

User Involvement Tool Kit – Disability Etiquette Guide

A practical and easy to use Tool Kit for Adult Social Care staff

To help you confidently and competently involve service users (older and disabled people, and people with long term health conditions) and carers

March 2011

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Disability Language and Etiquette

It is impossible to produce a definitive guide on disability language and etiquette. However, we hope this guidance will provide you with some information to help you to be competent and feel confident in your interactions with disabled people. We are very aware that this is one of your core client groups.

1. General Etiquette

You will find that most of the following is common sense. However, the following general guidelines will hopefully give you greater confidence in your interactions with disabled people.

- Do not make assumptions about an individual's ability to do certain things. Disabled people develop their own methods of overcoming the everyday problems they encounter.
- Treat disabled people as you would treat any other person, i.e., as a woman, as a man, as a parent, as a worker.
- Do not be embarrassed if you use common expressions such as "see you later" or "Can I give you a hand?", then realise they may obliquely relate to persons impairment.
- Do not assume that an offer of assistance will automatically be welcome. Offer it and wait until your offer is accepted. Even then, do not assume you know the best way of helping. Instead, listen to what the disabled person tells you about their support needs.
- People are often tempted to talk to a disabled person's Personal Assistant, especially in situations when a person is perceived to have high needs or communication issues. It is important to talk directly to the disabled person.
- Do relax, speak normally and stand in front to allow eye contact to be made, in the same way you would when talking to anyone else.

2. Language

A 'social model' approach to disability states that people with impairments are disabled by physical and social barriers, rather than a particular impairment or medical condition. The social model has influenced a civil rights-based view of equality for disabled people. It is a key concept for service providers to understand to enable them to take the necessary actions to dismantle the barriers that exclude and limit the life chances of disabled people. This includes looking at language.

This section provides explanations to help you with a general understanding of words and phrases that are mainly acceptable to disabled people, and those which may give offence.

- The term **the disabled** implies a homogeneous group separate from the rest of society and, therefore, is seen as negative.
- The term **disabled people/person** signifies identification with the disability rights movement and usually an understanding of the social model of disability, i.e. that people are disabled by the environment and other people's view of them and not by their specific impairment.
- To place 'person' before impairment (for example, person with a visual impairment) is often viewed positively because it shows that people are individuals and not a homogenous group, as is often implied by negative terms like 'the blind' or 'the visually impaired'.
- The term **the handicapped** is offensive to many disabled people because its origins has ancient associations with 'cap in hand' and begging.
- The term **deaf and dumb** is the granddaddy of all negative and offensive labels pinned on Deaf and hard of hearing people. The Greek philosopher Aristotle pronounced Deaf people as 'deaf and dumb' because he felt that Deaf people were incapable of being taught, of learning, and of reasoned thinking. To his way of thinking, if a person could not use his/her voice in the same way as hearing people, then there was no way that this person could develop cognitive abilities.
- **Invalid** is an offensive word because this equates impairments with illness and can be construed as 'not valid' or 'worthless'. It is connected to the word 'invalid', as in, 'incorrect', or 'not true'.
- Wheelchair-bound is also considered an offensive term as it suggests that a person is trapped inside their wheelchair, when in fact a person's wheelchair represents freedom and greater independence.

- Personal Assistant, Enabler, Support Worker are some of the ways in which many disabled people describe the assistants they use. Assistants are often employed directly by the disabled person using Social Services funding. This means disabled people maintain choice and control over their own lives.
- **Personal Assistant users** will often keep their assistant politely in the background. Do not interfere with this, relax, and be guided by the disabled person. (Many disabled people will have a personal assistant/support worker.)
- **Carer** usually refers to people who give informal unpaid assistance, usually a family member or close friend.

Best Practice

Language

- 1. Don't get too 'stuck' on what language you use, but be aware that some terms may give offence.
- 2. If you do use the 'wrong' word, apologise to the person and ask them what term they would like you to use.
- **3.** The term 'disabled person' gives offence to very few people and is the most neutral expression to use.
- **4.** You will rarely need to know the details of someone's impairment, but you do need to know what their access and communication needs are, for example, large print, a BSL interpreter, or Blue Badge parking.

2.1 Language Guide

This is a general guide to appropriate and inappropriate language, but it is important to find out from the person you are speaking to how they prefer to address disability-related language.

Do Say	Avoid using
Disabled people	The Disabled
Disabled people	People with disabilities
Disabled person	Invalid
Impairments	Disabilities
Living with	Suffers from
Person with mental health issues	Mentally ill
People with learning disabilities	Mentally handicapped
D/deaf, deafened, hard of hearing	The Deaf / deaf and dumb
Blind/visual impairment (specify)	The Blind
Access requirements	Special Needs
Accessible toilet	Disabled toilet
Blue Badge-holder parking	Disabled parking
Wheelchair user	Wheelchair bound

3. Involving people with mobility impairments

- When talking with a wheelchair user, either get a chair and sit down or ask if they prefer you to stand or crouch. If you do stand, do not tower over people looking up can result in a stiff neck. Stand a little way away so that you can have a conversation eye to eye, on an equal level.
- Prior to inviting wheelchair users to a building, obtain information about the access to that building. Provide the wheelchair user with the information, so that they can make a decision about whether or not the building will be accessible to them as an individual. If the building is not accessible, you can then arrange for the meeting to take place in another location.
- A wheelchair is part of the 'body space' of the person using it. Do not lean on it unless you would usually lean on the person themselves.
- If you wish to speak to the Personal Assistant of the wheelchair user, request permission and make sure that you do not place yourself in a position that excludes the disabled person from the conversation.
- In public places or offices, ensure that items are not left lying around on the floor. Make sure there are adequate spaces for people to get around and that access is safe for everyone.

4. Involving people who are D/deaf, deafened and hard of hearing

4.1 D/deaf culture

Deaf culture describes the social beliefs, art, literary traditions, history, values, and shared institutions of Deaf people who use a sign language.

When used in this cultural sense, the word 'deaf' is often capitalised in writing, and referred to as 'big D Deaf'.

Culturally Deaf people tend to/may often view 'deafness' as a difference in human experience rather than a <u>disability</u>.

Deaf culture therefore does not automatically include all people who are deaf or have a hearing loss. Like most cultures, the exact boundaries of Deaf culture are contested. For example, perennial questions arise as to where hearing people who have Deaf parents and sign fluently fit in.

4.2 Background information

There is no 'typical' D/deaf or hard-of-hearing person. D/deaf and hard-ofhearing patrons come from diverse backgrounds and use differing communication modes.

If you are going to have a meeting with a Deaf person who is a British Sign Language (BSL) user, it is important to organise a qualified and registered BSL interpreter.

Key Contact

If you work in the Adult Social Care directorate, your contact for booking a BSL interpreter is Laura Hall (Extension 4964; Email L.Hall@dorsetcc.gov.uk)

Some people with hearing impairments are not BSL users. They might use a combination of lip reading / lip speakers, or might wear hearing aids. It is therefore important to make sure you establish what each individual's preferred method of communication is and ensure that this is made available prior to activities/meetings.

- The usual etiquette for getting someone's attention is to tap them lightly on the arm, between the shoulder and the elbow. At large meetings or conferences, flicking the lights is seen as acceptable within the Deaf community; however, this would not necessarily be perceived as acceptable for a hearing person to do, particularly if it is a one-to-one or small meeting. We suggest you take guidance from the BSL interpreter at the event as to the best way to call people to attention.
- Always speak directly to the person, never to a third party.
- Speak in a natural, conversational tone. It is not necessary to speak loudly or to over-enunciate.
- Be aware that effective communication via written notes has limitation; BSL has a very different structure from English, and D/deaf people may therefore have limited literacy skills in English.
- Make direct eye contact. Natural facial expressions and gestures will provide important information to your conversation.
- When talking, do not allow your face and mouth to be obscured. Avoid holding things near your mouth eating, smoking or waving your hands in front of your face these things can be distracting.
- Bright and dark places can be a barrier to clear communication. Good lighting is important, but keep in mind the glare factor and do not stand in front of a bright window.
- Ensure that background noise is kept to a minimum.
- If a person is lip reading, speak clearly and slowly but do not exaggerate your speech. Be aware that lip reading has its limitations, as many words look the same on the lips, and even the best lip reader would only be able to lip read 50-60% of what is being said.
- If a word or phrase is not understood, rephrase it by using different words with the same meaning.
- Changing the topic of conversation abruptly can cause confusion. Use transitional phrases between topics, such as 'let's talk about exams now'.

4.4 Working with BSL interpreters and lip speakers

- If a person uses a BSL interpreter, address your comments and questions to the Deaf person, not the interpreter.
- Always speak in a natural, conversational tone. The interpreter will tell you if something needs to be repeated or if you need to slow down.
- Normally, the BSL interpreter sits opposite the Deaf person. Depending on the situation, however, the Deaf person will be able to advise on the best arrangement for effective communication.
- Interpreting is physically and mentally demanding so plan for frequent breaks. Generally, a BSL interpreter working alone should have 10mins break in every half hour. However, this may vary for individuals and type of event, so do discuss this with the BSL interpreter beforehand.
- It is useful to provide any written material to the interpreter in advance of a meeting so that they can familiarise themselves with details about the meeting.

4.5 If you're speaking to someone who's D/deaf or hard of hearing try these tips:

- Even if someone is wearing a hearing aid, it doesn't mean that they can hear you. Ask if they need to lip read you.
- Make sure you have the listener's attention before you start speaking.
- Speak clearly but not too slowly, and don't exaggerate your lip movements. Use natural facial expressions and gestures.
- If you're talking to a D/deaf person and a hearing person, don't just focus on the hearing person.
- Don't shout! It's uncomfortable for a hearing aid user and it looks aggressive.
- Find a suitable place to talk, with good lighting, away from noise and distractions.
- Remember not to turn your face away from a D/deaf person. Always turn to your listener so they can see your face.
- Check that the person you're talking to can follow you. Be patient and take the time to communicate properly.
- Use plain language and don't waffle. Avoid jargon and unfamiliar abbreviations.

5. Involving people who are visually impaired

- First of all, identify yourself clearly, and then introduce anyone else who is present and where they are placed in the room.
- Ask the person if they require any assistance and, if so, how best this should be provided.
- When offering a handshake, say something to indicate that you wish to shake hands.
- When meeting someone out of their home or in their workplace, ask what central point they are familiar with and arrange to meet them there. Please ensure you arrive at the agreed time and make your presence known when they arrive by introducing yourself.
- When offering a seat, speak the person through the process (chair on right, left, back of you, etc) and place the person's hand on the back or the arm of the chair, so that they are aware of the position of it.
- At the end of a conversation, do not just leave. Say when you wish to end a conversation, or when you are moving away.
- If you are running a meeting or an activity that visually impaired people will be attending, make sure that materials are prepared in advance in accessible formats so that everyone has the same access to the information available. Ensure that you ask the attendees what format they would like it in, for example, large print, Braille or if it is helpful to have the information emailed to them in advance.
- Always **say** what you want, as gestures are useless communication tools to most visually impaired people.
- Always talk to the visually impaired person and not to his or her guide or support worker.
- If a visually impaired person attends a meeting or an event without a guide or support worker then ensure that assistance with refreshments and locating the toilets is offered even if they do have a guide dog/white stick.
- Do not interact with a guide dog without prior agreement of the visually impaired person. These are working dogs and some people prefer that you do not pet them.

5.2 Making information accessible to people with visual impairments

Some designs can be unclear, confusing and difficult to read for many people, including people with visual impairments. The Royal National Institute of Blind People (RNIB) has produced **'Clear Print Guidelines'**¹ to help avoid this.

RNIB Clear Print Guidelines

What is Clear Print?

Clear Print is RNIB's print design guidelines for all types of documents. The guidelines have been specially created to enable everyday information to be immediately accessed by more people.

clear print

Who benefits from Clear Print?

Because Clear Print is designed to be used for all documents, it has far reaching benefits. A clearly designed and easy to read document will convey your essential information to everyone who reads it and in the process can convey a positive view of the originating individual or organisation.

Top tips for achieving Clear Print:

- Document text size should be 12-14 pt, preferably 14 pt.
- The font you choose should be clear, avoiding anything stylised
- All body text should be left aligned
- Use bold sparingly, only highlight a few words rather than a paragraph
- Keep the text layout clear, simple and consistent
- Don't use blocks of capitalised letters, and try not to use any italics or underlining
- Text shouldn't be overlaid on images
- The substrate or coatings should not be glossy or reflective
- The contrast between the text and background is as high as possible
- All text should be the same orientation on the page
- Space between columns of text is large enough to be distinct
- Any information conveyed in colour or through images is also described

¹ For further information about Clear Print, see RNIB's See it Right book, contact: <u>accessibleinfo@rnib.org.uk</u> or visit <u>www.rnib.org.uk</u>

6. Involving people who have learning difficulties

- Don't make assumptions.
- Position yourself at the same level.
- Position yourself so that the person can see your face.
- Keep your hands away from face.
- Never shout.
- Use simple words and sentences.
- Always check information has been understood.
- Minimise background noise wherever possible.
- Don't use jargon.
- Don't talk too fast.
- Take time to listen and understand.
- Explain things very clearly.
- Speak to the person and not their support worker.
- Don't be afraid to ask people to repeat themselves. Tell them that you did not understand.
- Don't pretend that you have understood what was said when in fact you didn't.
- Don't assume that people will be able to find another point of advice. You might need to give some extra support.
- Go back over the information. Say the main points again.
- Use a variety of information support tools, such as pictures. For example, draw a clock with time when arranging a meeting or talking about a start, open or close time.

7. Involving people with speech impairments

- Make eye contact and be especially attentive with a person who has difficulty speaking or who uses a communicator.
- Wait quietly and listen whilst the person talks.
- Resist the temptation to speak for the person, or to finish their sentences.
- Some people may prefer to be asked questions that require either a short answer, or a nod or shake of the head. Offer this option if it is appropriate to the situation or ask if they will write down words or phrases you are having difficulty understanding.
- Be sure you understand fully what the person means before making any assumptions.
- It can be helpful to say what you have understood and ask the person to confirm or clarify.
- If you don't understand what is being said, don't be afraid or embarrassed to ask the person to repeat it, maybe several times.
- Don't make assumptions about the person's hearing or intellect just because he or she has difficulty speaking.
- If the area is noisy, take account of this and, if possible, move to a quieter area.

8. Involving people who have mental health issues

8.1 General Etiquette

- Do not make assumptions
- Ask people what is the best way for them to work with you
- Do not have events or meetings in the early morning
- Ask people if they require a reminder about your meeting
- Make yourself aware of the "Recovery Model" see <u>www.mentalhealth.org.uk/help-information/mental-health-a-</u> <u>z/R/recovery/</u>

8.2 Sign posting

Dorset Mental Health Forum will help you to work with them in an efficient and effective way. They can help with a range of issues from developing questions to recruitment and collation of feedback.

Key contact

You can contact Dorset Mental Health Forum if you have any questions: Tel: 01305 257172 Email: <u>admin@dorsetmentalhealthforum.org.uk</u> Website: <u>www.dorsetmentalhealthforum.org.uk</u>

9. Involving people with hidden impairments or long term health conditions

9.1 General Etiquette

A large number of people have hidden impairments and/or health conditions. It is not our job to ask people specific issues about their condition or its impacts; however, we do need to make sure that people feel comfortable to attend and take part in the activities we are facilitating.

Key to this is asking people about their needs prior to an event. This could include a specific type of chair (with arm rests, or a high back). It could mean requesting information/handouts in advance so they have time to absorb information at their own pace – particularly relevant to impairments where fatigue, medication or pain management affects concentration levels.

Whatever the issue, ask in advance. A template of the DCC event booking form, including access needs questions, is included in the **User and Carer Involvement Tool Kit**.

9.2 Making information accessible

All people benefit from information that is in plain English and concise. However, as mentioned above, it should be noted that medication and fatigue issues linked to some long term health conditions can sometimes limit concentration span, and some people may also feel overwhelmed by an excess of information.

- Send information in advance so that groups can meet to discuss the issues you need help with.
- When planning your activity, think about regular breaks, etc.

Key contact

For advice and guidance from Dorset PCT on accessing groups with long term health conditions, contact **David Corbin (Tel: 01305 361474; Email:** <u>david.corbin@dorset-pct.nhs.uk</u>)

10. Running Pan Impairment Consultations

Some issues affect people across all of the impairment groups, and there are a number of benefits to be gained from bringing people from across the impairment groups together to discuss issues.

We need to consider how we make such events as accessible to the widest number of people. For more information on making events accessible, see the **User and Carer Involvement Tool Kit**.