



Deafblindness position paper

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About this document

The purpose of this position paper is to inform service planning and improvement in relation to speech and language therapy for people who are deafblind.

This document may be helpful for:

- Speech and language therapists (SLTs)
- Education professionals
- Clinical service managers
- Local budget holders
- External stakeholders
- Government bodies
- Commissioners

A note on terminology

This document intends to use positive language about disability. Depending on the context, 'person-first terms' like 'a person with CHARGE syndrome' or 'a person who is deafblind' and 'community-identifying terms' like 'Deafblind people' are used. Sometimes a term is used because there is legal recognition or a reason in the context of a statutory policy.

Generally when writing about people who are deafblind, sentences can get long and clumsy to read. We have tried to strike a balance using positive terms and keeping things easy to read.

Phrases like dual sensory loss, dual sensory impairment or multi-sensory impairment are also used to describe problems with hearing and vision. In this document the term deafblind is used.

We recommend that when speaking about an individual or a group of people, and it is possible to check, you should always use the words that they are most comfortable and identify with.

If you have any feedback about terms used in this document, please [contact us](#).

Introduction

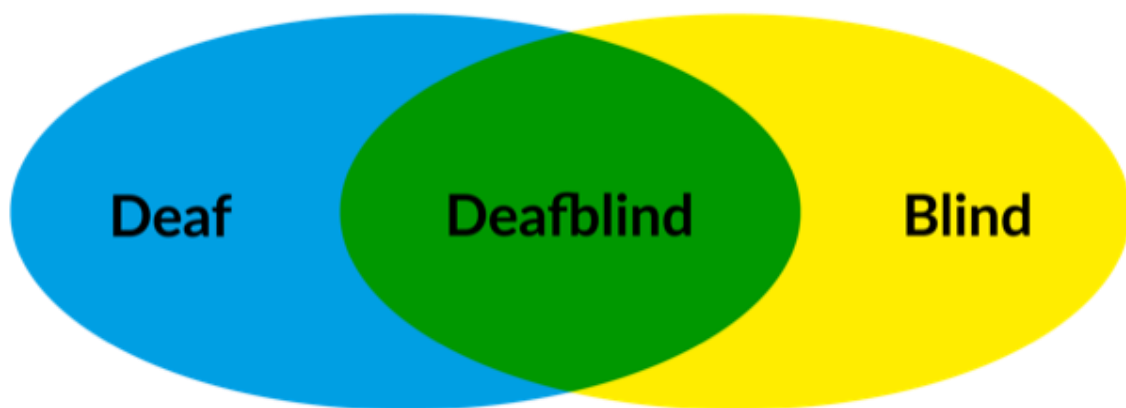
Deafblindness is when someone has a problem with both seeing and hearing. When someone has difficulty seeing or hearing clearly they can usually compensate with other senses. For example, to some extent, a deaf person can compensate using their vision and a blind person can compensate using their hearing. When someone has problems with both hearing and vision,

it makes it harder to compensate with the rest of the senses. This is known as deafblindness. Very rarely, deafblind people are completely deaf and completely blind, most deafblind people have some hearing and/or vision.

Different people have different combinations of hearing and vision difficulty and there are four groups:

- People who are deaf but have some vision
- People who are blind but have some hearing
- People who have both some hearing and vision
- People who are totally deaf and blind

Deafblindness is a unique disability and is different to being blind or being deaf. Some people find it helpful to think about these differences similarly to mixing colours. If deaf/hearing impaired is likened to the colour blue, and blind/vision impaired is likened to the colour yellow. When mixed together they don't make a bluey-yellow (someone who is mostly deaf but doesn't see so well) or a yellowish-blue (a person who is mostly blind and can't hear as much), but they make a whole new colour in itself, green (someone who is deafblind). Deafblindness is the same, a whole new and unique disability which needs its own way of thinking about support, solving problems and making a difference to people's lives.



Everyone who has deafblindness experiences difficulties with getting access to information about the world, communicating with other people and moving about as independently as possible.

There are lots of causes of deafblindness. Some people are born deafblind, before they have learnt language (this is called congenitally deafblind). For many people who are born deafblind the cause of their deafblindness is unknown. Other people develop deafblindness as they get older, and some people have deafblindness as a result of an illness or accident (both of these are

called acquired deafblind). Most people with deafblindness are older people with changes to their hearing and vision as they age.

There are lots of causes that people are born with, because of complications at birth or because of changes in their genes. Common syndromes caused by these gene changes include Usher Syndrome, CHARGE Syndrome, and Down's syndrome.

Worldwide the World Federation for Deafblindness prevalence study indicates that deafblind people make up between 0.2% and 2.0% of the population (World Federation of the Deafblind, 2018).

Separate estimates suggest that there are 440,000 people with deafblindness in the UK; of these 23,000 are estimated to be children. Within these estimated numbers it is expected that 5,000 children, 33,000 working age adults and 136,000 older people are expected to have significant deafblindness (described as 'more severe' by researchers) and will require support from trained professionals who understand the impact deafblindness can have on independence, development, daily life and communication (Robertson and Emerson, 2010).

Children who are deafblind are sometimes called a 'low-incidence, high-needs' group. This means there are not very many of them, but they often need a lot of support in school to learn and develop. As these children get older their needs often remain the same into adulthood.

There is a growing population of older people with age-related dual sensory loss (deafblindness).

Not everyone identifies as being deafblind and may prefer to be called something else. Other words for describing deafblindness include dual sensory loss, dual-sensory impairment or multi-sensory impairment.

The role of the SLT

Speech and language therapists (SLTs) have a central role in identifying, managing and intervening with both adults and children with deafblindness. An SLT may be involved at the following points in an individual's pathway:

- Assessment
- Diagnosis
- Treatment/therapy
- Long-term management and support
- Education and impact reduction

Scope of the role

The speech and language therapist working with a child or person with deafblindness should be familiar with RCSLT clinical guidelines related to this client group. They should have specialist knowledge and experience of working with this client group or at least receive support from a SLT who is a specialist in this area.

The overall aims of the speech and language therapist working with an individual with deafblindness includes identification and assessment of:

- The methods of accessing information about the world
- Receptive and expressive skills both verbal and non-verbal
- Social interaction
- Eating, drinking and swallowing skills

The clinical differential diagnosis of communication difficulties of deafblind people often needs to include knowledge of co-existing and differentiating diagnoses such as profound and multiple learning disabilities (PMLD), autism spectrum disorder (ASD) and learning disability. The support of other professionals in the field and multidisciplinary working is essential in an assessment of the whole person.

The speech and language therapist should possess an understanding of:

- The impact of sensory impairment on development, communication and eating, drinking and swallowing.
- The strengths, merits and risks associated with communicative mode selection and issues around the assessment, decision making and support to implement such mode.

During assessment, the speech and language therapist should consider:

- The impact of impairment of distant and near senses on communication and memory, including social interaction and language concept development.
- The impact of sensory factors in eating, drinking and swallowing needs, influence of distance senses impairments and any physical eating, drinking and swallowing needs.

The speech and language therapist should also support the following:

- Parents and carers understanding of individual's sensory needs and supporting early interaction and development of play and understanding of the world.
- The provision of an appropriate Inclusive Communication Environment to promote the impact this has on the development of communication and interaction.
- The facilitation of person-centred decisions, considering the impact on families and other key relationships, particularly at key points of transition to new services.

- Acquisition, development and maintenance language as per the identified appropriate modality.
- Training about the different types of communication modalities that might be appropriate, including those specifically applicable to the tactile modality.
- Assessment and training for augmentative and alternative communication aids (AAC).
- Multidisciplinary working with other professionals, particularly teachers of the deaf, teachers of the visually impaired, teachers of multisensory impaired, and intervenors, or other 1:1 support roles, and parents, with an understanding of boundaries between roles.

Policy context

The rights and support for vulnerable people and people with disabilities are underpinned by policy and law. These broad policies and initiatives equally apply to deafblind people. In addition, there are a number of government policies which apply specifically to deafblind people or people with sensory impairment across the lifespan.

Broad policies

England

- [Accessible Information Standard, 2016](#)
- [Care Act, 2014](#) (see deafblind duties)
- [Children and Families Act, 2014](#)
- [Special Educational Needs and Disability Code of Practice](#)

Scotland

- [Additional Support for Learning](#)
- [BSL \(Scotland\) Act, 2015](#)

Wales

- [The Additional Learning Needs Code for Wales 2021](#)
- [Additional Learning Needs and Education Tribunal \(Wales\) Act 2018](#)
- [Social Services and Well-being \(Wales\) Act, 2014](#) (see deafblind duties)

Northern Ireland

- [Special Educational Needs and Disability Act \(Northern Ireland\) 2016 \(SEND Act\)](#)
- [SEN regulations and Code of Practice](#)

Deafblind duties and responsibilities

Early intervention

In England, the general duties in the SEND Code of practice identifies the role health services have in working with families to help them to understand their child's needs. When a child is under compulsory school age and health services are of the opinion that the child has, or probably has, Special Educational Needs (SEN), they must inform the child's parents and bring the child to the attention of the appropriate local authority. The health service must give parents the opportunity to discuss their opinion and signpost to appropriate advice and intervention before the child starts school. Support can include advice from a number of services, but particularly important for those with deafblindness is the support provided by speech and language therapists and specialist teachers of sensory impairment.

Local authorities have a responsibility to consider commissioning visiting services for children with hearing or vision impairment (which includes deafblind children).

'Early Support' is identified as an approach for the better delivery and coordination of services for disabled children. It is of note that multi-sensory impairment (deafblindness) is featured within the support resources provided by the Early Support Programme.

(Department for Education, 2015)

Education

Sensory impairment is considered one of the core special educational needs (SEN)/additional learning needs (ALN) categories for children with SEN/ALN. This means that children and young people in this category may continue to need support up to 18 in Scotland and Northern Ireland, and up to 25 in England and Wales.

Statutory assessment of education needs of children with deafblindness should include the involvement of a specialist teacher of deafblindness. This is recognised in the England, Wales and Northern Ireland statutory guidance around SEN/ALN.

In England, children who have 'severe sensory impairment' (diagnostic level) should have a statutory assessment for an Education Health and Care Plan.

In England, it is advised that specialist advisory teachers should hold the 'mandatory qualification to teach children with deafblindness' and teachers of classes of deafblind children must be taught by teachers who hold the 'specialist mandatory qualification'.

Local authorities in England have a responsibility to hold a register of disabled children and young people, including up to date details of those who have hearing and vision impairment.

(Department for Education, 2015)

Social care

Local authorities in England and Wales have a responsibility to:

- Identify and make contact with all deafblind people (children and adults) in their area.
- Assessments of needs for care and support should be carried out by suitably qualified person(s) with experience and skill in assessing deafblind people. In particular, assessment should include the need for communication, one to one human contact, social interaction and emotional wellbeing, mobility, assistive technology and (re)habilitation support.
- Support services provided are accessible to deafblind people and ensure that deafblind people have access to specifically-trained one-to-one support workers (if they need one).
- Information and advice should be accessible to deafblind people.
- There should be a senior manager (at Director level) in each area who has responsibility for deafblind services.

(Department of Health, 2014; Welsh Assembly Government, 2014)

Health

In England, the Accessible Information Standard (AIS) aims to make health and social care information accessible to all people with a disability or sensory loss.

All services that provide NHS care or treatment, (including independent providers of NHS services), adult social care (including social services) and public health services must follow the AIS.

Services must:

- Identify patient, service user, carer and parent's information and communication needs, where they relate to disability, impairment or sensory loss.
- Record information and communication needs clearly, and in a set way.
- Highlight (or flag) individuals' needs in files or notes, so it is clear what action needs to be taken to meet them.

- Gain permission or consent and when appropriate, share an individual's information and communication needs with other services; like other providers of NHS and adult social care.
- Take action to make sure individuals receive information they can access and understand, and receive communication support if it is needed.

(NHS England, 2016)

Best practice recommendations

Best practice can be described in terms of clinical, professional and strategic involvement. The recommendations for best practice included here are based on both professional consensus, emerging specialist evidence base and established generalist evidence base.

Clinical

Assessment and intervention

Speech and language therapists (SLTs) who specialise in working with people who are deafblind should:

- Work within a multidisciplinary team (MDT) to help each individual to reach their potential.
- Complete informal and formal assessments within a holistic assessment framework of language and communication skills in cooperation with the individuals, and key communication partners, including parents/carers, education staff including 1:1 support roles, co-workers and other involved professionals.
- Modify assessment for accessibility to explore individual communicative potential and development, including dynamic and cumulative assessment methods.
- Establish current level of language, communication and swallowing functioning.
- Provide necessary feedback to all relevant people following assessment.
- Take a lead role in working with the individual, their family, 1:1 support roles, co-workers and/or care team to make informed choices regarding ways to communicate (eg oral, signed, tactile, mixed, AAC).
- Provide specialist intervention and ongoing support focusing on individual goals informed by assessment findings. Intervention will be delivered by direct, indirect and consultancy models of intervention. For many individuals, interventions are best delivered by their 1:1 support workers across the day overseen by the SLT.

- Have a comprehensive knowledge of the various assistive, hearing and vision technologies and treatment available.
- Maintain an in-depth and current knowledge of inclusive communication and the ways of communication appropriate for deafblind individuals (including bodily-tactile communication and tactile signing, such as hand-under-hand or hands on signing).
- Provide detailed and accurate written reports when required.
- Liaise with appropriate agencies and attend case conferences and other meetings.

Where an individual who is deafblind attends an educational placement SLTs should:

- Liaise closely with the appropriate Qualified Specialist Teachers (Qualified Teachers of Multi Sensory impairment (QTMSI), Deaf (QToD) and Vision Impairment (QTVI)) and other education staff. For further information, see RCSLT BATOD [best practice guidance for Collaborative Working between Qualified Teachers of the Deaf and Speech and Language Therapists](#).
- Contribute to initial assessments, reassessments and reviews of Education and Health Care Plans (EHCPs) (England), Individual Development Plan (IDP) (Wales), Co-ordinated Support Plans (CSPs) or Child's Plan (Scotland) and Statement of Special Educational Needs (Northern Ireland) when required.
- Provide training through individual, group and workshop sessions for parents, family and education staff on topics related to deafblindness, speech, language and communication and technology.
- Contribute to planning the school day for children and liaise with teachers and other education staff on communication development and to provide speech and language therapy support to the child as required.

Training and support

SLTs working with individuals who are deafblind should:

- Provide training to the wider MDT and carers regarding deafblindness, language and communication, technology etc.
- Participate in clinical meetings to raise awareness of the value of speech and language therapy in working with individuals who are deafblind. This might include: Multidisciplinary Team (MDT) meetings, annual reviews (in educational settings), Team Around the Child (TAC) and/or Team Around the Family (TAF) meetings, Getting It Right for Every Child (GIRFEC) meetings, Mental Capacity, Best Interests meetings and Continuing Care or Care planning meetings.

Professional

SLTs working with individuals who are deafblind should:

- Maintain standards of practice, such as referral times, documentation, team discussion, consent, capacity and decision-making. These standards should be audited and reviewed regularly.
- Establish and maintain professional relationships with all members of the MDT.
- [SLTs have a responsibility to attend training themselves in order to keep their skills and knowledge up-to-date and are able to practise safely and effectively.](#) Personal competence in a communicative mode should not restrict or influence the choice of individuals' communicative mode or affect achieving communicative competence.
- Collect service activity data to map speech and language therapy activity and identify unmet needs for service development.
- Consider the appropriate use of outcome measures; evaluating generic outcome measurement approaches against the role of individual or person-centred outcomes.
- Collate evidence to support research questions about the outcomes of speech and language therapy interventions and patient experiences.
- Contribute to Quality Improvement (QI) projects that are likely to have a positive impact on an individual's experience of working with the speech and language therapy service.
- In the context of deafblindness, it is important that SLTs look after their wellbeing and build resilience. They should seek support, clinical supervisions, counselling and debriefing when involved with challenging cases and situations.
- SLTs should be confident to report clinical incidents that are unintended or unexpected, and which causes or has the potential to cause harm to individuals. This helps organisations to understand and learn from these incidents in order to put systems in place and prevent them from happening again.

Strategic

- SLTs should participate in strategic meetings to raise awareness of the value of speech and language therapy in working with individuals who are deafblind. For example: regional Children's Hearing Services Working Groups (CHSWG), Clinical Reference Groups (CRG), Cross Party working Groups (CPG) and Deaf/Deafblind Planning groups.

Benefits of providing a speech and language therapy service in deafblindness

There is increasing evidence to demonstrate the impact of speech and language therapy involvement to influence local budget holders, decision makers and other stakeholders.

Listed below are some of the benefits of providing a speech and language therapy service specific to deafblindness. While these may be aspirational for some children or people with deafblindness they provide a structure to think about supporting people to the best of their ability.

Speech and language therapy activities	Communication and participation benefits	Broad life outcomes
Children and young people		
<ul style="list-style-type: none"> • Providing assessment, diagnosis, and appropriate intervention to children and young people who are deafblind • Identifying any specific language and communication difficulties existing over and above the impact of the individual being deafblind • Promoting the use of appropriate assistive technology (working with and involving families in decision making and promoting choice) 	<ul style="list-style-type: none"> • I can express myself, be understood and understand others • My speech, language and communication needs are identified early on • My family, friends and those around me understand my needs and are equipped to support my access to information, communication and social skills, play development and eating and drinking needs • I am able and confident to develop and maintain meaningful relationships 	<ul style="list-style-type: none"> • I am able to learn and meet my education potential • I am able to achieve my goals • I feel valued, included in my community and accepted to take a valuable place in society • I am healthy and happy • I feel supported and safe • I am in control of my life

<ul style="list-style-type: none"> • Supporting parents, staff and key workers in their ability to communicate with children and young people who are deafblind • Facilitating communication development • Facilitating language acquisition • Facilitating speech development • Supporting children and young people to meet their educational potential • Connecting families to relevant additional services, eg advisory teaching services • Provide training and support to families and other professionals so that they can safely support children with eating, drinking and swallowing needs and make mealtimes enjoyable 	<ul style="list-style-type: none"> • I am involved in decisions that affect me and contribute to my future planning • I feel confident in understanding what being deafblind means to me • I have the functional skills I need to participate in and lead everyday activities • I am aware of my capabilities and needs and am able to ask for help • I can manage and maintain my assistive technology and hearing and vision support tools to the best of my ability • My community is aware of, and adaptable to, my speech, language and communication needs • I am able and confident to take part in learning and education activities • I feel accepted and supported to take part in activities I enjoy • I know what my rights are regarding equal access • I feel confident when accessing the public services I need • I am able to eat and drink safely and enjoy my mealtimes 	<ul style="list-style-type: none"> • I am able to find and maintain employment or meaningful occupation
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Adults		
<ul style="list-style-type: none"> • Facilitating functional communication in different situations and with different communication partners. (Skill development may be facilitated with the deafblind individual or with the people around them) • Promoting communication development into adulthood due to the impact of sensory impairment on early development, ensuring communication is a positive experience • Working with employers to support access to employment (promoting the role of access to work, supported employment and apprenticeship schemes) • Connecting individuals to relevant additional services, eg mental health services • Empower individuals to understand their rights to access. Provide training and support to families and other professionals so that they can 	<ul style="list-style-type: none"> • I can express myself, be understood and understand others • My speech, language and communication needs are identified early on • My family, friends and those around me understand my needs and are equipped to support my access to information, communication and social skills, and eating and drinking needs • I am able and confident to develop and maintain meaningful relationships • I am involved in decisions that affect me and contribute to my future planning • I feel confident in understanding what being deafblind means to me • I have the functional skills I need to participate in and lead everyday activities • I am aware of my capabilities and needs and am able to ask for help • I can manage and maintain my assistive technology and hearing and vision support tools to the best of my ability 	<ul style="list-style-type: none"> • I am able to learn and meet my education potential • I am able to achieve my goals • I feel valued, included in my community and accepted to take a valuable place in society • I am healthy and happy • I feel supported and safe • I am in control of my life • I am able to find and maintain employment or meaningful occupation

<p>safely support children with eating, drinking and swallowing needs and make mealtimes enjoyable</p>	<ul style="list-style-type: none">• My community is aware of, and adaptable to, my speech, language and communication needs• I am able and confident to take part in learning and education activities• I feel accepted and supported to take part in activities I enjoy• I know what my rights are regarding equal access• I feel confident when accessing the public services I need• I am able to eat and drink safely and enjoy my mealtimes	
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(based on RCSLT, 2018)

Risks of not providing a speech and language therapy service in deafblindness

There is increasing evidence to demonstrate the risks of not providing speech and language therapy involvement, to influence local budget holders, decision makers and other stakeholders.

Listed below are some of the risks of not providing a speech and language therapy service specific to deafblindness.

Children and young people

Children and young people who do not access appropriate support are at risk of:

- Delayed or disordered speech and language development (Ask Larsen, 2016; Bruce, 2005; Dammeyer and Ask Larsen, 2016).
- Reduced motivation to communication due to low-readability of expressive acts resulting in missed attempts at communication (Nafstad and Rødbroe, 2013).
- Potential mental health difficulties (Dammeyer, 2012).
- Reduced educational attainment ([Department for Education's 2018 exam results, Scottish Government's 2018 attainment data](#), Jarrold, 2014).
- Diagnostic overshadowing and inappropriate diagnosis of intellectual/learning disabilities, autism spectrum disorder or other neurodisabilities (McInnes, 1999).
- Eating, drinking and swallowing difficulties related to the four stages of swallowing and self-restricted diets; associated with the underlying cause of deafblindness (eg prenatal/postnatal and acquired aetiology).

Adults

Adults who do not access appropriate support are at risk of:

- Speech, language and communication difficulties.
- Young people and adults who use BSL [or tactile sign language] rarely meet professionals who share their language. This means communication is often compromised, which has implications for the individual who is deaf [or deafblind] accessing all areas of healthcare, public services, education and employment (RNID, 2006; Sense, nd).
- Social exclusion and experience feelings of isolation and negativity (Hersh, 2013; Jaiswal et al, 2018).

- Mental health problems, behavioural, adjustment and emotional issues (Bodsworth et al, 2011; Wahlqvist et al, 2016).
- Difficulties learning new skills needed to access information, communicate and orientate independently with age (Simcock, 2017).
- Limited employment opportunities (Jarrold, 2014; World Federation of the Deafblind, 2018).
- Eating, drinking and swallowing difficulties related to the four stages of swallowing and self-restricted diets; associated with the underlying cause of deafblindness (eg prenatal/postnatal aetiology or causes related to aging or trauma).

There are also significant economic risks, which are described in the following public health section.

Public health

The Faculty of Public Health defines public health as:

"The science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society."

Public health in relation to deafblindness:

- Deafblind people are considered a hidden group – a low incidence, high needs group (Gray, 2006)
- Access to appropriate early intervention relies upon appropriate identification and the recognition of deafblindness as a unique disability (Murdoch, 2002)
- Some groups of people may be at higher risk of deafblindness due to their sensory impairment, or genetics (Dammeyer, 2013; Kancherla et al, 2013). People with deafblindness may be at higher risk of mental health issues, these include social exclusion, anxiety and depression (Bodsworth et al, 2011; Högner, 2015; Wahlqvist et al, 2016)
- People with deafblindness experience difficulties and inequalities accessing education, healthcare, employment and social life (Jarrold, 2014; World Federation of the Deafblind, 2018)
- Deafblindness can occur as a consequence of low uptake of vaccination (eg MMR). Deafblindness as a consequence of Rubella syndrome has been eliminated in parts of the world with high uptake rates (WHO, 2018)
- People with deafblindness need multidisciplinary management and support. Within that team, speech and language therapists have an important role in differential diagnosis (in

the prevention of diagnostic overshadowing) as well as management and training in relation to methods of communication and co-occurring eating, drinking and swallowing difficulties

Further information:

- [Mapping Opportunities for Deafblind People across Europe](#)
- [At Risk of Exclusion from CRPD and SDGs Implementation: Inequality and persons with deafblindness. Initial Global Report 2018](#)
- [Campaign to End Loneliness](#)

For more information see the RCSLT's information on [public health](#) and [factsheets](#).

Research priorities

Deafblindness research is in its infancy and the emergence of recent practices open more lines of investigation than they close.

Studies into research priority studies indicate that the following themes are of interest to speech and language therapy and the wider deafblind field.

- How deafblind people communicate and effective ways of teaching deafblind individuals and their communication partners.
- The role assistive technology has in supporting deafblind people to live independently.
- How deafblind people experience participation in society - the barriers and strategies to increase inclusion and active lives.
- The impact of personal perspectives on identities and how people self-identify.
- Transitions (along the course of diagnosis, between life phases and between service providers).
- Identifying the mental wellbeing and mental health needs of people with deafblindness, their course, treatments and recovery.
- Exploring the developmental and rehabilitation trajectories of specific causes of deafblindness, within congenital, acquired and genetic groups.
- Developing assessment tools with a focus on communication and the nature of tactile language and perception.
- Developing assessment tools with a focus on cognitive development and the nature of tactile memory and perception.

(Dammeyer, 2015; Janssen, 2018; Simcock, 2017; Wittich et al, 2016)

References

- Ask Larsen, F. (2016) Congenital deafblindness and bodily-tactile language acquisition [PhD, University of Copenhagen]. <https://doi.org/10.13140/rg.2.2.26532.27522>
- Bodsworth, S. M., Clare, I. C. H., Simblett, S. K., and Deafblind UK (2011) Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment. *British Journal of Visual Impairment*. 29(1), 6–26. <https://doi.org/10.1177/0264619610387495>
- Bruce, S. M. (2005) The Impact of Congenital Deafblindness on the Struggle to Symbolism. *International Journal of Disability, Development and Education*. 52(3), 233–251. <https://doi.org/10.1080/10349120500252882>
- Dammeyer, J. (2012) Children with Usher syndrome: Mental and behavioral disorders. *Behavioral and Brain Functions*. 8(1), 16. <https://doi.org/10.1186/1744-9081-8-16>
- Dammeyer, J. (2013) Symptoms of Autism among children with congenital deafblindness. *Journal Autism and Developmental Disorders*. 44(5). <https://doi.org/10.1007/s10803-01301967-8>
- Dammeyer, J. (2015) Deafblindness and dual sensory loss research: Current status and future directions. *World Journal of Otorhinolaryngology*. 5(2), 37. <https://doi.org/10.5319/wjo.v5.i2.37>
- Dammeyer, J., and Ask Larsen, F. (2016) Communication and language profiles of children with congenital deafblindness. *British Journal of Visual Impairment*. 34(3), 214–224. <https://doi.org/10.1177/0264619616651301>
- Department for Education (2015) *Special educational needs and disability code of practice: 0 to 25 years*. Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities. Department for Education.
- Department of Health (2014) *Care and Support for Deafblind Children and Adults Policy Guidance*. Mental Health - Divisional Intelligence Unit / 20007.
- Gray, P. (2006) *National audit of support, services and provision for children with low incidence needs* (Research Report No. 729). DfES Publications.
- Hersh, M. (2013) Deafblind People, Communication, Independence, and Isolation. *Journal of Deaf Studies and Deaf Education*. 18(4), 446–463. <https://doi.org/10.1093/deafed/ent022>
- Högner, N. (2015) Psychological Stress in People with Dual Sensory Impairment through Usher Syndrome Type II. *Journal of Visual Impairment and Blindness*. 109(3), 185–197. <https://doi.org/10.1177/0145482X1510900303>
- Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., and Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PLOS ONE*. 13(9), e0203772. <https://doi.org/10.1371/journal.pone.0203772>

Janssen, M. J. (2018, November) *Recent Advances in Deafblind Studies. Proceedings from VIII Brazilian Congress on Special Education XI Meeting of the Brazilian Association on Special Education*. VIII Brazilian Congress on Special Education XI Meeting of the Brazilian Association on Special Education, Brazil.

Jarrold, K. (2014) *European Deafblind Indicators—Mapping Opportunities for Deafblind People Across Europe*. European Deafblind Network.

Kancherla, V., Van Naarden Braun, K., and Yeargin-Allsopp, M. (2013) Childhood vision impairment, hearing loss and co-occurring autism spectrum disorder. *Disability and Health Journal*. 6(4), 333–342. <https://doi.org/10.1016/j.dhjo.2013.05.003>

McInnes, J. M. (Ed) (1999) *A Guide to Planning and Support for Individuals Who Are Deafblind*. University of Toronto Press.

Murdoch, H. (2002) *Early intervention for children who are deafblind* (p24). Sense.

Nafstad, A. V., and Rødbroe, I. B. (2013) *Communicative Relations: Interventions that create communication with persons with congenital deafblindness* (English Edition). Staped Sørøt, Fagavdeling døvblindhet/kombinerede syns-og hørselsvansker.

NHS England (2016) *Accessible Information Standard*. <https://www.england.nhs.uk/ourwork/accessibleinfo/>

RCSLT (2018) *Placing children and young people at the heart of delivering quality speech and language therapy: Guidance on principles, activities and outcomes*. Royal College of Speech and Language Therapists.

Robertson, J., and Emerson, E. (2010) *Estimating the number of people with co-occurring vision and hearing impairments in the UK - Research Portal*. Lancaster University. Centre for Disability Research.

Sense (nd) *It all adds up—A guide for healthcare staff on supporting patients with a dual sensory loss*. Sense.

Simcock, P. (2017) Ageing with a unique impairment: A systematically conducted review of older deafblind people's experiences. *Ageing and Society*, 37(08), 1703–1742. <https://doi.org/10.1017/S0144686X16000520>

Wahlqvist, M., Möller, C., Möller, K., and Danermark, B. (2016) Implications of Deafblindness: The Physical and Mental Health and Social Trust of Persons with Usher Syndrome Type 3. *Journal of Visual Impairment and Blindness*. 110(4), 245–256. <https://doi.org/10.1177/0145482X1611000404>

Welsh Assembly Government (2014) *Social Services and Well-being (Wales) Act 2014*. Welsh Assembly Government.

WHO (2018) *Vaccine Preventable Diseases Surveillance Standards Congenital Rubella Syndrome*. World Health Organisation. Available from:

https://www.who.int/immunization/monitoring_surveillance/burden/vpd/WHO_SurveillanceVaccinePreventable_03_CRS_R2.pdf?ua=1

Wittich, W., Jarry, J., Groulx, G., Southall, K., and Gagné, J.-P. (2016) Rehabilitation and Research Priorities in Deafblindness for the Next Decade. *Journal of Visual Impairment and Blindness*. 110(4), 219–231. <https://doi.org/10.1177/0145482X1611000402>

World Federation of the Deafblind (2018) *At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness*. World Federation of the Deafblind.

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