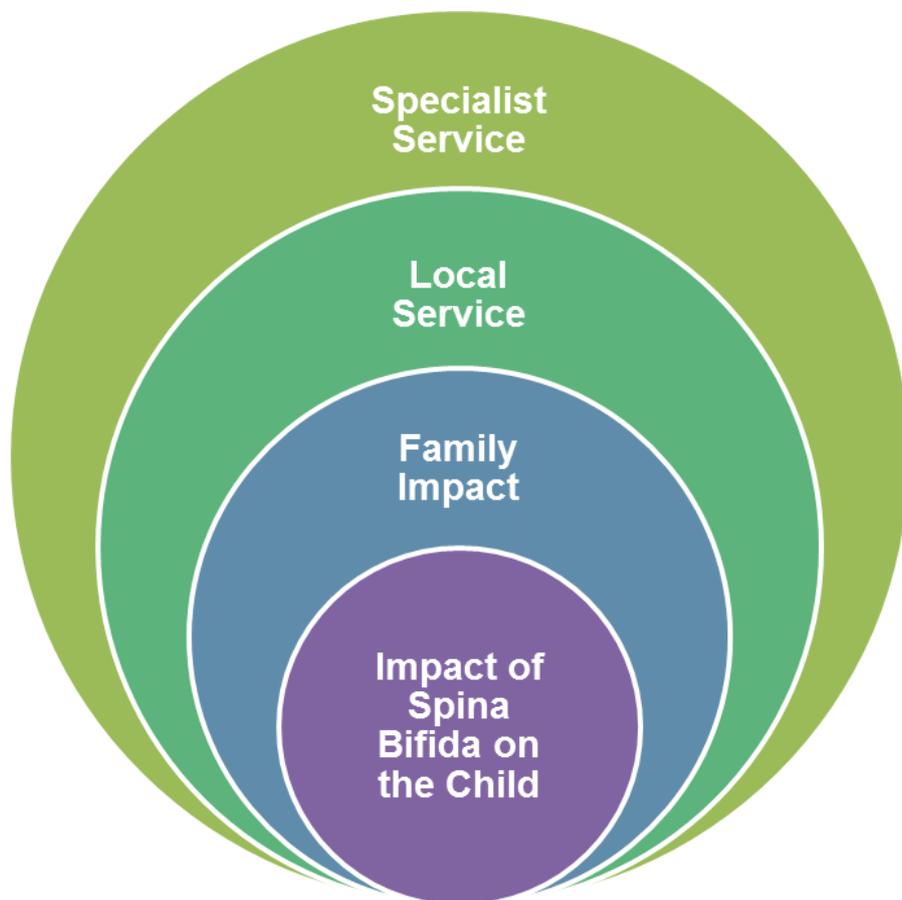


The Health and Therapy Needs of Children with Spina Bifida in Ireland



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Funded by the Children's Fund for Health, Temple Street Children's University Hospital

Executive Summary

The Health and Therapy needs of Children with Spina Bifida in Ireland

Chapter 1: Background

Spina bifida is a type of Neural Tube defect (NTD) which has been described as one of the most complex congenital conditions compatible with life (Liptak and El Samra, 2010). Ireland has one of the highest rates of NTDs in the world with an incidence of 1.17 per 1000 live births (McDonnell et al., 2014). It is estimated that there are at least 500 children (0-18 years) with spina bifida currently in Ireland (EUROCAT, 1991).

Spina bifida can affect nearly all body systems to some degree depending on the level of the lesion; with potential physical, motor, sensory, continence, cognitive and psychosocial difficulties (Northrup and Volcik, 2000). The life-long impact of spina bifida can have an estimated health services cost of €500,000 (Yunni et al, 2011).

Provision and coordination of care for children with spina bifida along with multidisciplinary team (MDT) working is essential to optimise health and therapy outcomes (Kinsman et al., 2000, Brustrom et al., 2012, Aldana et al., 2010). Temple Street Children's University Hospital (TSCUH) is the national paediatric neurosurgical centre providing care for all children born with Spina bifida since 2008. TSCUH also provides a MDT Spina Bifida clinic to support these children and families. This is consistent with international best practice (Merkens, 2006).

As a result of reported service inequities and the need to develop and improve services, a review of the health and therapy needs of children with spina bifida and their access to local and specialist services was undertaken. This project was completed by an Occupational Therapist, Physiotherapist and Consultant Paediatrician and was funded by the Children's Fund for Health within TSCUH fundraising department.

Chapter 2: Aims and Methodology:

The overall aim was to identify the health needs of children (aged 0 – 18 years) in Ireland with spina bifida. Specific objectives included:

1. To identify the availability of current services for children with spina bifida and make recommendations regarding children's health and therapy needs
2. To highlight the impact of spina bifida on children and their families
3. To provide an up to date literature review of international best practice
4. To gather feedback regarding the MDT Spina Bifida service in Temple Street

This mixed-method study gathered information from service providers (professionals working with children with Spina Bifida throughout Ireland) and parents / guardians over two phases (phase 1: quantitative questionnaires, phase 2: qualitative interviews). Ethical approval was obtained from the ethics committee of TSCUH. A focus group was completed with children (8-18 years) which was aided by the completion of the KINDL Spina Bifida quality of life questionnaire.

Quantitative data gathered from questionnaires was analysed by SPSS using correlations, frequencies and means. Qualitative data was transcribed verbatim and analysed using thematic analysis as described by Braun and Clarke (2006).

Chapter 3: Samples

Questionnaires were completed by 155 parent/guardians from a national spread which represented a 30% response rate of the total estimated population. 86% of respondents were mothers who represented children with a mean age of 5.7 years. Qualitative interviews were completed with 26 parents.

247 service providers completed questionnaires. They were represented by Physiotherapists (41%), Occupational Therapists (32%), Speech and Language Therapists (8%), Paediatricians (3%), Psychologists (4%), Clinical Nurse Specialists (2%), Social Workers (2%), Public Health Nurses (1.6%), Dieticians (1.2%) and other (6%). Service providers had an average of 8.5 years' experience and 7.02 children with Spina Bifida on their open caseloads. 25 service providers participated in qualitative interviews.

4 children participated in a focus group consisting of an 8 and a 10 year old boy, and a 13 and a 15 year old girl.

Key Findings

Chapter 4: Impact of spina bifida on children

A high proportion (20%) of the sample reported having a family history of Neural Tube Defects.

Children with spina bifida present with a variety of complex needs affecting multiple body systems and impacting on their ability to actively participate in daily life.

- 64% have a CSF shunt in place to manage hydrocephalus.
- 69% of children over 3 years require a wheelchair.
- 93% of children over 5 years require support to achieve continence.
- 55% have visual difficulties.

- Obesity is 5 times more prevalent than in the typically developing population.
- 14% have an intellectual disability.
- 50% of school-age children have low self-esteem.
- 96% require ongoing physiotherapy, 87% require ongoing Occupational Therapy.
- 89% of school-age children access mainstream schooling; however access can be dependent on whether supports for physical and toileting needs are available.
- 43% of children accessing special education fall within the average cognitive range.

Half of the school-aged children suffered from low self-esteem, which was influenced by age and difficulties with continence and weight. Social, emotional and psychological issues were prevalent against a background of limited availability of ongoing psychological support.

Chapter 5: Impact of spina bifida on families

The impact of spina bifida on the wider family unit was identified. Parents reported the significant burden of having to fight for services, co-ordinate and communicate between service providers. Parental difficulty acknowledging and envisaging their child's needs into the future was also identified.

Chapter 6: Health services to support children with spina bifida

The complex needs of children with spina bifida results in their need to access both local and specialist services.

Local services

Although there was timely initial access to teams, geographical disparities existed in relation to frequency of access to individual professionals. Children had good access to Physiotherapists, Occupational Therapists and Paediatricians, but limited involvement with Speech and Language Therapists, Social Workers, Family Support Workers, Psychologists, Dieticians and Orthotists. High demands on local services to provide equipment was identified as 83% of children already had equipment in place to support their needs. Orthoses, wheelchairs and standers were the equipment items most frequently utilised, requiring both trained professionals (Physiotherapist, Occupational Therapist and Orthotist) and funding for assessment and provision. The average wait-time for receipt of equipment was 6 months which caused frustration.

Specialist services

Only 46% of children had access to the MDT Spina Bifida clinic in TSCUH. Parents and service providers identified seven key professionals as most important to be present at the MDT Spina Bifida clinic: Neurosurgeon, Urologist, Orthopaedic Surgeon, Nurse Specialist,

Paediatrician, Physiotherapist and Occupational Therapist. At the time of data collection, a Urologist, Orthopaedic Surgeon and Occupational Therapist were not available at the clinic. Not all children who had access to the MDT Spina Bifida clinic were reviewed annually, as recommended by international best practice, due to inadequate resources and staffing levels.

Chapter 7: Key Recommendations

There is a comprehensive list of recommendations within this report, with the key recommendations outlined below.

Equity of access to professionals:

1. Parents and families require prompt access to information and specialist advice following the diagnosis of Spina Bifida.
2. A fully-staffed MDT Spina Bifida service should be available for inpatient care with an annual clinic review for all children with spina bifida in Ireland. The clinic team should consist of the following seven key professionals: Neurosurgeon, Urologist, Orthopaedic Surgeon, Spina Bifida Nurse Specialist, Paediatrician, Physiotherapist and Occupational Therapist. There should also be access to a Social Worker, Neuropsychologist, Speech and Language Therapist, Dietician, Play Therapist, Neuro-ophthalmologist, Orthoptist and necessary imaging services.
3. Local MDTs should be available for children with spina bifida throughout childhood with an emphasis on early intervention. Local access to a Physiotherapist, Occupational Therapist, Speech and Language Therapist, Psychologist, Social Worker, Nurse, Orthotist, Dietician, Paediatrician and Family Support Worker is required.
4. There should be increased frequency of provision of therapy services which is based on assessment of the individual child's needs.

Improved psychosocial support:

1. Family, peer and sibling support should be available antenatally, post-discharge from the tertiary hospital and on an ongoing basis to provide practical and emotional assistance.
2. All team members should be aware of and responsive to the child's psychosocial needs.

Specific health and therapy needs should be met:

1. A multidisciplinary approach to prevention and management of weight gain is necessary. Height, weight and BMI (centiles and Z scores) should be measured every 6 months by local professionals.
2. A comprehensive functional visual assessment should be available to all children with spina bifida who present with visual difficulties.
3. Trained nursing professionals should be available outside the national centre to assist with support and training of families and children with the objective of achieving social continence.
4. The process of prescribing, funding and providing equipment needs to be reviewed to enable timely provision that benefits the child and avoid unnecessary waste.

Inclusion of children in society and education:

1. Mainstream education should be encouraged for children with Spina Bifida, provided this is appropriate to their learning needs. Access to mainstream school should not be influenced physical or continence needs. Children may require Special Needs Assistants, Classroom Assistants, Resource Teachers or School Nurses to provide the necessary support.
2. Improvements in physical accessibility of the schools and community environments are necessary to increase independence and active participation in daily life.
3. Increased inclusion and engagement of children in activities such as adapted sports, extra-curricular activities and social events is essential for their health and well-being.
4. There is a need for increased public awareness about pre-conceptual care and folic acid supplementation in Ireland.

Development of transition process to adulthood:

1. Specific and directed transition planning should commence early in adolescence (between 12 and 14 years) as a priority and involve collaboration between the MDT Spina Bifida service, local services and adult services.
2. Co-ordinated spina bifida care within adult services requires development.

Acknowledgements:

Spina Bifida Associations

The Spina Bifida Team, Departments of Physiotherapy, Occupational Therapy, Neurosurgery & Research in Temple Street Children's University Hospital

Gatekeepers and participants

References

- ALDANA, P. R., WOOD, D. L., POSTLETHWAIT, R. A. & JAMES, H. E. 2010. Initiating, developing and evaluating a comprehensive spinal defects clinic: a clinical report. *Pediatric Neurosurgery*, 46, 329-334.
- BRUSTROM, J., THIBADEAU, J., JOHN, L., LIESMANN, J. & ROSE, S. 2012. Care Coordination in the Spina Bifida Clinic Setting: Current Practice and Future Directions. *Journal of Pediatric Healthcare*, 26, 16-26.
- EUROCAT 1991. Working Group. Prevalence of neural tube defects in 20 regions of Europe and the impact of prenatal diagnosis, 1980–1986. *Journal of Epidemiology Community Health*, 45, 52–8.
- KINSMAN, S. L., LEVEY, E., RUFFING, V., STONE, J. & WARREN, L. 2000. Beyond Multidisciplinary Care: A New Conceptual Model for Spina Bifida Services. *Eur J Pediatr Surg*, 10, 35-38.
- LIPTAK, G. S. & EL SAMRA, A. 2010. Optimizing health care for children with spina bifida. *Developmental Disabilities Research Reviews*, 16, 66-75.
- MCDONNELL, R., DELANY, V., O'MAHONY, M. T., MULLANEY, C., LEE, B. & TURNER, M. J. 2014. Neural tube defects in the Republic of Ireland in 2009–11. *Journal of Public Health*.
- MERKENS, M. J. 2006. Guidelines for Spina Bifida health care services throughout the lifespan. In: COUNCIL, P. A. (ed.). Washington DC: Spina Bifida Association.
- NORTHRUP, H. & VOLCIK, K. A. 2000. Spina bifida and other neural tube defects. *Current Problems in Pediatrics*, 30, 317-332.