

Oral Presentation

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## Needs assessment of school-going children and adolescents with spina bifida

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### Background

The Central Remedial Clinic (CRC) is a national organisation providing a range of specialised services for children and adults with physical disability. One such service provided is a specialist spina bifida service. The aims of the study were: 1. To assess the current level of need among school-going children and adolescents (aged 5–18 years) with spina bifida. 2. To obtain a measure of patient and parental satisfaction with the specialist spina bifida service provided by the CRC. 3. To implement improvements in the service.

### Methods

The parents of 42 children were invited to participate in the study. All lived in the Eastern Regional Health Authority and attended the specialist spina bifida service in the CRC. All but 1 agreed to participate. Each participated in a semi-structured interview, which included the completion of a questionnaire.

### Results

Of the 41 children, 22 were attending special schools and 19 were in a mainstream setting. 34.1% were incontinent in relation to bowel function. 56.1% were incontinent in relation to bladder function. The majority required assistance for toileting: 73.2% were dependent in relation to bowel function and 53.7% in relation to bladder function. A significant number were dependent in relation to personal care (61% for washing, 58.5% for dressing). Whilst there was a high satisfaction rating for the service provided by the CRC (92.7% generally happy), 30 families (73.2%) identified the need for additional services, particularly the need for home adaptation and counselling for both the child and parents. Among the improvements suggested by parents were increased information,

more therapy and improved communication within the multidisciplinary team.

### Conclusions

We have highlighted a high level of need within this population. Whilst parents may be happy with the current service provided, there is much room for improvement. The key demand is improved coordination of services, not only among the services provided by the CRC, but among all care-givers providing services on multiple sites in the Dublin area.