
STAGE 1

PROJECT REPORT

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

Celebrating, acknowledging and sharing the dreams, abilities & achievements of children and young people with disabilities.

December 2005

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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.

SECTION 1. BACKGROUND

1.1 PROJECT OVERVIEW

The 'What I'd Like You To Know About Me!' project began in 2004 with the development of a resource kit for service providers working with adults with disabilities. The wider applicability of this concept, however, became apparent during consultation with families, who indicated a need for a similar resource for families of 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 focuses on the research and development of family centred resource.

The proposed resource will support families to capture positive and factual stories/histories of their children which are dynamic and have continuity throughout the child's developmental years. The proposed resource, therefore, will create opportunities for families to celebrate, acknowledge and share the dreams, abilities & achievements of their child(ren). The proposed resource will be developed to be used in both the personal and service domains. At the personal level (i.e. for the family, guardian, friends, child or young person) it is intended that the resource will support and strengthen families to view their child with a disability positively and promote understanding within their support networks and in the wider community.

It is also intended that the resource will promote positive perceptions and interactions with service providers as well as minimising on-going repetition of information by parents. For example; the resource will create a print/copy-friendly document that can be taken to appointments. These 'profiles' will add value, enrich and provide input into existing individualised planning processes currently used across a range of sectors such as health, disability, children's services and education.

1.2 PROJECT AIM

To promote positive perceptions and interactions with 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 in a dynamic way throughout their developmental years (0-17 years).

1.3 PROJECT RESOURCES

The project is managed by Life's for Living Inc., with guidance and support from the Project Reference Group (refer to Appendix 6.1). The Project Team comprises Lis Burtnik (CEO), Victoria Wright (Project Manager), Silvia Lopresti (Project Officer). The project is endorsed and supported by the Life's for Living board of management.

1.4 OBJECTIVES AND TIMELINES

This project will be managed in three discrete stages which are aligned to key milestones. The fourth stage represents the ongoing maintenance and sustainability.

Project start date: June 2005 Project end date: Feb 2007

Stage 1: Research and concept development stage (June – Dec 05) – 6 months

Key Milestone: *By Dec 2005, the project will have confirmed the need and developed the concept for the tool to inform direction and provide the foundation for subsequent stages of the project.*

Stage 2: Production & testing stage (Jan – Aug 06) – 8 months

Key Milestone: *By August 2006, the project will have produced and tested the suitability and*

functionality of the tool with families of children and young people with disabilities and service providers across a variety of sectors

Stage 3: Promotion and implementation stage (Sept – Feb 07) – 6 months

Key Milestone: By February 2007, the tool will be promoted and available to families of children and young people with disabilities and service providers across the disability, health and education sectors.

Stage 4: Ongoing support, sustainability and evaluation (Mar 07 + ongoing)

Key Milestone The long term ongoing support, sustainability and evaluation of the tool beyond February 2007 has been established.

1.5 TARGET GROUPS

Primary: Children and young people with disabilities (0 - 17) and families.

Secondary: Services providers supporting children and young people with disabilities.

Tertiary: Siblings and other family support networks (e.g. grandparents)

1.6 STAGE 1 STRATEGIES

Stage 1: Research and Concept Development Stage – June – Dec 05 (6 months)	Expected completion:
1. Identify key stakeholders to consult with, provide background information and formally seek their participation (Introduction letter)	Achieved
2. Review and document relevant person centred initiatives/ resources/ mandates/plans at State, National and International levels which focus on a whole of child view, disability and children's rights.	Achieved
3. Develop a promotion plan to promote the project to parents and other key stakeholders through various communication channels <ul style="list-style-type: none"> - to parents and children/young people with disabilities (e.g. via agency/association newsletters, website, local media) - Life's for Living AGM 	Achieved
4. Develop series of questions to guide consultations and for discussion at agency reference/consultative group meeting	Achieved
5. Establish multi-agency reference group & hold initial meeting	Achieved
6. Establish parent advisory group	Deferred-06
7. Identify possible funding sources and submit funding applications.	Ongoing
8. Conduct consultations to capture the views of families, children and young people with disabilities and service providers (Refer to Consultation Plan)	Achieved
9. Present project at the ASSID (Australasian Society for the Study of Intellectual Disability) Conference in New Zealand.	Achieved
10. Analyse and collate project findings from consultations	Achieved
11. Discuss findings with reference group in order to finalise recommendations	Achieved
12. Complete Final Report with recommendations for Stage 2	Achieved
Milestone: Confirmation of need and development of the concept for the resource kit. Inform direction and provide the foundation for subsequent stages of the project.	

SECTION 2. METHODOLOGY AND DATA COLLECTION

Stage 1 of the project primarily involved a planning phase followed by promotion and consultation with families and service providers in order to seek their views on the value, format and content of the proposed resource. It also involved reviewing and documenting existing similar initiatives at a local, national and international level to determine whether similar resources exist and to learn and build on the work of others. This information was used to confirm the need and develop the concept for the resource. This section describes the promotion, consultation and data collection methodology used during Stage 1.

2.1 PLANNING

Before promotion could begin, the Project Team spent 1 month brainstorming and planning Stages 1 to 4 of the entire project. A comprehensive project and consultation plan was developed to guide the direction of the project. This plan documented detail such as the rationale and background of the project and the strategic context and supporting policies and strategies that supported the project concept. It also defined the project scope including the aim, key focus areas and objectives, timelines/action plan, target groups and locations, resources, quality measures, budget, expected deliverables and benefits. The plan documented consultation methodology, a risk management plan, identification of key stakeholders, Project Team/resources and reporting structure as well as an evaluation plan.

The planning period involved the development of a range of documents to support the promotion and consultation processes. For example, a 4-page project overview for distribution to key service providers and parent/carer associations as part of the promotion process. It contained information on the project background and Life's for Living's Phase I project which focused on adults with disabilities. It also contained information on the purpose and scope of the current project (Phase II – children and young people with disabilities), summary of project timelines, key activities for Stage 1 and information relating to the strategic context, policies and procedures at local, national and international levels which support and have informed the project.

A separate 3-page project overview was also developed for distribution to families during promotion and consultation. It contained information about Life's for Living, the origin of the concept, ideas for the resource, the benefits of the proposed resource, the type of information needed from families, how this information will be treated, confidentiality/consent and methods of participation for families (questionnaires, group sessions or 1:1 interview).

The planning process also identified key stakeholders with whom to promote/consult with. This selection process occurred through existing Life's for Living networks and the South Australian EnableNet database developed by the Disability Information Resource Centre. Invitation was extended to some service providers to be a part of a multi-agency Project Reference Group. Criteria for selecting these key stakeholders included those which worked with and were commonly accessed by families of children and young people with disabilities under 18 years of age and representing metropolitan and country areas. This group was established to ensure a coordinated and collaborative approach across a range of sectors and settings. The group comprised 13 representatives from the disability, education and health sectors.

The role of the Project Reference Group was to provide; feedback on the project plan, general advice, knowledge and expertise with regards to service provision to children and young people with disabilities and provide the project team with linkages to families and key contact personnel within their respective agency/ sector.

2.2 PROMOTION

The most effective and efficient method of reaching families of children with disabilities under 18 years of age was through disability service providers working with this target group and parent/carer associations. The Project Team acknowledged that this project would not reach all families particularly those whose children do not have a diagnosis and therefore do not access these services.

Promotion occurred from August to mid-September 2005 across metropolitan and country disability, education and health service provider networks. It involved seeking participation from service providers to contribute to the consultation process and requesting that the project be promoted to families within their networks. Families (mostly parents/carers) who contacted Life's for Living were also asked if they could promote the project through their networks.

Methods of promotion to service providers included an introduction letter from Life's for Living's CEO addressed to senior personnel of selected service providers/Associations (CEO/program managers, co-ordinators). The letter provided a summary and purpose of the project, background information on Life's for Living and its products and initiatives, the benefits of the proposed resource and an invitation to provide input into the project and to promote to families and other service providers within their networks. The letter was accompanied by the project overview described in Section 2.1. This package was sent to 61 service providers predominantly by post and in some cases by email.

Promotion to families was achieved by distribution of a parent invitation flyer inviting families to share their ideas about the project. The flyer provided detail about the different ways they could be involved, that is, in a group session, by filling in a questionnaire or at home with family and friends. It also provided examples of what the resource may contain. The flyer informed families of a \$20 gift voucher offered to each individual who participated in a focus group. The flyer was distributed through agency newsletters as inserts or in a summarised format, emailed to key agencies and Associations, regional health forums, regular parent groups, Life's for Living's website and by direct mail to selected special schools. Some services also sent this flyer by direct mail to families who use their services.

A 3-page project overview was sent to families who made initial contact with the Project Team and expressed a need for further information prior to involvement in the project, this overview is described in Section 2.1. Life's for Living's CEO also promoted the project through regional radio in a talk back segment and invited listeners to attend upcoming focus groups in the local area.

The most effective methods of promotion among families, that is, how they found out about the project are summarised in Table 1.

Table 1. Effectiveness of promotion methods

Form of promotion	No. of parents/carers	%
Word of mouth from other parents	18	37%
Word of mouth from service providers/associations	15	31%
Invitation flyer	8	16%
Direct mail/ post – project information mailed by some services to families (clients)	7	14%
Internet (Life's for Living website)	1	2%
TOTAL:	49	100%

In promoting the project through service provider networks, the Project Team needed to be aware of external ethics and consent procedures. Therefore, families were invited to contact Life's for Living

directly if interested in participating rather than going through other service providers. This enabled Life's for Living to use its own consent processes and resulted in minimizing potential delays and constraints associated with specifically targeting and accessing families through some service providers.

2.3 CONSULTATION

Consultation occurred from end September to mid November 2005. In order to confirm the need and develop the concept for the proposed resource, feedback was required from families and service providers. This was achieved using a range of consultation methods and by developing a series of questions specifically tailored to each group. Target groups for consultation were segmented in the following groupings: families of children with disabilities (under 18 yrs), children and young people with disabilities (under 18 yrs), adults with a disability and families (retrospective view), and service providers.

Service providers included organisations from disability, health and education sectors as well as parent/carer associations in metropolitan Adelaide and country South Australia which have direct contact with families of children and young people with disabilities. Consultation occurred with individuals at various levels such as managers, therapists, education consultants, allied health professionals, nurses and support workers. Also, ongoing liaison and consultation throughout Stage 1 occurred between the Project Team and Project Reference Group members, further information about this group can be found in Section 2.1 – Planning.

Following initial contact with Life's for Living, families and service providers who requested further information about the project were posted or emailed a package of information. This consisted of a letter thanking them for their interest, a project overview for families and a questionnaire (if this was their preferred method of participation). Some families were booked into a focus group or an alternative time arranged for a 1:1 telephone or face-to-face interview.

Table 2 provides a summary of stakeholders who participated in the project. Participation is measured by the number of individuals who provided input into to project by attending a focus group, submitting a questionnaire or answering questions via telephone or face-to-face interview.

Table 2. Numbers of stakeholders that participated in the project

Stakeholders who participated in project	Total
Parents/carers <ul style="list-style-type: none"> • 44 - parents/carers of children/young people under 18 yrs • 5 - parents of adults over 18 yrs (retrospective view) 	49
Service providers	24
Children/young people (under 18 yrs)	3
Adults with disabilities (retrospective view)	1

2.3.1 Methods of consultation

A flexible consultation methodology was used to ensure an inclusive approach that met the varying needs of participants. This included a combination of methods such as focus groups, questionnaires and 1:1 telephone or face-to-face interviews for obtaining feedback from participants. A series of questions were developed to guide these consultations (refer to Appendix 6.3). These methods and questions are summarised and described below, additional details are provided in Section 2.4 - Data Collection Methods.

Table 3. Numbers of participants for each consultation method.

Method of consultation	Total	Location breakdown	No. of parents	No. of service providers	No of children/young people and adults with disabilities
Focus groups/ group interviews	6	2 metro 4 country	24		2
Questionnaires	24	6 country 17 metro 1 QLD	29*	20	2
Focus groups + questionnaires (both)	4		4		
1:1 face-to-face/ telephone interviews	12		8	4	

* 24 questionnaires submitted with 29 parents contributing (joint responses by some)

Focus groups/ group interviews

Focus groups were conducted for groups of parents/carers (predominantly attended by parents), these consisted of small group sessions of up to 6 members, with an approximate duration of 2 hours. Participant numbers were kept small to maximise participation by all present and to ensure that feedback on all questions was received in the limited 2-hour time-frame. Focus groups were facilitated by Lis Burtnik (CEO, Life's for Living) who has extensive experience in the disability field and in group facilitation processes. They were held in various locations across metropolitan and country South Australia (Lameroo, Murray Bridge and the Riverland). Given the limited time available and the target number for consultation of 50 families, focus groups were only scheduled in areas where there was most interest among families.

Participation in focus groups was predominantly due to word of mouth promotion among parents/carers and service providers. A \$20 gift/meal voucher was provided to each focus group participant in acknowledgment of their time and contribution. Venue selection occurred in a number of ways including through advice from families and through discussion with service providers as well as use of a private meeting room in regional hotels. Copies of the Life's for Living resource developed for adults with disabilities in Phase I was also shown to participants as a way of explaining the proposed resource's potential form and content.

The Project Team was also invited by a disability service provider to discuss the project with a group of teenage children with disabilities at their regular support group meeting. They were invited to participate by answering a series of questions developed for children. The support worker for this group worked with 2 interested teenagers and produced a short video about what they would others to know about them.

Questionnaires

Questionnaires specifically tailored to service providers, parents/carers, children, young people and adults with disabilities were developed and distributed on request by post, fax or email. Questionnaires for families and service providers were also available from Life's for Living's website. Questionnaires for children and young people were developed due to interest expressed by some families. Four were posted out but none were returned and copies of these are included in Appendix 6.3.

1:1 face-to-face/ telephone interviews

Face-to-face/ telephone interviews were available to all key stakeholders as an alternative option to other methods of consultation. This method worked particularly well with participants who did not want to complete a questionnaire and unable to attend a focus group. The same questions used in the questionnaires described above were used to obtain information from specific key stakeholders

during 1:1 interviews. After the interview, responses were typed up in the questionnaire format in order to collate them electronically.

2.3.2 Questions to guide consultations

A series of questions which were developed to guide consultations (refer to Appendix 6.3), a summary of each set of questions is outlined below.

Children, young people and adults with disabilities who participated were asked to tell their story by sharing their life experiences in various settings and to document positive information that they would like others to know about them. This process provided them with the opportunity to experience how the resource may be used. Feedback from children in their early years was primarily achieved through consultation with parents/carers via focus groups, questionnaire and 1:1 interviews. This is also likely to occur when using the resource, that is, parents/carers documenting information on behalf of children.

Family members were specifically asked to provide feedback on their past & current experiences with family, friends and services, this provided them with the opportunity to tell their story. The purpose of this questioning was twofold, firstly to honour and acknowledge their experiences so that they felt heard. Secondly, to assist the Project Team to identify situations/environments in which the proposed resource could have the most impact as well as the strategies required to address potential barriers to using the resource.

Family members were also asked to share the positives qualities that they value in their child, their ideas for the format and content of the proposed resource, whether it would be a valuable tool for families, its potential benefits, how/where they would use it as well as any factors that would prevent its use. Feedback was also sought from families of adults with disabilities to obtain a retrospective view. Refer to Appendix 6.3.2 and 6.3.6 for questions used with families.

Service providers were asked to comment on the information they need to ensure positive interactions with children and young people with disabilities. They were also asked to document existing resources/plans/processes used within their organisation(s) to capture positive information about children and/or young people with disabilities, whether these processes are sufficient, the key personnel involved with collecting this information, whether they see value in the proposed resource, how it would be used in their organisation and the factors that would prevent them from using it. The purpose of this questioning was to document similar resources/initiatives and good practice currently used to collect positive information about children and young people with disabilities in children's services in South Australia. The Project Team is committed to learning from and building on the work of others and prevent potential duplication of resources.

2.4 DATA COLLECTION METHODS

A range of methods were used for collecting data throughout this project and included ongoing documentation and analysis of information collected, interviews and questionnaires. The methods for obtaining data and feedback from key stakeholders were informed and based on advice provided by a range of agencies and projects such as the South Australian Community Health Research Unit (SACHRU), AICAFMHA (Australian, Infant, Child, Adolescent and Family Mental Health Association), The Family Links Project (Commonwealth Department of Family and Community Services), as well as advice provided by the Project Reference Group.

2.4.1 Documentation and analysis of records

The Project Team kept an ongoing record of activities which involved collecting quantitative and qualitative data throughout the project. Although it required a commitment to document regularly, the team ensured that relevant evaluation information was collected along the way and that vital information was not overlooked. Examples of the type of information collected and methods used are described below.

An enquiry form was developed to keep a record of the number and type of enquiries received including demographic details. Data collected included name, address and contact details, date and method of initial contact (e.g. by phone or email), email address, record of information sent, whether the enquirer was interested in participating by attending focus group, 1:1 interview or filling out a questionnaire, the age of their child(ren) with a disability, how they heard about the project and whether follow up with each enquirer was complete. This form was developed as a quality measure to ensure that each enquirer was tracked and followed up accordingly.

Also documented were the number of letters, flyers, questionnaires distributed and to who, the number of enquires, questionnaires received, 1:1 interviews and focus groups conducted. The number of participants involved in the project and networks developed were also recorded. Furthermore, the Project Team conducted a review of literature and similar initiatives and resources which were summarised and are included in Section 3 - Key Findings. Documentation also involved informal feedback from participants as well as reflections and observations of the Project Team.

Regular progress reports were provided to Life's for Living's board of management and minutes of meetings held with the Project Reference Group were also written and distributed. The Stage 1 final report will be sent to the key stakeholders, other service providers consulted throughout the project, the Minister for Disability, The Honourable Jay Weatherill and project funding bodies. The final report will be available to families on request and through Life's for Living's website.

2.4.2 Interviewing individuals and groups

Consultation via 1:1 face-to-face and telephone interviews involved use of the same questions as those provided in questionnaires. Although a separate series of questions was designed to guide focus group discussions, these were quite similar in format and content used in the questionnaires for parents/carers.

This methodology was developed because the Project Team recognised that some participants preferred 1:1 or group dialogue and interacting with others rather than writing their responses in a questionnaire. This enabled more complex issues to be explored, questions to be clarified, provided rich data such as non-verbal data obtained through observations and was suitable for participants with varying literacy abilities.

2.4.3 Questionnaires

Questionnaires were specifically designed for each target group. They were distributed on request by post, fax or email and also available through Life's for Living's website. They provided participants with the choice of completing them in their own time and in the privacy of their own home where they had time to think about their responses. Although they were asked, participants were not required to provide their contact details if they preferred to remain anonymous.

2.4.4 Confidentiality

The Project Team also asked each participant whether s/he consented to having information they provided through consultation published. Consent was given verbally at focus groups/ 1:1 interviews and in writing through questionnaires. Participants were assured that confidentiality would be respected at all times and that their name/name of their child or organisation would not be revealed. They were also informed about how the information would be used and/or made public. All participants (whether by questionnaire, 1:1 interviews or through focus groups) were asked to provide their consent to having their responses published.

2.5.5 Process of analysis

In summary, quantitative and qualitative data received from questionnaires, focus groups and 1:1 interviews were documented, collated and summarised in electronic format according to various categories and groupings such as by stakeholder consulted, question asked, most frequent responses and general themes that arose. Each participant was assigned an internal code to enable the Project Team to track responses and ensure that all responses were considered in the analysis.

Quantitative data was easier to obtain from questionnaire responses. For example, family's responses were tabulated according to question and frequency of response. Examples of data collected in this way include age of child, relationship to child, demographics, responses to questions Q1 and Q2 (experiences before diagnosis), Q3.1 to Q3.3 (experiences at point of diagnosis), Q4.1 to 4.6 (current experiences in various settings), Q8 (preferred format of resource), Q9 (assistance required to use the resource), Q11 (value of proposed resource).

Service provider questionnaire responses which were of most relevance and therefore documented included similar initiatives and processes for documenting positive information about clients, whether these were sufficient, their view on the value of the proposed resource.

A summary of the key themes emerging from the feedback provided through consultations are documented in Section 3 - Key Findings of this report. They are supported by quantitative and qualitative data obtained as well as quotes from families and service providers which confirm the need and provide suggestions for concept of the proposed resource.

SECTION 3. KEY FINDINGS

The primary focus for Stage 1 of the 'What I'd Like You To Know About Me!' Phase II project was to confirm the need for the proposed resource for children, young people with disabilities and their families. The objective for Stage 1 was: *By December 2005, the project will have confirmed the need and developed the concept for the tool to inform the direction and provide the foundation for subsequent stages of the project.*

The project strategies for assessing this need primarily involved consultations with key stakeholders, specifically families, people with disabilities and those who provide services to children and young people with disabilities. The examination of 'the need' conducted in Stage 1 of this project encompassed an exploration of (a) whether the proposed resource was seen as necessary by stakeholders and (b) whether there were issues in the way that children and young people were perceived in their interactions with others in the community.

This section of the report highlights the key findings of the consultation stage (Stage 1) it provides evidence of confirmation of the need, specifically through a summary and analysis of responses documented from consultations held with family members, carers, service providers, children and young people with disabilities. This section also describes the suggestions collected to date about the proposed resource, an outline of key literature, and an investigation of similar initiatives locally, nationally and internationally.

3.1 CONFIRMATION OF NEED

3.1.1 Evidence provided by families

A flexible and inclusive consultation strategy was used to enable the maximum number of families to be involved in the project and to ensure that the consultation was accessible to a variety of participants. For the purposes of this report, the term 'families' has been used to describe the collective group which includes parents, grandparents, other family members, carers (including foster families) and also includes children and young people with disabilities.

Three main methods were used to consult with families; questionnaires, focus groups and personal interviews (for more detail refer to Section 2- Methodology and Data Collection). Consultations occurred in both regional and metropolitan South Australia and in total 53 participants provided feedback to the Project Team through the methods described above. Families clearly supported the development of the proposed resource and were able to identify specific requirements for its use as documented below.

Value of the proposed resource

Families were asked to provide feedback about the proposed resource and were specifically asked: *Do you think this would be a valuable tool for families of children and young people with disabilities?* One hundred percent (100%) of respondents (surveyed via questionnaire) indicated that the resource would be valuable. The Project Team also observed general agreement at each focus group that this resource would make a difference to the families of children and young people with disabilities.

Suggestions for use of resource

Family members also expressed collective enthusiasm for the proposed resource despite expressing ongoing concerns of time, energy and motivation. Many parents cited examples of situations and environments in which such a resource would be useful. The most common responses were; at respite, within school/kindy/child care and in hospital. Some parents reported that they would use the resource in all environments in which their children participated.

Increasing self-esteem

Several family members identified a need to increase their children's self esteem, that negative attitudes (particularly in the community) affected their children's view of themselves. This resource will support the development of positive self-esteem through focussing on abilities, achievements and positive stories. Children and young people will be active participants in writing their stories and sharing them with others.

Broader applicability of the resource

Some family members expressed a wish to be able to use a resource like this with all their children, not just their child with a disability. They emphasised the importance of involving siblings in the process and celebrating their abilities and achievements. Family members reported that often times siblings without disabilities felt they missed out on attention, the proposed resource would assist in highlighting the strengths and will celebrate each child in the family.

The need for a positive perspective

In addition, family members acknowledged a real need to re-direct the focus of professionals towards a positive perspective. They expressed wanting an emphasis on what their child is able to do (as opposed to their deficits/disabilities) and several parents indicated that they wanted their children to be seen as "children first".

"My daughter is made up of so much more than just her medical issues and behaviour problems. She is much more than her disability."

Family members who participated in focus groups were provided with sample profiles from 'What I'd Like You To Know About Me!' Phase I resource for adults with disabilities. This helped the participants to visualise the proposed resource including potential layouts and content. Family members got a flavour of how to use the resource by commenting on the positive qualities that they would like to communicate to others about their child.

"My child was originally expected to be unable to do much of anything. She was forecast to be unable to function much in any way, largely exist as a non-responsive non-capable person completely dependent on 100% support. She is now walking and running unaided (even if slowly), can jump unassisted (even if only to a low height), attends regular school, has a mischievous sense of humour, a fierce determination and will, and an ability to draw others into her world."

"She's gaining more confidence as people are more accepting – it's like watching a flower blossom."

"I'm sure one day he will use his drawing skills to impress the world."

"Wouldn't swap her for the world"

3.1.2 Evidence provided by Service Providers

In addition to families, service providers were the next critical group with whom to consult regarding the confirmation of need for the proposed resource. Twenty-four individual service providers representing a range of South Australian disability, education and health organisations participated in the project either by submitting a questionnaire or by personal interview. Fourteen service providers also committed to representation on the Project Reference Group and they were consulted through the communication mechanisms associated with this group such as stakeholder meetings and email correspondence.

The essential point to highlight from the service provider consultations is that the majority of service providers (88%) agreed that there is a need for the proposed resource. The remaining 12% provided no answer, were unsure or indicated that it would depend on families' view of the resource. This is an overwhelmingly positive result despite all service providers having some processes in place to capture

positive information about the children and young people they support (refer to Appendix 6.2). This outcome indicates the need for a resource that not only focuses on the positive but can also assist service providers in their work with clients.

Service providers were also asked to document the processes, plans, resources their organisation uses to collect positive information and report whether these are sufficient. Sixty-six percent reported that these were not sufficient, while 21% indicated either they were not sure or did not answer and 13% responded that processes within their organisations were sufficient but that the proposed resource was still valuable.

Those service providers that reported that their existing processes were sufficient also indicated value in the proposed resource. Overall, service providers indicated that the proposed resource would be valuable to them, could impact on their service delivery specifically in adding to existing planning processes used within their organisation(s). Some service providers also proposed ways in which they could incorporate the use of this resource into their organisations. One service provider indicated:

“There is a tendency when working with individuals with disabilities to gather copious information about their support needs/what they can’t do. This proposed resource would strengthen the ability of the people with whom the learner interacts in a variety of settings, to view the learner from a positive perspective. It would personalise much of the information gathered and truly support the principle that they are a person/individual first – who has a disability.”

It is a positive outcome that several service providers commented on the need to acknowledge families as experts:

“Families know their child better than anybody else. The family is a wealth of information that needs to be accessed.”

“I am sure families would welcome an informative document for their child which talks in the first person about their needs, hopes, dreams which can be carried with them to ensure everyone who is providing support knows what this child wants/needs.”

3.1.3 Similar Initiatives

As part of the confirmation of need for this resource, the Project Team investigated and critiqued other similar initiatives at local, national and international levels, which may duplicate and/or partially function in a similar way to the proposed resource. The summarised results of this investigation are presented in Table 4. This research highlights that a similar resource controlled by families for use across a range of settings does not exist. This also suggests, therefore, that it is not possible to adapt a resource that currently exists to suit the needs of the target group (with the exception of Phase I ‘What I’d Like You To Know About Me!’) and that the project is validated to continue in the development of the proposed resource. The need to document and share positive information about children and young people with disabilities is evidenced by the initiatives and resources documented below.

Other examples of existing processes, plans and resources developed and used by South Australian disability, education and health service providers to obtain positive information about children and young people with disabilities have also been examined and are summarised in Appendix 6.2.

Table 4: Summary of similar initiatives: national and international, highlighting the similarities and differences to the proposed resource.

Name of resource /initiative	Description	Developed by/ source	Information collected	
			Similarities	Differences
1. Welcome to the World Letter	As part of “Celebrations Project” being trialled in 2 London hospitals in Neonatal Units	Parents for Inclusion (UK) www.parentsforinclusion.org	Celebratory Hard copy Acknowledges child for their right to be part of the community	Letter format Refers only to the time of birth, does not go across ages Does not capture information about key life areas, abilities and achievements
2. All About Me Booklet	Booklet developed by a parent about her son. Published on the Inclusive Solutions website.	Individual parent in Scotland inspired by the Essential Lifestyles Planning Tool www.inclusive-solutions.com/stephensbook.asp	Family-centred-driven Celebratory Written in first person - from the perspective of the child. Collects positive information e.g. Introductory story about me, Glossary of terms, things I’m good at, photos Hard copy Other people can add to it.	11 pages long Not available for other parents to use the same format.
3. Gift Box concept	A box of cards for collecting information on strengths, abilities, interests and dreams of the person.	Disability is Natural Group (US) www.disabilityisnatural.com/store/index.html	Celebratory Positive information about child Hard copy Used to share gifts of child at planning meetings Can be used in the community	Information collected on cards
4. Parent Stories /Noticeboard magazine	Collection of stories from parents and other family members of children with a disability.	Assoc. for Children with a Disability (Victoria) www.acd.org.au	Sharing one’s story web-based and hard copy Providing encouragement and support to families	Does not provide opportunity to document and celebrate the child’s achievements, or information about the child. Mainly a support tool for parents. Educational
5. Online Diary and other life diary concepts	Various sources- online diary for recording feelings and experiences. A means for recording family history/other information about a person’s life	For example; My-Life.cc www.my-life.cc	Captures feelings, experiences, and impressions of the person’s life.	For everybody - not necessarily for people with disabilities Not aimed specifically at children

6. The Personal History Book	For documenting personal history in easy format using templates documents information about life stages from birth to retirement.	Treasure Chest Products www.treasurechestproducts.com	Sharing one's story Hard copy Covers life stages	Binder format Not aimed specifically at children No web based version
7. iParenting stories	Parents can read and submit their own stories to share with other parents	iParenting.com (US) www.iparentingstories.com	Positive Web – based Sharing stories	All parents, not just parents of children with disabilities Not in printable form for use in situations with the child or in the community.
8. Special Kids Diaries and parent stories	Families sharing their stories, and a child's diary that includes other's perspectives	iParenting.com (US) www.specialkidstoday.com	Focus on story of the child Colourful Web-based Aimed at families/children with disabilities	Links parents with each other Discussion forum Info. available in Spanish Diary format
9. Person-Centred Planning principles & tools (MAPS & PATH)	Used as planning tools with trained facilitators with the focus on "What kind of life do I want to live and what would it take to get it?"	Founding Publishers: Jack Pearpoint & Marsha Forest www.inclusion.com	Focus is on the individual Firmly rooted in the Values of Inclusion Includes person's dreams, gifts/abilities, needs, their story Questions asked include; Who is the person as an individual, dreams, stories, gifts, what does s/he need now?, who will help her/him?	Used as a planning tool with trained facilitator A public process with key people in person's life contributing to the plan
10. My Orange Book - Personal handheld health record for disabled children	Personal Health Handheld record to inform teachers and health professionals about the child's health needs.	Cornwall Partnership National Health Service (NHS) Trust – Wales www.wales.nhs.uk (Search for 'Orange')	Written from perspective of child - meant to be the child's voice on how best to care for them. Handheld record Staff read the book so that they better understand the child. Family controlled /minimises repetition of information.	Available in Welsh language Medical focus only
12. Health Support Plan	A plan designed to be used by families to record the health support needs of their child	Department of Education, Training and Employment SA	Provides information about the support needs of the child Family controlled	Health -centred Education sector focussed

3.1.4 Supporting Documentation and Principles

Establishing the need for the proposed resource has involved a close examination of the literature including similar studies which have documented the experiences of families and that have captured some of the struggles and joys of their journey(s). Several core themes emerge from the literature that directly relate to the project and includes; family quality of life, attitudes and perceptions in the community, parental and sibling experiences (in particular with professional services) and the impacts of disability on the family. The literature that has the most resonance with this project is the stories from children with disabilities and their parents. These articles support the need for the project and bring additional weight to the data collected in the focus groups and consultations.

Theme 1: Family Quality of Life

According to Smith-Bird and Turnbull (2005) family quality of life is described as that which addresses the needs of all family members rather than just the child (with a disability). This theory also places emphasis on highlighting the strengths of families and the need to work in partnership with professionals. Family strength is a concept that has also been examined by Darley et al; (2002). Their study documents the responses of families with regards to their strengths and the changes in their family after having a child with a disability. Out of the study, six core strength areas emerged including; teamwork, family support, patience, hard work, adaptability and spiritual strength. The core theme of this article supports the concept of the proposed resource specifically in relation to proving a resource that can be used by the whole family. It also provides further evidence of the need for families to control and generate the information that will be captured by the resource. The authors indicate the importance of focussing on strengths and of acknowledging the contributions of families:

“Clearly, they are a powerful resource, one that should be acknowledged, nurtured, called upon and celebrated.”

Family quality of life is also affected by the way that society responds to disability. As reported during the project consultations, and as referenced by Dowling and Dolan (2001) families can often be exposed to a myriad of negative experiences. In particular, the constant battle for funding and services leads to families feeling frustration, exhaustion and anxiety (Dowling and Dolan, 2001). Other findings of the study indicated that families also experienced the following; increased mental health issues for primary carers, increased isolation, public intolerance and an increased financial burden. These types of studies also reinforce a need to provide families with a means to focus on the positive aspects of their lives and to present their child in the best possible way.

Theme 2: Positive Impacts of Disability

It should also be mentioned that in contrast to the aforementioned commonly reported negative experience(s), Stainton and Besser (1998) report on the positive impact of children with a disability on families. Their study found 9 main themes of positive contribution including; source of joy and happiness, increased sense of purpose and priorities, expanded networks and community involvement, increased spirituality, source of family unity and closeness, increased tolerance and understanding, personal growth and strength, positive impacts on others, and interactions with professionals and the service system. These impacts appear to be rarely reported in the literature, however, project consultation yielded many responses on the positive impacts that children with disabilities have had on their family (refer to Section 3.4 - Unexpected Findings).

Theme 3: Sibling Experiences

The documentation of sibling experience(s) also emphasises both the negative and positive aspects of having a brother/sister with a disability. In a review of the literature Keefe and Del Rosario (2003) indicate that sibling relationships and reactions to disability are complex and cannot be attributed to just a few factors. However, some of the benefits or positive effects of having a sibling with a disability were reported by various studies as; having increased empathy, compassion and understanding and increased psychological well-being (stability, self-concept). Positive impacts were also reported on by Banks et al; (2001) who indicated that; increased understanding of disability, closer family relationships, enhanced practical skills and increased maturity were all considered to be positive impacts. Conversely, the negative impacts included; lack of sleep, less attention, increased

stress, problems with friends and being teased. It is this situation which leads the Project Team to conclude that creating a resource that also caters for siblings would be exceptionally valuable and have a lasting impact.

Theme 4: Focus on the Positive

The numerous initiatives and resources documented in Table 4 and Appendix 6.2 provide evidence for the concept of using a positive focus and strengths based approach for families with children with disabilities. Service providers consulted during Stage 1 of the project also confirmed this through documenting the strengths based initiatives used within their organisations. Evidence also exists in the literature, of particular interest is the work of the Beech Centre on Disability (Kansas, USA) which provides a wealth of information about the way that disability is viewed by parents and the community. This information is also educative, providing parents with ways to focus on the strengths of their child.

3.2 THE RESOURCE

3.2.1 Benefits of the resource- families

The consultation process involved asking family members, carers and service providers about their ideas regarding the form and content of the proposed resource. The Project Team also collected data about the difference that the resource would make to family members and their child with a disability. Participants were asked the question: *can you describe the positive difference this resource will make for you and your child?* Some of the responses and proposed benefits are documented below:

“Help people to see my child in a more positive light. Help reduce the number of times I have to repeat his story.”

“This will provide information and acknowledge our child’s existence in the community. People will be able to read this to understand more about disability.”
“Save time having to explain it to every person that we deal with. This is the most time consuming part of having a child with a profound disability because there is so much information that needs to be relayed and without the information things generally go pear shaped very quickly.”

“It can be used with NEP (negotiated education plan). Then they have no excuse for not reading it. It serves as a way of re-educating professionals.”

“I know stuff but it’s in my head. If it’s down then I won’t forget things – I can use it with the respite worker who comes to my house.”

“You get really tired of telling the story. Not to mention the fact that if you’re relying on your memory for the history of your child’s development, particularly for specialists appointments where small things can be really significant, you’re liable to get into trouble.....something that records all the positive, happy stuff would be great.”

3.2.2 Format and Layout

Families were asked to provide feedback about the format of the resource and were given a series of potential formats from which to choose, these options were: web-based (internet), hard copy, CDROM or other. Respondents were able to tick any answer(s) that applied, the results are as follows: web-based: 13, hardcopy: 18, CDROM: 12, other: DVD, note book sized. This supports the Project Team’s original theory of creating a dual format resource. Due to technological considerations, it is most likely that the resource will be produced as both a web-based (internet) resource and a hard copy with possible adaptation to a CDROM dependent on funding and time considerations.

3.2.3 Assistance to use the resource

In order to ascertain if there were barriers that would prevent families using the resource, they were asked to respond to the following question: *What assistance do you think you would need to use a resource like this?* The results are indicated in the table below in order from the most common response to the least common response. As is evident by this data, many families selected 'time to use the resource' as the most common form of assistance, with 'help completing the profile' and training to use the resource as the second and third most common responses. The information provided by this question has informed recommendations about the development of the resource (refer to Section 5 - Recommendations) in particular that the resource is designed to be a user-friendly format that is easy to navigate and fill in. Further, the Project Team will engage in planning long-term strategies for the sustainability of the project including training resources and having dedicated personnel to provide support and guidance to families (refer to Section 5- Recommendations).

Table 5: Assistance required to use the resource as reported by families.

Form of assistance	No. of responses
Time to use resource	16
Help with completing the profile	14
Training to use resource	7
Access to computer	5
Access to printer/photocopier	5
Access to the internet	3
Training/help to use the computer	3
Did not respond	3
Any other (please describe)	0

Note: Respondents were able to choose more than one answer

Families were also specifically asked if there were any potential barriers to their use of the proposed resource, the responses were varied and are summarised below;

- Time to use resource
- Enough copies available for family/friends to use
- Confidentiality and distribution of information
- Size (preferring a compact version)
- Easy to fill in/carry around
- Needing someone to look after the children while it is completed
- Internet access
- Five participants responded that there would be no factors would prevent them using the resource.

3.2.4 Content

One of the most critical parts of the consultation process was to ask families for feedback about the information that the proposed resource should capture. Participants were given examples of the types of information that they resource may collect and were asked specifically about the things that would be relevant for their child. This feedback has provided the Project Team with a starting point for designing the resource, however further consultation regarding content will occur with the Parent Advisory Committee (to be established for Stage 2). Of the suggestion made, the following is a summarised list (these suggestions have been categorised for the purposes of this report);

Table 6: Summarised suggestions for resource content- families

Category	Suggestions
General	The child's history in summarised form including what s/he can do, what s/he can't and what support has been provided.
	This is what you need to know about my disability
	How I see my world
	Family history (important information about my family)
Positive	Achievements and goals
	Likes and dislikes
	Important people in my life/ my family
	What's special to me/ favourite things
	Joys and fears
	My emotions/ my feelings
	What I can do right now
	Things that make me laugh
	Soothing tips
	What I'm proud of
	Relaxation time
Support needs	Toileting/sleeping (including posture)/feeding routines
	What things make me really happy when I'm sad – here parents can list things they have found helpful in calming / reassuring their child eg, swings, certain songs, particular toys.
	Dietary needs and methods of eating meals
	Information about my mobility and equipment
	My communication and how to communicate with me
	Developmental stage
	Behaviours
	Medications and how to support me with my medication
	Things that are hard for me
	Things to know when I am in hospital (separate section)
	Seizure records
	How to know if I need a break
	Skills
How I like to learn eg by listening, doing, singing, making etc	
Things to watch out for	Danger areas and alerts
	What to do if I'm upset
	Things that worry me/ how I show you I'm worried
	Things I should avoid
	Situations/ things that cause anxiety and how to manage it
	Situations in which I need to be protected
Other suggestions about the resource	Photo on front cover
	Changeable size for printing
	Easy to fill in and update
	Parent tips and stories
	Quick find index (possibly on front cover) – which shows where the critical information is located e.g. epilepsy management

Table 7: Summarised suggestions for resource content- service providers

Category	Suggestions
General	How child / family like to work with the service provider what works / what doesn't.
	Information about the disability including any additional impairments such as sensory impairments
	Any family issues
	Information about the child's school
	Developmental assessments, adaptive skills
Positive	Likes and dislikes e.g. food, places, activities, music etc
	Play and leisure
	Ways to encourage positive behaviour
	Family, extended family, friends and support
	Things that make the child laugh/smile
	The positive things the parents say about their child
	Hobbies/pastimes/pets
	Future aspirations and dreams
	Strengths
	Favourite stories
	Social skills
	Ways to relax
Support needs	Communication style
	Physical support needs
	Ways to cope with pain or discomfort
	Daily routines
	Daily living skills/ level of independence – how much the child can do for him/herself
	Health needs
	Developmental stage
	Behaviour needs
	Coping with change
	Mobility

3.2.5 Feedback from Service providers

Service providers were asked: *what sort of things do you like to know about a child or young person with a disability to assist you in interacting positively with him/her?* The information collected provides the project with key subject areas to be considered as content for the resource. Even though the resource content will be mainly directed and controlled by the family, the stories will be used with service providers and it is therefore very important that their input is considered. A comparison of the responses from family members and service providers reveals many commonalities in the types of information that should be captured by the resource.

3.3 KEY ISSUES IDENTIFIED DURING CONSULTATION

As part of the consultation process, families were asked to share their experiences about their interactions with various service providers, friends and family. The purpose of this questioning was twofold, firstly to acknowledge the experiences of parents and provide a way in which they could share some of the difficulties they have faced as family members and carers of children with disabilities. Secondly, to be able to document the current experiences of families when using services and when interacting with others in their community. Information such as this provides useful clues as to the situations in which the proposed resource could have the most impact. It also provides information on the types of strategies required to address potential barriers for use. This section of the report focuses on the key issues that were identified by family members and carers during consultations (they are listed in no-particular order).

Lack of information

Many parents reported a lack of access to information and resources, particularly at the time of diagnosis and beyond. They also reported frustration at not knowing how “the system” works and how to access services or find funding. There was a general lack of awareness of what services were available to them and their child.

“I think they assume you know what is available and where to find it”

“...it is strongly apparent that even the agencies, service providers, and government do not seem to have a good understanding of what is available to carers or persons with disability. I seem to have to go “agency shopping” to find out what I can access for me and my child. This extends to disability service providers, government agencies, education system, Centrelink, no-one has a full picture of what can be provided.”

“What we tended to hear a lot, from most organisations is what they couldn’t do”

Focus on negativity

Families expressed that there was a tendency to be required to focus on issues, negative behaviours and support deficits in order to attract funding or gain the necessary support(s) for their child. This suggests that the service delivery system reinforces a negative perspective and rewards deficits in exchange for access to services and funding for various support(s).

“Only way to get funding is to document all the bad things”

“Through lots of hard work on my and my child’s part, she is “highly functional” which means she attracts much less support. This is poor reward for effort on our part..”

Changes to friendships

Commonly reported was a loss of, or change in close friends when the child was born/diagnosed. Families reported both positive and negative responses from family members at the time of diagnosis, sometimes the negativity continued on an ongoing basis.

“I lost a lot of friends and they stay away because they don’t understand and I still don’t know exactly what to tell them.”

“I do remember one ex – friend saying that when (our daughter) was diagnosed with Ataxic Cerebral Palsy, “she’ll never have any friends”. That was a really awful thing for someone to say to me. And not true. What that showed me was her complete ignorance”

“Again we have had the whole spectrum of experiences. Some “friends” we don’t see any more because they were not able to cope with our son’s behaviour. Some of our family have been so wonderful we would not have survived without them.”

Time of diagnosis

There was a varied response when family members and carers were asked about their experiences at the time of diagnosis, ranging from shock, relief, to despair. Some family members reported that their experiences were very negative, this was particularly attributed to the way in which they were told about their child's disability and the support (or lack thereof) that they had after this.

"We were told over the phone..... My husband was away and I was on my own. It was terrible."

"I was told at 1 am in the morning half asleep that she had some sort of syndrome but they didn't know what but it was going to affect her life and they didn't know how long she would live."

"I was disappointed with the way I was told he just said -He would have lots of problems right throughout life"

"I was told, go away and read about it"

"If you are told the diagnosis in a good way it helps you. It was dumped on me. When they throw the terminology around it could be Chinese it means nothing to me."

The experiences that were negative were quite traumatic for families especially, in one case, where a doctor strongly suggested termination of the pregnancy or in other cases where the diagnosis was not communicated sensitively. However, some families reported that the medical practitioner was positive and supportive, providing them with support, reassurance, contacts and information about their child's disability.

Scrutiny in the community

A commonly expressed concern was that of being scrutinised when families went out into the community and many feared negative reactions from others. Some families felt that individuals in the wider community viewed their child's behaviour as the result of bad parenting.

"Partly I feel as if everyone is looking at us, judging us"

"There is not enough awareness in our community about disability. More education needs to happen. At child care, hospitals, kindy, schools etc. Info desks at shopping malls etc."

Lack of time, energy and resources

One of the most commonly reported impacts was a lack of time and energy. Families indicated that looking after their child(ren) could be an exhausting process, particularly for those families with children with more complex needs.

"...we have up to 22 different specialists, dept, GP, services involved in our daughter's care – hearing, ent, eyes, gastro, dieticians, paediatricians, physio, O/T, speech pathologist etc."

Financial strain was also an issue reported by several families, with some needing to give up work to care for their child(ren) and compounding this is the cost of private care (child care, carer's, medical specialists).

"We cannot have a holiday because we cannot find care for our little girl or a carer to come. It is extremely expensive.."

"Obviously more time allows lots more to be done. I need to work to survive financially, but I need to devote time to my child's development. Without money I

can not provide the basics to live, but without time I can not develop the skills of my child.”

Repetition of stories

Families reported ‘information fatigue’ from having to repeat their child’s stories over and over in all aspects of their child’s care. In addition, the amount of paperwork involved in service provision was viewed negatively by families.

“The constant need to restate information already presented to one service provider to each and every other one that I also need to access. This is a common and recurring comment I hear, especially with in the one hospital system. Each and every section of a hospital seems to want to hear the same information restated rather than have a centralised record.”

Other issues raised by families

Several other issues were raised during the consultation process and these include; lack of respite services, feelings of depression and anxiety in both parents/carers and children particularly where the child(ren) had experienced trauma. Some families discussed their fears about what will happen to their children when they are no longer around to protect and look after them. Another concern was sickness or poor health of the carer, leading to anxiety about who will look after their child. During rural consultations many family members expressed that there was a lack of understanding from some service providers about rural issues, that there were barriers to service access due to a rural location.

3.3.1 Family Perspective- what would have made a positive difference?

Family members were also asked to provide feedback to the Project Team about what, in their opinion, would have made a positive difference to their experiences, particularly in their early dealings with professionals. Not surprisingly, the key things that would have made a critical difference to families were very straightforward, with access to information being one of the most common responses. From other data acquired, it is apparent that communication of diagnosis in an appropriate time and place and in a sensitive, respectful and supportive manner would have made a significant difference to families. The responses are summarised as follows;

- An opportunity to connect with other families in a similar situation
- Access to information, resources and explanation of their options
- Having a diagnosis
- Having psychological help (i.e. counselling, therapy)
- Increased knowledge and awareness about disability amongst service providers

Family members and carers also provided information about what would make a difference for their child beyond diagnosis and in their current situation. Again, these factors are not extraordinary, families simply want access to services, for them and their child to be treated respectfully and to obtain the support that they require. A summary of these responses is presented below.

- More respite
- Having a support network that provides love, encouragement and is positive and sensitive to their child’s needs.
- Having a supportive and caring peer networks for kids within the school system and for the class environment to be supportive.
- For their child to be treated with respect
- For their child to have opportunities to reach their potential
- For their child to use their strengths and have their achievements celebrated by others
- For their child to have a positive self-esteem
- For others to look beyond their child’s disability
- For service providers to recognise the family member(s) as the expert on their child

Clearly, having a means to focus on the positive aspects of their child's life and development and celebrating their achievements goes some way towards laying the foundation for addressing some of the points outlined above. Specifically, the use of the proposed resource will provide a way to show others a child's potential and view the child beyond their disability.

3.4 UNEXPECTED FINDINGS

3.4.1 Difficulties in focussing on positives

Despite the wishes of family members to shift the focus of others toward positive perceptions of their children, the Project Team observed that during focus groups most participants struggled when asked to identify the positive qualities that they see in their child (in response to the question "how do you see your child?"). The Project Team consistently needed to re-phrase the question and provide several examples in order for participants to be able to answer the question. When family members began focusing on the positive, they soon went back to the negative experiences which have tended to dominate their life. They commented:

"It's hard to find the positives."

"We don't hear many positives about him because usually people focus on what he's done wrong."

These observations could potentially be attributed to participants experiencing difficulty in shifting focus from discussing their experiences (mostly negative) to looking at the positive aspects of their experience. Family members may be so entrenched in looking at issues as they advocate for support that it is very difficult to change their thinking. This unexpected outcome reinforced the need to use an experienced and skilled facilitator, who was able to re-direct the group. Another important observation is that the concept of achievement and ability appeared to vary amongst family members and carers. While some expressed that every little achievement was cause for celebration, one parent related:

"My child hasn't achieved anything, he hasn't gone to university".

3.4.2 Strengths of families

Children with disabilities oftentimes are born into families where there has been no previous history of disability. Therefore families, not surprisingly, have to cope with a myriad of feelings and emotions during their children's developmental years and beyond. If a diagnosis was not made at birth, such as in the instance of Down Syndrome, many families reported that they knew intuitively something was wrong well before an official diagnosis was made. Some families whose child is so unique that a diagnosis is yet to be made reported that, coupled with the frustration and uncertainty of not knowing what their child's future held due to lack of a diagnosis, have a further struggle to access services and support.

What became apparent during the consultation process as the Project Team met and talked with families was their amazing resilience. Against sometimes overwhelming odds, families have learnt ingenuity, become super sleuths in finding out all they can about their children's conditions, developed advocacy skills well beyond the scope of most professionals and have taken the art of networking to another level. These talents are rarely acknowledged, not only by the human service industry as a whole, but also by the families themselves. What an untapped resource they are.

SECTION 4. EVALUATION

Evaluation of Stage 1 focused primarily on impact and process evaluation including identification of factors that strengthened and limited the project, these are discussed in detail in this section. An outcome evaluation, which measures whether the overall aim was achieved, was not conducted as it can only be measured at the end of the entire project once the resource has been developed.

Appendix 6.4 includes details of the Stage 1 Process Evaluation Plan which summarises process indicators used to measure the success of the project objective and strategies, data collection methods and the results.

4.1 IMPACT EVALUATION

The Stage 1 project objective states: *By December 2005 the project will have confirmed the need and developed the concept for the tool to inform direction and provide the foundation for subsequent stages of the project.* The following indicators were used to assess the extent to which this objective for was achieved.

Impact indicator 1: Participants in Stage 1 will report a need for the resource.

Participants who reported that the proposed resource would be valuable for families of children with disabilities included 100% of families (including children) surveyed via questionnaire followed by general consensus among parents/carers at focus groups. Furthermore, 88% of all service providers surveyed via questionnaire and personal interview also reported value in the proposed resource (for further information refer to Section 3 – Key Findings).

Impact indicator 2: Recommendations for the content, format and general concept of the proposed resource based on consultation findings are summarised.

Recommendations which inform the direction for subsequent stages of the project are outlined in Section 5. Recommendations regarding the development of the resource resulted from consultations held with parents/carers, children and young people with disabilities and key disability, education and health services.

Families were specifically asked to comment on the preferred format of the resource, their ideas on the content, suggestions of where/how they would use the resource and the factors that would prevent its use. Suggested and preferred formats recommended by participants include electronic and hard copy. They also reported that the format and content needs to be simple, easy to use and accessible for families. Further consultation with parents will be required in Stage 2 where a Parent Advisory Group will be established using parent contacts from Stage 1. This group will guide the development of the resource and ensure that the process remains family-centred.

Impact indicator 3: Funding secured for continuation of the project.

Funding for continuation of project has been secured for an additional 3 months until March 2006 through the Adelaide Bank Charitable Foundation. Life's for Living has submitted applications to various funding bodies whose grant specifications match the needs of the project.

4.2 PROCESS EVALUATION

4.2.1 Evaluation Strategies

The strategies which supported the project objective and the process indicators used to assess and measure the success of these strategies are outlined below. The process evaluation also identified factors that strengthened and those that limited the project activities. These are also outlined in Section 4.2.2 and 4.2.3.

Strategy 1: Identify, review and document similar initiatives which focus on a whole-of-child view, disability and children's rights

Process indicator: Analysis and summary of findings

Similar initiatives and resources at local, national and international levels were identified, analysed and documented. Also documented were processes and plans currently used by various South Australian disability, education and health service providers to record positive information about children and young people with disabilities. A summary of similar initiatives (national and international) highlighting the similarities and differences to the proposed resource are provided in Section 3.1.3. Existing initiatives/ process used by South Australian services to record positive information about children and young people with disabilities are outlined in Appendix 6.2.

Strategy 2: Build capacity through collaborative partnerships

Process indicators: Networks developed, number of letters sent, multi-agency and parent advisory groups established

Cooperative and collaborative partnerships were formed with key service providers representing the disability, education and health service sectors commonly utilised by families of children and young people with disabilities. Introduction letters and a project overview were mailed to 61 organisations seeking their involvement and partnership in this project. From this, a multi-agency Project Reference Group with representatives from 13 organisations was established. A Parent Advisory Group was not established as originally planned because the Project Team decided that it was important to develop a relationship with families through consultations first and that such a group would be more useful when developing the resource in Stage 2. However, when asked, some parents indicated that they would be interested in being a part of this group and become involved in further consultations. These family members will be approached at the beginning of Stage 2.

Strategy 3: Promote the project to parents, service providers and other key stakeholders

Process indicators: Number of promotion flyers distributed and where to; number of responses from parents, children and service providers

There were a total of 49 parents/carers, 24 individual service providers, 3 young people and one adult with disability who participated in this project.

An invitation flyer in hard copy and electronic format was distributed to 61 organisations for promotion to families and other key staff/ personnel through various mediums such as agency newsletters, email distribution via specific agency networks, existing forums/committees (e.g. Riverland Health Forum) and disability resource centres. Promotion to parents occurred primarily through these organisational networks. It was difficult to measure exactly how many flyers were distributed because many service providers and family members forwarded project information through their own networks.

The Project Team did not promote the project through the print media as originally planned. The team did approach a regional print media agency however, there was no reply. However, Life's for Living's Chief Executive Officer promoted the project through regional radio and invited listeners to attend regional focus groups.

Life's for Living was also successful in its application to present the project at the Australasian Society for the Study of Intellectual Disability (ASSID) Conference in New Zealand, October 2005. The audience was very responsive and enthusiastic about the project with some members indicating a need for such a resource in New Zealand and also requested future project updates.

Other international interest in the project has also been expressed from disability organisations and parent associations from the UK and the US. These have also requested to be kept informed about project progress as well as being informed of the availability of the resource on completion. Meetings

with some of these organisations have been scheduled by Lis Burtnik, Life's for Living's CEO who will be travelling to the US in March 2006.

Strategy 4: Identifying possible funding sources

Process indicator: Funding submissions meet all criteria

Funding bodies whose grant specifications match the needs of the project were identified and applications have been submitted. This is an ongoing strategy with additional funding secured until March 2006 (refer to impact indicator 3 in Section 4.1).

Strategy 5: Conduct consultations and identify issues that support/prevent the promotion of positive perceptions and interactions with children and young people with disabilities

Process indicators: Consultation plan developed, number of interviews and focus groups, number of participants and their feedback

A consultation plan was developed and incorporated into the Project and Consultation Plan. In order to maximise the level of participation by target groups, the project used a flexible consultation approach consisting of focus group discussion, questionnaires and 1:1 face-to-face or telephone interviews.

A series of questions related to key topics identified by the Project Team as relevant for determining the need and developing the concept for the proposed resource. Details on key topics target groups were asked to comment on are outlined in Section 2 – Methodology.

All target groups were consulted with the exception of siblings who will be consulted in Stage 2. There were a total of 49 parents/carers, 24 service providers, 3 young people and 1 adult with disability who participated in this project. Twenty four family members were involved in focus groups, 29 submitted a questionnaire with 4 using both methods. There were 2 focus groups held in metropolitan Adelaide and 4 in country South Australia (Lameroo, Murray Bridge and the Riverland).

Three young people aged 13-17 years provided feedback by submitting a questionnaire or by producing a short video of their responses to the questions. This video was shown during the presentation at the ASSID Conference in New Zealand.

The Project Reference Group advised that a retrospective view would also add value to the project. Therefore, feedback was sought and received from 5 parents/carers with adult children with disabilities and one adult with a disability.

Parents/carers reported satisfaction with the project by expressing their enthusiasm for the proposed resource despite lack of time, energy and motivation experienced by most families. They also thanked the Project Team for providing them with the opportunity to share their story, particularly with other parents. Some parents reported that they found the experience to be cathartic and looked forward to the final outcome.

Strategy 6: Analyse, collate and distribute project findings

Process indicator: Summary of key findings from consultations

All the data received from participants via questionnaires, focus groups and 1:1 interviews were collated and categorised by stakeholder groupings, questions asked, frequency of responses and points/topics emphasised the most. Each participant was designated a code to assist the Project Team in tracking all data responses. Documentation of key themes emerging from consultations documented in Section 3 - Key Findings. Further detail on methodology used to collect data from consultations can be found in Section 2.4 – Data Collection Methods.

The final report for Stage 1 will be distributed to the Minister for Disability, The Honourable Jay Weatherill MP, the Project Reference Group, Life's for Living board of management, funding bodies

and available to families and other service providers through the Life's for Living website.

4.2.2 Factors that strengthened the project

A range of factors contributed positively to the project and these are described below.

The resourcefulness, determination, knowledge and experience of family members who were involved in the project contributed to an informative and relevant project consultation process. Parents/carers promoted the project within their own networks with word of mouth among being the most effective promotion strategy, this resulted in increased involvement by families who may not have otherwise participated.

Using a family-centred consultation approach which sought the views of families, not just service providers, and also the positive nature of the proposed resource were factors which made participation in the project attractive to families. Families were enthusiastic about the proposed family-centred resource that will be controlled and maintained by families and one they can use when interacting with a variety of sectors and settings to prevent them from having to repeat information about their child.

The project used a flexible consultation approach using a range of methods that met the varying needs of participants. These included focus group sessions, written questionnaires (sent by post, email or fax) and 1:1 face-to-face or telephone interviews. The location and timing of focus groups was organized to suit participants. For example, some parents preferred their focus group to be held straight after their weekly parent meeting as it was more convenient for them. Child care support was provided to this group whose children (with disabilities) were under school age so that they could participate in the focus group with minimal interruption.

Families felt acknowledged and heard, they reported that the project provided them with the opportunity to tell their story which validated and honoured their experiences. This resulted in trust and bonding within focus group sessions and a general willingness and openness to contribute as well as share their ideas and views about the resource. They also reported that having the opportunity to share their story with others was valuable.

Targeting specific parent groups for consultation (e.g. parent support groups) was a useful and effective strategy and actually increased participation. Follow up by the Project Team with families and service providers who were sent questionnaires also increased the participation rate.

At focus group sessions, the Project Team showed families its sample client profiles which were created from the resource kit developed in Phase I. Showing these examples helped families get a general sense of the format and content of the proposed resource for children/young people with disabilities. Furthermore, having an experienced group facilitator at each focus group contributed positively to the group dynamics and information was obtained in a respectful and sensitive manner. Although parents did not expect it, they appreciated the \$20 incentive offered to them for attending the focus group. This was intended as an incentive for participation as well as to honour families for their time and contribution.

Having a clear and thorough Project and Consultation Plan assisted the Project Team to remain focused on project activities and the outcomes that needed to be achieved by the end of Stage 1. It also assisted the team to meet project timelines, to communicate and promote the project to key stakeholders including funding bodies.

Cooperative and collaborative partnerships with key service providers from sectors commonly accessed by families (disability, education & health) and the creation of a multi-agency Project Reference Group provided the Project Team with linkages to families of children with disabilities. These networks also assisted with promotion of the project within their respective organisations, knowledge and expertise of working with children and young people with disabilities, venues for focus groups which improved access for some parents. Furthermore, country disability networks work very

closely with education and health sectors which resulted in effective and efficient promotion and sharing of information to families in local areas.

The Project Team provided the project with the resources (personnel) to conduct the leg work for the project, making it attractive for key service providers to be involved. It also ensured that a coordinated and systematic approach was applied throughout the duration of the project.

4.2.3 Factors that may have limited the project

While most strategies were achieved there were some limiting factors associated with various activities, these are described below.

Minimal time was allocated in the project plan for follow up with families and service providers, particularly in relation to attendance at focus groups and/or submission of questionnaires. This became a resource intensive activity for the Project Team.

Some of the factors that may have been a barrier to participation by families include lack of time and energy and the need to attend to family issues or emergencies. Information overload among families may have prevented them from making initial contact. Parents/ carers who participated in the project reported feeling overwhelmed with the amount of paper work and information they receive on a regular basis. As a result, some parents said that they forgot to submit their questionnaire and appreciated the reminder, others said they misplaced their project information in a pile of other paperwork.

Other factors which may have prevented participation in the project include family involvement in many other projects, surveys, focus groups; other events (such as disability information sessions) which were scheduled on the same week as the country focus groups; a lack of confidence among some parents/carers, feeling like they don't have much to offer; limited literacy skills; the length of the questionnaire; and a lack of child care in some cases may have prevented some parents from participating.

The Project Team did not provide families with a timeframe for the consultation stage which has resulted in enquires still being received by the Project Team well after the end of the consultation period. Furthermore, promotion by some organisations was delayed resulting in interested families finding out about the project at the end of the consultation period.

SECTION 5. 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.

APPENDIX 6.1 Project Reference Group

DISABILITY

Organisation	Name
Autism SA	Jon Martin – CEO
Can Do 4 Kids	Claire Cotton – General Manager, Community Services
Can Do 4 Kids	Helen Riley- Family Support Services - Blind/Vision Impaired
Community Accommodation & Respite Agency (CARA)	Barb Keane – Executive Manager
Community Accommodation & Respite Agency (CARA)	Liz Wallace- Executive Manager
Community Lifestyles Inc (Murray Bridge)	Sue Michael - Manager
Down Syndrome Society of SA	Ann Squire - Senior Education Consultant
IDSC (Child & Youth team/ Options Coordination)	Sue Deeprise Regional Manager
Interchange Inc.	Carrie Quigley- Teen Companion Program
Novita Children's Services	Sue Gibson - Research Physiotherapist & Project Officer
Siblings Australia Inc	Kate Strohm- Director

HEALTH

On committee as individual with expertise in Public Health and children's services	Diana Hetzel
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EDUCATION

Department of Education & Children's Services	Margaret Lynch – Manager, Disability Curriculum Policy and Research Learning Improvement and Support Services
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APPENDIX 6.2 Local initiatives

Types of process, plans and resources used by South Australian disability, education and health service providers to capture positive information about children and young people with disabilities.

Summary of process/ plan/ resource	Description of positive information collected by the process/plan/resource
Review and Planning Session / Service Plans	Current skills, likes related to this skill Abilities and achievements (as relevant to therapy goals) Records achievement against goals set
Chat Book	Things I like to do, photos of child doing activities, etc.
Respite stay information	Informs the child's family of what the child has participated in/ achieved while at respite. Information collected- toileting and feeding self, interacting with other children and activities undertaken
Personal profiles	Child's personal likes/dislikes re recreation etc Personal interests, family, close friends, life areas eg work etc. Gives information to provide a positive stay in respite.
Personal diary	Uses most effective communication methods for a particular person using compics, photos or whatever the person requires. It may take the form of a board, photo album, signs on their wheelchair tray or information recorded on their communication device.
"I am able to"...document	Summary of strengths
Initial contact form	The things a child enjoys Skills a child has in a number of areas
Assessment Interview Form	Collects information about: what the child enjoys doing/spending their time on, how they describe themselves/how their family describe them, strengths, capabilities, gifts the young person has. Also collects information about situations that don't work, dislikes, frustrations, fears, and general information
Support Plan	The gains a child has made, new skills learned.
Negotiated Education Plan (NEP) and Needs Assessment	Contains a specific section which documents the abilities, strengths, motivations, hopes, dreams of the learners. Information related to the education of learners with disabilities.
Personal record, newsletters, word of mouth, special family days & camps	Families sharing experiences/stories
Informal mechanisms (e.g. discussions with families, written reports to parents, agency newsletter, media releases, events)	Reports of achievements to parents, contribution of parent stories, positive experiences

APPENDIX 6.3**Questionnaires and focus group questions**

- 6.3.1 Copy of Service Provider Questionnaire
- 6.3.2. Copy of Questionnaire for families
- 6.3.3 Copy of Questionnaire for children with disabilities
- 6.3.4. Copy of Questionnaire for young people with disabilities
- 6.3.5 Copy of Questionnaire for adults with disabilities (retrospective view)
- 6.3.6 Copy of questions for focus group consultation

6.3.1 QUESTIONNAIRE FOR SERVICE PROVIDERS

1. As a service provider, what sort of things do you like to know about a child or young person with a disability to assist you in interacting positively with him/her?
2. Could you name and describe the specific resources/ tools/ plans/ processes your organisation have in place for collecting information about children/young people with disabilities.

Name of resource/plan/ process (e.g. Special Needs File, Individualised Service Plan, NEP etc)	Description of information it collects

3a. Do these resources/tools/plans/processes (listed above) enable you to record the *positive stories, abilities and achievements* of children/ young people with disabilities?

3b if yes, please name the resource/process and describe the positive information it collects.

Name of resource/ process (E.g. NEP, newsletter etc...)	Description of <u>positive information</u> it collects

4a. Are the resources/ processes (listed in 3b) sufficient for collecting positive information about children and young people with disabilities?

4b If No, why not? - What are the gaps/ issues?

5. Who would be the critical person that would collect and collate this kind of data from families in your organisation? (e.g. therapist, support worker)

6. Can you identify any factors that may prevent staff from documenting and sharing the positive stories, dreams, abilities and achievements of children/ young people with disabilities? (e.g. *insufficient time, attitudes of staff/ parents, fragmentation of information collection*)

7. Do you think the proposed 'What I'd Like You To Know About Me!' Resource described on page 1 of this questionnaire would be a valuable resource for families?

8. Can you describe how this resource may be used in your organisation?

6.3.2 QUESTIONNAIRE FOR FAMILIES

Note: Families were given 1/3 page to respond to most questions, however the space has been shortened for the purposes of this report.

About this questionnaire

Life's for Living is working on a 2-year project to research and develop a resource which supports the capturing and sharing of positive and true-life stories and creates positive profiles of children and young people with disabilities. This project is based on another project with an adult focus by Life's for Living- details are available at www.lifesforliving.com.au.

The resource will enable children and young people with disabilities (and their families) to record and share important information about themselves. Examples of information we think is important to collect: abilities, achievements, dreams, fears, leisure interests, routine, likes/dislikes, emotions, health, goals, behaviour needs.

This information would be able to be printed and/or made into a book and carried around/shared by the child/young person and their family (especially with teachers, disability workers, health professionals). It will mean that the person can communicate their individuality and inform others of who they are beyond their disability. It will also mean that the child/young person and their family will not have to keep repeating the same information constantly.

The first six months of this project (June – Dec 2005) involves asking families what they think should be included in this resource and giving them an opportunity to tell their story including the challenges and joys. Your experiences and ideas are very important to us and will help us to decide what the resource will contain.

Confidentiality and anonymity will be respected at all times. Life's for Living will not tell anyone your name or the name of the service(s) your child uses. However, we do ask for your name and contact details so that we can contact you if we need to clarify something in your questionnaire and/or let you know how the project is going and whether you'd like to be involved at a later stage. Please call us if you would like a copy of our Privacy Policy.

We hope that the children, young people and their families will be our guiding lights in this process. With your guidance, we hope to create something that will not only be a positive resource, but one that will be informed and directed by children and their families.

Contact details (OPTIONAL)

Your name: _____

Postal address: _____

Contact phone number: _____

Best time/day to call: _____

Email address: _____

General information about you

Where do you live? (Please tick): Metro Adelaide Regional/Country SA
VIC NSW ACT QLD TAS NT WA

Age of your child? (Please tick): 0-5 yrs 6-12 yrs 13-17 yrs 18+

Relationship to child: Father Mother Guardian Other relative

Other _____

Where did you find out about the project?

Name/organisation _____

Other (e.g. website/ newsletter) _____

Instructions: This questionnaire is in three parts: A- Telling your story, (questions 1-7), B- Your ideas about the resource (questions 8-11) and C - Consent to publish your stories.

We have only allowed small spaces for responses but attach additional pages if you would like. We have used some "tick boxes" to help us with data collection and to gather some statistics.

It is important to note the consent form at the end of the questionnaire, please sign it if you agree to Life's for Living publishing parts of your story –this is optional (names will be changed).

Please feel free to pass this questionnaire on to other family members or other interested parties or for extra copies call Life's for Living on 08 8277 3300.

A. Telling your story

Please share your experiences by answering the following questions and ticking the boxes most relevant to you (attach more pages if needed).

1. **What were your experiences of people with a disability before your child was born?** (e.g. through family, friends etc...)

Level of experience (please tick)

None Very little Some experience Lots of experience

Details _____

2. **What were your perceptions/ attitudes towards people with disabilities?** (e.g. what messages did you receive about people with disabilities, what would you/ others say)?

Overall my perception/attitude was: (please tick)

Negative Slightly negative Indifferent Positive

Details _____

3. **When your child was diagnosed as having a disability:**

3.1 **What was your experience?** (How did you and your partner react?)

Negative Slightly negative Indifferent Positive

Details _____

3.2 How supportive was the medical practitioner/ agency to you at the time?

Not supportive Some support offered Indifferent Very supportive

Details _____

3.3 How did other family members react-siblings, extended family and friends? (Describe the attitudes towards you, your child and other family members)

Negative Slightly negative Indifferent Positive & supportive

Details _____

3.4 In your own words, describe what could have been done to create a positive difference to your experience? (e.g. additional support, information, attitude of service provider etc.).

Details _____

4. Describe your personal experiences when you and your child with a disability visit/ interact with the following: (Describe your emotions, the attitudes towards you, your child and other family members e.g. siblings).

4.1 Medical services (GP, hospital, specialists, community health service)

Overall my experiences are:

Negative Slightly negative Indifferent Positive

Details _____

4.2 Child care/ education settings (kindergarten, school, child care)

Overall my experiences are:

Negative Slightly negative Indifferent Positive

Details _____

4.3 Therapy services (e.g. Occupational Therapists, Speech Pathologists, Physiotherapist)

Overall my experiences are:

Negative Slightly negative Indifferent Positive

Details _____

4.4 Disability service providers (e.g. accommodation, respite, Options Co-ordination etc..)

Overall my experiences are:

Negative

Slightly negative

Indifferent

Positive

Details _____

4.5 Community facilities (e.g. supermarket, sporting facilities, library etc..)

Overall my experiences are:

Negative

Slightly negative

Indifferent

Positive

Details _____

4.6 Family and friends

Overall my experiences are:

Negative

Slightly negative

Indifferent

Positive

Details _____

5. What positive qualities would you like others to know about your child? (list the abilities, achievements, personal qualities)

Details _____

6. What positive qualities do others see in your child (e.g. what do siblings, extended family, friends, and other support networks say about him/her?)

Details _____

7. In your own words please write down any other experiences you would like to share. *E.g. what are the things you remember most, what are the strengths / qualities you have which have enabled you to deal with everything that comes with having a child with a disability, what tips would you give other parents who have just had their child diagnosed with a disability....)*

Details _____

B. Your ideas about the resource

We would like your input into the content of the resource we wish to develop. Some ideas so far for the content of this tool 'What I'd Like You To Know About Me!' include: My story, dreams, hopes, abilities, achievements, what I'm scared of, what good things other people like my family and friends say about me, things I am good at, what I like/ don't like, my emotions – how I feel when...., etc....

8. What sort of information would you like this resource to capture about your child that would help promote positive interactions when you and your child are in contact with various services? For example with medical services (GP, hospital, specialists, community health service), child care/ education settings (kindergarten, school), therapy services (e.g. Occupational Therapists, Speech Pathologists, Physiotherapist), disability service providers (e.g. respite), community services (e.g. supermarket, sporting facilities, library etc.), family and friends.

Details _____

9. What format would you find easiest to use? Keep in mind ease of updating and storing information.

- Web – based (internet)
- Hard copy
- CDROM
- Other _____

10. What assistance do you think you would need to use a resource like this?
(tick any that apply to you)

Access to a computer

Access to the internet

Access to printer/photocopier

Time to use resource

Training to use resource

Training/help to use the computer

Help with completing the profile/writing stories

Any other _____

11. Is there anything that would prevent you from using a resource like this?

Details _____

12 Do you think this would be a valuable tool for families of children and young people with disabilities?

YES

NO

UNSURE

12.1 If yes, can you describe the positive difference this resource will make for you and your child?

Details _____

12.2 How and where would you use it? In what settings would it be useful? (which settings- medical/health, school, child care, with family and friends etc...)

Details _____

C. Would you like to submit your story for publication?

We would like to document and publish some parent stories or quotes from parents, as we see that this is a very powerful voice to share with the community. Examples of how we may make the information you provide public include: Report to the Minister, funding bodies, Project Report(s), Life's for Living Website, promotional materials (brochure, newspaper etc), future training materials, within the actual resource, published papers.

If you would like to submit your story, Life's for Living will ensure confidentiality **and anonymity are respected at all times** by changing the names in your story and your name as the author. People's real names will not be used). We will not tell anyone your name or your child's name or the name of the service your child uses.

I acknowledge the statement above and provide my consent to having my story included as part of this project.

Signed: _____

Date: ____/____/ 2005

Print name: _____

Contact phone number: _____

6.3.3 QUESTIONNAIRE FOR CHILDREN WITH DISABILITIES

INTRODUCTION

Life's for Living is working on a project to develop a resource for children and young people with disabilities (and their families) to write down important information about themselves. This information can then be used with other people in their family, at school, when visiting the hospital/doctor, respite etc... Examples of information to collect includes: their abilities, achievements, dreams, fears, leisure interests, routine, likes/dislikes, emotions, etc...

The purpose of this questionnaire is to give children and young people the opportunity to "tell their story" by sharing their life experiences and information about themselves that they would like others to know about them. It will give children and parents a taste of what it will be like to use the proposed 'What I'd Like You To Know About Me!' resource. Their experiences and ideas will help Life's for Living decide what the resource will contain and what it will look like. The questions can be answered at home or in a group environment with other children.

Given the potential broader applicability of this resource for use by all children, not just those with disabilities, we would also like to get feedback from these questions from children who do not have a disability.

If you are the person writing down the information expressed by the child/ young person, please do so as if you are their interpreter. That is, as if they have dictated it to you and you write it from their experience/ perspective. Please invite others who know the child really well to assist you too.

If your child/ young person can describe their own experiences or uses symbols/ images in their communication, include them too. Photographs are a fantastic way of illustrating points as well.

Life's for Living would like to document and publish children's stories and quotes. It will **ensure confidentiality and anonymity at all times** (real names and name of service used by the child **will not be made public**). Their stories and ideas are a powerful voice to share with the community. A consent form to be signed by the Parent/Guardian is attached at the end of this questionnaire.

Notes to parent/ guardian or other facilitator:

- *Feel free to use creative methods e.g. cut-outs of pictures, drawings, poster (butcher's paper) whatever would encourage participation from the children in this group.*
- *For children answering these questions themselves, could you encourage them to respond in the first person so that they personally declare and own their statements e.g. "The things I am good at are"...., "What I'd Like You to Know About Me is..." etc..*

QUESTIONS

Are you a person with a disability? YES/ NO Please write here YES or NO.....

How old are you? Please write down how old you are here:.....

A. Important questions about you

We would like to ask you some questions because we want to hear your story and to know what positive information YOU would like others to know about you.

1. What do you like best about School (ie, your friends, teachers). What don't you like about it?
2. What do you like best about going to the doctor or hospital. What don't you like about it?
3. What do you like best about going to therapy. What don't you like about it?

4. What do you like best about going out? (e.g to shops, library, sport) - What don't you like about it? (What we want to get a feel for here is how people interact with them in these settings? What are the people like?)
5. What would be some of the good things you can say about YOU!!!
6. What do you dream about/ wish for?
Note: to facilitator – It needs to be achievable and possible. An example of what one young person said in a person-centred planning session in Scotland was “being a doctor”. Facilitator then asked what is it about being ‘a doctor’ that you like? Person said “People listen to you because you wear a white coat”. So this girl’s dream is “to be listened to”.
7. What do you really like and don't like?
8. What are the things you are good at (abilities, achievements)?
9. Who are the special people in your life? (e.g mum, dad, auntie, uncle, cousin, friends etc..) & what do you like best about them?
10. What are the good things they say about you? *Example: The good things that mum/ grandma etc...say about me are...*
11. What are the things that you do for others?
12. What do you need others to do for you? (support needs)
13. What are you scared of? *Example: The things that scare me the most are....*
14. What makes you happy (or makes you feel good)?
15. What makes you sad (or what upsets you)?
16. What other things would you like people to know about you?

Thank you so much for your time. We look forward to hearing back from you!!

CONSENT

Feedback from my child will inform the content and format of the person-centred resource ‘What I'd Like You To Know About Me!’ for children and young people with disabilities.

Life's for Living would like to document and publish my child's story and/or quotes as this is a very powerful voice to share with the community. Examples of how information will be made public include: writing reports to the Minister and funding bodies; via Life's for Living Website, promotional materials (brochure, newspaper etc), future training materials, conferences and published papers.

Life's for Living will make sure that **confidentiality and anonymity will be respected at all times**. It will not publicly reveal my child's name or the name of the service my child uses.

PARENT/ GUARDIAN CONSENT

I accept the statements above and hereby consent to my child _____
(name)

to be involved with Life's for Living's 'What I'd Like You To Know About Me!' Project.

Signed: _____ Date: ____/____/ 2005

Print name: _____

Telephone: _____

6.3.4 QUESTIONNAIRE FOR YOUNG PEOPLE WITH A DISABILITY

INTRODUCTION

As per Questionnaire for Children – See 6.3.3 above

QUESTIONS

A. Important questions about you

These are the same as those used in Questionnaire for Children – See 6.3.3 above.

B. Your ideas about the resource

We would like to produce a resource for children and young people with a disability so that they can write down important information about themselves. This information can then be used to share with other people in their family, at respite, school etc..

1. Do you think the questions you have just answered would be good to use? Please write Yes or No here:
2. What other questions do you think the resource should include? *Just pretend you were little again. What kind of things would you have liked others to know about you? Please list your ideas here:*
3. What format would be easiest to use? Please write the word “Yes” next to your answer. For example:
Hard copy (book): Yes. You can say “yes” to more than one response.
 - Web – based (internet - computer):
 - Hard copy (book):
 - CD-ROM:
4. Do you think this resource is a good idea? Please write the word “Yes” or No here:
5. Do you have any other ideas to share?

CONSENT

As per Questionnaire for Children – See 6.3.3 above

6.3.5 QUESTIONS FOR ADULTS WITH A DISABILITY

INTRODUCTION

As per Questionnaire for Children – See 6.3.3 above

QUESTIONS

Are you a person with a disability? YES/ NO Please write here YES or NO.....

How old are you? Please write down how old you are here:.....

A. Important questions about you

The reason why we are asking these questions is because we would like to hear your story and to know what positive information YOU would like others to know about you.

1. What do you like best about going out? (e.g. to shops, library, sport) - What don't you like about it? (What we want to get a feel for here is how people interact with them in these settings? What are the people like?)
2. What do you like best about going to the doctor or hospital? What don't you like about it?
3. What do you like best about going to therapy? What don't you like about it?
4. What would be some of the good things you can say about YOU!!!
5. What do you dream about/ wish for?
6. Tell us what you like and what you don't like
7. What are the things you are good at (your abilities, achievements)?
8. Who are the special people in your life? (e.g. mum, dad, auntie, uncle, cousin, friends etc...) & what do you like best about them?
9. What are the good things they say about you? E.g. The good things that mum/ grandma/ my uncle etc.. say about me are...
10. What are the things that you do for others?
11. What do you need others to do for you? (support needs)
12. What things would you like people to know about you?
13. What are you most scared of?
14. What makes you happy (or makes you feel good)?
15. What makes you sad (or what upsets you)?

Thank you so much for your time. Your ideas will help us so much!!

B. Your ideas about the resource

These are the same as those used in Questionnaire for Young People - See 6.3.4 above.

CONSENT

As per Questionnaire for Children and Young People – See 6.3.3 and 6.3.4 above.

6.3.6 QUESTIONS FOR FOCUS GROUPS

Introduction

Purpose / format of the focus group

Your experiences

Topic
Before
Before your child was born, did you have any personal experience with a person with a disability (e.g. through family, friends etc...)
What was your perception/ attitude towards people with disabilities?
Upon diagnosis
When your child was diagnosed as having a disability: What was your experience? (How did you react?) How did the medical practitioner/ agency interact with you at the time? How did other family members i.e. siblings, extended family, friends interact react (Describe the attitudes towards you, your child and your family) What would have made a positive difference to your experience?
Current experience
Describe your personal experiences/ issues you face (both positive and negative) when you and your child with a disability interact with: <ul style="list-style-type: none">• Medical services (GP, hospital, specialists, community health service)• Child care/ education settings (kindergarten, school)• Therapy services (e.g. Occupational Therapists, Speech Pathologists, Physiotherapist)• Disability service providers (e.g. accommodation, respite etc...)• Community services (e.g. supermarket, sporting facilities, library etc...)• Family and friends Notes: Describe your emotions. (Describe the attitudes towards you, your child and other family members).

Positive stories about your child

How do YOU see your child?
How do others see your child? (What do siblings, extended family, friends, other support networks say about him/her?)
How would you like others to see your child?

Content of the tool

We'd like to develop a tool which captures the positive stories about children & young people with disabilities so that they are fully known for their abilities and as living interesting and fulfilling lives.
--

(Show sample of what tool will look like). Some ideas so far for the content of this tool 'What I'd Like You To Know About Me!' include:

My story, dreams, hopes fears, What other people say about me, Things I'm good at, What my family, friends says about me, Likes/dislikes, My emotions/ How I feel when.....

APPENDIX 6.4 Process Evaluation Plan– Stage 1

STRATEGIES	TASKS/ ACTIVITIES	PROCESS INDICATORS	DATA COLLECTION METHODS	RESULTS
Identify, review and document similar person-centred initiatives/ resources and plans at state, local, national and international levels which focus on whole of child view, disability and children's rights.	Conduct literature review via internet, libraries, organisational contacts	Analysis of records, summary of findings	Documentation	South Australian, national and international similar initiatives documented
Build capacity, share knowledge and experiences through the creation of collaborative partnerships/ networks and participation from parents, children and young people with disabilities (0 – 17 years), siblings and service providers from disability, education and health sectors.	<p>Identify key stakeholders, provide background information and formally seek their participation</p> <p>Organise stakeholder meeting</p> <p>Establish advisory groups</p>	<p>Networks developed</p> <p>No. of Intro Letters sent and to whom</p> <p>Multi-agency and parent advisory /reference groups established</p>	Document activities	<p>Networks established with key disability, education and health organisations</p> <p>Multi-Agency reference group established</p> <p>61 organisations informed about the project</p>
<p>Promote the project to parents, service providers and other key stakeholders using a range of communication channels including:</p> <ul style="list-style-type: none"> • agency/association newsletters, magazine, websites • e-news (email distribution via networks) • local print media • existing forums/ committees/ conferences • disability resource centres 	<ul style="list-style-type: none"> • As above • Develop promotional flyers/ advertising • Present at ASSID Conference New Zealand (Oct 05) • Present at Life's For Living AGM- 21st September 2005 	<p>Amount and no. of promotion flyers distributed and where</p> <p>Number of responses from parents and their children, service providers</p>	Documentation count	<p>Flyers distributed to 56 organisations</p> <p>49 parents/carers, 24 service providers and 4 people with disabilities participated in project. Siblings were not consulted in Stage 1.</p>

Identify possible funding sources to secure long-term support, commitment and sustainability of the project beyond Stage 1	Submit funding applications	Funding submissions meet all criteria	Documentation	Funding secured for additional 3 months to March 2006
Conduct consultations with children and young people with disabilities, parents/ families and service providers.	Develop consultation plan Develop series of questions to guide consultations Acknowledge participants for being involved (after the consultation via letter, website etc...)	Consultation Plan developed No. of interviews, and focus groups booked No. of participants and their feedback (satisfaction) with process	Documentation of the following: Interviews with individuals (face-to-face or telephone) Focus group discussions Survey/ written questionnaire via mail or email	Consultation plan developed 24 parents participated in total 6 focus groups (2 metro & 4 country SA) 29 parents participated via questionnaire Most stakeholders reported support for proposed resource and enthusiasm
Identify the issues which prevent and the factors which support the promotion of positive perceptions and interactions with children and young people with disabilities so that they are fully known and respected for who they really are as individuals. (participants given opportunity to “tell their story”)				
Analyse, collate and distribute project findings	Gather data	Summary of findings from consultations	Documentation, progress report to advisory group, board of management and Minister for Disability	Progress report for Stage 1 highlights key findings, issues and recommendations for the future

Source: Evaluation plan template sourced from South Australian Community Health Research Unit (SACHRU)