
EXECUTIVE SUMMARY

The 'What I'd Like You To Know About Me!' Phase II project represents the second phase of a research and development project conducted by Life's for Living in 2004. This project created a CDROM resource kit for service providers that focussed on capturing holistic and positive information about people with disabilities. The product was launched in 2005 and has attracted commendations from service providers across Australia. The concept for the resource was developed by Life's for Living and the project also involved Kristen Brown and Julia Southwell (Occupational Therapy students from the University of South Australia). Family and service provider feedback received during the project indicated that there was a need for a similar resource, controlled by families for children and young people with disabilities.

Phase II of the 'What I'd Like You To Know About Me!' project began in June 2005 and attracted funding from the Ian Potter Foundation (\$26, 700) and the Adelaide Bank Charitable Foundation (\$15, 000). Life's for Living provided in kind support by way of resources, administration and project management. The Project Team continues to have an ongoing funding strategy that involves identifying and submitting applications to funding bodies that meet the needs of the project. The 'What I'd Like You To Know About Me!' Phase II project is currently funded until March 2006.

The project is being managed in stages with Stage 1 having reached its conclusion (December 2005). Stage 2 (product development and testing) will begin in January 2006 and Stage 3 (promotion and implementation) will begin in September 2006 and conclude in February 2007.

The project is targeted at children and young people with disabilities and their families. The aim is to promote positive perceptions of children and young people with disabilities through the provision of a resource which enables their dreams, abilities and achievements to be acknowledged, celebrated and shared. The proposed resource will be used by families to capture and 'celebrate the positive' with a strong focus on ability. It will enable families to write stories and collect and record important information about their child(ren) which will impact on their interactions both in their personal relationships and within service settings.

The primary focus for Stage 1 (research and concept development stage) of the 'What I'd Like You To Know About Me!' Phase II project was to confirm the need for the proposed resource via extensive consultation with families (49 families participated- including parents, grandparents, foster parents, carers, children and young people with disabilities) and service providers (24 participants). Consultations were conducted using a flexible consultation strategy that involved various methods including questionnaire, personal interview, telephone interview and focus groups (refer to Section 2- Methodology). The project was promoted widely through various newsletters/flyers and by parents (word of mouth) in the disability and education sectors, with some promotion in the health sector. The response rates for consultation were, considered to be very good particularly as there were many factors which may have created barriers to participation for families, including lack of time, child-care difficulties and lack of confidence (refer to Section 2- Methodology).

This report provides a comprehensive account of the methodology, key findings, evaluation, and recommendations for Stage 1 of the project.

Summary of key findings

The value of the proposed resource is supported by evidence from consultations with families and service providers, analysis of similar initiatives, documentation of relevant literature and supporting principles and policies. Families substantiated the concept through 100% agreement (29 respondents via questionnaire) that the resource would be valuable to children and young people with disabilities (and their families). General consensus and enthusiasm for the concept was also demonstrated at focus groups (24 families represented), despite recognition that families often experience a lack of time, energy & motivation. Families also recognised the value of the resource for improving the self-esteem of their children and many commented on the usefulness of the proposed resource for all children (with and without disabilities). Consultations also provided valuable information about the resource concept in terms of content (what information families would like captured by the resource), situations of use (where and with whom they would use it) and format.

Consultations with service providers also produced an exceptionally positive result, with 88% of respondents indicating that the proposed resource would be valuable, the remaining 12% indicated no answer, unsure or that it would depend on how families viewed the resource (for more detail refer to Section 3- Key Findings). In fact, although service providers identified mechanisms in their own organisations that captured positive information about clients, the majority also indicated that there were gaps in the collection of this information (66% indicated that information captured was not sufficient, 21% did not answer/not sure, the remaining 13% indicated that process were sufficient but that the resource would still be valuable). This feedback indicates that the resource, although used and controlled by families, will also impact positively on service provision.

Analysis of similar initiatives, at local, national at international scales indicates that the proposed resource, that is, a resource controlled by families for use across a range of sectors, does not currently exist. As reported in Section 3- Key Findings, this indicates that the project will and should continue into Stage 2 which will involve resource development, production and testing.

Recommendations

The conclusion of Stage 1 of the project yields a number of recommendations which relate to the results presented in Section 3- Key Findings. In summary, the recommendations will guide the creation of the resource and pertain to input from families and service providers in its development and testing (content, form, and layout). Several of the recommendations relate to adequate trialling of the resource with families including use with all children (with and without disabilities) and in different service settings. The final recommendation correlates to the issue of sustainability of the resource beyond its production.

This report makes the following recommendations:

1. Produce a dual format resource (electronic and hard copy) that is simple, easy to use and accessible for families to use with their children.
2. Involve key service providers with specialised expertise in the development of the resource, who can advise on specific content.
3. Establish a Parent Advisory Group with interested parents consulted in Stage 1 to guide development of the resource.
4. Trial the resource with families in various settings accessed by families of young children – i.e. through disability, education and health networks/linkages made in Stage 1
5. Trail the resource with children and young people with disabilities at various developmental stages and at key transition points e.g. entering preschool, entering school, from junior primary to primary, from primary to secondary and to post school options.
6. Consult with siblings of children/young people with disabilities using focus group format in conjunction with Siblings Australia.
7. Continue to identify strategies for long term sustainability of the resource particularly to assist families in developing and maintaining information in this resource about their child.

Conclusion

The 'What I'd Like You To Know About Me!' Phase II project involves collaboration across the disability, health and education sectors, in conjunction with families of children and young people with disabilities. The evidence provided in Stage 1 (consultation) adds considerable weight both to the project concept and the necessity to provide families with a resource that meets their needs. Families have injected the project with enthusiasm, strength and knowledge and their voices have been captured within this report. They have provided the Project Team with the evidence needed to take the project beyond concept development and into resource development and production. They have indicated, along with service providers, that the proposed resource would not only be valuable to them, but would make a positive difference in their lives and those of their children.