

# Ways of working with ARCHES participants Guidelines

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This document was originally produced in 2016 to inform the development of participatory research groups in London, Vienna, Madrid and Oviedo for the ARCHES project. This is an adaptation that should serve as a guideline for comparable participatory research projects in the cultural field.

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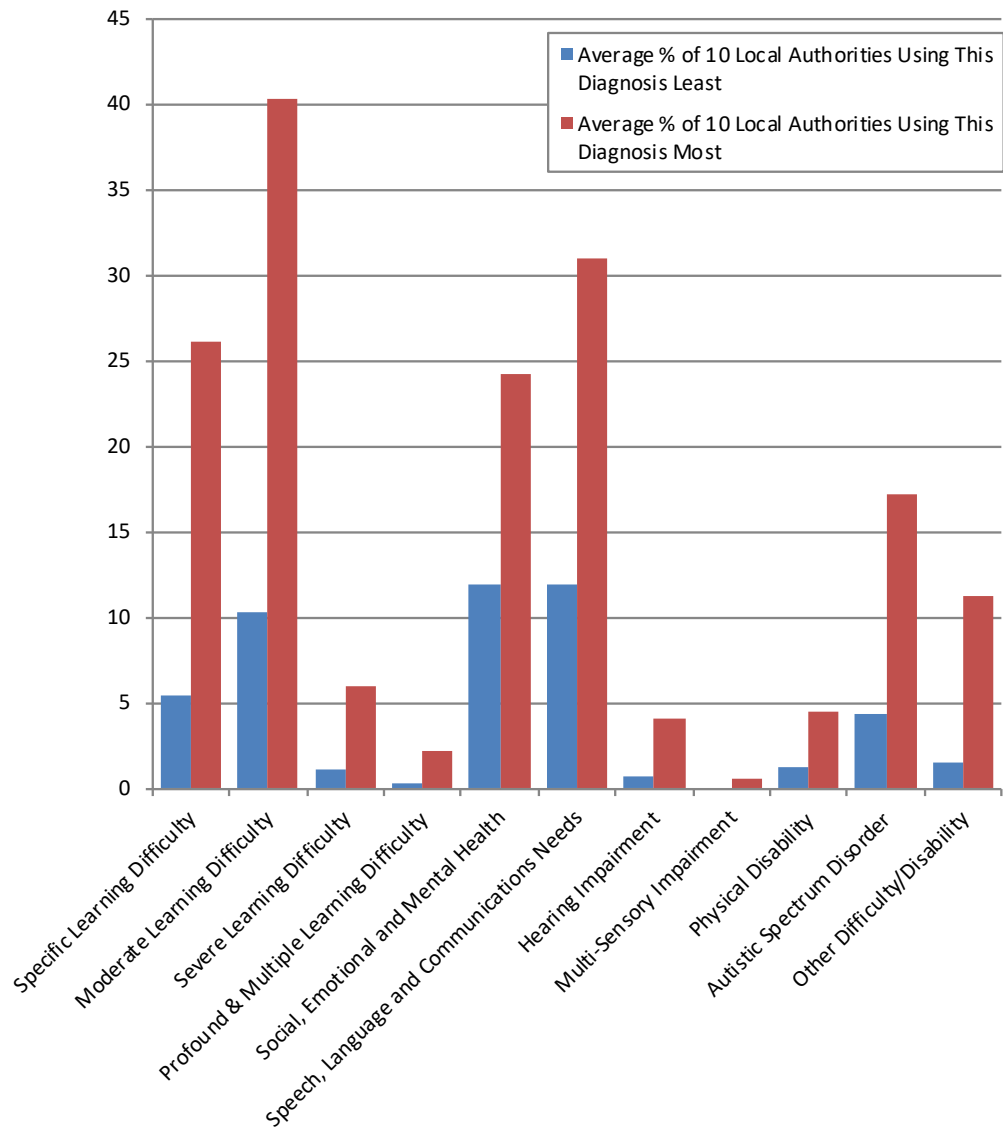


## **1. Project Principles**

Disability is a result of the way society is organised. Disabled people can be supported to be autonomous and valued citizens by removing barriers that restrict life choices. Barriers to inclusion are not just a physical thing but are also attitudinal and institutional, often based on stereotypes and inherent prejudices. (For example, disabled people are frequently identified by their impairments or differences, which are seen as unchangeable and/or responsive to interventions.) ARCHES seeks to work in ways that prevents such attitudinal barriers and the resulting physical and institutional barriers which disabled people face.

## **2. Principles for this Document and the Language we use**

It is tempting to feel that we can identify a particular category of individual and then identify a range of characteristics associated with that category, and on this basis assume that we can design an appropriate approach for that individual. However there are major limitations to adopting such an approach. Firstly the capacity of services to both create categories and allocate people to them is widely recognised as being inadequate and deeply flawed. For example in England in 2015, the variation for all categories of diagnosis was at least four times higher in local authorities that used the category most than in those that used it least (see table 1). Even the OECD (Organisation for Economic Co-operation and Development) recognise that categories can only be used as a tool for reflection (see OECD, 2012).



The second challenge in adopting a category based response is that people come with a whole range of characteristics, some of which might be seen as impairment related but most of which are a consequence of their social and cultural backgrounds and experiences. Given these challenges it is far more effective to presume that we cannot predict specific needs for any individual and should respond according to the situation. This is not to say that we cannot describe effective ways of working which will have a universal relevance or might be broadly useful to different categories of impairments. These guidelines therefore try to outline these effective ways of working and



to highlight where certain practices might have relevance for a specific audience, accepting that this cannot be generalised across that specific population.

We are also aware that terms are understood in different ways in different countries and that there is inconsistency in terminology, both within and between nations, across all categories. While language and terminology are continually debated and open to change, people with disabilities is currently the term most widely used and accepted by the disability community in the United States and in Ireland, the emphasis being on the person ahead of the disability. In Britain, disabled people is the preferred term, the emphasis being on the disabling of people through the physical, institutional, systemic, economic and attitudinal barriers that society creates rather than on an individual's disability/impairment (Arts and Disability Ireland 2010).

The complexity around labelling is particularly in evidence in relation to the term learning difficulty/disability. In England for example, 'learning difficulties' was the standard educational term for children who needed additional support, but in 2014 was replaced with the concept, 'learning difficulties and disabilities', whilst the term 'learning disabilities' was still evident in much legislation associated with wider social care arenas. This latter term however was broadly used to refer to an intellectual impairment which affects someone's everyday life for the whole of their life. This is very different to its meaning in other countries, where it refers to people who are in some way restricted in their capacity to engage with certain aspects of formal learning, in particular reading, written expression, arithmetic. How these learning disabilities are identified and how they are understood is open to wide interpretation.

When we refer to people with learning difficulties we are referring to those who would most likely fall under the categories 'moderate, severe and profound learning difficulties' within the UK. This refers to a lifelong cognitive impairment. We are adopting the language advocated by self-advocates such as Simons (1992) and self-advocacy

groups such as People First (People First 1992, 2006). They request that we recognize individuals as people before anything else, and that we use the term 'learning difficulties' to remind others that they can learn for the whole of their lives like everyone else (Goodley, 2001). It is important to recognise that this is not a reference to people with mental health difficulties or autistic people. People with learning difficulties can also have a mental health difficulty or be autistic people too, but these are separate aspects of their diagnostic identity.

It is important to recognise however that different communities and different individuals within those communities choose to use different terms. Paddy Ladd, a Deaf activist and academic, argues that specific use of the term 'Deaf' (with a capital D) describes cultural and political identity, distinct from the clinical term 'deaf' (Ladd, 2001). He makes a clear distinction between those with a hearing impairment and the culturally Deaf, for whom the term 'Deaf' is a source of pride which signals a rich cultural and linguistic heritage. His distinction between pride in being 'Deaf' and his rejection of 'deafness' is an example of the difference between the acceptable and unacceptable label. We also refer to people from the Deaf community as having a communication difference, since signing languages are as rich and complex as any other language.

The complexity of the terminology when talking about people with sight loss is similar to the Deaf community. In 2006, the National Health Service in England renewed its definition of visual impairment (VI) as follows: "There has been a change in the terminology of the registers, blind and partial sight should now be expressed as severely sight impaired (blind) and sight impaired (partially sighted). This change was lobbied for by service users/patients as it more accurately describes their situation as people who may be technically blind or partially sighted could have useful residual vision" (NHS, 2006). Blind person can be an identifiable social and cultural category – i.e. people who think of themselves as similar to other people who are blind, like women or British-Asian. As a result some people think



of themselves as a cultural group based on their impairment (Hayhoe, 2012). Additionally, different organisations use different terms and it is very much down to the individual's preference what they would like to be labelled as. For example, Transport for London uses the abbreviation 'VIP' (Visually Impaired Person). This abbreviation may have a positive connotation in popular culture but is disliked by some members of this community. Looking at some of the descriptions within different communities like 'sight loss' and 'partially sighted' emphasise the disability more. For this reason, we have decided to use 'visual impairment'.

### **3. Communication**

#### **3.1. Tips for hearing people**

Communicating with someone who is deaf is not difficult but you do need to be patient and take the time to make sure you are communicating properly. Even if someone is wearing hearing aids it doesn't mean they can hear you perfectly. Ask if they need to lip-read. If you are using communication support, always remember to talk directly to the person you are communicating with and not the interpreter. Before you start speaking to the participant make sure you have their attention. Either wave or tap them on their arm – although make sure not to shock the person, as they may not hear you approaching. Face the person so they can lip-read your speech. Speak clearly, using plain language, normal lip movement and facial expressions. Keep your voice down, as it's uncomfortable for a person with a hearing aid if you shout; it also looks aggressive. Check whether the person understands what you are saying and, if not, try saying it in a different way. It is particularly useful to learn fingerspelling or some basic Sign Language. When talking to the Exploration Group or other partners, where there is a mix of deaf and hearing people ensure that you do not just focus on the hearing people who may be responding in ways with which you are more familiar.

### **3.2. Tips for engaging people with learning difficulties**

People with learning difficulties are frequently used to people talking about them, rather than to them and to having things presented in ways that are not accessible. You should try to avoid this. Your communications with the Exploration Group will benefit from establishing early that your communication will be accessible. You need to ensure that the subject is of interest to the participants and in some way reflects their priorities. Participants need to have a clear structure to activities and communications and to be given time to develop their understanding and to search for meaning. Using different mediums will help. For example, including senses such as touch, smell and sight can play an important role and reduce the need for verbal explanation. For some participants, the use of such senses will be their primary form of communication. Transitions should not be rapid and pressured. The enthusiasm of people with learning difficulties for new experiences, and the pace at which they work, also means that supporters can easily direct a process with their own ideas, ways of working and/or ambitions without being aware of it. Staff must allow the participants to direct the process of the activity rather than require them to follow.

### **3.3. Tips for communicating with deafblind participants**

People who are Deafblind don't all have complete loss of both senses; individuals might have one sense stronger than the other. They will also have different experiences of their sensory impairments. For example, they may have experienced them for the whole of their life or for some part of it. As with any individual they will have a wide variety of other attributes which can present opportunities or challenges for communication. You may find that they have a different understanding of the concept of language and consequently use symbols, objects which have a specific communicative meaning, sign language, braille and other communication systems. They may however have experience of spoken and written language and have consequently adapted their use of these as their senses





altered. It will be important to take the lead from people who know the person who is deafblind and with whom they have successful relationships. They may for example use communication methods such as deafblind manual alphabet, sign systems such as sign language, visual frame signing, hands-on signing and block alphabet or facial sensing approaches such as Tadoma and reading systems such as Braille and Moon.

### **3.4. Tips to enhance the description of an object to all participants**

Speak slowly and clearly. Give the participants time to absorb and find what you are describing. Some will need to form a mental impression of it, others will come to understand your meaning more slowly. People may also need extra time when handling a tactile image. Make the description interactive by asking the visitor questions, encouraging them to express their impressions. You should try to ask questions which are relevant to the group or the individual to which it is directed; for example, you may focus your questions upon a specific object within a painting for one visitor, but a range of objects for another or the overall artistic impression within its historical context. Check your presumptions of knowledge as well as your presumptions of a lack of knowledge. Words that seem obvious to you may not be understood by the listener; even simple words such as pronouns or directional instructions. You should try to use everyday words and terms when describing and check for understanding. You should also not be afraid of using words that you might associate with a sensory impairment such as 'sight' or 'see'. Describe colours and explain appropriate sounds and smells, which relate to the object. Again, don't presume, keep an open mind. For example, some blind visitors have lost their vision over time and still have a visual memory of colours. When starting to describe an object talk about its position in the room, give the dimensions of the object (compare it to everyday objects to make them relate to it), use the basic information on the label with the name, title or subject of the object as well as the style of the work.

Place the object within a historical and social framework and if appropriate in context with other works examined on the session/tour. Move in a logical, sequential order giving precise and accurate instruction for moving from one place to the next. Once the scene is set with your general description, start looking at the specific details and take time to show the relationship between details and the entire object. Look at the interest or experience of the visitors to determine when to finish. Some participants will also benefit from the provision of different resources such as large prints, magnifying glasses and tactile/raised images/text. You will need to be flexible in making a connection between these resources and the item under discussion.

### **3.5. Providing additional communication opportunities**

Communication support could include: note takers, lip speakers, sign language interpreters, deafblind interpreters and/or speech to text reporters. There is a belief that many people with learning difficulties find pictorial additions to signs beneficial. Pictograms, symbols and story-board style pictures from everyday are deemed to be particularly useful and should be used whenever and wherever possible. Symbols and pictures should support any text. The usage of costumes and story-telling also brings a space to life. People frequently respond best to an approachable, knowledgeable and patient guide. Visits are most effective when more senses are being used. Resources need to have strong contrast in colour and texture to be accessible to all. Audio text at the press of a button is very well received. Videos and music create a sense of place and reduce reliance upon reading text to access information, as do interactive video games. You need to be aware of the risk of overload, however. For example, some participants will need to focus upon a specific input or will need a sense of seclusion in order not to feel overwhelmed by an activity or space. You may also find that participants may not be aware of how to access and visit the heritage site. They may benefit from focussed pre-visit information, including more mundane matters such as information about transport and available workshops.



### **3.6. The importance of the support workers**

Having a consistent presence of supporters is a key factor in the continued involvement of people with learning difficulties. Supporters can raise issues and serve as advocates to mediate problems as they emerge based on their experience of being with a person. Therefore, it is necessary to constantly communicate with the supporters too. However, whilst they are of key importance supporters should not be the ultimate voice of the participants. Supporters, despite having the best intentions, can easily dominate the proceedings. Providing the supporters with a voice will reduce the incentive to incorporate their views into the participant's feedback. It is also worth recognising support workers' priorities may not always fit with the wishes of the person they are supporting. This can have a profound impact on a person's ability to attend and participate.

### **3.7. How to work with an interpreter**

If you have booked an interpreter for your deaf and hard of hearing participants it would be helpful if you give him/her in advance some information regarding the subject, unusual names and specialist terms you will talk about. Give the interpreter a week to get back to you regarding follow-up questions. Allow more time for the meeting (depending on the communication method it can take up to 50-70% longer with deafblind). Interpreters need breaks so make sure you schedule it. An interpreter can only work for 45 minutes without a break. If the session is longer, you might need to book two interpreters. If you book an interpreter for a formal event provide them with an outline of the set-up. Warn the interpreter prior to the event if you are going to demonstrate anything or read long passages. When talking in the gallery, agree with the interpreter where you both will be standing before looking at the artwork. When presenting look directly at the audience as some might be lip-reading. When you have finished a few sentences, look at the interpreter to see if s/he needs time to catch up. When presenting an object point to things but try to avoid large

gestures so that you do not distract from the interpreter or your own face. When showing the object don't continue talking whilst looking at it, turn back to the interpreter and audience before you continue. After your talk, the audience may want to check meanings with the interpreter or ask questions. Make sure to wait and see if the interpreter is answering a question from the audience.

## **4. Physical Access**

### **4.1. An inclusive environment for all**

Participants need places with good lighting (important for lip-readers as well as people with a visual impairment), which are spacious and have little to no background noise. Have plenty of seating availability throughout the site. You and the rest of the staff members must be welcoming, engaging and flexible, treating all participants with respect. If you promise to do something you should deliver it, otherwise it will demotivate the participants. This will enable you to build trust over a long period of time and create a stronger relationship with and amongst the exploration group. You and the staff members will benefit from having a variety of experiences with the users. For example, sharing a break for food will be important for you as a social opportunity and as a chance to refocus your group. For blind and partially blind visitors it is recommended that the museum offers access for guide dogs (with a water bowl and information on available 'spending areas').

### **4.2. Mobility friendly environment**

Providing physical access is not just a matter of having ramps and lifts that will allow visitors to explore the heritage site to the fullest, important as these are. Clear, large and symbol-based signs and materials are important to indicate what the participants can or cannot do and where to go and not to go. Colour coding for direction is helpful and needs to be contrasting and consistent. Accessible bathrooms and a quiet room/changing room are also necessary to give



privacy if needed. You should also be prepared and have spare wheelchairs available in case a participant might feel weak or tired, with routes prepared for larger wheelchairs if needed. Arranging for someone to assist in guiding the user of the wheelchair may also be appropriate.

### **4.3. Tips on how to guide a wheelchair user**

When guiding a wheelchair user concentrate on the route and the individual's needs. It takes time to guide someone successfully. There is no need to overburden the participant with chitchat. Guiding users is about giving them information. When giving the user relevant information keep it short and clear. People will not remember routes if staff hurry and are distracted. Never open or close doors with the footrests of a wheelchair as it might frighten the user and is very impolite. By turning 90 degrees, people will notice the change in direction as cutting corners makes people think they are still going in a straight line. Warning people when they are about to turn a corner and by placing a hand on the corresponding shoulder (left shoulder for a left turn, right shoulder for a right turn), helps people to adjust their body position in advance and maintain balance. Be careful as touching people without warning may trigger a fit or an involuntary movement. Explaining people about permanent landmarks, smell, sound, textures and clues helps people find their way. For people to remember a route staff must allow wheelchair users to stop and take their time to identify the environment. If the wheelchair user has no idea where he is going and with whom, they will not feel comfortable. Participants might have difficulty hearing you when being pushed and/or in a busy environment. It is therefore helpful to face the user and tell them before setting off, who is pushing them and where they are going. Include the user in decisions about the route and changes along the way, and the landmarks which you wish to use. Competent guiding skills are important to develop; they provide an opportunity to reinforce language with people who have a limited understanding of the spoken word and to teach routes to the user if they may want to visit the

institution independently. Consistency enables users to know the route regardless of who is guiding them.

#### **4.4. Tips on how to guide blind people and people with a visual impairment**

When approaching the participant, introduce yourself and communicate clearly when offering help and listen to their response (they may clarify whether and what help they want). Ask how they would like to be guided. Rather than you taking or holding their arm, allow them to take your arm. Mention if you are approaching kerbs and steps say whether they want to go up or down and any potential hazards that lie ahead and where they are. When guiding someone into a seat, place their hand on the back of the seat before they sit down, so they can orientate themselves. Make sure they know where they are and which way they are facing in relation to their environment. Say when you have finished providing assistance and are leaving them. Do not be afraid to use words or metaphors connected to the visual world, such as "Ah, I see!", and do not change your way of speaking for the sake of political correctness, as it will sound artificial. People with a visually impairment use these expressions themselves and will not feel offended if you say "Let us now look at the next example" or something like this.

### **5. Suggested visit schedule**

It is intended that there will be weekly meetings with the Exploration Groups. In addition to these meetings the Exploration Group may plan visits by smaller groupings or other users. These alternative visits will need to be arranged in a manner which is both suitable to the visitors and the sites involved. The format for weekly meetings may change across time, however from the outset meetings will need to be flexible in their organisation for individuals and the whole group. For example, it is important to recognise that transport issues will often cause problems for those attending.



A good pattern for the initial sessions will be:

- Introductory activity
- One hour visit/workshop
- Short recall activity to capture initial impressions
- Lunch (with discussion)
- Longer recall activity to record and explore people's experience

Starting a visit before 11am can cause problems with transport; however, the specific needs of each Exploration group needs to be taken into consideration. It is appropriate to focus on one contained aspect of the museum or technology during each visit. It is essential to remember the broad range of interests, skills, capacities and understandings the participants bring with them and the need to provide open ended activities that allow for people to engage and enjoy themselves in a way which is appropriate to these interests, skills, capacities and understandings. Given the level of sustained attention which can be expected, the focused activity should be for a maximum of one hour and a break for food should follow shortly after, serving as an important social and refocusing opportunity. Discussions about a visit can take place after such a break within a site's café and still be effective; though again the effectiveness of the approach needs to be assessed in the context of each group of researchers. To facilitate understanding by the museums and/or technology group, at least one member of staff should attend the post-visit recall meeting. During a session in addition to the many approaches identified above in the guidelines, you might consider providing symbols, photographs, visual questionnaires, observation opportunities, discussion in the moment, discussion retrospectively, drawing pictures and writing labels, brainstorming activities, taking photographs, recording with video or relevant apps, using postcards of artefacts, bring sensory artefacts to individuals, workshops, regular meetings, discussion/interviews/ questionnaires. The supporters will facilitate the sharing and recording of ideas. Digital cameras effectively allow for a rapid recall and discussion but may present technical challenges and raise

issues of ownership. All participants will enjoy having their work recognized and showcased. Allow each participant to share and showcase their thoughts and ideas at the end in the group. This will not only give everyone an active voice, but also feel part of a community.

## **6. Enacting our principles of participation, consent, security and privacy**

The ARCHES participatory research groups were organised and managed in line with principles of participation, consent, security and privacy.

### **6.1. Principles of participation**

- ARCHES is enabling the research voice of the members of the participatory research groups.
- ARCHES must ensure the members of the participatory research groups are active, recognised and willing participants.
- The intention of all those involved must be to do 'research with' rather than 'research on' the participatory research group members.
- Individual members of the participatory research groups will join the project on a volunteer basis and will be able to leave whenever they so wish.
- Data collection methods will also be developed in collaboration with the research group so they can best identify, capture and record their experiences and views.
- As much as external partners may wish to prioritise particular issues or approaches and their evaluation, the priorities of the participatory research groups and their knowing involvement are paramount.
- Diverse forms of communication must be used to engage with authentic user perspectives and the diverse forms of evidence that this produces must be valued and treated as significant markers of certainty.
- The approach to research must acknowledge that participation is a negotiated matter of social engagement and cannot be driven by an imposed external timetable.





## 6.2. Principles of consent

- Consent and assent is an ongoing, unfolding process, to which the research teams need to be alert at all times. It will be demonstrated by engagement as well as through verbal or signed agreement. In keeping with the UK Mental Capacity Act (MCA), people will be treated as able to make their own decisions until it is evident that they cannot.
- Consent will be made via the communication medium in which the person is most adept (verbal and/or augmented communication), and recorded with the person's initials (or alternative if necessary), witnessed by an advocate.
- The prospective members of the participatory research teams need to meet the researchers before the project begins. Informed consent will be sought following this meeting. Agreement to participate will be viewed as provisional consent.
- Consent is provisional upon the research being conducted within the outlined framework, continuing to develop within participant expectations, and there being no adverse change in the person's ability to give consent.
- Participants will be encouraged to share information with people they trust, who in turn will be encouraged to ask questions.
- Research teams must be alert to collective pressures upon individual members to
  - participate in activities with which they are not comfortable.
- Consent and assent materials must be accessible to people with the range of sensory and intellectual impairments, to ensure all participants are consensually involved in the project.
- Information will be given verbally, supported by sign/symbols/illustrations and repeated on more than one occasion.
- Supporters and other professionals involved must give their informed consent to participate using the agreement form, which will be completed prior to any data collection taking place.



### 6.3. Principles of security

- Interventions and equipment will carry no potential dangers beyond those that the participants would typically face when carrying out such activities without the research taking place.
- The activities undertaken will be those identified by the participatory research groups and the supporters with whom they have established a working relationship.
- The university, technology company and heritage site staff will witness practices rooted in everyday relationships elsewhere; they will engage in discussion with relevant management or services at the earliest opportunity if there is evidence of any practices which cause concern for an individual's well-being.
- There is a need to be constantly alert to the potential for breaches of confidentiality and trust between research group members, impacting upon personal and collective well-being.
- The UK researchers will hold appropriate Disclosure and Barring certificates.

### 6.4. Principle of privacy

- Research notes and visual records along with interview material and transcripts will be kept in secure conditions.
- The project will be registered with the Open University Faculty Data Protection Officer.
- Any personal information will be kept on an OU secure server. We will aim to keep collected datasets separated from personal identity information at the point of collection. Any key linking codes to identity information such as names, addresses and telephone numbers would then be kept secure and separate from the dataset, accessible only to the investigators. This however may not be acceptable to some members of the participatory research group and the methods they choose to develop. We will need to be flexible in balancing our needs for privacy with their needs for representation. This is a key aspect of the research approach being adopted.

- Images and other audio visual footage are the property of the individual. Each individual will be informed in person of the possible use of photography and other data collection methods as part of ARCHES research sessions. If subsequently we wish to use any material, we will need to seek further specific permission.

## **7. Staff profile**

Suggested Job Description for working on a participatory project

1. An understanding and experience of working within museums and museum education and education outreach.
2. Considerable personal and/or professional experience of spending time with people with an intellectual and/or sensory impairment or a communication difference.
3. Understanding of advocacy, self-advocacy and a commitment to support the voices of others.
4. A capacity to communicate clearly and effectively, and to write and present ideas.
5. Ability to work patiently and creatively with a range of different individuals, services and organisations.
6. Ability to work effectively and flexibly in a team and collaboratively with others.
7. Ability to work to deadlines and to take responsibility for the support of all aspects of the Museum's involvement within the project.
8. Commitment to equal opportunities policies and practices.
9. Ability and willingness to travel for work purposes, nationally and internationally.
10. Experience with and interest in a variety of software applications and communication devices.
11. Native or near native proficiency in Spanish/German and English.
12. A working knowledge of Spanish/German and/or a sign language.

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These guidelines have been compiled looking at a variety of different sources such as: Action on hearing loss, (n.d.), Deaf Awareness, [online] Available at: <https://www.actiononhearingloss.org.uk/supporting-you/factsheets-and-leaflets/deaf-awareness.aspx> [Accessed on the 25th October 2016].

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