



**Cerebral Palsy
Register *for* Scotland**
A joint project between Napier University and NHS Scotland

Summary Report

**Evaluating the experience of children with cerebral palsy and their parents in
the transition from primary school to secondary school**

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Introduction

This report represents the findings from a 3 year project which was partially funded by the charity 'Cerebra'. The work was also submitted towards the degree of Doctor of Philosophy at Edinburgh Napier University, Edinburgh.

The work set out to be participatory and to gather the experiences of young people with cerebral palsy (CP) as they move from primary to secondary school, along with that of their parents. The views of both disabled young people and their parents are poorly represented in the literature of this field, thus this work went some way to rectifying this.

Two groups of families were recruited; those who had made the transition prior to the implementation of the Education (Additional Support for Learning) (Scotland) Act (2004) (ASL) in 2005 (Pre ASL group), and those making the transition after it had come in (Post ASL group). This act was introduced to improve the educational experiences, including transitional periods, of all young people with additional needs.

The families were recruited through the Cerebral Palsy Register for Scotland (CPRS), a research based register of children with CP living in Scotland. This aided the response rate the project received, as it was able to build on an existing relationship, and had the opportunity to convey information about the project via the CPRS newsletter and website.

Parents and young people participated in interviews discussing the transition. Those in the Pre ASL group participated in a single interview reflecting on the transition, whilst those in the Post ASL group had three interviews throughout the course of the transition.

In total 25 families participated in the work, 16 in the pre ASL group and 9 in the post ASL group. The young people were representative of young people with CP, some of whom had mild CP, others who had more severe CP. There was also a mixture of experiences from mainstream and special schooling throughout Scotland. An additional 23 families participated through a questionnaire which contributed towards verifying the findings.

Executive Summary

Key findings

- The ASL act has had little impact on the transition from primary to secondary school.
- When choosing a school parents and young people want choice.
- When moving into mainstream secondary school many of the young people encountered a lack of understanding of their impairment.
- For many young people and their parents the main concerns prior to moving into secondary school were issues pertaining to mobility.
- Parents reported that they felt the need to fight for access to services for their child during this time.
- Both parents and young people valued being informed throughout the transition, and rated obtaining information as being very important.

Additional Support for Learning: Within this work there was little evidence of this act improving the experiences of the young people and their parents, as both the pre and post groups largely reported similar experiences. Parents in the post ASL group expressed that they felt the act had no impact on their child's educational experience. Many of the parents seemed confused as to what the act was for, and their rights under it.

Choice: When choosing a secondary school parents and young people wanted to be able to access all schools and have a choice. In particular the majority of parents wanted their child to attend the local school. They felt this would incorporate their children into the local community. The young people agreed with this decision, and expressed a desire to remain with friends from the local area.

Some parents felt that their child would benefit from attending a special school. This was often due to the belief that at mainstream school their child would be identifiably different from other pupils, and that to date integration practices continued to exclude disabled pupils. These parents wanted the option of special schooling to be available to other parents in the future.

A lack of understanding: Many of the young people attending mainstream schools encountered a lack of understanding from teachers, support assistants, and other pupils on

making the transition. In most cases this consisted of the young person having unrealistic expectations placed on them, or of having their actions questioned.

Mobility concerns: Prior to moving to secondary school the young people primarily discussed concerns which were linked to issues related to mobility. These included concerns regarding accessing the school, navigating stairs, and moving around a larger school carrying a school bag. Such concerns were also echoed by their parents. This is in contrast to much of the literature which highlights bullying as being the major concern of young people when making the transition.

The need to fight: When discussing services during the transition parents used language and terminology which suggested that they felt in conflict with service providers. Many of the parents felt that they were required to fight on behalf of their children for them to obtain access to relevant services.

To be informed: Throughout this work both the young people and their parents stressed the importance of being informed for the duration of the transition, via written material or oral information. Most of the parents felt it was important to have a contact person who could keep them informed throughout the transition, and could answer questions as they came up.