

## Accessibility and Requirements for Assistive Devices in Children with Spina Bifida in Latvia

*Agnese Kāposte*<sup>1,2</sup>, *Anna Zakajeva*<sup>2,3</sup>, *Jelena Stunzane*<sup>1</sup>,  
*Olga Jusinska*<sup>4</sup>, *Anita Vetra*<sup>1,2</sup>, *Aivars Vetra*<sup>5</sup>

<sup>1</sup> Children's Clinical University Hospital, Latvia

<sup>2</sup> Rīga Stradiņš University, Latvia

<sup>3</sup> Rīga East Clinical University Hospital, Latvia

<sup>4</sup> Health Centre "Baltezers", Latvia

<sup>5</sup> National Rehabilitation Centre "Vaivari", Latvia

**Introduction.** Spina bifida is congenital malformation of neural tube that affects development and functioning of a child. Most common type of spina bifida is myelomeningocele which is 81% of all spina bifida cases according to National Spina Bifida Patient Registry data. A wide variety of adaptive equipment typically is required for individuals with spina bifida. The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) is an outcome measurement instrument designed to evaluate a person's satisfaction with the assistive technology device.

**Aim, Material and Methods.** The aim of the study was to detect patient needs for assistive devices and to analyse accessibility of assistive aids in children with spina bifida in Latvia. Retrospective data of 90 patients with spina bifida diagnosis was collected from archive of Children's Clinical University Hospital and Vaivari Assistive Technology Centre (VATC). Data were collected for the period 01.01.1997–31.12.2014. Satisfaction of patients and their caregivers with assistive devices used during the past year supplied by VATC was evaluated by means of telephone survey with QUEST. All data was sorted and processed using Microsoft Excel programme.

**Results.** The average amount of cases of spina bifida during the period of time mentioned above was 5 cases per year. The most common type of spina bifida was myelomeningocele – 43 out of 90 cases (47.7%). The most common level of damage was lumbo-sacral – 61 out of 90 cases (67.7%). 36 out of 90 patients have never appeared in the VATC data base. Most common of all assistive devices which were supplied by VATC since 2005 for the patients included in research were orthopaedic footwear (41.9%), ankle-foot orthotics (AFO) (21.9%), knee-ankle-foot orthotics (KAFO) (6.7%), bimanual wheelchair (5.3%) and spinal orthoses (4.4%). The average waiting time for devices mentioned above respectively is 70; 52; 51; 355; 60 counting in days. Average waiting time for a bimanual wheelchair was the longest out of all assistive devices – 355 days, while the shortest waiting time was for finger splint, which was 3 days. 65.22%. 40 QUEST questionnaires were collected on technical aids supplied by VATC. The most important satisfaction items for wheelchair users were comfort (23.3%), safety (20%) and service delivery (16.6%), for users of orthosis the ease and comfort of usage (20%). Top 3 most important satisfaction items for both custom made and ready to wear orthopaedic footwear users were effectiveness and comfort (16.6%), the ease in adjusting (fixing, fastening) parts of the shoe (11.1%). Spina bifida patient requirements for assistive device were recorded via telephone survey. There were requirements for reciprocal HKAFO, for better accessibility of vertical standers, wider choice of orthopaedic footwear.

### Conclusions.

1. Data collection was difficult due to difference in classification used by different specialists.
2. Most assistive devices are supplied by VATC; however, a significant part of technical aids are supplied by other sources.
3. Lower satisfaction with services is due to long waiting time, absence of follow-up programme.