

**National Occupational Standards**

**Sensory Services:**

**Standard 11 - Support the independent living skills of Deafblind people**

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## **STANDARD 11 - SUPPORT THE INDEPENDENT LIVING SKILLS OF DEAFBLIND PEOPLE**

### **ELEMENTS OF COMPETENCE**

1. Support the Deafblind person and their key people with needs and to articulate their requests
2. Work with the Deafblind person to engage in both day-to-day life and in new activities
3. Evaluate the effectiveness of support with the Deafblind person and their key people.

### **ABOUT THIS STANDARD**

This standard is about how you support the independent living skills for Deafblind people. The standard is relevant for all levels. Sections of the standard can be used for induction purposes, professional development and for training.

For this standard you will be expected to work in partnership with others to identify, plan, take action and evaluate activities that support the independent living skills for Deafblind children, young people, adults and their families.

Although the primary responsibility for your professional development rests with you, the standard also requires management support to facilitate the continuing professional development of the workforce.

### **Evidencing your performance, knowledge and understanding**

The **performance criteria** sections under each element and the **knowledge and understanding** section indicate areas that you should be able to evidence in relation to your performance or knowledge and understanding.

### **Values underpinning the whole of this standard**

The values underpinning this standard have been derived from the key purpose statement<sup>1</sup>. You must work within the principles and values of the relevant service standards, guidance and codes of practice /conduct for health and social care in the four countries to achieve this standard.

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<sup>1</sup> The key purpose of the sensory services workforce is to empower people who use these services to maximise their independence, opportunities, strengths and skills.

## **Key principle**

Communication underpins the entire standard and all the standards in this suite. It is vital that those working in the field of sensory impairment with children, young people and adults have the necessary and appropriate skills to communicate effectively with people who may use a range of communication tools/ techniques or methods. This standard relates to those working with people who are Deafblind and all communication must be appropriate to their needs. It is also important that workers recognise the need for specialist communication skills and the risk of miscommunication.

## **Knowledge and understanding**

The knowledge and understanding for this standard will relate to country specific regulatory requirements and codes of practice applicable to the scope of your work and those of colleagues. It will also relate to your role and to the level of responsibility you have within your organisation to undertake activities to achieve a high quality service.

## **KEY WORDS AND CONCEPTS**

This section provides explanations of the key words and concepts used in this particular standard. Note, in National Occupational Standards it is quite common to find words or phrases used that you will be familiar with, but which, in the detail of the standards, may be used in a very particular way. Therefore, we would encourage you to read this section carefully before you begin working with the standard and to refer back to this section as required.

## **Acquired**

Acquired Deafblindness is when a person is born without a sensory impairment and at some time in their life develops both, or is born with a single sensory impairment and at some time in their life develops the second. This may be due to an accident, illness, and a genetic condition, e.g. a syndrome such as Usher, Alstrom, and Stickler, etc. or as a result of aging in later life. In children and young people if these problems occur later in life, it is referred to as acquired Deafblindness.

## **Active support**

Support that encourages the Deafblind person to maximise their independence and promotes lifestyle choices. In the case of children and young people this would also be relevant to the role of parent/ carer or the children themselves as part of their own care planning process.

The unique nature of Deafblindness is that it should be recognised that for the individual to remain independent they may require one-to-one support.

## **Communication**

This standard makes it explicit that you:

- Must have the skills to be able to effectively communicate with the Deafblind person, or in a case where specialist communicators are needed arrange for these to be put in place. These skills include active listening
- Should use the individual's preferred means of communication both receptively and expressively in the most appropriate format, e.g. British Sign Language (BSL), Irish Sign Language (ISL), or a sign system, e.g. Sign Supported English visual frame, close up and hands on, communication passports, Deafblind manual alphabet, Block alphabet, Braille, Moon, Tadoma, or any other preferred human and technological aids to communication or a combination of any of the above
- Need to be constantly aware that communicating with a Deafblind person is complex and that the risk of misunderstanding is significant

It is important to be flexible when helping a person who is Deafblind to communicate and it may be helpful to use a range of communication methods together. This is often called the total communication approach. It is important to stress that Deafblind people have a great range of communication needs, which may change over time. Also some Deafblind people may use two or more methods of communication to express themselves, but receive information by using different methods(s). For example:

- A child who has some sight, is profoundly Deaf and has physical disabilities, may learn to understand sign language, but may need to find another means to express him or herself
- Someone with Usher syndrome may have learned British Sign Language as a young person, but may need to adapt the way they receive signs as his or her vision begins to change
- An older person may have always used speech and hearing to communicate, but may need to learn to use hearing aids and low vision aids as his or her vision and hearing change over time  
(Source: SENSE 2008)

## **Congenital**

When someone is born with combined sight and hearing difficulties this is called congenital Deafblindness. Examples of this include conditions such as Rubella or CHARGE. Congenital can also refer to people who have lost vision/ hearing before the acquisition of language, i.e. very early years.

## **Deafblind**

Deafblind is the recognized term used by national government in both the UK and the world community. There is a clear Department of Health description in the local authority circular "Social care for Deafblind children and adults" (2001) 8, and in the DES Policy Statement (1989). Both describe Deafblindness as a unique and different disability, the impact of which requires an appropriate and specialist response:

*"Persons are regarded as Deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility"*

(Source: DH LAC (2001) 8).

*"The term Deafblind is used to describe a heterogeneous group of children who may suffer from varying degrees of visual and hearing impairment, perhaps combined with learning difficulties and physical disabilities, which can cause severe communication, developmental and educational problems"*

(Source: DES Policy Statement 1989).

## **Disadvantage, discrimination and social exclusion**

This relates to race, gender, religion, sectarianism, language, age, class, disability (including sensory disability), poverty, culture, belief and sexual orientation.

In practice you must take account of the relevant policies and procedures within your organisation or agency.

## **Empowerment**

Empowerment is a process of enabling individuals (children, young people and adults) who are at a disadvantage at both personal and organisational levels to gain more autonomy and control over their lives.

## Hearing impairment

Hearing impaired is no longer a term that is commonly used. Largely it has been replaced by the terms "Deaf" and "Hard of Hearing". A variety of terms are used quite specifically in this standard as follows:

- **Deaf:** deaf with a small "d" simply refers to the medical condition of hearing loss. However, most people who use BSL/ISL refer to themselves as Deaf. The use of upper case "D" indicates a language preference and is also a political and cultural term of belonging to the Deaf community. It is used in the same way that people who belong to a national, cultural or religious group would describe themselves, for example, as French or Muslim. It is for this reason that many Deaf people do not define themselves as disabled, rather they describe themselves as belonging to a cultural or linguistic minority
- **Deafened:** A person who was born hearing and subsequently became severely or profoundly deaf
- **Hard of hearing:** A general term used to describe people with a range of hearing loss and communication needs
- **Deafblind:** This term applies to people with dual sensory loss. Some people who are Deafblind have no hearing or vision, others have a degree of hearing loss or vision impairment (see full definition above)

## Individuals

In the standard "individual" refers to children, young people and adults who are Deafblind and who may require health and/or social care and children's, educational or training services. It also refers to advocates and interpreters or people who work with them to express their views, wishes or feelings and to speak on their behalf.

## Issues

Issues means, what impacts on the Deafblind person or is relevant to their experience. The use of the word "issue" does not imply a difficulty, but simply an aspect of the person's life that is the focus of the current work.

## **Key people**

Key people include: family, communicator guides, interveners, Deafblind workers, friends, carers, support worker, role model, befriender, advocates, habilitation/ rehabilitation workers and others with whom the individual has a supportive relationship.

## **Partnership working**

The process of working collaboratively with specialists in the dual sensory impairment field, visual impairment field or Deaf and Hard of Hearing field whether statutory, voluntary or health to support Deafblind people with their needs, to help them articulate their requests and to raise the profile of Deafblindness issues and offer appropriate support.

## **Rehabilitation/ habilitation**

Rehabilitation involves a wide range of support that aims to maximise independence, skills and confidence. Rehabilitation can involve helping people to regain abilities or functions lost due to illness or injuries.

Habilitation defines the coordinated use of medical, social, educational, and vocational measures to help people develop their functional ability. This contrasts with helping people to regain abilities lost due to illness or injuries rather than people who have been born with impairments.

## **Response to poor practice**

Your response to poor practice may involve: offering constructive feedback, offering information and advice to enable the individual(s) concerned to access appropriate guidance and support and/ or reporting incidents of bad or dangerous practice to the appropriate authority.

## **Rights**

The rights that individuals have to:

- Be respected
- Be treated equally and not be discriminated against
- Be treated as an individual
- Be treated in a dignified way
- Have privacy
- Be protected from danger and harm
- Be cared for in a way they choose

- Have access to information about themselves
- Communicate using their preferred methods of communication and language

In the case of children and young people, they have the right to be actively involved in the decisions that affect them.

## **Risks**

Risk is the inevitable consequence of people taking decisions about their lives. But it means different things to different people. There is no one definition. In social care, as in the rest of life, risk can be viewed negatively. Because of perceptions of risk which may or may not be real, a person might be prevented from doing things which most people take for granted. So perceived risk must be tested and assessed against the likely benefits of taking an active part in the community, learning new skills and gaining confidence. What needs to be considered is the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks.

A decision about the perceived or actual risk needs to be taken in conjunction with the person using services themselves, as well as the professionals involved. Just as taking a risk is a personal choice, levels of risk are perceptions, and a judgement about an acceptable level of risk should be a joint decision.

## **Signpost**

Means to assist individuals to access the most appropriate information about other services and groups that will support their identified needs.

## **Services**

Refers to services provided by your own organisation or other agencies.

## **Social Model of disability**

The Social Model of Disability says that disability is caused **by the way society is organised**, rather than by a person's impairment\* or difference.

The Social Model of disability looks at ways of **removing barriers which restrict life choices** for people with impairments or differences.

When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Disabled people developed the Social Model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

(\* Impairment is defined as the limitation of a person's physical, mental or sensory function on a long-term basis.) Extract from *children in the picture* [www.childreninthepicture.org.uk/au\\_socialmodel](http://www.childreninthepicture.org.uk/au_socialmodel)

### **Sources of information**

Will include a wide variety of current information. For example from:

- Professional organisations, e.g. professional bodies, trade associations and trade unions
- Professional contacts, e.g. colleagues, mentor, supervisor, tutors/lecturers and researchers
- Written sources, e.g. professional journals, research reports and policy documents
- Networks such as black and minority ethnic groups to consider cultural issues, e.g. fasting, festivals and priorities.

### **Supervision**

Supervision involves a process of supportively reviewing a person's work decisions to develop their practice. It can be formal, informal, provided from within your organisation, provided from outside your organisation, (Note, it is recognised that supervision in relation to work with children and young people is different to the supervision of work with adults).

### **Support**

Refers to the support you provide. It includes: verbal explanation, written information, accompanying the individual or arranging for this to happen.

### **Transitions**

Transitions are daily and intermittent changes in a person's life that may affect their well-being, the way they behave and develop and their ability to continue to learn and cope with other changes.

There are two major types of transitions: the first includes transitions within daily life, for example with adults moving from and to home/the provision to a day centre; and for children going from and to home/the provision to school. They also involve changing activities and routines within the day where there are differing expectations and requirements from the child, young person or adult.

The second is intermittent and involves a significant change for the person. These transitions can be divided into three categories. First, those that are common to most people; for example, when people move from one form of accommodation and living environment to another. Second, those that are shared by a significant number of peers, such as families separating. Third, those that are personal and may not be shared or understood by others.

For children and young people, the first will include transferring between years in the same school, or college or transferring from one school to another. It could also include transitional experiences such as physical changes, e.g. the onset of puberty. The second may be their parents divorcing. The third being in foster or residential care, having a parent or carer who abuses drugs or alcohol, or being a young carer.

(Source: Leadership and management NOS Ref: LMC B3)

### **Transition planning**

The transitional years between school and adult life are stressful for most young people, but for those with complex disabilities such as Deafblindness, even more so. Choices for Deafblind young people may be limited, and many young people will continue to be dependent on their families. This is despite the fact that all young people with a statement of educational needs are entitled to a transition plan following their Year 9 annual review.

Transition should not be seen as something that happens as a young person approaches the age of 18. It should start at 13+, and this early start is particularly important for those with complex and multiple needs, where co-ordinating many services will require time. Services need to develop knowledge of the individual young person and their needs. Specialist input will be needed to ensure adult services are appropriate.

### **Values and principles**

Are those specified by: professional bodies, government, your employer, service users and their carers and by relevant national bodies.

## **1 Element 1 - Support the Deafblind person and their key people with needs and to articulate their requests**

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### **Performance Criteria**

You need to show that according to your level of experience and seniority you:

- a) Ensure that the Deafblind person and their family has the information they need to:
  - Understand what is happening
  - Make informed choices
  - Get what they choose
- b) Ensure that the Deafblind person and their family are as involved as possible in any decision which affects them
- c) Recognise and respect the individuality and value of each person and their right to equal treatment
- d) Encourage the Deafblind person to act and live independently
- e) Support the Deafblind person and family members to take well judged risks
- f) Ensure communication materials are produced in the right formats and make an effective contribution to decision-making processes
- g) Absorb complex information quickly, effectively and confidently and present it clearly to all the relevant parties
- h) Provide advice without stepping into a counselling role
- i) In the case of children and young people include their parents in the information gathering and evaluation process where appropriate, as they often have excellent skills and knowledge
- j) Record outcomes agreed and discuss them with the individual
- k) Write clear and effective reports on needs and requests.

## **2 Element 2 - Work with the Deafblind person to engage in both day-to-day life and in new activities**

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### **Performance Criteria**

You need to show that according to your level of experience and seniority you:

- a) Support the Deafblind person to meet with and engage with others
- b) Work together with the Deafblind person to identify realistic opportunities for new activities
- c) Ensure that expectations are discussed in order that false or unrealistic expectations are not raised
- d) Provide (or signpost the individual to) additional information in the most appropriate format when it is required or would be useful
- e) Act as an advocate for the Deafblind person when this is necessary for them to express their views, wishes or feelings effectively
- f) Support the Deafblind person to have an active social life and a network of friends
- g) Support the person to access educational and social opportunities
- h) Support mobility and orientation including guiding safely and appropriately inside and outdoors
- i) Enable the use of appropriate assistive technology and equipment
- j) Ensure that the Deafblind person is supported to stay safe
- k) Ensure that equal opportunities and diversity are assured and demonstrated
- l) Encourage participation and engage key people
- m) Support family members with any concerns they may have
- n) Work collaboratively across a range of agencies to ensure the best outcome for the Deafblind person
- o) Work effectively in a multidisciplinary team, both with colleagues and with people from outside your organisation.

### **3 Element 3 - Evaluate the effectiveness of support with the Deafblind person and their key people**

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#### **Performance Criteria**

You need to show that according to your level of experience and seniority you:

- a) Discuss the effectiveness of the support services with the Deafblind person and, where appropriate, their family and other key people and ensure you listen actively to their feedback
- b) Evaluate the use of any specialist reports of other professionals
- c) Explore ways that the support might be improved
- d) Identify any gaps in support
- e) Review the contributions of others and recommend improvements where appropriate
- f) Identify the scope for new services that would better meet the Deafblind person's needs and take this forward with others.

## **KNOWLEDGE AND UNDERSTANDING**

Competent practice is a combination of the application of skills and knowledge informed by values and ethics. This specification details the knowledge and understanding required to carry out competent practice for the performance described in this standard.

When using this specification it is important to read the knowledge requirements in relation to expectations and requirements of your job role.

You need to show that you know, understand and can apply in practice according to your level of experience and seniority:

### **A. CORE VALUES**

#### **Use and develop methods and systems to communicate, record and report**

1. Legal and organisational requirements on equality, diversity, discrimination, rights, confidentiality and sharing of information when communicating, recording and reporting with individuals, key people and others
2. Knowledge and practice that underpin the holistic person-centred approach which enables you to work in ways that:
  - Place the individual's preferences and best interests at the centre of everything you do
  - Provide active support for the individuals
  - Recognise the uniqueness of individuals and their circumstances
  - Empower individuals to take responsibility (as far as they are able and within any restrictions placed upon them), and make and communicate their own decisions about their lives, actions and risks
3. Methods and ways of communicating that:
  - Support equality and diversity
  - Support the rights of people to communicate in their preferred way, media and language
  - Are ethical and adhere to any codes of practice relevant to your work

- Respect other people's ideas, values and principles
  - Ensure people's dignity and rights when identifying and overcoming barriers to communication
4. How to manage ethical dilemmas and conflicts for individuals, those who use services and staff/colleagues, about communication, recording and reporting
  5. How to challenge information, documents, systems, structures, procedures and practices that are discriminatory, especially in relation to individuals' communication and information needs.

**Contribute to the development and maintenance of healthy and safe practices in the working environment**

6. Legal and organisational requirements on equality, diversity, discrimination, rights, confidentiality and sharing of information when contributing to the development and maintenance of healthy and safe practices in the working environment
7. Methods and ways of working that:
  - Support equality and diversity when contributing to the development and maintenance of healthy and safe practices in the working environment
  - Are effective when dealing with, and challenging information, documents, systems, structures, procedures and practices that are discriminatory
  - Are ethical and adhere to any codes of practice relevant to your work
  - Respect other people's ideas, values and principles when contributing to the development and maintenance of healthy and safe practices in the working environment.

**Take responsibility for the continuing professional development of self and others**

8. Up-to-date knowledge and practice of legal and organisational requirements for equality, diversity, discrimination, rights, confidentiality and sharing of information and how to update and develop your own, and the practice of other staff on these
9. How to access training and development to enable you to manage ethical dilemmas and conflicts for individuals, those who use services and staff.

## **B. LEGISLATION AND ORGANISATIONAL POLICY AND PROCEDURES**

1. Knowledge of the practical impact of relevant legislation (different at different levels) on your day-to-day work
2. Define the legal and accepted definition of Deafblindness
3. Knowledge of relevant legislation policy and practice and can apply it in a variety of situations, e.g.:
  - Education
  - Social care
  - Benefits
  - Housing
  - Disability rights
4. Health and Safety legislation:
  - Awareness of the different hazards that may face staff, visitors, contractors and Deafblind people within their area of responsibility
  - How to implement systems of work that minimise exposure to such hazards on a day-to-day basis
  - How to implement corporate policies and procedures necessary to ensure safety
  - Knowledge of technical aids and equipment safety.

## **C. THEORY AND GOOD PRACTICE**

### **In relation to self**

1. Standards within your own work and the sector
2. Learning theories, teaching methods and learning styles for your own use
3. Theories about reflective practice and methods that are effective in monitoring your own performance
4. Approaches to knowledge and evidence based practice
5. Know how to seek support and critically evaluate your own involvement
6. Provide clear examples of professional and unprofessional behaviour and know how to challenge poor practice effectively.

### **In relation to partnerships and collaboration with others**

7. Knowledge of local authority departments: how they operate and who are the key people in each case
8. Knowledge of key organisations and professionals that may be relevant to a Deafblind person
9. Awareness of day-to-day ethical dilemmas and where and how to seek support
10. Absorb complex information quickly and effectively,
11. Maintain confidentiality and keep appropriate accurate records
12. Work effectively in a multi-disciplinary team, both with colleagues and with people from outside the organisation
13. Understand and use the specialist reports of other professionals
14. Monitor the effectiveness of a service with an individual
15. Awareness of power issues in various work settings and the impact these have on service outcomes, e.g. domiciliary settings, sheltered housing settings, etc.

### **In relation to Deafblindness**

16. Can state the most common conditions related to Deafblindness
17. Recognise the day-to-day impact of those conditions on a person's life
18. State the different causes of Deafblindness and the impact of them on individual children, young people and adults
19. State the prevalence of Deafblindness amongst children, young people and adults
20. Recognise the difference between acquired and congenital Deafblindness
21. Understand the mechanism of advocacy and other support available
22. Understand the limits of your role
23. Able to demonstrate practical application of your knowledge through:
  - Carrying out assessments of need (as appropriate)
  - Making confident professional judgements
24. Empower Deafblind people and their families through the provision of appropriate information.

## **In relation to communications**

25. Methods of consulting with different groups including children and young people and adults, their organisations or groups and actively listening to their feedback
26. Methods for collecting, analysing and interpreting feedback to enable decisions to be made about your support
27. Understanding of the impact of multiple impairments. Be aware of the potential for miscommunication in these circumstances and therefore carefully plan how you will communicate with the individual and use or arrange the most effective communication methods
28. Having the skills to plan communication in advance and making sure either you have the necessary skills in place or have access to the specialist communication skills needed
29. Be aware that individuals may prefer to express themselves using a different mode of communication compared with how they prefer to receive information and adapt how you communicate accordingly
30. Be resourceful when overcoming barriers to communication and barriers restricting the independence of the people you support
31. Takes a flexible approach to working with individuals and their families/ key people
32. Give advice without stepping into a counselling role
33. Write clear and effective reports.