

Poster presentation

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Changing needs for children and adults with spina bifida and hydrocephalus in Northern Ireland

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Background

The needs of persons born with Spina Bifida (SB) and/or Hydrocephalus (H) may change with age. ASBAH has in response to this sought the views of persons with Spina Bifida (SB) and/or Hydrocephalus (H) on its Northern Ireland database, to identify what the different needs may be. The results indicate that with the transition from childhood to adulthood there is a change in the perceived need.

Materials and methods

Postal questionnaire sent out from ASBAH to all persons with SB and/or H on its Northern Ireland database.

Results

770 questionnaires were distributed and 134 (17%) were returned. 98 adults (M:F 45:51) and 36 children (M:F 18:18) responded. The main issues raised by the adults were, personal care and support (12.5%), problems with accessibility (12.5%), increased benefits/better income (15%), transport difficulties (20%), finding employment (5%), help socialising (12.5%) and adaptations and equipment (10%). Within the children's responses, the main issues identified were personal care and support (17%), problems with accessibility (17%), increased benefits (17%), transport (17%), better medical care (10%), lack of friends (10%), help socialising (6%), and adaptations and equipment (6%). In both groups, these needs were identified as areas where study days would be of benefit to both children, their parents and to adults.

Conclusion

This survey confirms that as persons born with SB and/or H move from childhood to adulthood there is a perceived change in their needs that has to be addressed. The changing need is a reflection of the difficulties in maintaining a position within society when born with Spina Bifida and/or Hydrocephalus. It identifies areas where services should meet this changing need.