

‘WHAT I’D LIKE YOU TO KNOW ABOUT ME!’ PHASE II

STAGE 2 REPORT

PROJECT

Executive Summary

The ‘What I’d Like You To Know About Me!’ project began in 2004, with the creation of a CDROM resource kit for service providers working with people with disabilities. The aim of this resource was to support service providers to document positively focussed information about the people they support. Families involved in consultations during this project indicated that if such a resource had been available to them when their children were younger then the interchange between families and service providers could have been less fragmented and difficult. This feedback led Life’s for Living to look at developing a resource tailored specifically to children and young people with disabilities and their families.

Therefore Phase II of the ‘What I’d Like You To Know About Me!’ project focuses on children and young people with disabilities and their families. The project began in 2005 and aims to research and develop a family centred resource which enables children and young people with disabilities to record information about what is important to them, how they want to be supported and with a focus on their abilities rather than their disability. The intention of the resource is that families can use it with people in both the child’s personal lives and service networks.

This is a 20-month project and managed in four distinct stages as shown below:

- Stage 1: Research and concept development stage (June – Dec 05) – *consultation and confirmation of need (Achieved)*
- Stage 2: Production & testing stage (Jan – Aug 06) – 8 months (*Achieved*)
- Stage 3: Promotion and implementation stage (Proposed dates: Sept – Feb 07) – Currently on hold until funding is available.
- Stage 4: Ongoing support, sustainability and evaluation (Proposed dates: Mar 07 + ongoing)

Stages 1 and 2 of the project have reached their conclusion. Stage 1 of the project involved extensive family consultation and research into existing similar initiatives/resources at local, national and international levels. Service providers representing health, disability and education sectors were also consulted. Findings from Stage 1 confirmed the need for this resource in both web-based and hard copy formats and also verified the need for a resource that is family centred where the information is controlled and managed by families for use across a range of settings. Stage 2 of the project involved the actual development of a prototype (test version) of the resource in a web-based format, and testing its effectiveness when used by families across a range of settings. The resource was tested with a total of 33 participants comprising 14 families and 19 service providers.

Families were supported to use the resource to create a profile about their child (a profile is a series of pages of information about their child; the information is typed into the resource and then printed). The resource testing involved asking families to use the resource and then seeking their views about (1) the technical aspects of the website (2) the impact of the resource. Feedback was

obtained from families and service providers in education, health and disability settings with regards to the impact and relevance of the resource. Responses were sought specifically relating to the experiences of children and families in different settings; interactions with staff and the development of relationships with service providers in relation to care of the child.

Funding to date has included grants from the Ian Potter Foundation (\$26,700), the Adelaide Bank Charitable Foundation (\$15,000) and the South Australian Department for Families and Communities (\$30, 000). The project requires further funding to refine the resource, develop a hard copy version, to promote, educate families and service providers and build in sustainability measures for the future.

This report provides a comprehensive account of the methodology, key findings, evaluation and recommendations from Stage 2 of the project.

Summary of key findings and Recommendations

There was significant agreement among families and service providers that this resource would be most useful and relevant in situations where the child is previously unknown to the service provider. In other words in situations where children begin using a new service; when a new staff member is introduced to the child; at key stages (such as transition points in education); during a hospital visit or when new information about the child emerges.

Furthermore, based on the feedback provided by participants it was found that the effectiveness of the resource will depend on a range of factors:

- the existence of an ongoing support structure to assist families in using the resource;
- families making the time to create their child's profile and keeping the information up to date;
- relevance of the information given to service providers, and
- time constraints experienced by families and service providers

The completion of Stage 2 has also resulted in the following recommendations:

1. Promote the resource to both families and service providers for use particularly with new staff; when approaching a new service; at key developmental stages or transition points; and when new information about the child emerges.
2. Establish specifically tailored support strategies which address accessibility issues faced by some families who are not computer literate or do not have access to a computer/ internet or printer at home.
3. Seek funding for designated support personnel whose role is to assist families in creating profiles, provide ongoing follow up, managing feedback and resource maintenance.
4. Provide a flexible support structure that gives families the option on how they wish to be assisted when creating profiles (such as preferred time and location, 1:1 or group basis).
5. Test the resource over an extended period of time (e.g. 6 months)