LOCAL AUTHORITY CIRCULAR  
LAC(DH)(2009)6

To: The Chief Executive  
County Councils  
Metropolitan District Councils  
Shire Unitary Councils  
London Borough Councils  
Common Council of the City of London  
Council of the Isles of Scilly  
Strategic Health Authorities  
Directors of Childrens Services  
Directors of Adult Services

Date: 23 June 2009

SOCIAL CARE FOR DEAFBLIND CHILDREN AND ADULTS

Gateway Reference 11835

1. SUMMARY

1.1 The Statutory Guidance which is attached to this Circular is issued under Section 7 of the Local Authority Social Services Act 1970. The Guidance applies to Local Authorities with social services responsibilities (hereafter referred to as “Local Authorities”).

1.2 This Circular replaces LAC(2001)8 which was cancelled on 28 February 2006 and it sets out a summary of actions, as stated in the Guidance, that Local Authorities are expected to take in relation to Deafblind adults and children.

1.3 This guidance can be found on the Department of Health website at: www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH_4004454.
1.4. This guidance should be read, and given effect to, in the context of Local Authority Circular (DH) (2009) ¹ which sets out information to support councils and their partners in the ongoing transformation of adult social care as set out in Putting People First (PPF)².

1.5 PPF is a shared vision and cross-sector commitment to the transformation of Adult Social Care. It confirms that reform can only be delivered through partnerships across central and local government and signals a sector-wide agreement on the direction of travel, and the commitment to delivering significant change to adult social care by April 2011. At its heart is a pledge to ensure that all public bodies work together towards a society that enables individuals to have maximum choice and control over their lives and values the contribution that all citizens can make, whether they need support from others now or in the future.

1.6 Many Deafblind people are not known to their local social services authority. Of those who are in contact with social services, not all are identified as having dual sensory impairment nor are they in receipt of appropriate services. This applies to both adults and children.

2. ACTION

2.1 Local Authorities are asked to take the following action as set out in more detail in the attached guidance:

- identify, make contact with and keep a record of Deafblind people in their catchment area (including those who have multiple disabilities including dual sensory impairment);

- ensure that when an assessment is required or requested, it is carried out by a specifically trained person/team, equipped to assess the needs of a Deafblind person - in particular to assess need for one-to-one human contact, assistive technology and rehabilitation;

- ensure services provided to Deafblind people are appropriate, recognising that they may not necessarily be able to benefit from mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses;

- ensure that Deafblind people are able to access specifically trained one-to-one support workers if they are assessed as requiring one;

- provide information about services in formats and methods that are accessible to Deafblind people; and

- ensure that one member of senior management includes, within his/her responsibilities, overall responsibility for Deafblind services.

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¹ Local Authority Circular (DH) (2009) 1: Transforming Social Care, Department of Health, http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_095719
3. ENQUIRIES

Enquiries about this Circular should be made to:

Social Care Partnerships and Innovation (SCPI)
SCPI-PIIL-CORRES@dh.gsi.gov.uk

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1. In 2000, the Department of Health completed a consultation exercise looking at social care services for Deafblind children and adults. A consultation group was convened, including representatives from Deafblind UK, Sense, Royal National Institute of Blind People (RNIB), Royal National Institute for Deaf People (RNID), Association of Directors of Adult Social Services (ADSS), Local Government Association (LGA) and service users. In addition, comments were invited, via the Department of Health website, and received from Local Authorities, service users and others with an interest. The exercise concluded that the needs of Deafblind people were often not identified nor were those assessed as needing community care always provided with appropriate services. It was agreed that significant improvements were required to identify, correctly assess and provide appropriate services for people with dual sensory impairment.

2. This circular sets out to re-issue and update the original Guidance contained in Local Authority Circular LAC(2001)8 which responded to these concerns and the recommendations put forward by the consultation group.

Deafblindness - Definitions and Descriptions

3. Whilst there is no generally accepted definition of Deafblindness there is a working description that has been accepted over many years. Persons are regarded as Deafblind “if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss” (Think Dual Sensory, Department of Health, 1995). Deafblindness can be found in all age groups, including children, but the incidence is greatest in older adults.

4. The term ‘dual sensory loss’ can be used interchangeably with Deafblindness denoting the fact that combined losses of sight and hearing are significant for the individual even where they are not profoundly deaf and totally blind. It is the way in which one sensory impairment impacts upon, or compounds the second impairment, which causes the difficulties, even if, taken separately, each single sensory impairment appears relatively mild.

5. Many people do not define themselves either as Deafblind or having dual sensory loss. They may use such phrases as “I don’t see too well or hear too well”. However, they do describe their vision and hearing loss in terms which indicate that they have significant difficulties in their day-to-day functioning and may need support to live independently. These people could be described as having a combined sight and hearing loss if the deterioration or progressive loss of their sight and/or hearing causes a significant functional impact in one or more of the following:
   - communication;
   - access to information; or
   - mobility

Congenital and Acquired Deafblindness

6. Four basic groups of people experiencing Deafblindness have been identified:
   - those who are hearing and sight impaired from birth or early childhood;
   - those blind from birth or early childhood who subsequently acquire a hearing loss that has a significant functional impact;
   - those who are deaf from birth or early childhood who subsequently acquire a significant visual loss;
   - those who acquire a hearing and sight impairment later in life, that has a significant functional impact.

7. The impact of dual sensory impairment on an individual will vary according to the learning opportunities they have had. People who are born Deafblind may have little or no formal language and only limited understanding of the world because they have never been able to watch/listen to other people and the things going on around them. In contrast people who acquire their Deafblindness may have the advantage of remembered sight and/or hearing and are more likely to have had access to language learning. Methods of communication will therefore vary, and may include:
   - Clear speech and lip reading
   - Lipspeaking
   - British Sign Language or a sign system e.g. Sign Supported English
   - Visual Frame Signing, Close-up Signing, Hands-on Signing, Hand on Hand Signing
   - Braille and Moon
   - Block Alphabet
   - Deafblind Manual Alphabet
   - Note taking
   - Electronic communication (with Braille output or large font on screen)
   - Individual's own personal signs
   - Makaton
   - Large Print (font size 16 or above)
   - A combination of any of the above or any method preferred by the individual

8. In all cases, those who provide information, or are involved in assessment of, or in service provision for Deafblind people, should take the initiative to establish the maximum possible communication. This will ensure that individuals, as well as those who care for them, are as fully engaged as possible in assessment, planning and provision and are able to have choice and control over their lives. It should be recognised that such involvement may take time to establish. There is, therefore, clear value in noting the preferred method of written and verbal communication on case notes.
Recognising Deafblindness

9. There are issues surrounding locating and contacting Deafblind people not known to Local Authorities. People with dual sensory impairment who receive social services may not be recognised as being Deafblind. This can be because an initial assessment was carried out when only one sense was impaired or because both senses have deteriorated since the care package (including residential placement) has taken place. It can also be because other disabilities (such as learning disability) 'mask' the Deafblindness. A particular approach for helping non-specialists recognise and understand the impact of Deafblindness is to provide a set of descriptors, one for people born Deafblind and the other for those who acquire the disability. This can be an important aid to identifying the appropriate type of intervention needed which may be different for the two groups. Descriptors for both groups can be found at Annex 1.

Legislative Background

10. Local Authorities functions relating to social services provision for disabled adults are set out in section 29(1) of the National Assistance Act 1948 and section 2 of the Chronically Sick and Disabled Persons Act 1970 (“the 1970 Act”). The combined effect of these provisions is that Local Authorities may, and in certain circumstances must, make arrangements for promoting the welfare "of persons aged 18 or over who are blind, deaf or dumb or who suffer from mental disorder of any description and other persons aged 18 or over who are substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed by the Minister."

11. Local Authority functions relating to the provision of social care for children and families are set out mainly in section 17 of, and Part 1 of Schedule 2 to, the Children Act 1989. Under these provisions, Local Authorities must provide an appropriate range and level of services for children who need them to achieve or maintain a reasonable standard of health and development, or who are disabled. In addition, Section 2 of the 1970 Act also applies to disabled children in the same way that it applies to disabled adults, by virtue of section 28A of the 1970 Act.

12. Local Authorities also have a duty, under section 1(1) of the 1970 Act to inform themselves of the number of persons in their area to whom section 29 of the National Assistance Act 1948 applies.

Status of the Guidance

13. The following Guidance is issued under Section 7(1) of the Local Authority Social Services Act 1970. This means that Local Authorities must follow it unless there are exceptional reasons not to do so.

Identification

14. Local Authorities are asked to identify, make contact with and keep a record of Deafblind people in their catchment area. In doing so they should be aware that many of those who are known to Local Authorities as having learning disabilities, multiple disabilities or problems associated with age, may also have dual sensory
impairment. Deafblind children should be included on the register of Disabled Children which Local Authorities are required to maintain under the Children Act 1989 (Schedule 2, paragraph 2).

15. For children, the early identification of difficulties and effective intervention to meet their needs is crucial to ensuring their health and well-being, and in helping them succeed in education. Councils should ensure that the identification of Deafblind children and early intervention to meet their needs is part of their strategy for securing childcare and education opportunities for children from the early years through to adulthood.

16. The Government recognises the importance of people having access to high quality information and advice, appropriate early interventions and being able to exercise choice and control over the services and support they need. Local Authorities with adult social services responsibilities should take a balanced approach to prevention and early intervention and deliver personalised services, enabling deafblind people to develop solutions that work for them.

17. The Common Assessment Framework (CAF) for children and young people (Department for Children, Schools and Families 2008)

http://www.everychildmatters.gov.uk/deliveringservices/caf/

process offers practitioners in all agencies the opportunity, together with children and their families, to identify possible (low level) additional needs, and the services which may be required to meet those needs, at an early stage. The CAF process can help bring practitioners and agencies together to provide better service provision, co-ordinated by a Lead Professional. Information gathered as part of the CAF process can be used to inform any specialist assessment, which may be required subsequently to meet needs that are more complex.

18. However, Deafblind children (many of whom will also have additional disabilities) will often have been under the care of local paediatric services since birth, although the full extent to their disability may not become apparent until later. They require follow-up by the child development team with access to specialist audiology and ophthalmology services. Local arrangements should ensure early referral for support to Local Authority children’s social services and to voluntary organisations where relevant.

19. Deafblind children are considered as Children in Need under the Children Act 1989. It should be possible to identify Deafblind children on the Social Services Disability Register. The child and their family should be offered an assessment based on the Framework for the Assessment of Children in Need and their Families (Department of Health 2000) in order to determine what services it will be most appropriate to offer. Good quality assessments will encourage active partnerships between mainstream and specialist services working together to manage disabled children’s inclusion in family life, education and community services ('Assessing Children in Need and their Families: Practice Guidance', Department of Health, the Stationery Office, 2000, London). The Early Support programme provides a framework of multi-

4 http://www.everychildmatters.gov.uk/deliveringservices/caf/
agency training and resources to facilitate these partnerships across health, childcare/early education and social services, putting the child and their family at the centre of service provision.

20. The roll-out of a Newborn Hearing Screening Programme (NHSP) was announced in December 2000 by the Department of Health following research and advice from the UK National Screening Committee. The NHSP has been fully introduced across all 122 sites in England. This was managed in a phased introduction and gives all parents the opportunity to have their baby’s hearing tested shortly after birth. The test identifies hearing loss and impairment on average 2 years earlier than previous methods giving children the opportunity to keep pace educationally and socially. Over 1600 newborn babies are screened each day at 122 sites in England. More details are available at http://www.hearing.screening.nhs.uk.

Assessment

21. There is a need to recognise the effect that dual sensory impairment has on the following key factors to maintaining independence;

- autonomy and the ability to make choices and take control of your life;
- health and safety,
- managing the daily routines of personal and domestic life,
- involvement in education, work, family, social and community activities.

22. Local Authorities should ensure that as soon as an initial assessment identifies that a person may have a dual sensory impairment, a specialist assessment is arranged, to be carried out by a specifically trained experienced person/team equipped to assess the needs of a Deafblind person - including communication, one-to-one human contact, social interaction and emotional wellbeing, support with mobility, assistive technology and rehabilitation.

23. The assessment should take account of the current needs of the person being assessed and those that will occur in the near future. It is easier for a person to learn alternative forms of communication before their Deafblindness has deteriorated to the point where they are no longer able to use their preferred method of communication. Local Authorities will want to note the value of early recognition of the deterioration of one or both senses toward Deafblindness when looking at the assessment of those with a sensory impairment. This is particularly important with regard to children.

Service Provision

24. Local Authorities need to recognise the importance of providing appropriate personalised services to Deafblind people. This may mean commissioning services that are specifically designed for Deafblind people. Those with dual sensory impairment may not be able to benefit from mainstream services. Similarly, as those with one sensory impairment become Deafblind they may no longer be able to benefit from services aimed primarily at blind people or deaf people who are able to rely on their other sense.
25. Local Authorities will want to ensure that they are able to access the services of specifically trained one-to-one support workers (e.g. communicator-guides, interveners, Language Service Professionals (LSPs)), for both adults and children whether from within their own staff, by the use of consortia arrangements or by contracting with independent providers, for those people they assess as requiring one.

**Funding Sources**

26. Local authority funding for social services is derived from a variety of sources both from within central Government and also determined locally. It is for individual local authorities to manage and direct their own resources in accordance with local priorities and the needs of the communities to which they are accountable. The legislative basis upon which Local Authorities have responsibility to provide services to Deafblind people is outlined above.

**Information**

27. Deafblindness poses particular challenges in ensuring that information and services are accessible in ways that comply with the requirements of the Disability Discrimination Act 1995 and the regulations made under that Act. In the same way that Local Authorities ensure that information they produce and issue about services, procedures etc. is accessible to those with one sensory impairment, so they should ensure that such information is also available in formats and methods that are accessible to Deafblind people. Local Authorities will need to consider not only various sizes of Large Print, as well as Braille, Moon, audio or video (subtitled or signed) versions but also computer disk or use of e-mail (to be accessed by specialist technology), text-phones and Type-Talk. For some Deafblind people no method of communication other than tactile communication delivered by another person is available (e.g. hands-on sign, Deafblind manual). In these rare circumstances, the provision of a suitably skilled communicator e.g. an interpreter and/or LSP to deliver information would be appropriate.

**Monitoring Progress**

28. Local Authorities working with their local partners should include the needs of Deafblind people in their Joint Strategic Needs Assessment (JSNA). Through their benchmarking activities, they should also monitor their progress in contacting Deafblind people in their area, for example by comparing the number of people with whom they have contact with the number identified by other councils as well as with national estimates of the incidence of Deafblindness.

29. Ultimately the measure of success will be that Deafblind people will be able to:

- where appropriate, live independently
- stay healthy and recover quickly from illness
- exercise maximum possible control over their own life and, where appropriate the lives of their family members
- sustain a family unit which avoids children being required to take on inappropriate caring roles
- participate as active and equal citizens, both economically and socially
- have the best possible quality of life, irrespective of illness or disability and
- retain maximum dignity and respect.

31. The focus should be to continue building the strengths and capacity of individual Local Authorities to make local decisions on priorities reflected through improvement targets in Local Area Agreements. Local Authorities will need to continue to work with health partners in their Local Strategic Partnerships to undertake JSNAs, which will in turn be informed by, and support other needs assessments and plans (eg the Sustainable Community Strategy and local housing strategies). This reflects the shared responsibilities for health and wellbeing of citizens, families and communities as set out in the NHS Operating Framework\(^7\).

\(^7\)The Operating Framework for the NHS in England 2009/10: high quality care for all, pp43
ANNEX 1: DESCRIPTORS FOR CONGENITAL AND ACQUIRED DEAFBLINDNESS

Congenital Deafblindness

People who are born with hearing and sight impairment may display any of the following characteristics:

- no response to sound and/or light or little/poor response
- tactile defensiveness - avoiding touch (children - especially younger children)
- problems with eye contact/social participation at an early age
- slowness in developing and generalising skills (children)
- adopting an unusual posture for undertaking tasks - using residual hearing or sight eccentrically (children)
- difficulty making sense of the world around them
- developmental delay
- personalised methods of communication
- repetitive behaviour
- behaviour likely to harm themselves or others
- withdrawal/isolation
- use of smell, taste, touch to gain information

Acquired Deafblindness

People who acquire a hearing and sight impairment later in life may display any combination of the following characteristics:

Hearing:

- non-response when you speak from behind
- need for the television/radio/stereo to be louder than is comfortable for others
- difficulty following speech with unfamiliar people or accents
- difficulty following changes of speaker during conversation
- lack of awareness of noises outside immediate environment, e.g. building works, traffic noise
- tendency to withdraw from social interaction
- use of hearing aids, loop system etc
- complaints that everyone mumbles or speaks too quickly

Vision:

- need for additional lighting
- lack of awareness that you have changed position
- inability to find things when placed in unfamiliar position
- clumsiness
- unusual use of touch to support mobility or task
- difficulties caused by changes in light levels
- difficulties with unfamiliar routes of places
- difficulty recognising someone they know until they introduce themselves
- difficulties with television and newspapers
- unusual eye contact