP)
Resource type	Factsheet □
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	https://www.dementivoices.org.uk/wp-content/uploads/2016/01/DEEPGuide-Setting-up-an-influencing-group.pdf

[Back to table of contents](#)

2. Inclusive language

Contents:

- 2.1. How to spot (and challenge) negative language in the media
- 2.2. Person Centred Language Guideline
- 2.3. Dementia Friendly Language
- 2.4. Dementia Language Guidelines
- 2.5. Dementia Words Matter: Guidelines on Language about Dementia
- 2.6. Guide for journalists

Number and name of resource	2.1. Person Centred Language Guideline
Summary of content	The guidelines introduce person-centred terms meant to maintain dignity and respect. The person-centred language focuses on the person, not on their condition and helps reduce the fear and stigma surrounding dementia.
Source	Alzheimer Society of Canada
Resource type	Toolkit ✨
Barriers addressing	Discriminatory language Stigma
URL	https://alzheimer.ca/sites/default/files/2017-11/Person_Centred_Language_Guidelines-e.pdf

Number and name of resource	2.2. How to spot (and challenge) negative language in the media
Summary of content	A blog from the Alzheimer's Society advising on how people can challenge negative language and harmful stereotypes. Provides a link to the dementia-friendly media and broadcast guide, which calls on journalists and broadcasters to change the conversation around dementia.
Source	Alzheimer's Society
Resource type	Practical tips ◆
Barriers addressing	Discriminatory language Stigma
URL	https://www.alzheimers.org.uk/blog/how-spot-and-challenge-negative-language-media

Number and name of resource	2.3. Dementia Friendly Language
Summary of content	Resource highlights the importance of language as a tool to empower people living with dementia. Provides preferred terms for the condition, people and impact.
Source	The Alzheimer Society of Ireland
Resource type	Toolkit ✨
Barriers addressing	Discriminatory language Stigma
URL	https://alzheimer.ie/wp-content/uploads/2018/12/Dementia-Friendly-Language.pdf

Inclusive language

Number and name of resource	2.4. Dementia Language Guidelines
Summary of content	Promotes the consistent use of appropriate, inclusive and non-stigmatising language when talking or writing about dementia and people living with dementia.
Source	Dementia Australia
Resource type	Toolkit ✳
Barriers addressing	Discriminatory language Stigma
URL	https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf

Number and name of resource	2.5. Dementia Words Matter: Guidelines on Language about Dementia
Summary of content	This guide is primarily for journalists, organisations and communications departments. The recommendations were made by people with dementia to promote accurate, balanced and respectful terms.
Source	Dementia Engagement and Empowerment Project (DEEP)
Resource type	Toolkit ✳
Barriers addressing	Discriminatory language Stigma
URL	http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

Number and name of resource	2.6. Guide for journalists
Summary of content	A webpage compiling facts and figures for journalists and those with an interest in young onset dementia. The webpage also includes guidance around what Young Dementia UK considers to be acceptable terminology and preferred language when writing about young people with dementia.
Source	Young Dementia UK
Resource type	Factsheet □
Barriers addressing	Discriminatory language Stigma
URL	https://www.youngdementiauk.org/guide-journalists

[Back to table of contents](#)

3. Engaging and consulting with people with dementia

Contents:

- 3.1. How to Include People with Dementia in the Activities of Alzheimer Associations
- 3.2. Meaningful Engagement & Representation of People with Dementia
- 3.3. Strengthening the Involvement of People with Dementia
- 3.4. From Seldom Heard to Seen & Heard
- 3.5. Collecting the Views of People with Dementia
- 3.6. Listen to Us: Involving People with Dementia in Planning and Developing Services
- 3.7. Devising a Dementia Toolkit for Effective Communication
- 3.8. Core Principles for Involving People with Dementia in Research
- 3.9. Involving People with Dementia: Making Involvement Count

Number and name of resource	3.1. How to Include People with Dementia in the Activities of Alzheimer Associations
Summary of content	Written to guide staff and volunteers of Alzheimer's associations on ways to be more inclusive of people with dementia. Examples include: supporting sharing of direct experiences to the development of programmes and services and helping Alzheimer associations develop a greater understanding about the experience of people living with dementia. The resource aims to help reduce stigma, inequality and discrimination and enable a person with dementia to feel valued and included.
Source	Alzheimer's Disease International (ADI)
Resource type	Factsheet □
Barriers addressing	Dementia-specific accessibility Engagement & representation Stigma
URL	https://www.alz.co.uk/adi/pdf/involving_pwd.pdf

Number	3.2. Meaningful Engagement & Representation of People with Dementia
Summary of content	Created for staff and volunteers of all organisations working and involving people with dementia. The guide is designed to foster relationship building between staff and volunteers and people with dementia; promote the inclusion of the voices of those with dementia; improve meaningful engagement and capacity building within organisations to collaboratively address the needs of persons with dementia.
Source	Alzheimer Society of Canada
Resource type	Toolkit ✨
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	https://alzheimer.ca/sites/default/files/files/national/meaningful-engagement/meaningful_engagement_e.pdf

Engaging and consulting with people with dementia

Number and name of resource	3.3. Strengthening the Involvement of People with Dementia
Summary of content	Written to facilitate involving people with dementia in the planning, delivery and evaluation of health, social care and other support services.
Source	Care Services Improvement Partnership (CSIP) Older Peoples Mental Health programme
Resource type	Toolkit ✨
Barriers addressing	Discriminatory language Stigma
URL	https://dementiapartnerships.com/wp-content/uploads/sites/2/strengthening-involvement.pdf

Number and name of resource	3.4. From Seldom Heard to Seen & Heard
Summary of content	Website of the campaign bringing members of Dementia Alliance International (DAA) together to improve outcomes for people living with dementia and their carers who come from seldom heard groups.
Source	Dementia Action Alliance (DAA)
Resource type	Practical tips ◆
Barriers addressing	Engagement & representation Stigma
URL	https://www.dementiaaction.org.uk/joint_work/dementia_and_seldom_heard_groups

Number and name of resource	3.5. Collecting the Views of People with Dementia
Summary of content	Resource provides tips for organisations and local services to engage with people with dementia and collect their views on dementia policy, services and support in an organised, respectful and supportive way.
Source	Dementia Engagement and Empowerment Project (DEEP)
Resource type	Toolkit ✨
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	http://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf

Number and name of resource	3.6. Listen to Us: Involving People with Dementia in Planning and Developing Services
Summary of content	The report explores how people with dementia can be involved in service planning and development of services. It also aims to assist in developing policies and practices that are needed to enable people with dementia to contribute as fully as possible.
Source	Dementia North Centre
Resource type	Practical tips ◆
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	http://www.mentalhealthpromotion.net/resources/listen-to-us.pdf

Engaging and consulting with people with dementia

Number and name of resource	3.7. Devising a Dementia Toolkit for Effective Communication
Summary of content	Practical advice on effective participation of people living with dementia through a person-centred approach lens. (*Requires subscription to journal)
Source	Nursing and Residential Care Journal
Resource type	Toolkit ✱
Barriers addressing	Dementia-specific accessibility; Engagement & representation
URL	https://www.magonlinelibrary.com/doi/abs/10.12968/nrec.2012.14.3

Number and name of resource	3.8. Core Principles for Involving People with Dementia in Research
Summary of content	Primarily intended for research purposes, these principles can be used in any inclusion project. The principles challenge researchers across all disciplines to evaluate how people living with dementia are involved and valued in research but also to think about how knowledge is constructed in dementia research.
Source	Scottish Dementia Working Group (SDWG)- Research sub-group
Resource type	Practical tips ◆
Barriers addressing	Dementia-specific accessibility Engagement & representation Discriminatory language
URL	http://dementiavoices.org.uk/wp-content/uploads/2014/06/Involving-people-with-dementia-in-research1.pdf

Number and name of resource	3.9. Involving People with Dementia: Making Involvement Count
Summary of content	Resource written by people living with dementia, care supporters, volunteers, staff and Local Involvement Networks (Links) Health Watch to give practical communication and language examples. It provides tools and techniques for staff to facilitate and support people to express their preferences and get involved in activities.
Source	South West Dementia Partnership
Resource type	Toolkit ✱
Barriers addressing	Engagement & representation Discriminatory language Stigma
URL	https://dementiapartnerships.com/wp-content/uploads/sites/2/what-works-resource-pack.pdf

[Back to table of contents](#)

4. Self-advocacy on dementia

Contents:

- 4.1. I CAN! I WILL! Idea library: Raising public awareness
- 4.2. Self-advocacy strategies- library of resources for people affected by dementia
- 4.3. Self-advocate video stories
- 4.4. Speaking Up About Dementia: A Simple Guide to Raising Your Voice 14
- 4.5. Hello Our Voices Matter
- 4.6. The Many Voices of Dementia Advocacy
- 4.7. Hear What I Say: Developing Dementia Advocacy Services
- 4.8. Making an Impact Together
- 4.9. Independent Advocacy for People Living with Dementia and Unpaid Carers
- 4.10. Sound bytes After Diagnosis
- 4.11. Collection of videos by Ontario Dementia Advisory Group (ODAG) on Facebook group page

Number and name of resource	4.1. I Can! I Will! Idea library: Raising public awareness
Summary of content	Dementia specific platform for people wanting to raise awareness of dementia.
Source	Alzheimer's Disease International (ADI)
Resource type	Factsheet □
Barriers addressing	Discriminatory language Stigma Engagement & representation
URL	https://icaniwill.alz.co.uk/icaniwill/library/people-with-dementia/raise_awareness.html

Number and name of resource	4.2. Self-advocacy strategies- library of resources for people affected by dementia
Summary of content	Series of factsheets offering guidance on advocating for people affected by dementia
Source	Alzheimer Society British Columbia
Resource type	Toolkit ✨
Barriers addressing	Engagement & representation Confidence & skills development
URL	https://alzheimer.ca/en/bc/Get-involved/Advocacy/Self-advocacy-strategies

Number and name of resource	4.3. Self-advocate video stories
Summary of content	A collection of 6 videos featuring people with dementia who have become advocates, sharing their journeys and stories.
Source	Alzheimer Society British Columbia
Resource type	Video ★
Barriers addressing	Engagement & representation Confidence & skills development
URL	https://www.youtube.com/playlist?list=PLQ9NxeOiTFhSakB5pZNDmSCUe7ZRRWiDw

Self-advocacy on dementia

Number and name of resource	4.4. Speaking up about Dementia: a Simple Guide to Raising your Voice
Summary of content	A guide to learn more about becoming an advocate. Explains what advocacy is, how to speak to others about dementia, and offers tips and examples of templates.
Source	Alzheimer Society British Columbia
Resource type	Practical tips ◆
Barriers addressing	Discriminatory language Stigma
URL	https://alzheimer.ca/sites/default/files/files/bc/advocacy-and-education/advocacy/2016-03-05_advocacy%20guide.pdf

Number and name of resource	4.5. Hello Our Voices Matter
Summary of content	Part of the DAI website, this page includes a collection of videos of DAI members sharing their personal stories of being diagnosed, and then living with dementia.
Source	Dementia Alliance International (DAI)
Resource type	Videos ★
Barriers addressing	Engagement & representation Stigma
URL	https://www.dementiaallianceinternational.org/services/hello-our-voices-matter/

Number and name of resource	4.6. The Many Voices of Dementia Advocacy
Summary of content	A short film aimed at supporting and encouraging people affected by dementia to self-advocate, speak publicly and/or develop confidence to represent themselves. The film contains short clips of people living with dementia talking about their experiences of self-advocating, motivation and tips on speaking publically.
Source	Dementia Alliance International (DAI), 3 Nations Dementia Working Group and Alzheimer's Society
Resource type	Video ★
Barriers addressing	Confidence & skills development Engagement & representation Stigma
URL	https://youtu.be/CE9TVGS-Jww

Number and name of resource	4.7. Hear What I Say: Developing Dementia Advocacy Services
Summary of content	Resource gives an overview of dementia advocacy (2003) in the UK and suggestions of how to establish new services and develop existing ones.
Source	Dementia North Centre
Resource type	Practical tips ◆
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	https://www.bjf.org.uk/web/documents/resources/HearWhatISay.pdf

Self-advocacy on dementia

Number and name of resource	4.8. Making an Impact Together
Summary of content	The aim of the guide is to help other people with dementia in influencing and activism groups.
Source	Dementia Engagement and Empowerment Project (DEEP) and Innovations in Dementia
Resource type	Toolkit 🌟
Barriers addressing	Engagement & representation Confidence & skills development
URL	http://www.dementiavoices.org.uk/wp-content/uploads/2016/11/Making-An-Impact-Together.pdf

Number and name of resource	4.9. Independent Advocacy for People Living with Dementia and Unpaid Carers
Summary of content	A scoping study commissioned by the Life Changes Trust in order to establish the progress of independent advocacy and dementia in Scotland in 2016.
Source	Life Changes Trust
Resource type	Factsheet ☐
Barriers addressing	Engagement & representation
URL	https://www.lifechangestrust.org.uk/sites/default/files/publications/Independant%20Advocacy%20and%20Dementia%20Report.pdf

Number and name of resource	4.10. Sound Bytes After Diagnosis
Summary of content	The video shares soundbites to follow after a dementia diagnosis. Created by a person with dementia.
Source	Ontario Dementia Advisory Group (ODAG)
Resource type	Video ★
Barriers addressing	Engagement & representation Stigma
URL	https://www.youtube.com/watch?v=EvdFCs9qxNQ

Number name of resource	4.11. Collection of videos by Ontario Dementia Advisory Group (ODAG) on Facebook group page
Summary of content	A collection of videos developed to support ODAG's strategy. The videos highlight the importance of collaboration with people with dementia, and develop best practices for companies creating products and services for people with dementia.
Source	Ontario Dementia Advisory Group (ODAG)
Resource type	Video ★
Barriers addressing	Engagement & representation Stigma
URL	https://www.facebook.com/pg/OntarioDementiaAdvisoryGroup/videos/?ref=page_internal

[Back to table of contents](#)

5. Human rights

Contents:

- 5.1. Brief for Alzheimer associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People living with Dementia.
- 5.2. Extending Community-based rehabilitation (CBR) to older persons: A Global Imperative
- 5.3. The Human Rights of People Living with Dementia: from Rhetoric to Reality
- 5.4 Our Dementia our Rights
- 5.5 By Us for Us Guides
- 5.6 PANEL and the Charter of Rights
- 5.7 The Rights of Persons with Dementia

Number and name of resource	5.1. Brief for Alzheimer Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People living with Dementia.
Summary of content	Created to enable Alzheimer associations to monitor the protection of the rights of persons with dementia under the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
Source	Alzheimer's Disease International (ADI) and Dementia Alliance International (DAI)
Resource type	Factsheet □
Barriers addressing	Dementia-specific accessibility Engagement & representation Protection
URL	https://www.alz.co.uk/sites/default/files/pdfs/crpd-brief-alzheimer-associations.pdf

Number and name of resource	5.2. Extending Community-based Rehabilitation (CBR) to Older Persons: a Global Imperative
Summary of content	Video presentation of Prof. Peter Mittler made for the 2nd World CBR congress conference in Kuala Lumpur in September 2016.
Source	Dementia Alliance International (DAI)
Resource type	Video ★
Barriers addressing	Engagement & representation
URL	https://www.youtube.com/watch?v=Qzcui3mLOUQ

Human rights

Number and name of resource	5.3. The Human Rights of People Living with Dementia: from Rhetoric to Reality
Summary of content	Resource includes section on ways Alzheimer associations and self-advocacy organisations can use the United Nations Convention on the Rights of Persons with Disabilities to make a difference at the policy level.
Source	Dementia Alliance International (DAI)
Resource type	Practical tips ◆
Barriers addressing	Engagement & representation
URL	https://www.dementiaallianceinternational.org/wp-content/uploads/2016/05/Human-Rights-for-People-Living-with-Dementia-Rhetoric-to-Reality.pdf

Number and name of resource	5.4 Our Dementia Our Rights
Summary of content	The purpose of this guide is to bring facts about some of the key rights relating to dementia in the UK together in one place. In doing this, the resource hopes to empower people with dementia, their carers and their advocates to use their rights. There is reference to campaigning together, support and advocacy
Source	Dementia Engagement and Empowerment Project (DEEP) and & Innovations in Dementia
Resource type	Factsheet □
Barriers addressing	Dementia-specific accessibility Engagement & representation
URL	http://dementivoices.org.uk/wp-content/uploads/2016/11/Our-dementia-Our-rights-booklet.pdf

Number and name of resource	5.5 By Us for Us Guides- Library of resource files and links
Summary of content	A series of guides created by people with dementia and/or partners in care. The guides are designed to equip people with dementia with the necessary tools to enhance their well-being and manage daily challenges.
Source	Research Institute for Aging
Resource type	Toolkit ✱
Barriers addressing	Dementia-specific accessibility Engagement & representation Protection
URL	https://the-ria.ca/resources/by-us-for-us-guides/

Number and name of resource	5.6 PANEL and the Charter of Rights
Summary of content	The Cross-Party Group on Alzheimer's at the Scottish Parliament produced a Charter of Rights which aims to empower people with dementia and those who support them to ensure their rights are respected.
Source	Scottish Human Rights Commission
Resource type	Factsheet □
Barriers addressing	Engagement & representation
URL	http://www.scottishhumanrights.com/health-social-care/dementia/

Human rights

Number	5.7 The Rights of Persons with Dementia
Summary of content	The Chair of the Ontario Dementia Advisory Group explains the rights of persons with dementia as guaranteed under the UN Convention on the Rights of Persons with Disabilities.
Source	Ontario Dementia Advisory Group (ODAG)
Resource type	Video ★
Barriers addressing	Engagement & representation
URL	https://www.youtube.com/watch?v=Cp4qhQacPI

[Back to table of contents](#)

Non-dementia specific resources

6. Co-production, access and participation

Contents:

- 6.1. Towards Inclusion: A Guide for Organisations and Practitioners (2017)
- 6.2. Digital accessibility Toolkit – Tools and Guidance for Producing Accessible Content (2018)
- 6.3. Inclusion Made Easy - A Quick Program Guide to Disability in Development
- 6.4. 6 ways to make your sessions more inclusive
- 6.5. Report on Good Practice in E-inclusion, Ethical Guidance and Designing a Roadmap (2009)
- 6.6. Disability Inclusion Toolkit Enabling Inclusive Youth Work (2016)
- 6.7. Lived experience influence participation toolkit – library of resources
- 6.8. Framework for Patient and Public Participation in Primary Care Commissioning
- 6.9. Inclusion: Making it Happen - Key Elements for Disability Organisations to Facilitate Inclusion
- 6.10. Co-production in social care: What it is and how to do it
- 6.11. Co-production with different groups
- 6.12. The Co-production Commitment

Number and name of resource	6.1. Towards Inclusion: a Guide for Organisations and Practitioners (2017)
Summary of content	Resource has a focus on low and middle-income countries. It includes practical actions and example toolkits for planning, implementing and measuring disability inclusion.
Source	Capacity 4 Development; Disability and Development Network
Resource type	Toolkit ✨
Barriers addressing	General accessibility Engagement & representation
URL	https://asksource.info/sites/asksource.info/files/towards-inclusion.pdf

Number and name of resource	6.2. Digital accessibility Toolkit – Tools and Guidance for Producing Accessible Content (2018)
Summary of content	Provides guidance on ensuring digital resources are accessible and inclusive for all.
Source	CBM International
Resource type	Practical tips ◆
Barriers addressing	General accessibility
URL	https://www.cbm.org/fileadmin/user_upload/Publications/CBM-Digital-Accessibility-Toolkit.pdf

Co-production, access and participation

Number and name of resource	6.3. Inclusion Made Easy - a Quick Program Guide to Disability in Development
Summary of content	This guide offers quick access tools to easily embed disability-inclusive practice into international development programs. It is focused specifically at the program level, supporting operational staff in mainstreaming disability. It aims to give practical guidance on how to ensure people with a disability are included in international development programs.
Source	CBM International
Resource type	Practical tips ◆
Barriers addressing	General accessibility Engagement & representation Stigma
URL	https://europa.eu/capacity4dev/disability-and-development-network/document/inclusion-made-easy-quick-program-guide-disability-development-cbm

Number and name of resource	6.4. 6 ways to make your sessions more inclusive
Summary of content	Website for Dementia Friends Champions explaining simple actions they can take to make all their sessions more inclusive. Suggestions can be applied to any other workshop or session.
Source	Dementia Friends England and Wales
Resource type	Factsheet □
Barriers addressing	General accessibility Discriminatory language
URL	https://www.dementiafriends.org.uk/WEBArticle?page=6_more_inclusive_sessions#.XN05sC-ZOqB

Number and name of resource	6.5. Report on Good Practice in E-inclusion, Ethical Guidance and Designing a Roadmap (2009)
Summary of content	Examples of good and ethical practices for e-inclusion - including respect for autonomy, right to dignity, social solidarity, inclusion and social justice.
Source	International Federation on Ageing
Resource type	Practical tips ◆
Barriers addressing	General accessibility
URL	https://www.ifa-fiv.org/wp-content/uploads/2012/12/059_Report-on-good-practices-ethical-guidance-15-Nov-09.pdf

Number and name of resource	6.6. Disability Inclusion Toolkit Enabling Inclusive Youth Work (2016)
Summary of content	Inclusion toolkit, focused on youth to explore some of the issues and actions they need to take.
Source	Mencap and Youth Inclusion Hub Northern Ireland
Resource type	Toolkit ✨
Barriers addressing	General accessibility
URL	https://www.mencap.org.uk/sites/default/files/2016-06/TOOLKIT-NI.compressed.pdf

Co-production, access and participation

Number and name of resource	6.7. Lived experience influence participation toolkit – library of resources
Summary of content	The website is a library of resources including tools, case studies and other resources for involving people with lived experience (of mental health) in the development of work and the organisation.
Source	Mind
Resource type	Toolkit ✨
Barriers addressing	General accessibility Engagement & representation Confidence & skills development
URL	https://www.mind.org.uk/workplace/influence-and-participation-toolkit/tools-case-studies-and-other-resources/

Number and name of resource	6.8. Framework for Patient and Public Participation in Primary Care Commissioning
Summary of content	Specific to the National Health Service in England, however gives a good framework for both the 'why' and the 'how' of involving people at the higher levels of decision making.
Source	NHS England
Resource type	Practical tips ◆
Barriers addressing	General accessibility Engagement & representation
URL	https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/framwrk-public-partcptn-prim-care.pdf

Number and name of resource	6.9. Inclusion: Making it Happen - Key Elements for Disability Organisations to Facilitate Inclusion
Summary of content	Report looks at how disability organisations can enhance their function in facilitating inclusion. Report also identifies barriers to participation and inclusion at an individual and family level, staff and organisation, and community level.
Source	Scope Australia
Resource type	Practical tips ◆
Barriers addressing	General accessibility
URL	https://www.scopeaust.org.au/wp-content/uploads/2015/02/Inclusion-making-it-happen-report.pdf

Number and name of resource	6.10. Co-production in social care: What it is and how to do it
Summary of content	What is co-production? recommendations; how to do co-production; good examples and video resources.
Source	Social Care Institute for Excellence (SCIE)
Resource type	Practical tips ◆
Barriers addressing	General accessibility
URL	https://www.scie.org.uk/publications/guides/guide51/

Co-production, access and participation

Number and name of resource	6.11. Co-production with different groups
Summary of content	Includes specific advice for groups of older people, seldom heard groups and those with mental health issues
Source	Social Care Institute for Excellence (SCIE)
Resource type	Practical tips ♦
Barriers addressing	General accessibility Discriminatory language
URL	https://www.scie.org.uk/co-production/people/

Number and name of resource	6.12. The Co-production Commitment
Summary of content	Provides a starting point/inspiration for organisations who want to understand the basics of involvement and make a commitment to doing more of it.
Source	Social Care Institute for Excellence (SCIE)
Resource type	Practical tips ♦
Barriers addressing	General accessibility Engagement & representation
URL	https://www.scie.org.uk/co-production/week/commitment

[Back to table of contents](#)

7. Campaigning - strategy and tips

Contents:

- 7.1. Guidance Note: Good practice Approaches for Engaging with Social Movements for Women's Rights
- 7.2. NCVO Knowledge Bank: campaign and awareness
- 7.3. Your guide to campaigning with Oxfam
- 7.4. Seeds for Change Knowledge Bank: campaign, co-op or project

Number and name of resource	7.1. Guidance Note: Good Practice Approaches for Engaging with Social Movements for Women's Rights
Summary of content	Guidance based on research from 13 countries, providing good practice approaches when building or engaging with movements in order to progress women's rights . Focus on low and middle-income countries.
Source	ActionAid
Resource type	Practical tips ◆
Barriers addressing	General accessibility Confidence & skills development
URL	https://www.actionaid.org.uk/sites/default/files/publications/guidance_note_good_practice_approaches_2016_0.pdf

Number and name of resource	7.2. NCVO Knowledge Bank: campaigns and awareness
Summary of content	Various guides for non-profit organisations on campaigning and influencing, communications, media, marketing and branding.
Source	National Council for Voluntary Organisations (NCVO)
Resource type	Toolkit ✳
Barriers addressing	Engagement & representation Confidence & skills development
URL	https://knowhow.ncvo.org.uk/campaigns

Number and name of resource	7.3. Your guide to campaigning with Oxfam
Summary of content	Useful tips on getting started and things to take into account when starting to create a network.
Source	Oxfam
Resource type	Factsheet □
Barriers addressing	Engagement & representation Confidence & skills development
URL	https://www.oxfam.org.uk/get-involved/campaign-with-us/how-to-campaign/campaign-tools-and-resources

Campaigning - strategy and tips

Number and name of resource	7.4. Seeds for Change Knowledge Bank: campaigns, co-ops or projects
Summary of content	A bank of resources designed to help people be more effective in their campaigns, co-ops or projects.
Source	Seeds for Change
Resource type	Toolkit ✱
Barriers addressing	Engagement & representation Confidence & skills development
URL	https://www.seedsforchange.org.uk/resources

[Back to table of contents](#)

8. General self-advocacy

Contents:

- 8.1. Being Heard: A Self-advocacy Guide for Carers
- 8.2. Campaigning and advocacy factsheets and guides
- 8.3. Self-advocacy for Inclusion: A global report
- 8.4 The Advocacy Charter
- 8.5. Empowerment - A guide to influencing your local services
- 8.6. Celebrating 10 years of the CRPD
- 8.7. Advocacy toolkit
- 8.8. Advocacy Skill Building Toolkit
- 8.9. Voiceability advocacy resources
- 8.10. Advocacy Toolkit Skills for Effective Self and Peer Advocacy

Number and name of resource	8.1. Being Heard: a Self-advocacy Guide for Carers
Summary of content	A toolkit for care supporters with practical guidance to get their voices heard, under three chapters: 'The system' (UK-specific information on the external environment and the rights one might need to get their voice heard); 'Communicating effectively' (skills around communication, assertiveness and negotiation and influencing); 'Emotions & thinking'.
Source	Carers UK
Resource type	Toolkit ✨
Barriers addressing	Confidence & skills development
URL	https://www.carersuk.org/search/self-advocacy-eng

Number and name of resource	8.2. Campaigning and advocacy factsheets and guides
Summary of content	Range of self-advocacy factsheets on how people can influence their own local services.
Source	Disability Rights UK
Resource type	Factsheet ☐
Barriers addressing	General accessibility Engagement & representation Confidence & skills development
URL	https://www.disabilityrightsuk.org/campaigning-and-advocacy

General self-advocacy

Number and name of resource	8.3. Self-advocacy for Inclusion: a Global Report
Summary of content	Provides guidance from self-advocates on good practice and sets out some recommendations for a global initiative to support self-advocacy. Tips to overcome personal, family and organisational barriers and develop self-advocacy skills.
Source	Inclusion International
Resource type	Practical tips ♦
Barriers addressing	Confidence & skills development Discriminatory language
URL	https://inclusion-international.org/wp-content/uploads/2016/11/Global-report-on-self-advocacy.pdf

Number and name of resource	8.4. The Advocacy Charter
Summary of content	A charter developed to help advocacy providers define and promote key advocacy principles. In poster format (longer form and easy read).
Source	National Development Team for Inclusion (NDTi)
Resource type	Practical tips ♦
Barriers addressing	General accessibility
URL	https://www.ndti.org.uk/resources/publications/new-advocacy-charter

Number and name of resource	8.5. Empowerment - a Guide to Influencing your Local Services
Summary of content	A range of practical guides to support, inform and enable people with disabilities to influence local decision making processes – taking an active part in the services they receive (UK focus).
Source	The Royal Association for Disability Rights (RADAR)
Resource type	Practical tips ♦
Barriers addressing	General accessibility Confidence & skills development
URL	https://www.disabilityrightsuk.org/sites/default/files/pdf/Empowerment%20Guide.pdf

Number and name of resource	8.6. Celebrating 10 years of the CRPD
Summary of content	Inspirational video celebrating 10 years of the Convention on the Rights of Persons with Disabilities (CRPD). Members of the UN Committee on the Rights of Persons with Disabilities explain what the Convention means to them, how it has changed lives and challenges ahead.
Source	The Office of the High Commissioner for Human Rights (OHCHR)
Resource type	Video ★
Barriers addressing	General accessibility Stigma
URL	https://www.youtube.com/watch?v=sQuMh9N5cNQ

General self-advocacy

Number and name of resource	8.7. Advocacy Toolkit
Summary of content	Practical tools for the development and management of advocacy work including chapters on: strengthening the foundation for advocacy; developing an advocacy strategy; monitoring and evaluating; managing knowledge; managing risks; building relationships and securing partnerships.
Source	Unicef
Resource type	Toolkit ✱
Barriers addressing	Confidence & skills development
URL	https://www.unicef.org/cbsc/files/Advocacy_Toolkit.pdf

Number and name of resource	8.8. Advocacy skill building toolkit
Summary of content	This toolkit is a guide for Centres for Independent Living and others to conduct interactive and engaging advocacy skills workshops for emerging Independent Living leaders and youth with disabilities. It describes how to introduce advocacy through the facilitation of unique activities and discussions, identifying issues of importance, and putting advocacy skills into practice.
Source	University of Montana, Research and Training Center on Disability in Rural Communities
Resource type	Toolkit ✱
Barriers addressing	Confidence & skills development
URL	http://rtc.ruralinstitute.umt.edu/resources/advocacy-skill-building-toolkit/

Number and name of resource	8.9. Voiceability advocacy resources
Summary of content	Explains different types of advocacy including self-advocacy and independent mental health advocacy.
Source	Voiceability
Resource type	Practical tips ◆
Barriers addressing	Confidence & skills development
URL	https://www.voiceability.org/about-advocacy/

General self-advocacy

Number and name of resource	8.10. Advocacy Toolkit Skills for Effective Self and Peer Advocacy
Summary of content	This Advocacy Toolkit provides individuals with information and skill building exercises to develop and enhance self and peer advocacy skills. The focus is on persons who have been labelled with mental health and/or substance abuse problems, but the advocacy skills can be learned and practiced by anyone.
Source	Wisconsin Coalition for Advocacy
Resource type	Toolkit * *
Barriers addressing	Confidence & skills development
URL	http://www.disabilityrightswi.org/wp-content/uploads/2018/04/Advocacy-Tool-Kit.pdf

[Back to table of contents](#)

9. Safeguarding

Contents:

- 9.1. Safeguarding Adults Policy May 2018
- 9.2. Safeguarding Adults at Risk of Harm Toolkit
- 9.3. Guidelines for Working with Vulnerable Groups
- 9.4. Young People and Legal Consent Sheet 1: Background to consent (2018)

Number and name of resource	9.1. Safeguarding Adults Policy May 2018
Summary of content	Tips on engaging adult at risk volunteers (p.7); health and safety; and supervision of adults at risk - To ensure effective supervision in order to safeguard adults at risk in Oxfam's care. Use of personal data about adults at risk (p.7); ways Oxfam protect the personal data of adults at risk. E.g. research with adults at risk must be well thought through and special attention must be given to Oxfam's procedures for safeguarding adults.
Source	Oxfam GB
Resource type	Practical tips ◆
Barriers addressing	Protection
URL	https://www.oxfam.org.uk/~media/Files/OGB/What%20we%20do/About%20us/Plans%20reports%20and%20policies/Safeguarding/Safeguarding%20Adults%20Policy%20approved%20May%202018.ashx

Number and name of resource	9.2. Safeguarding Adults at Risk of Harm Toolkit – library of resources
Summary of content	The toolkit provides info sheets, templates, and handy guides for all the primary care team. The toolkit assists good knowledge and use of relevant legislation when promoting good care for adults at risk of harm, or those lacking the capacity to make decisions for themselves.
Source	Royal College of General Practitioners
Resource type	Practical tips ◆
Barriers addressing	Protection
URL	https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/safeguarding-adults-at-risk-of-harm-toolkit.aspx

Safeguarding

Number and name of resource	9.3. Guidelines for working with vulnerable groups
Summary of content	Guidance to all University College London (UCL) staff and students on the expected standards of behaviour when working with children, young people and at risk adults.
Source	University College London (UCL)
Resource type	Practical tips ♦
Barriers addressing	Protection
URL	https://www.ucl.ac.uk/human-resources/working-vulnerable-groups

Number and name of resource	9.4. Young People and Legal Consent Sheet 1: Background to Consent
Summary of content	Youth focused but useful guidelines around accessing capacity and capacity to consent, e.g. issues surrounding young people's right and ability to provide consent under New South Wales law.
Source	Youth Action (NSW)
Resource type	Practical tips ♦
Barriers addressing	Protection
URL	https://d3n8a8pro7vhmx.cloudfront.net/youthaction/pages/1464/attachments/original/1519272835/YA_Factsheet_1_background.pdf?1519272835

[Back to table of contents](#)

Barriers index

The tables below show another way of filtering resources in the directory by the barrier they address. For an explanation of the content of each resource please refer to the main section using the page and resource number on the right hand side.

Types of barriers:

- General accessibility (physical and social)
- Dementia-specific accessibility (physical and social)
- Discriminatory language (based on condition)
- Stigma (based on condition, age or gender)
- Engagement & representation (identifying, engaging and participating)
- Confidence & skills development (to participate in campaign and self-advocacy work)
- Protection (of at risk groups)

Barrier: General accessibility	Source	Page Number	Resource Number
Guidance Note: Good Practice Approaches for Engaging with Social Movements for Women's Rights	ActionAid	24	7.1
The Advocacy Charter	National Development Team for Inclusion (NDTi)	27	8.4
Towards Inclusion: a Guide for Organisations and Practitioners (2017)	Capacity 4 Development; Disability and Development Network	20	6.1
Digital accessibility Toolkit – Tools and Guidance For Producing Accessible Content (2018)	CBM International	20	6.2
Inclusion Made Easy - a Quick Program Guide to Disability in Development	CBM International	21	6.3
6 Ways to Make your Sessions More Inclusive	Dementia Friends	21	6.4
Campaigning and Advocacy Factsheets and Guides	Disability Rights UK	26	8.2
Report on Good Practice in E-Inclusion, Ethical Guidance and Designing a Roadmap (2009)	International Federation on Ageing	21	6.5
Disability Inclusion Toolkit Enabling Inclusive Youth Work (2016)	Mencap and Youth Inclusion Hub Northern Ireland	21	6.6
Lived Experience Influence Participation Toolkit – Library of Resources	Mind	22	6.7
Framework for Patient and Public Participation in Primary Care Commissioning	NHS England	22	6.8

Inclusion: Making it Happen - Key Elements for Disability Organisations to Facilitate Inclusion	Scope Australia	22	6.9
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Barrier: General accessibility	Source	Page Number	Resource Number
Co-production in Social Care: What It is and How to do It	Social Care Institute for Excellence (SCIE)	22	6.10
Co-production with Different Groups	Social Care Institute for Excellence (SCIE)	23	6.11
The Co-production Commitment	Social Care Institute for Excellence (SCIE)	23	6.12
Empowerment - a Guide to Influencing Your Local Services	The Royal Association for Disability Rights (RADAR)	27	8.5
Celebrating 10 Years Of The CRPD	The Office of the High Commissioner for Human Rights (OHCHR)	27	8.6

Barrier: Dementia-specific accessibility	Source	Page Number	Resource Number
How to Include People with Dementia in the Activities of Alzheimer Associations	Alzheimer's Disease International (ADI)	10	3.1
Brief for Alzheimer Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People Living with Dementia.	Alzheimer's Disease International and Dementia Alliance International	16	5.1
Meaningful Engagement & Representation of People with Dementia	Alzheimer Society of Canada	10	3.2
Extending Community-Based Rehabilitation (CBR) to Older Persons: a Global Imperative	Dementia Alliance International	16	5.2
Supporting and Accommodating People with Dementia at Professional Conferences and Other Events	Dementia Alliance International	7	1.1
Involving People with Dementia as Members of Steering or Advisory Groups	Dementia Engagement & Empowerment Projects (DEEP)	7	1.2
Setting up an Influencing Group	Dementia Engagement and Empowerment Projects (DEEP)	7	1.3
Collecting the Views of People with Dementia	Dementia Engagement and Empowerment Project (DEEP)	11	3.5
Our Dementia Our Rights	Dementia Engagement and Empowerment Project (DEEP) and & Innovations in Dementia	17	5.4
Listen To Us: Involving People with Dementia in Planning and Developing Services	Dementia North Centre	11	3.6
Devising a Dementia Toolkit for Effective Communication	Nursing and Residential Care Journal	12	3.7

By Us For Us Guides	Research Institute for Aging	17	5.5
Core Principles for Involving People with Dementia in Research	Scottish Dementia Working Group (SDWG)	12	3.8
Barrier: Discriminatory language	Source	Page Number	Resource Number
I Can! I Will! Idea Library Raising Public Awareness	Alzheimer's Disease International	13	4.1
Dementia Friendly Language	The Alzheimer Society of Ireland	8	2.3
Speaking up about Dementia: a Simple Guide to Raising your Voice	Alzheimer Society British Columbia	14	4.4
Person Centred Language Guideline	Alzheimer Society of Canada	8	2.1
How to Spot (And Challenge) Negative Language in the Media	Alzheimer's Society	8	2.2
Strengthening the Involvement of People with Dementia.	Care Services Improvement Partnership (CSIP)- Older Peoples Mental Health Programme	11	3.3
Dementia Words Matter: Guidelines on Language about Dementia	Dementia Engagement and Empowerment Projects (DEEP)	9	2.5
6 Ways to Make Your Sessions More Inclusive	Dementia Friends	21	6.4
Self-advocacy for Inclusion: a Global Report	Inclusion International	27	8.3
Co-production with Different Groups	Social Care Institute for Excellence (SCIE)	23	6.11
Involving People with Dementia: Making Involvement Count	South West Dementia Partnership	12	3.9
Guide for Journalists	Young Dementia UK	9	2.6

Barrier: Stigma	Source	Page Number	Resource Number
"I Can! I Will! Idea Library 'Raising Public Awareness'"	Alzheimer's Disease International (ADI)	13	4.1
How to Include People with Dementia in the Activities of Alzheimer Associations	Alzheimer's Disease International (ADI)	10	3.1
Dementia Friendly Language	The Alzheimer Society of Ireland	8	2.3
Speaking up about Dementia: a Simple Guide To Raising Your Voice	Alzheimer Society British Columbia	14	4.4
Person Centred Language Guideline	Alzheimer Society of Canada	8	2.1

How to Spot (and Challenge) Negative Language in the Media	Alzheimer's Society	8	2.2
Barrier: Stigma	Source	Page Number	Resource Number
Inclusion Made Easy - a Quick Program Guide to Disability in Development	CBM International	21	6.3
Strengthening the Involvement of People with Dementia.	CSIP (Care Services Improvement Partnership) Older Peoples Mental Health programme	11	3.3
From Seldom Heard to Seen & Heard	Dementia Action Alliance	11	3.4
Hello Our Voices Matter	Dementia Alliance International	14	4.5
The Many Voices Of Dementia Advocacy	Dementia Alliance International, 3 Nations Dementia Working Group and Alzheimer's Society	14	4.6
Dementia Words Matter: Guidelines on Language About Dementia	Dementia Engagement and Empowerment Projects (DEEP)	9	2.5
Sound Bytes After Diagnosis	Ontario Dementia Advisory Group (ODAG)	15	4.10
The Rights of Persons with Dementia	Ontario Dementia Advisory Group (ODAG)	18	5.7
Collection of Videos by Ontario Dementia Advisory Group (ODAG) on Facebook Group Page	Ontario Dementia Advisory Group (ODAG)	15	4.11
Involving People with Dementia: Making Involvement Count	South West Dementia Partnership	12	3.9
Celebrating 10 Years of The CRPD	The Office of the High Commissioner for Human Rights (OHCHR)	27	8.6
Guide for Journalists	Young Dementia UK	9	2.6

Barrier: Engagement & representation	Source	Page Number	Resource Number
How to Include People with Dementia in the Activities Of Alzheimer Associations	Alzheimer's Disease International	10	3.1
Brief For Alzheimer Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People Living with Dementia.	Alzheimer's Disease International and Dementia Alliance International	16	5.1
Meaningful Engagement & Representation of People with Dementia	Alzheimer Society of Canada	10	3.2
Towards Inclusion: a Guide For Organisations and Practioners (2017)	Capacity 4 Development; Disability and Development Network	20	6.1

Inclusion Made Easy - a Quick Program Guide to Disability in Development	CBM International	21	6.3
Barrier: Engagement & representation	Source	Page Number	Resource Number
From Seldom Heard to Seen & Heard	Dementia Action Alliance	11	3.4
Hello Our Voices Matter	Dementia Alliance International	14	4.5
Extending Community-based rehabilitation (CBR) to Older Persons: a Global Imperative	Dementia Alliance International	16	5.2
The Human Rights of People Living with Dementia: from Rhetoric to Reality	Dementia Alliance International	17	5.3
The Many Voices of Dementia Advocacy	Dementia Alliance International, 3 Nations Dementia Working Group and Alzheimer's Society	14	4.6
Involving People with Dementia as Members of Steering or Advisory Groups	Dementia Engagement and Empowerment Projects (DEEP)	7	1.2
Setting up an Influencing Group	Dementia Engagement and Empowerment Projects (DEEP)	7	1.3
Collecting the views of People with Dementia	Dementia Engagement and Empowerment Projects (DEEP)	11	3.5
Our Dementia Our Rights	Dementia Engagement and Empowerment Project (DEEP) and & Innovations in Dementia	17	5.4

Barrier: Engagement & representation	Source	Page Number	Resource Number
Listen to us: Involving people with Dementia in Planning and Developing Services	Dementia North Centre	11	3.6
Hear What I Say: Developing Dementia Advocacy Services	Dementia North Centre	14	4.7
Making an Impact Together	Dementia Engagement and Empowerment Project (DEEP) and Innovations in Dementia	15	4.8
Campaigning and Advocacy Factsheets and Guides	Disability Rights UK	26	8.2
Independent Advocacy for People Living with Dementia and Unpaid Carers	Life Changes Trust	15	4.9
Lived experience influence participation toolkit – library of resources	Mind	22	6.7
NCVO Knowledge Bank: Campaign and Awareness	NCVO	24	7.2
Framework for Patient and Public Participation in Primary care Commissioning	NHS England	22	6.8

Devising a Dementia Toolkit for Effective Communication (2012)	Nursing and Residential Care, Vol. 14, No. 3 · Care Analysis Interaction	12	3.7
Barrier: Engagement & representation	Source	Page Number	Resource Number
Your guide to campaigning with Oxfam	OXFAM	24	7.3
By Us for Us Guides	Research Institute for Aging	17	5.5
Core Principles for Involving People with Dementia in Research	Scottish Dementia Working Group	12	3.8
PANEL and the Charter of Rights	Scottish Human Rights Commission	17	5.6
Seeds for Change Knowledge Bank: campaigns, co-ops or projects	Seeds for Change	25	7.4
The Co-production Commitment	Social Care Institute for Excellence (SCIE)	23	6.12
Sound bytes After Diagnosis	Ontario Dementia Advisory Group (ODAG)	15	4.10
Collection of videos by Ontario Dementia Advisory Group (ODAG) on Facebook group page	Ontario Dementia Advisory Group (ODAG)	15	4.11

Barrier: Confidence & skills development	Source	Page Number	Resource Number
Guidance Note: Good Practice Approaches for Engaging with Social Movements for Women's Rights (2016)	ActionAid	24	7.1
Self-advocacy strategies- library of resources for people affected by dementia	Alzheimer Society British Columbia	13	4.2
Self-advocate Video Stories	Alzheimer Society British Columbia	13	4.3
Being Heard: a Self-advocacy Guide for Carers	Carers UK	26	8.1
The Many Voices of Dementia Advocacy	Dementia Alliance International, 3 Nations Dementia Working Group and Alzheimer's Society	14	4.6
Dementia Language Guidelines	Dementia Australia	9	2.4
Hear what I Say: Developing Dementia Advocacy Services	Dementia North Centre	14	4.7
Making an Impact Together	Dementia Engagement and Empowerment Project (DEEP) and Innovations in Dementia	15	4.8
Campaigning and Advocacy Factsheets and Guides	Disability Rights UK	26	8.2
Self-advocacy for Inclusion: a Global Report	Inclusion International	27	8.3

Lived experience Influence Participation Toolkit – library of resources	Mind	22	6.7
NCVO Knowledge Bank: Campaign and Awareness	NCVO	24	7.2
Barrier: Confidence & skills development	Source	Page Number	Resource Number
Your guide to campaigning with Oxfam	OXFAM	24	7.3
Seeds for Change Knowledge Bank: campaign, co-op or project	Seeds for Change	25	7.4
Empowerment – a Guide to Influencing Your Local Services	The Royal Association for Disability Rights (RADAR)	27	8.5
Advocacy Toolkit	Unicef	28	8.7
Advocacy Skill Building Toolkit	University of Montana, Research and Training Center on Disability in Rural Communities	28	8.8
Voiceability Advocacy Resources	Voiceability	28	8.9
Advocacy Toolkit Skills for Effective Self and Peer Advocacy	Wisconsin Coalition for Advocacy	29	8.10

Barrier: Protection	Source	Page Number	Resource Number
Brief for Alzheimer Associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by People living with Dementia.	Alzheimer's Disease International and Dementia Alliance International	16	5.1
Hello Our Voices Matter	Dementia Alliance International (DAI)	14	4.5
Extending Community-based rehabilitation (CBR) to older persons: A Global Imperative	Dementia Alliance International (DAI)	16	5.2
Safeguarding Adults Policy May 2018	Oxfam GB	30	9.1
By Us for Us Guides	Research Institute for Aging	17	5.5
Safeguarding Adults at Risk of Harm Toolkit – library of resources	Royal College of General Practitioners	30	9.2
Guidelines for Working with Vulnerable Groups	University College London	31	9.3
Young People and Legal Consent Sheet 1: Background to consent (2018)	Youth Action (NSW)	31	9.4

[Back to table of contents](#)

Contact information for additional support:

- **Dementia Alliance International** - a registered non-profit organisation whose membership is exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world
www.dementiaallianceinternational.org
- **Alzheimer's Disease International (ADI)** - the international federation of Alzheimer associations around the world
<https://www.alz.co.uk/>
- **National Alzheimer's associations (ADI members)¹**
Alzheimer associations provide information and support and can advise on any services available in your country, as well as answer any specific questions. Alzheimer associations exist in many countries around the world; find the association in your country
<https://www.alz.co.uk/associations>
- **Alzheimer Europe**- an organisation aiming to make dementia a European priority, promote a rights-based approach to dementia and strengthen the European dementia movement.
<https://www.alzheimer-europe.org/>

Dementia Working Groups (Groups in existence June 2019. Ordered alphabetically):

- **3 Nations Dementia Working Group** <https://www.3ndementiawg.org>
- **Alzheimer's America Early Onset Dementia Advisory Group (AAEODAG)**
http://www.alz.org/about_us_early_stage_advisory_group.asp
- **Alzheimer's New Zealand Dementia Advisory Group**
<http://www.alzheimers.org.nz/our-voice/consumer-advisory-group>
- **Dementia Advocacy and Support Network International (DASNI)**
The first active advocacy group
<http://www.dasninternational.org/>
- **DEEP the UK Network of Dementia Voices**
<https://www.dementivoices.org.uk>
- **Dementia Australia Advisory Committee**
<https://www.dementia.org.au/about-us/advisory-groups/dementia-advisory-committee>
- **Dementia Awareness Advocacy Team**
<https://www.facebook.com/dementiaawarenessadvocacyteam/>

¹ This list is not exhaustive- there are other Alzheimer associations and working groups that may not be part of Alzheimer's Disease International or Alzheimer Europe.

- **European Working Group of People with Dementia (EWGPWD)**
<http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia>
- **Finnish Memory Working Group**
<https://www.muistiliitto.fi/en/alzheimer-society-finland/working-group-people-memory-diseases-and-caregivers>
- **Flemish Working Group for People with Dementia**
www.dementie.be
- **Highlands Dementia Working Group**
<http://www.sdwg.org.uk/local-groups/inverness-dementia-group/>
- **Icelandic Working Group of People with Dementia (IWGPWD)**
(website under development)
- **Irish Dementia Working Group (IDWG)**
<http://dementivoices.org.uk/group/irish-dementia-working-group/>
- **Japan Dementia Working Group (JDWG)**
<http://www.jdwg.org/>
- **Ontario Dementia Advisory Group (ODAG)**
<http://www.odag.ca>
- **Scottish Dementia Working Group**
<http://www.sdwg.org.uk/videos/home/about-us-sdwg/>
- **Southern Dementia Advisory Group**
<http://www.southerndag.org>
 - **Kiama Dementia Advisory Group**
<https://www.southerndag.org/kiama-project>
- **Taiwan Dementia Advisory Group**
(website under development)

In Development:

- **Singapore Dementia Working Group**

[Back to table of contents](#)