SUMMARY

Service Needs of Children with Limb Reductions

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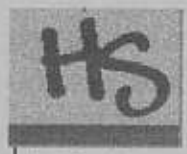

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PART 1
INTRODUCTION

This report summarises the main findings of a research project undertaken for Rehabilitation Management Limited (RML) in 1997/98. The aim of the research was to identify and investigate issues relevant to the provision of prosthetics (and other) services to children aged 0-16 with limb reductions living in the Northern Health Funding Authority (HFA) region.

The full report of the study is available from RML or the authors.

Research questions

Specific questions examined in the study include:

Potential client population

- How many children in the Northern HFA region have limb reductions?
- How many children in the Northern HFA region would benefit from limb prostheses?
- What kind of children with limb reductions would benefit from limb prostheses?
- What prosthetics and other services do children with limb reductions currently use?

Service development

- What is the best way to regularly assess and review the prosthetics and other services needs of children with limb reductions?
- What is the best way for RML to maximise or enhance the range of choices for children already in contact with RML services?
- What kind of children with limb reductions would benefit from alternative therapies or approaches provided in conjunction with, or instead of, prosthetics services?
- How can RML liaise in the most effective way with other agencies to enhance outcomes for children with limb reductions?

Costs

- What are the short-term and long-term costs of providing prosthetics and other services to children with limb reductions?

Other information gaps

- Are there other information gaps that need to be addressed?

Research Methods

Three separate but complementary research methods were used to explore the research questions. These were:

- a review of recent scientific research literature on children with limb reductions
- a statistical analysis of available health and demographic data
- in-depth interviews with caregivers of children with limb reductions and health professionals who provide services to children with limb reductions (this part of the research was approved by the North Health Ethics Committee).

Key results from these three research strands are summarised in the rest of this report.

PART 2

LITERATURE REVIEW

Prosthetic, surgical, and other physical management

Research issues

- Most of the published literature on the rehabilitation needs of children with limb reductions focuses on congenital rather than acquired reductions, but these two groups have certain distinct needs.
- To date, studies of the rehabilitation needs of children with limb reductions have used relatively limited research techniques. This has been particularly the case for studies investigating the best time to introduce prostheses and the effectiveness of different prosthetic and non-prosthetic interventions.

Prosthetic management

- The research literature indicates that decisions on prosthetic management should take account of the psycho-social, functional and developmental needs of individual children, and address their parents' concerns.
- Most studies support the use of prostheses for children with lower-limb reductions.
- However, non-prosthetic management is identified as the best option for some children with limb reduction.
- Prostheses should genuinely extend the range of things that children can do, rather than simply providing another way of doing what they are already capable of doing.
- Prostheses should be designed to achieve the best fit, alignment and cosmetic effect.
- There are differing views about what is the best age or developmental stage to introduce prostheses to young children.
- Early introduction of prostheses may help children achieve developmental milestones and may mean they are less likely to reject their prosthesis later on.
- However, early fitting of a prosthesis may also inhibit the development of independent eye-stump co-ordination and the sensation of touch.

- Passive and body-powered prosthetic devices are usually introduced first, with myoelectric options being considered when children are older.
- Different types of prostheses have their own advantages and disadvantages, and their use should be considered in the context of individual children's needs.
- Children need to be trained to use their prostheses so they can achieve maximum independence and do the things they want to do.
- After a prosthesis is first introduced, its fit and ongoing functional value should be regularly assessed.
- Questionnaires such as the Child Amputee Prosthetics Project Functional Status Inventory (CAPP-FSI) may be useful in assessing children's levels of functioning.
- A significant proportion (about a third) of children with upper-limb reductions abandon their prostheses when they are older.
- Younger children tend to stop using prostheses because they say they can manage just as well without them. Teenagers who stop using prostheses are more concerned about their appearance.
- Children with shorter upper-limb stumps and longer lower-limb stumps are less likely to abandon their prostheses.

Surgical intervention

- Surgery may be useful for some children with limb reductions, as it can improve joint function, prepare a limb for prosthetic fitting or lengthen bones.

Use of special devices and technical aids

- Special devices based on very simple technology can be useful for children with limb reductions. Examples include:
  - sticks with attachments which make performing certain tasks and reaching easier
  - modified scissors and cutlery
  - a set of portable steps.

Use of other body parts

- Children with congenital upper-limb reductions can often effectively use other parts of their bodies (feet, mouths, chins) to do all sorts of tasks.
- These children can also use their residual limbs to assist them during many activities, including certain activities involving fine-motor movement.

Psycho-social issues

Research issues

- Very few studies have examined whether children with limb reductions experience more psycho-social problems than other children.
- A few well-designed evaluation studies have assessed the effectiveness of different prevention and rehabilitation strategies for children with psycho-social problems.

Incidence of psycho-social problems

- Children with limb reductions may have a slightly higher risk of psycho-social problems than other children.
- Factors thought to influence the degree to which children with limb reductions experience psycho-social problems include:
  - the child's temperament
  - the incidence of 'daily hassles'
  - the child's perception of their physical appearance
  - the child's perception of the degree of positive support they get from parents, teachers, classmates and friends.
- The risk of psycho-social problems does not appear to be associated with children's age, sex, socio-economic status or the degree of their limb reduction.
- Specific screening devices like the Child Behaviour Checklist (CBCL) may be effective for identifying psycho-social problems among children with limb reductions.
- Problems encountered by children and adolescents with acquired limb reductions include: disrupted studies and employment; restricted access to facilities; poorer relationships with classmates; difficulties reaching or sustaining independence; and feelings of self consciousness.

Psycho-social interventions

- The following psycho-social interventions may be effective in reducing the psycho-social problems experienced by children with limb reductions:
  - reducing family conflict
  - developing family cohesion and organisation
  - increasing social support from classmates, teachers and parents
  - enhancing self esteem
  - improving access and mobility

- educating classmates
- maintaining school work during hospitalisations
- providing pain management for children with acquired limb reductions.

- Studies also recommend that interventions:
  - use a multidisciplinary team
  - respond early to parents' questions and concerns
  - acknowledge parental grief reactions
  - provide appropriate information
  - offer introductions to other families with limb-absent children (or support groups)
  - consider families' financial and emotional resources
  - include other family members in programmes (other than parents)
  - use a home-centred approach as far as possible
  - co-ordinate services from other agencies and organisations.

- Other psycho-social strategies documented in the research literature that may be effective include:
  - enhancing skills and self esteem through physical activities like skiing
  - using amputee dolls to help with preparation for prostheses, education of other children, and communication and role playing.

Personal and social attitudes

- The personal attitudes of people with limb reductions are important. Some people with limb reductions may attempt to appear as 'normal' as possible. Others may try to raise public awareness by an open display of their limb reduction.
- Wider social responses to people with disabilities are also important. They include making changes to the local environment and living spaces to make it easier for people with limb reductions to lead independent lives.

Cultural issues

- Studies in a few countries have looked at national and culture-specific beliefs about children's limb reductions and associated management strategies.
- These studies show that cultural contexts can influence beliefs related to the cause of limb reductions, amputation, the use of prostheses and cosmesis.