

LISTEN TO US

Supporting Families with Children with Disabilities: Identifying Service Responses that Impact on the Risk of Family Breakdown

Executive Summary

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Researchers:

Lloyd Owen

Meg Gordon

Margarita Frederico

Brian Cooper

The Family Resilience Project was undertaken on behalf of the National Disability Administrators by the School of Social Work and Social Policy at La Trobe University, Victoria. The project was managed by the Disability Services Division of the Department of Human Services, Victoria.

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School of Social Work and Social Policy, La Trobe University.

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Further Information

For further information, please contact:

Disability Services
Department of Human Services
Level 19, 555 Collins Street
Melbourne VIC 3000
Ph: 03 9616 8427

Disclaimer

This report was commissioned by the National Disability Administrators and undertaken by researchers from the La Trobe University. The views represented within this report are those of the authors and do not necessarily reflect the position or policy of National Disability Administrators or the individual Commonwealth and State/Territory Governments.

The recommendations within this report are intended to inform the processes and priorities of the National Disability Administrators group. While the recommendations may assist the National Disability Administrators or the individual Commonwealth and State/Territory Governments in the development of future priorities and policies, these recommendations must be considered in the broader context of existing initiatives, competing priorities and alternative perspectives.

Acknowledgements

'Listen to Us' is the report of a comprehensive examination of services with potential to strengthen and support families of children with disabilities, and has itself called on the strengths, abilities and experiences of a wide range of families, service providers and researchers.

This project has relied heavily on the experience, time, goodwill and initiative of the many informants, including those who made contact with the research team following project publicity. The contribution of family members and service providers who commented on our research approach, piloted our questionnaires, responded to our surveys, participated in our two focus groups or volunteered to share their experience by telephone or email, has been outstanding. Most of these contributors remain anonymous but are represented by those to whom the researchers express their gratitude, listed in Appendix 1.

The project has been supported by two groups. Members of our National Advisory Group, nominated to represent the eight State / Territory Disability Administrators, are listed in Appendix 2. The Advisory Group met only by teleconference. It's members have played a critical role in guiding the project, clarifying the service context in their jurisdiction, validating our research approach and two survey instruments and in the distribution of questionnaires for the National Survey of Programs and Services. Additionally, in Western Australia, Queensland and Victoria, Advisory Group representatives played major roles in establishing contact with families as part of our Family Survey, focus groups and wider consultation with families.

The Project Reference Group met in Victoria. This group was made up of disability service representatives from Commonwealth and Victorian Government Departments and a range of non-government services including a parent organisation. Members of the Reference Group and the organisations they represent are listed in Appendix 3. Members of this group further validated our research approach and instruments, piloted the questionnaire for service providers and in three instances took a major role in distributing the Family Survey to their membership or client base. They have also been indefatigable in identifying and clarifying issues and in providing constructive comment for drafts of this report. The contributions of all Reference Group members have been greatly appreciated, and the exceptional contributions of Anne-Maree Newbold, Lisa Braddy and Frances Floyd call for special acknowledgement.

The Family Resilience Project was undertaken by a research team based at the School of Social Work and Social Policy at La Trobe University, Bundoora. Meg Gordon, of Triple "P" (Policy, Planning, Programs) Consultancy in Brisbane, undertook the extensive literature review for the project. Lloyd Owen, Margarita Frederico and Brian Cooper, of La Trobe University, took joint responsibility for the research design and development of survey instruments and oversaw implementation and analysis of the National Surveys of Programs and Services and of Family Perspectives. The consultants were ably supported by Dr Anthony Lunken, Jessica Letch, Josh de Bruin, Sonya Holm and Sue Jones, Research Associates/ Assistants at various stages throughout the project cycle.

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Lloyd Owen, Principal Researcher

Executive Summary

'Listen to Us' is the report of the Project formally titled ***Supporting Families with Children with Disabilities: Identifying service responses that impact on the risk of family breakdown***. The report is a comprehensive examination of service responses that can strengthen and support families with children with disabilities, and thus impact positively on their capacity to continue to care for the child at home. The project was undertaken on behalf of the National Disability Administrators of the Commonwealth, States and Territories of Australia by the School of Social Work and Social Policy at La Trobe University, Victoria. It was managed by the Disability Services Division of the Department of Human Services, Victoria and supported by a National Advisory Group comprising representatives of State and Commonwealth Disability programs.

The focus of this report is on children and young people to the age of eighteen years who have a disability and their families. It examines the capacity and resources of both the immediate family, of their extended family and friendship networks, and of professional service systems to meet their support needs. The purpose of the research was to identify key factors that, with early targeting and support, may strengthen the capacity of families to care for their children.

Specifically the key issues this project and report examine are:

- What are the critical factors that increase the likelihood of families remaining intact?
- What best practice interventions are effective with these factors?
- What can be done at what life cycle stage to increase the effectiveness of assistance?
- Where should resources be focussed for best results? (DHS 1998)¹

The report is structured to provide an introduction to current issues and practice in relation to supporting families with a child or young person with a disability. The context is initially set through an overview of the research method, followed by contextual discussion with a Reference Group that included service providers and a parent representative. An extensive literature review is then presented, followed by two reports: one on family perspectives on their needs and resources, and the second on services and programs throughout Australia, including the views of service providers. The final chapter presents the conclusions drawn and recommendations based on the project findings.

The approach taken to meet the aims of the Family Resilience Project included a literature review, a survey of 279 family carers of children with disabilities, two focus groups with carers and service providers, two case studies, and a national survey of 160 service providers. In addition to the support of the National Advisory Group and a Project Reference Group based in Victoria, consultations were held with advocacy groups and families including representatives of the Aboriginal and Torres Strait Islander community.

The literature review is presented in two sections. Chapter Two provides a review of frameworks for understanding the impact of a child's disability on the family and on the child and the implications for ways in which family support is provided. The review highlights the additional challenges that raising a child with a disability poses for many

¹ Department of Human Services, Victoria November 1998. ***Supporting Families with Children with Disabilities*** (Research Project Specification)

families and the complex interaction within the wider social political and economic environment of the family. The fact that a child is living in the family home is not alone a sufficient indicator of total quality of life, or of positive outcomes for either child or family. A complex range of interacting factors influence both the family's stress and their capacity to adjust and adapt individually and collectively. In ecocultural theory terms the family 'accommodates' the needs of the child with a disability. A clear finding from the literature is that the unmet needs of the family as a whole impact on this family 'accommodation' process, as well as the impact of the child's disability and level of support needs, in any consideration of out-of-home placement by the family.

A review of 'service models' is presented in Chapter Three, using a framework drawn from the disability literature and the Australian Institute of Health and Welfare's classification of health and community services. The review illustrates the need for a range of quality services for families with children with disabilities, and for more consistent policy goals (both across services and across early childhood and school age periods), that address both child and family outcomes. The value of early intervention services is highlighted, along with the possible need for broadening of early intervention models and practices, to include stronger focus on parent-child relationships, social competence in children and prevention of challenging behaviours. The review stresses the importance of both change-oriented/ interventive and supportive/ facilitative strategies being available at primary, secondary and tertiary levels of intervention. The report further highlights the importance of informal support systems for families and the impact that community attitudes to disability have on the adaptation and capacity to support within the extended family and friendship networks. It is acknowledged that Australian service systems have not yet explored the capacity and limits of informal support.

The report on family perspectives in Chapter Four presents the voices of family caregivers, in a powerful presentation of the importance of support from both professional service systems and their informal networks, where appropriate. Many parents report their frustration with services' lack of responsiveness to their needs. These findings support the literature in recognising that it is the level of child's support needs together with other family needs, and the level of congruence between these needs and the services provided, which are key factors in the consideration of permanent out-of-home care for children and young people with disabilities. The carers also challenge the perception that placement of a child in out-of-home care necessarily means the family has failed or 'broken down'. A goal of family connectedness remains despite any short or long term absence from the family home. Indeed as many young people mature positive preparation for independent living or varying degrees of supported housing will occur. An additional finding relates to cost as a source of dissatisfaction with professional services and also as the major single reason reported by carers for not being able to access adequate professional services for their child.

The report of the service system is presented in Chapter Five. This provides a wide overview of the complex and fragmented services available for families with a child with a disability, provided in both the disability sector and in the universal education, health and family welfare sectors. This is reflected also in the range of legislation that addresses disability. This report highlights that families with children with severe or profound disabilities negotiate an extremely complex service system, and that assistance with coordination or integration of services on a local basis, and in a culturally sensitive manner, is a priority for many families.

Input gathered in the project affirms the significance in the lives of families with children with disabilities of both the disability services, funded and provided under the Commonwealth/ States Disability Agreement and Home and Community Care Program,

and the array of services derived from other sources. Concern is focussed more on the fragmentation and potential for both overlap and gaps that arises from this complexity, making information, advocacy and coordination of support services priorities for many of the families. Parents generally value local Area Coordination developed in Western Australia. This model has been evaluated and found to result in a reduction in numbers of people with disability moving away from home and in increase of those moving back to their homes. In other States co-ordination / case management practice may include a brokerage role and a number of service providers have pointed to the value of flexible discretionary funds to meet particular needs as they arise. A measure of control by families over utilisation was also valued. The literature review highlighted the scope for cross-sectoral initiatives with education, health, community services and disability sectors, including co-location of services, as a means of reducing fragmentation and increasing accessibility.

The survey identified that individual and family life stage perspective is a valuable tool for service planning and coordination but there is little evidence among the material submitted to the project of long term planning in the culture of services. The value is also affirmed of systemic and ecocultural perspectives that take account of needs and resources at the individual/interpersonal level, family, community and cultural societal levels. As noted in the literature review and family survey, many parents experience a lack of congruence between the needs of their child and family as a whole, and the services they are able to access. The families' comments also supported the literature review's findings about the impact of community attitudes on families.

Both the family input and literature review endorsed the need for a wide range of different kinds of support throughout the families' lifecycle, including the impact on families of the level and way in which child-focussed services such as education and allied health are provided. This reflects the trend toward more flexible and comprehensive family support programs, inclusive of children with disabilities. Both families and providers have signaled the importance of sufficient and appropriate respite care (or 'short breaks'), including both in-home and out-of-home based services. A number of respite programs pointed to the value of flexibility and choice for parents as to when and how respite hours might be best utilised. In line with international trends in service models, the study findings endorsed the value of recreational and developmental forms of respite that are designed to provide positive inclusive experiences for the children as well as a 'break'. The importance of being able to accommodate emergency care requirements for the children with disabilities was also highlighted.

It has been noted also during the project that families appear to be under represented overall among the bodies involved with stakeholder representation and advocacy. There is a need to identify or clarify the National and State/Territory options and facilitate the inclusion of family and child/young person viewpoints in the negotiation of service system structures and resources.

The report highlights the importance of listening to families to understand the most effective and supportive ways for providing support for the child with a disability through their family. While generally, the principles utilised in the service delivery system support adequate care, there are service gaps, difficulties with access and obstacles with the delivery of services. Whilst some families are well supported by the services it would appear that most families in the survey had difficulties accessing appropriate services. The particular circumstances of more vulnerable families who may be acutely affected by additional demands need to be addressed to reduce negative impacts on the child and all family members.

The Family Resilience Project has confirmed that families' reasons for considering relinquishment of the care of a child or young person prematurely are complex and inter-related. The researchers have been impressed, however, at the tremendous resilience that most families demonstrate in undertaking the management of care of their child with a disability and their family as a whole.

'Listen to Us' presents the following recommendations to support best practice measures in services providing assistance for the families of children and young people with disabilities. They are designed to enhance the capacity of the service system to respond to families in a way that is consistently congruent with their support needs.

The introductory and final chapters of this report provide a summary of the project purpose, methodology, findings and conclusions, and can be read together as a summary report. The full report includes also an extensive literature review and reports of the family and service provider surveys and consultation.

Recommendations

Toward an Enabling Legislative and Policy Environment

The study identified that there was little reference to the child's family context in the legislation and policy material, discussed in Chapter Five, which provides the underpinning and backdrop for service development and delivery for Australian families raising children who have a disability. More active acknowledgement and inclusion of the appreciation that family wellbeing improves child wellbeing is warranted based on the literature and the study results. Acknowledged also are the explicit references to child and family in the UN Convention on the Rights of the Child which Australia has ratified. Article 23 embodies the rights of the child with a disability, parents and carers.

There is an array of organisations associated with the disability field and some concerned with related issues. A stronger family focus through a more formal representation of family views is considered desirable as discussed in Chapter Five. It is also important to recognise that the contemporary vision embodied in policy and legislation about the rights and opportunities for people with disabilities creates additional demands for families and service systems.

It is recommended that the National Disability Administrators (NDA) encourage:

- Recognition that the pivotal role of families in providing secure, nurturing environments for children with disabilities must be supported in a way which addresses the needs of the family as a whole;
- The development of legislation and policy frameworks for children's services that are inclusive of the needs of families with children and young people with disabilities;
- The adoption of practices that utilise a rights-based focus, reflecting the United Nations Convention on the Rights of the Child; and demonstrate an appropriate balance in ensuring that children's rights and the rights of all family members are protected and promoted;
- Consultative opportunities in the process of ongoing policy development with bodies equipped to convey the views of families of children with a disability;
- The adoption of the principles for best practice drawn together in this project for the development and implementation of policy and services to children and young people with disabilities and their families; and
- Measures to recognise and address the resource implications for families, communities and services of contemporary policies of inclusion of children with disabilities in families and communities.

Toward an Acceptable Accessible Service System: The HOW of Service Delivery

A key issue identified in both the family and service provider surveys is that the service system is not always attuned to family needs, or fails in its appreciation of the importance of maintaining the functioning of the whole family and addressing the needs of each member - including the children with disabilities - in a balanced way.

Coping, as well as morale, is enhanced by respectful skilled professional work which is timely and accessible. The establishment and maintenance of the necessary organisational structures and culture will be influenced by shared principles and attitudes and by continued attention to staff selection, orientation, support and supervision as well as to staff training and development. It is also important that organisational structures are maintained which permit workers adequate time and means to work in this way.

It is recommended that the National Disability Administrators (NDA) take action to:

- Address the complexities of the services system that provides assistance to families with children with disabilities, including the accessibility and coordination between services for both children and families by developing opportunities for cross sectoral and intergovernmental communication and coordination at local, regional, State and National levels;
- Ensure that families are supported in their attempt to access all mainstream services to ensure equality of access to responsive services that will enable the family to participate in the community and to realise the potential of each family;
- Ensure parents, children and young people are engaged in a genuine partnership with service providers which can include: full participation in service decision-making; input to consumer feedback and service reviews; participation in ongoing management and planning at regional and state levels; and representation on Boards/Committees;
- Ensure the principles for best practice established during this project are recommended for adoption in the development and implementation of services to children and young people with disabilities and their families;
- Ensure the theoretical perspectives related to the goal of enabling families to thrive in a conducive family oriented ecocultural context be promoted and developed with ongoing research to further underpin evidence based practice. This demands comprehensive, flexible, locally accessible services which are well connected to specialised inputs when they are needed;
- Ensure the duration and level of support available from services be congruent with the severity of the impact of the child's or young person's disability;
- Ensure the emotional factors faced by families in caring for a child or young person with a disability be considered by services and that parent support groups be supported by the service system and ensure that promotion of the range of effective professional and formal service responses be undertaken;
- Ensure that professional training standards for service delivery be developed to ensure staff capability; and
- Ensure that professional education be undertaken to ensure that workers are able to:
 - (1) Engage in a genuine partnership with families which is guided by family priorities, and are able to provide specialised knowledge-based support and professionally initiated intervention in ways that strengthen families, affirm family strengths and promote family confidence and competence while appropriately challenging where necessary restrictive family practices;
 - (2) Recognise the importance of cultural identity and culturally appropriate behaviour; and

- (3) Ascertain the feelings and wishes of children and young people, including those with severe disabilities and communication challenges.

Toward an Effective Comprehensive Service System: The WHAT of Service Delivery

There is strong support for the need for comprehensive flexible service systems which operate across primary, secondary and tertiary dimensions. Various supplementary combinations are also necessary to deal with the considerable degree of geographical, social and cultural diversity in the Australian jurisdictions. Drawing on literature, inputs from service providers including State and Territory administrators, families and the study reference groups, this project has identified a set of principles, framework of services and some pointers for coordination and delivery. Feedback from families suggests that services are differentially available and that gaps and shortfalls are often apparent.

The provision of services should take into account the importance of a mix of both informal and formal supports for families with children or young people with disabilities. Initiatives to maintain and develop informal networks including links to other parents and mutual support networks should be pursued. They should not replace the maintenance and development of an effective formal service system.

It is recommended that:

- Flexible individualised supports are provided by enabling discretionary funding for families with children with disabilities to be as widely available as possible;
- The availability of specialised equipment, building modification, transport aid and domestic relief is encouraged;
- Parenting skills education and resource materials be available to parents of children with disabilities in particular, including information about preventing the emergence of challenging behaviours and about managing behaviour;
- Respite - now more commonly termed 'short breaks' - continue to be provided as a critical service supporting parents, with much stronger priority being given to service models which provide culturally normative and inclusive developmental, leisure and socialisation opportunities for children and young people with disabilities;
- Initiatives to maintain and develop informal networks including links to other parents and mutual support networks should be pursued, but should not replace the maintenance and development of an effective formal service system;
- Families have access to locally relevant information, and support where required, to assist them to navigate the services system and coordinate the services they require;
- An information strategy be developed for informing families about services available to them via booklets and newsletters, including web site access and maintained via the system of carer resource centres;
- Adequate levels of supportive and interventive services be provided for families already experiencing high levels of difficulty and/or stress;
- Family-centred behaviour intervention models be provided for situations where challenging behaviour has already developed;

- A review of the level of income support for families with children with disability to take into account the number of children with disabilities in the family, the support levels needed and the extra expenses incurred by families including those in rural and remote areas;
- Services, particularly specialist services and secondary consultations, are made more accessible to people living in rural and remote areas;
- The potential usefulness of comprehensive family assessment frameworks in addressing families' stated needs for holistic support be explored; and
- Account be taken of research in progress in New South Wales concerning the most appropriate means of supporting children with disabilities and other family members where child abuse or neglect is likely to add to vulnerability.

Critical Family Life Span and Individual Life Stage Needs

The key life span issue is building resilience early with preventive strategies, lifelong planning, capacity to intervene at times of crisis and continuing access to support are key concerns. Needs are amplified during individual life stage transitions and particular life course points and events and these can add to risk and vulnerability. However, strategies to prevent and intervene early are important in developing and maintaining resilience, and an array of these as well as secondary and tertiary intervention responses has been identified from the literature and from the service system inputs.

It is recommended that:

- Services are encouraged to embrace practices which take into account the developmental stage of the child and attempt to intervene to assist the family as early as possible and promote primary intervention to support families with children with disabilities so that assessment and intervention can be better geared to age/stage factors of the child;
- Families have access to a wide range of accessible core supports throughout the family life cycle and that these supports can be provided in a timely manner to families during key life events;
- Greater attention be given to access to primary level strategies that will assist in strengthening families and prevent the development of family difficulties and maintain quality of life for all family members;
- Policy development and service planning initiatives take into account lifecourse considerations for each family member, including children with disabilities, as well as family life cycle considerations; and
- That support be given to exploration of a range of models and practices designed to intervene early and reach vulnerable families, including early behavioural interventions which promote family capacity to nurture and sustain the care of their child, and practices and supports which foster and sustain enduring parent-child relationships and child social competence, community membership and relationships.

Toward an Informed and Inclusive Community

Family coping capacity is affected by the attitudes of wider family, friends and neighbours, the wider public and of workers in the service system toward disability in

general, toward the particular disability of their child and toward the particular needs of the family and all its members. Education on a number of levels may help to alleviate negative effects and more importantly open the way for more supportive attitudes and behaviour. The importance of community building and inclusion initiatives is highlighted. It is recommended that:

- Community education in disability awareness should be undertaken for the following groups: the general community; family members and friends with potential to participate in support; the disability services workforce, and health, education and welfare professionals; and
- Support be given to community building and community development initiatives designed to enhance support to families and their community membership.

Future Research

Many questions were beyond the scope of this project. The variety and scale of need in the field makes the search for sufficient resources, and for more effective and efficient ways of meeting need, an imperative. The existing body of research provides some information about ways of achieving this and has spawned a range of service enhancements. There are, however, few longitudinal studies examining the impact of support and services provision on family resilience and there is a need for smaller scale testing of innovation, monitoring of service usage and the evaluation of delivery and outcomes. The following are recommended:

- Progress in reducing permanent placements of children with disabilities away from their birth families should be monitored. It will be necessary in some States / Territories to institute cross-sectoral monitoring of placements, so that both family-based and facility-based placements, both ad hoc and planned placements, and also Disability, Child Welfare and Health placements are counted;
- That longitudinal research be undertaken to increase knowledge of the needs of families of children with disabilities and effective means of support for them. The research should include action research and evaluation projects and be conducted in collaboration with children and young people with disabilities, their families and service providers;
- That future research includes evaluation of the effectiveness of early prevention, including different early intervention and behaviour intervention strategies and their impact on placement rates;
- That research on service usage by families including the use and role of respite care - or 'short breaks' - be undertaken to further understanding of how such services may be effectively provided in ways which support families, foster children's development and sustain child-family relationships;
- That research on the gendered nature of caring be undertaken with particular note of the gender specific needs in counselling; and

That research on issues related to siblings be undertaken, in particular on the positive and negative aspects of relationships with the child with disability and on the long term effects on resilience and life chances for both the children with disabilities and for their siblings.

Note

The 'Listen to Us' report can be read in several ways:

- Chapters One and Six provide an overview of the project aims and research approach, the findings, conclusions and recommendations. Together these chapters can be read as a summary report without Chapters 2-5, the Appendix or Bibliography.
- Chapters Two and Three have the potential to stand alone (with the extensive bibliography) as an in-depth review of the Australian and international research literature of the field. They focus on theoretical frameworks for the family support needs of children with disabilities and their families and on the practice and policy issues and service models relevant to these needs.
- Chapter Four reports the voices of families with children with disabilities and their needs, and provides an analysis of factors related to consideration to place a child or young person.
- Chapter Five provides a national overview and an analysis of service policies and provision, including service provider views.
- All six chapters, with their related contents, numerous cross-references, Appendices and Bibliography, also lend themselves to electronic publication for down loading from the Internet and/or on a CD-ROM.