

Identification of Deafblind People and Associated Support Needs in Northern Ireland

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1.0 Executive Summary

In 2011, the Regulation and Quality Improvement Authority (RQIA) carried out a Review of Sensory Services across all of the Trusts in N. Ireland. The Review recommended that each Trust should hold a database detailing the number and needs of all people who have a co-existing hearing and visual loss (Deafblindness). It was agreed that this needs assessment would be taken forward as part of the Regional Physical and Sensory Disability Strategy (2012-15), under the auspices of the Regional Sensory Impairment Group work stream.

In 2013 the Health and Social Care Board (HSCB) commissioned the Western Health and Social Care Trust (WHSCCT) to lead on a regional analysis of the number and needs of people who have a co-existing vision and hearing loss, resident within N. Ireland. As part of this process the WHSCCT through a procurement process commissioned an external provider (Sense) which had established expertise and experience in this area to offer support in taking this Project forward.

This Report provides an analysis and evaluation of the findings across the five Health and Social Care Trust (HSCT) areas.

The Project was overseen by a regional Project steering group with representation from each of the Health and Social Care Trusts (HSCTs), the HSCB and a range of voluntary organisations with sensory disability expertise. Within each of the HSCTs a local steering group was established with representatives from mental health, learning disability services, older person services and children's services.

The results of the analysis of data show that:-

- There was a significant variance in the numbers and needs of people identified as experiencing a co-existing hearing and visual loss across each of the Trusts. This ranged from 141 people per 100,000 in the WHSCCT to 21 per 100,000 within the NHSCT.
- The numbers of people identified increased with age and reflected similar increases in other regional and international studies.
- The reported number of people / children experiencing co-existing hearing and visual loss within Learning Disability and Children's Disability was significantly less than that indicated by previous prevalence studies (CeDR,

Roberts & Emmerson 2010; Fellingner, J.; Holzinger, D.; Dirmhirn, A.; Van Dijk, J.; and Goldberg, D. 2009)

- Current data collection systems used by the HSCTs had limitations on information detailing the needs and numbers of people with co-existing visual and hearing loss.
- The 2011 RQIA review of Sensory Support Services highlighted that Deafblindness was not recognised across all of the HSCTs / Health & Social Care Board in the same way as visual and hearing impairment. This was reflected in:
 - the information held on this client group within existing information and data collection systems;
 - the limited training and expertise of staff working across all programmes of care
 - the limited formal arrangements with specialist external providers.
- There was limited evidence of previous service planning, service standards and policy development for this client group prior to the undertaking of this Project
- The majority of people identified as deafblind were referred by specialist sensory service staff members. There appeared to be a lack of knowledge and ownership from staff working across programmes of care outside of specialist sensory services in identifying and referring clients with co-existing hearing and visual loss for further assessment of their needs.
- The impact of awareness training provided as part of the initiative was limited in terms of resultant referrals. However, the involvement of key people / champions within specific programmes of care significantly improved the effectiveness of awareness training.
- Assessment processes used across HSCTs did not provide opportunities to identify people with co-existing hearing and visual loss.
- There was limited expertise across services (HSCTs and voluntary sector) to provide specialised assessment for those people who have complex communication needs secondary to their co-existing visual and hearing loss.

- Some of the individuals identified by programmes of care outside of Physical Disability and Sensory Impairment had not been in receipt of support from sensory services and were able to receive immediate targeted interventions to support their dual sensory needs.

4.6 Recommendations and Dissemination

4.6.1 Identification Process

- Deafblind awareness training should be provided as part of sensory awareness training across each of the Trusts and across all sectors within the Trusts i.e. primary / secondary / community.
- Regional guidance and standards on the identification, referral and assessment process for deafblind people should be developed and implemented by each Trust.
- Each Trust's liaison arrangements between sensory services and other programmes of care should ensure a specific emphasis on deafblindness.
- Specific training and support on deafblindness should be targeted at Children's Disability Services and Learning Disability Services as the knowledge deficit identified has been deemed a priority.
- Current regional assessment templates (NISAT, UNOCINI) should be amended to capture and accurately reflect the needs of deafblind people.
- Statistics on deafblindness should be collated by each Health & Social Care Trust / Health & Social Care Board equivalent to that collated on individuals with visual or hearing impairment – a minimum data set should be developed to capture appropriate information to inform commissioning and service delivery.
- Each Trust should have an identified lead within Sensory Services responsible for deafblindness.
- Each Trust should examine and identify how existing information and data collecting systems can support the identification of people with deafblindness e.g. NIECR and Child Health system etc.
- Consideration should be given to ensuring that primary healthcare providers are aware of the importance of identifying deafblindness and referring to the appropriate support agencies.

4.6.2 Assessment Process

- All Trusts should develop and implement a clear pathway on referral and assessment processes for people with deafblindness - this should be a subset or condition-specific pathway which emanates from the new regional sensory care pathways for hearing and sight loss currently under production – a consistent approach should be developed.
- The relevant HSCT sensory team should be notified of all individuals identified as having deafblindness. The team will then assess the individuals screening tool to determine the appropriate level of need and any subsequent intervention.
- Each Trust area should have a designated sensory team member with a specialised qualification on deafblindness (certificate in deafblindness).

4.6.3 Future Service Planning

Information

- Trusts should ensure that information systems will make provision for the accurate collection of data on the needs and numbers of people with deafblindness.
- The RQIA Inspection of Sensory Support Services 2011 recommended that

each Trust should have in place a local sensory strategy which describes service development / planning requirements to meet the needs of people with deafblindness. This information should be incorporated into the development of the regional sensory care pathway

- Consideration should be given to the introduction of best practice guidelines for primary healthcare providers, to facilitate increased awareness levels.

Commissioning

- The Health & Social Care Board commissioning plans for future service provision will reflect demographic trends and population profiles as identified via local needs analysis. A large majority of the deafblind population are aged 60+ and a significant proportion of the general population over 80 will have dual sensory loss. Consideration should therefore be given to the inclusion of deafblind statistics in relevant information sources.
- Each Trust should develop processes which will ensure that service planning has direct contact and involvement of people who have deafblindness.
- The HSCB in conjunction with the Trusts should consider the development of a Regional Implementation plan to ensure the consistent implementation of report recommendations.