

## **Summary Report:**

**Scoping project on integrated effective service provision for children and young people with physical disabilities**

This is a summary of the first stage of a research programme on effective services for students with disabilities, commissioned by the Ministry of Education's Advisory Reference Group for Students with Physical Disabilities. The summary covers the key themes from the report on the scoping project - Integrated and effective service provision for children and young people with physical disabilities - and outlines a plan for the next phase of the research.

## **Introduction**

The Ministry of Education convenes an Advisory Reference Group for Students with Physical Disabilities (the Reference Group). The Reference Group, made up of parents, health professionals, early childhood teachers, teachers, and principals as well as representatives of disability organisations and education unions, is a rich resource of knowledge and experience of students with physical disabilities.

Part of the Reference Group's brief is to promote and support robust research into effective integrated teaching, learning and therapy practices so that children and young people with physical disabilities successfully overcome barriers to learning and develop their potential to participate effectively in life.

The Wylie Report (2000), reviewing special education provision, highlighted particular concerns for students with physical disabilities, especially around what makes for effective occupational therapy and physiotherapy services. Picking up on these concerns, funding has been provided for a research programme to look at "best practice therapy provision in Education and the costs associated with that provision".

The Ministry of Education, in conjunction with the Reference Group, commissioned a scoping project to design the research programme. This report summarises the key themes from the report on the scoping project - *Integrated and effective service provision for children and young people with physical disabilities* - and outlines a plan for doing the next phase of the research.

The research programme will be an important and challenging piece of work that will help take a major step towards understanding what makes for the integrated provision of services to children and young people with physical disabilities.

## **WHY IS RESEARCH NEEDED?**

Special Education 2000 (SE2000), a policy progressively implemented from 1996 to 2000, provides resourcing options and initiatives for early childhood centres and schools. These provide education support for children and young people with special educational needs.

SE2000 brought a radical change to the distribution of resources for children and young people with special educational needs. However, there are ongoing issues around resourcing for particular groups of children and young people, including students with physical disabilities.

The Ministry of Education, in conjunction with the Reference Group, commissioned the scoping project to design a research programme that would answer questions in two key areas:

- What is the current range and level of therapy and other services provided to

overcome barriers to learning for students with physical disabilities in New Zealand? What are the characteristics of current users and what are perceived levels of “unmet” need?

- What would coherent and effective models of therapy and other service delivery for students in the compulsory school sector with physical disabilities look like? What would such integrated models, with the student at the centre, look like across a spectrum of services, settings, and locations? The Reference Group was particularly concerned to ensure that these models would reflect a holistic view of outcomes, focusing on life outcomes rather than just disability.

The purpose of the research programme is to gather understandings which will contribute to improving service provision for students with physical disabilities, their families and whanau by informing both policy development and decisions about resourcing.

### **A STRONG FOUNDATION FOR THE RESEARCH**

Before starting to design the research, the Reference Group realised that it first needed to answer some fundamental questions:

- How do we define physical disability for the purposes of the research?
- What do we mean by integrated effective service provision?
- What might be the characteristics and hallmarks of integrated effective service provision?

The Reference Group commissioned Dr Trevor McDonald, Pat Caswell (University of Otago), and Merolee Penman (Otago Polytechnic) to undertake a scoping project that would help answer these questions and guide the shape of the next stage of the research programme.

### **Collaboration between the scoping team and the Reference Group**

The scoping report was the product of close collaboration between the scoping team (the authors of the report) and the Ministry’s Reference Group. Through its Research Sub-committee, the Reference Group has played an active role in shaping the project and ensuring that at all times the focus remained on the needs of students, their families and whanau.

As the project developed, the Reference Group and the scoping team came to the realisation that any exploration of service effectiveness could not focus solely on therapy provision but instead would need to look at service provision from the overall perspective of the student. For this reason, the research does not explore the effectiveness of specific therapies in isolation. Rather, it looks at key indicators of effective integrated service provision, including therapy, across a wide range of service delivery settings.

## **How was the scoping study done?**

To answer the questions about how to define physical disability, and what integrated effective provision might look like, the scoping study involved:

- a review of New Zealand and international literature about the provision of integrated therapy services to students with physical disabilities
- 59 key informant interviews with students, parents, education and health professionals, advocates and others. Interviewees were asked questions about the meaning of the term 'physical disability', about the services currently available to students with physical disability, about how they would like to see these services provided and what would be needed to provide them. Where appropriate, they were also asked how they would know if a new model of integrated service delivery was working.

The key informants were selected on the recommendations of the Reference Group and were drawn from a range of people, settings and locations. This approach aimed to canvas the views of people familiar with the sector and/or who had experience of physical disability. It was intended that the views in the report represent a select, informed group, rather than being representative of the whole sector or of all organisations in the sector. The interviews complement the literature review, rather being a comprehensive source of data themselves.

One of the exciting elements of the project was the way the literature review and the interviews supported and confirmed the themes emerging from the other. This gives confidence to the findings of the report and to forming the basis for recommendations for the design of the research.

## **Towards a definition of physical disability**

There are a range of traditions and frameworks for defining physical disability. The scoping team found that definitions of physical disability in the literature tend to be constructed around one or more of these four dimensions:

- limitations imposed by physical and social environments
- limitations determined by social attitudes, beliefs and values
- disabilities defined as deviations from the norm
- definitions built around the need for services.

The scoping team concluded that access to the activities of daily living and active participation in their communities should be a critical element in thinking about and defining physical disability.

The scoping report asserts that any definition of students with physical disability needs to take account of:

- the personal experiences and perspectives of people with physical impairments
- the context within which the disability is manifested
- participation in educational, social and vocational settings
- the effect of social and attitudinal barriers
- the expectations normally imposed on peers of similar age and status
- current definitions – notably Special Education 2000.

These elements confirm and support widely held views about the interaction between a person's physical capacity and the physical and social environment, and the importance of putting the disabled person<sup>1</sup> at the heart of service provision.

Among those interviewed, there was no commonly held idea of physical disability. Physical disability was seen by some as a personal issue that changed according to an individual's circumstances, and could only be understood as that person's experience of life. Some students with apparently significant physical disabilities did not see themselves as very different from their peers. Here is one comment from the report:

*I think that one of the great misconceptions is that people try and give a generic term for physical disability which I don't think is possible because the definition of disability is something that makes it difficult or impossible for you to do something. . . so a disability can be so forward and far reaching. It's really quite a personal thing. (Student)*

This comment and others like it reflected the findings from the literature review that the personal experiences and perspectives of the people involved must inform any definition of physical disability.

The attitudes of others were important to students' and families' perceptions of disability. Maori who were interviewed saw physical disability within the context of a range of other needs and challenges experienced by many families. This is a comment by an educator:

*. . . we've had similar cases in our work where there are multiple needs, maybe with more than one child in the family, but also the health needs of Mum or the primary caregiver . . . and you've got all the other kids and if they're being shifted round a lot it's getting them in and out of schools . . . and so many families are (falling) between the gaps. We lost one last year with significant needs, [who] hasn't shown up anywhere. (Educator)*

Experiences related by people interviewed supported the finding from the literature that any definition of disability must take account of the attitudes of groups and communities as well as individuals. For example, in speaking of the Samoan community's attitude to physical disability, one person said this:

*That's like I said to you, like the attitude towards disability, like no one has a disability, everyone's the same. They may have a hearing impairment or visual impairment, that's not disability. They can do other things as well. (Professional)*

Integral to people's comments about the characteristics of physical disability was the impact of the environment on the student, and the way in which the presence of environmental barriers can create physical disability, as this comment shows:

*I guess at school I mostly felt excluded just because there weren't that many exceptions made for me. Like there were certain things I just couldn't do. Like sit on the ground and run and stuff. Just really the general layout of the classroom and the pressures put on you by teachers and the children, kind of like stopped me from wanting to do general things. (Student)*

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<sup>1</sup> This term is consistent with the New Zealand Disability Strategy, as recommended by the New Zealand Disability Strategy sector reference group that the term 'disabled people' be used.

The presence or absence of functional skills was mentioned frequently by those interviewed as a part of the definition of physical disability. As the literature indicated, being unable to do the things they want to do, or that other people can do, was an important dimension of physical disability for the students and others interviewed.

Participants also talked of physical disability leading to educational disadvantage. Here are the words one parent used:

*I don't know how to describe it, an educational disadvantage, not an intellectual, I suppose, disability per se, but your mind is limited because of the physical limitation. One thing leads to the other. (Parent)*

The need for extra support to access the curriculum was another dimension that participants introduced to their definition of physical disability.

A key tension the scoping report identified was the importance that any definition used does not 'label' students but is still clear enough to identify those who need services. Even so, definitions based on students' support needs are not necessarily flexible enough to take account of changes in those needs over time.

One of the key challenges for the research programme, therefore, will be to incorporate the dimensions of physical disability identified by the scoping project into a practical definition that is both meaningful and useful.

### **Integrated effective service provision**

The scoping report examined what the literature said about key features and characteristics of integrated effective service provision, and what the people interviewed considered such provision might look like. The purpose of this inquiry was to clarify the essential features that would need to underpin different models of integrated effective practice. How these characteristics will manifest themselves in practice will be explored in more depth in the research programme.

The research team found that increasingly in the literature the term '**integrated**' in relation to children and young people with disabilities in educational settings has become synonymous with inclusion. However, they argue for a much wider interpretation of the term integration – one that includes professional and programme integration.

The scoping team found a number of other characteristics associated with '**effectiveness**' including:

- the opportunities available to individuals, their families and whanau to consider options and choose interventions
- the active role of the young person, their family and whanau in contributing information and making informed decisions based on accurate and accessible information
- a focus on the development of functional skills
- therapy 'treatment' options that occur in natural environments and become 'part of the child's life'
- models of service provision which can be tailored to individual children and their families.

The scoping project sought out models of integrated effective provision and found they had a number of common elements including:

- interagency collaboration
- collaborative models of service provision
- family involvement.

While interagency collaboration was one of the intentions behind SE2000 and has been widely endorsed before and since, the researchers found that New Zealand was not alone in facing difficulties in achieving such collaboration. The literature says that good interagency collaboration requires:

- trust and respect
- common goals
- the recognition of individual agencies' strengths
- stability of personnel
- flexibility in service delivery issues
- communication systems that do not rely on parents and caregivers to be the main link.

Interviewees also referred to lack of interagency collaboration. They reported variation in the interpretation of the health/education interface in the provision of services. Transition between services was difficult, with some participants commenting particularly on the comprehensiveness of early intervention and early childhood services in comparison with those available to students in the years of compulsory education. Families also objected to having to be the link between numerous agencies and professionals who appeared not to communicate directly.

The many comments from people interviewed about the lack of co-ordination and integration of services suggested to the scoping team that there was a need for the focus of the research to shift from trying to determine a single model of service provision. Instead, the research needed as a goal a much greater understanding of the need for, and an increased commitment to, a range of models that reflected the integration of different philosophies about treatment, the goals of service provision, structures and, ultimately, services themselves.

It is essential for agencies to establish collaborative practices, and the concept of local ownership requires that the people actively involved in a student's life also develop ways of working together as a team. There are a number of requirements for effective teaming, the most important of them being the commitment of individual team members to teamwork – to sharing their own knowledge and respecting the contribution of others.

The literature confirmed that the role of parents and families is crucial in the assessments and interventions that characterise the lives of young people with physical disabilities. It is equally clear, however, that the relationships between parents and professionals are complex and can be fraught with difficulties.

Family members' views also meshed with the literature in this respect. There were comments about the way services with which they had contact did not respect their wishes, and that it was sometimes very difficult to achieve real communication with services provided to the student at school. Those Maori who were interviewed did not feel that their needs were always respected. Among the families who were interviewed there was a view that the IEP process, while it had its frustrations, was at least a step towards a consistent approach between home and school programmes.

The literature review found that models of effective practice can vary from student to student. For example, models appropriate to Maori will need to take into account Maori perceptions of disability and of service effectiveness. Planning for service provision should seek to involve Maori at all levels, should recognise the importance of whanau and community and should wherever possible be undertaken by people who understand and value Maori perspectives.

To the people interviewed, integrated effective practice would be practice that overcomes some of the problems they currently experience. It would:

- be consistent in the responsibilities of sectors, agencies and services
- demonstrate co-ordination and collaboration between agencies
- support consistent staffing and clear role definition
- involve families fully, without expecting them to co-ordinate services
- promote and foster effective teamwork
- offer professional support and development to enhance the skills of teachers, therapists and teacher aides
- have funding flexibility, sustainability and transparency.

In addition, interview participants said that the student with physical disabilities, their families and whanau, should always be at the centre of any models of integrated effective service provision. This had not often been their experience.

The Reference Group endorsed the findings of the scoping report that identifying the principles of integrated service provision is more critical than developing a specific model of service provision. Just as important is the message that integration needs to be at a number of levels and across agencies, and is about more than just the integration of services around individual students.

#### **DEVELOPING CRITERIA FOR ASSESSING INTEGRATED EFFECTIVE SERVICE PROVISION**

The literature review highlighted a range of potential indicators of integrated effective service provision to students with physical disabilities:

- extensive family involvement
- learning and achievement of the student
- acceptance, inclusion and friendships with peers
- the availability of support to adapt the curriculum
- a focus on multiple dimensions of the quality of life
- a commitment to accountability, and a means of ensuring it.

When people interviewed were asked how things would look if there was an integrated effective model of service provision, they told the scoping team that if such a model was in place students with physical disabilities would:

- have opportunities to develop relationships with peers and supported by sensitive arrangements for the provision of necessary therapies
- be happy
- receive support that was practically oriented and directed towards the improvement of their physical skills
- have equitable access to, and choice between, good quality services
- access services that respond to their individual needs.

These findings support an approach to the research programme that seeks to further clarify the characteristics of integrated effective service provision, with the understanding that such characteristics could be found in a range of models of service provision, not just one type of setting or model.

### **The research programme**

The Ministry and the Reference Group are working with an expert research team to finalise the research programme methodology. Associate Professor Dennis Moore (University of Auckland) plans to lead the team. Team members span a range of expertise including database analysis, occupational therapy, speech language therapy, physiotherapy, service provision, educational research, health services research, costing/econometric analysis, disability research, and evaluation/program provision research expertise. In line with the aims of the research programme, the team blends a mix of education and health research expertise.

The research programme will result in:

- a synthesis of existing information from a range of sources to give a picture of the distribution of resources/funding streams for this group of students, and the quantum of resourcing on a national/regional basis; and
- an assessment of existing therapy and other provision in a range of settings, benchmarked against the principles of integrated effective service provision identified in the scoping study.

This will yield a better picture of patterns of service use and resource distribution, and provide an overall context for assessing resourcing for therapy provision. Looking at how integrated effective service provision works in practice, in real services and settings, will result in valuable information that will contribute to the further development of services for students with physical disabilities.

### **Endnote**

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