

SUPPORTING FAMILIES WHO HAVE A CHILD WITH A DISABILITY

FOR FAMILIES FIRST
INNER WEST

SPRC Report 1/03

University of New South Wales Research Consortium
Social Policy Research Centre
Disability Studies and Research Institute
December 2002

For a full list of SPRC Publications see, www.sprc.unsw.edu.au or contact:
Publications, SPRC, University of New South Wales, Sydney, NSW, 2052, Australia.
Telephone: +61 (2) 9385 7800 Fax: +61 (2) 9385 7838 Email: sprc@unsw.edu.au

ISSN 1446 4179

ISBN 0 7334 2072 9

December 2002

The views expressed in this publication do not represent any official position on the part of the Social
Policy Research Centre, but the views of the individual authors

UNSW Research Consortium

Social Policy Research Centre

Karen Fisher, David Abello, Jacqueline Tudball and Katherine Cummings

Disability Studies and Research Institute

Phillip French, Therese Sands and Leanne Dowse

Authors

Jacqueline Tudball, Karen Fisher, Therese Sands and Leanne Dowse

Contact details

Karen Fisher, Senior Research Fellow, Social Policy Research Centre, University of New South Wales, Sydney NSW 2052, ph 02 9385 7813, fax 02 9385 7838, email karen.fisher@unsw.edu.au

Acknowledgements

We would like to thank the following people:

- Reference Group members, including people from Inner West Families First and the Inner West Early Childhood Intervention Coordination Project, who assisted with document collection and participant recruitment;
- Organisations who provided documents, recruited families and participated in focus groups;
- Colleagues who provided invaluable feedback on early conceptualisation and draft reports;
- Focus group participants from organisations who gave up valuable work time to take part in this research; and
- Most particularly, we would like to thank the families we interviewed who were willing to revisit what were often painful experiences. A special thank you to the children of these families who allowed us to preoccupy their parents' attention and disrupt playtimes.

Contents

Summary	i
1 Introduction	1
2 Literature Review	2
2.1 Family Perspective	2
2.2 Assessment	2
2.3 Holistic Approach to Family Needs	3
2.4 Information and Communication	3
2.5 Family Characteristics	4
2.6 Models of Disability	4
3 Methodology	6
3.1 Interviews	6
3.2 Documentation	6
4 Findings	7
4.1 General Issues	7
4.2 Key Issues and Suggestions from Participants	9
5 Implications for Supporting Families	20
5.1 Communicating Assessment Outcomes	20
5.2 Principles of Support during Assessment	21
5.3 Supporting Families Through the Assessment Process	22
6 Conclusion	24
Appendix A Interview Schedules	25
Appendix B Suggestions from Respondents	27
Appendix C Service Types Included in the Research	28
References	29

Summary

Little scrutiny has been directed toward the nature of the assessment of children with a disability or what support needs families may have specific to the assessment process. A need for this analysis emerged from the responses of families who participated in a study conducted by Families First Inner West Sydney in 2001 about general support needs of families with young children. This project was conducted by the UNSW Consortium of the Social Policy Research Centre and the Disability Studies and Research Institute.

Literature review

Most parents can be considered as the experts where their own children are concerned (Gilding, 1991). However, with parents of children with disabilities, an historical overview of research shows that the views of professionals are frequently favoured over those of parents (Shakespeare et al., 1999, cited in Case, 2000).

Dowling and Dolan (2001: 24) concluded that ‘... social organisation disables not just the family member who has an impairment, but the whole family unit, specifically when that family member is a child.’ Families will have different perspectives from those of professionals in the disability field and those of the general public. In particular, families know better than most that there are times of great joy with their child. Perhaps the most important reason to consider the family perspective is that it is often necessary for parents to take on an advocacy role with respect to their disabled child. Research which is grounded in the social experiences of people with disability and their families can help redress this imbalance and can contribute to a more inclusive framework to improve the quality of policy and service delivery.

A child with a disability may experience a lifetime of assessments for a host of reasons (Sattler, 1992). Identification and diagnosis of impairment and assessing eligibility for services are two of the most common purposes of assessment, of which the former is often profoundly significant and the latter extremely frustrating (McDonald et al., 2002). For many families, professionals conducting assessments are effectively the gatekeepers to the variety of services and resources that may be needed to support their disabled child (Dowling and Dolan, 2001: 26-27).

Families express dissatisfaction with communication in relation to the periods before, during and after assessment. In particular, communication methods that are insensitive to the family experience ‘... can have a direct bearing upon parents' emotional recovery from the trauma of diagnosis’ (Quine and Rutter, 1994, cited in Case 2000: 282).

There are a number of social factors associated with the experience of disability. For families with disabled children, these interact to produce ‘... unequal opportunities and outcomes in work, leisure, finance and quality of family life’ (Dowling and Dolan, 2001: 21). The effect of these can be far-reaching by impacting on family activities, relationships and future aspirations and plans.

This more social understanding constructs disability in terms of social experiences and perceives disability as an outcome of the relationship between individuals and socio-structures. Social theory pertaining to family experience of disability can be described as *evidence-based*. Models that are evidence-based can provide a

framework that policy makers and service providers can use to understand the experiences of families and thus formulate goals and methods for service delivery.

Methodology

To maximise the utility of a small sample, a mixed methodology was designed, interviewing families who have a child with a disability; and other stakeholders (such as people who provide assessment, family advocacy group representatives) and service providers. Case workers were prioritised over managers, as they have direct contact with families. Focus groups, face-to-face and telephone interviews were employed. Sixteen families were recruited from a variety of backgrounds including, culturally and linguistically diverse, Aboriginal background and differing socio-economic status. The ages of children ranged from five months to eight years.

Service documentation was collected in order to augment the information gained from interviews. They were analysed for evidence of acknowledgement of the importance of early and timely access to services for families.

General issues

Understanding of disability. When asked to define 'disability', most service providers were primarily concerned with the direct implications of impairment to their work. Broader social disadvantages and needs that characterise the experience of disability appeared to be of secondary concern. This contrasts to the broader and more inclusive definitions offered by a number of parents, particularly those with older children who have had time to develop a relationship with their child that is distinct from their child's impairment.

Family characteristics. Whilst none of the families interviewed felt that issues of ethnicity, socio-economic or familial characteristics impacted on their assessments, much of what they said reflected cultural differences in the way they experienced the assessment process. Service providers and advocacy groups on the other hand, explicitly raised this as a major issue. The disparity is most likely due to the fact that individuals tend not to define themselves in terms of broader macro structures, rather than the absence of culture as an influencing factor.

Early intervention. Much of the experience of childhood disability is characterised by waiting – waiting to see how an impairment manifests, waiting for test results, waiting for vacancies to become available. The primary concern of parents here was that their child is missing the window of opportunity to help their kids be all they can be.

Policies and procedures. For many service providers, no formal policies or procedural guidelines were maintained about their practices. Many service agencies had a commitment to verbal communication with families and as a result, had very little printed material. As many workers were in small teams, they preferred to communicate verbally with each other as well.

Suggestions from respondents

Families and service providers made suggestions about some of the key issues, as summarised below.

- Parents and service providers frequently suggested better links and communication between service providers and awareness of the services offered by different agencies.
- Many respondents mentioned transport as one factor that would make it easier for them to attend to the needs of their child with a disability as well as those of other family members.
- Respite was often mentioned as a way for families to maintain family life and alleviate stress. Family support and advocacy group representatives raised this as an important issue, particularly in the early days before families receive services.
- Service organisations able to provide some generic services for all family members was mentioned as being offered by some service providers.
- Both families and service providers suggested client support and centralised assessment to reduce the need to have the same tests for different services and agencies.
- Families urged that professionals delivering results of assessments should acknowledge the child and family's strengths and discuss how these strengths could assist the child and family manage the impairment.
- Family advocacy groups reported that contact with other families in similar situations was invaluable in providing emotional support, information, networking and the sense that they are not alone.
- Families asked for opportunities to meet with professionals outside the clinical setting. A representative for a family support group gave an example of this where families and professionals participate in seminars.
- Parents asked for more direct involvement in the development of support services so the support is relevant and sensitive to their needs.
- Parents suggested revisiting options for assessing children in their own homes. They insisted that parents should be present. In the exceptional circumstances preventing this, they suggested that a full explanation of the reasons and the outcome of the assessment should be given.
- Parents suggested that to 'fill the gap' in contact that waiting lists involve for families, information needs to be given regarding other support services that are available. They thought peer support through informal support networks would be most suitable. They also emphasised that respite services to help families maintain family life would also help with the distress experienced during this period of isolation.
- Families suggested that service agencies should communicate their assessment outcomes and service provision decisions to families based on the child's capacities rather than on the impairment. For the most part, clinicians interviewed talked about the impact of disability on the family in terms of the child's development and capabilities.

Implications for supporting families

Principles emerged from the research to support families for agencies assisting families who do not wish for a diagnosis, are in the process of receiving assessments or as follow-up to assessment.

Communicating assessment outcomes

1. Present brief information in the first instance.
2. Give families the positive information as well as the negative.
3. Give the family a fact sheet about the impairment.
4. Provide opportunities for follow-up.
5. Refer families to a peer support agency.

Principles for support during assessment

1. Communication and connections
2. Holistic approach
3. Family-centred perspective
4. Open door policy
5. Targeted services
6. Networked and coordinated services
7. Cultural awareness and inclusiveness

Supporting families through the assessment process

We recommend allocation of responsibility to support and inform families when their children are being assessed. Two parts to the models are proposed: responsibilities for supporting families allocated within all assessment services and an independent service for supporting families.

1 Introduction

Expectant parents experience a range of exciting and daunting emotions when they are anticipating their baby's birth. Often there is much that is needed in terms of support and plans are made to accommodate the arrival of their baby.

Yet few parents are aware of the possibility that their baby may have additional needs. Parents may have considered issues around having a child born with impairment in the context of antenatal testing during pregnancy. The birth of a child who has an impairment is however, for most families, an alien and unfamiliar experience, which may have a profoundly negative impact on what is otherwise a joyous occasion.

The ultimate intention of assessment is to facilitate the positive life experience of the child and their family and assist them to attain their full potential. It is via the outcomes of assessment that a family often begins to learn the characteristics of the impairment their child had been diagnosed with and the support they may require. However, little scrutiny has been directed toward the nature of the assessment process itself or what support needs families may have specific to the assessment process. Considering the often lengthy and repetitive nature of assessment, it seems highly likely that there are a number of unidentified needs experienced by families who experience this process.

A need for this kind of analysis emerged from the responses of families who participated in a study conducted by Families First in the Inner West in 2001 about general support needs of families with young children (Families First Inner West, 2002). This project represents the intention of Families First in the Inner West to further explore families' experience of assessment.

Over recent decades there has been a growing recognition that our awareness of social issues is influenced by the concepts and language we use. Challenges to prejudicial attitudes and stereotypes have resulted in changes in the way we talk about disadvantaged groups. This process has also been going on in the disability field where terms which have negative connotations are beginning to give way to descriptors which are more acceptable to people with disabilities.

At the same time there has been a growing realisation that an individual's experience of disability is much more than just the direct effects of a particular condition. This has given rise to a distinction in terminology which identifies 'impairment' as the condition an individual experiences, usually defined by a medical diagnosis. 'Disability' on the other hand has come to be understood as the experience that is imposed on people as a result of their impairments. Disability is a form of social oppression in the same way we understand sexism and racism. This experience results from the way that society is organised so that people with impairments face physical, social, organisational, attitudinal and economic barriers. A simple example might be where a wheelchair user would be disabled by buildings that have stairs but not if a ramp or lift is included in building design.

The terminology used in this report reflects this distinction between impairment and disability. Exceptions are in the literature review where different terminology is used in other jurisdictions, when someone is quoted or where the meaning is clear from common usage.

2 Literature Review

Most parents can be considered as the experts where their own children are concerned. Much of the family research conducted would support this, as parents are most often considered to be reliable and valid informants on their children's lives (Gilding, 1991). However, with parents of children with disabilities, an overview of research shows that the views of professionals are frequently favoured over those of parents (Shakespeare et al., 1999, cited in Case, 2000). New approaches to understanding disability as a social experience and not primarily a medical problem has seen the inclusion of family views as an emerging priority in contemporary research. The current study is a contribution to this research.

2.1 Family Perspective

The importance of including family views has been demonstrated in a number of recent papers. Through in-depth interviews with 38 families, Dowling and Dolan (2001: 24) concluded that '... social organisation disables not just the family member who has an impairment, but the whole family unit, specifically when that family member is a child.' It would appear that focusing solely on the disabled child is not to her benefit, nor to the benefit of any other family member. In order to improve outcomes for children with disabilities, a family perspective needs to claim a more central place in the attention of researchers and policy makers.

Families will have different perspectives from those of professionals within the disability field and those of the general public. In particular, families know better than most that there are times of great joy with their child. Case, for example, found that '... parents describe their children as attractive, friendly, happy and interested/bright' (2000: 281). This is a finding shared by Rosenau, who through her long experience working with families of disabled children, has found that words such as 'benefit', 'joy', 'cool' '... are terms used by people with disabilities or their family members to describe their identity or experience' (2002: 1).

Perhaps the most important reason to consider the family perspective is that it is often necessary for parents to take on an advocacy role with respect to their disabled child. A number of qualitative studies indicate the need parents express to 'fight' for the services and support their children need (Case, 2000; Ali et al., 2001; Banks et al., 2001). There may be a number of reasons for this, but commonly it relates to the differential perceptions parents and service providers have of children with disabilities (for example, Bhattacharya and Sidebotham, 2000). Brown (1998, cited in Case, 2000) describes this phenomenon by employing an 'orchestra' analogy. The professional power that service providers hold can result in a lack of advocacy and control by parents: 'In short, [parents] lack the ability to advocate for their child, due to professional control of the parent-professional relationship' (Case, 2000: 272). Research which is grounded in the social experiences of people with disability and their families can help redress this imbalance and can contribute to a more inclusive framework to improve the quality of policy and service delivery.

2.2 Assessment

A child with a disability may experience a lifetime of assessments for a host of reasons (Sattler, 1992). Katz (2000: 1) lists some of these as being:

...to determine progress on significant developmental achievements; to make placement or promotion decisions; to diagnose learning and teaching problems; to help in instruction and curriculum decisions; to serve as a basis for reporting to parents; and to assist a child with assessing his or her own progress.

Identification and diagnosis of impairment and assessing eligibility for services are two of the most common purposes of assessment, of which the former is often profoundly significant and the latter extremely frustrating (McDonald et al., 2002). For many families, professionals conducting assessments are effectively the gatekeepers to the variety of services and resources that may be needed to support their disabled child (Dowling and Dolan, 2001: 26-27).

Research regarding views on the assessment process indicates the dual effect of receiving a diagnosis and a name for a condition, referred to as a 'label'. It often allows access to services that would otherwise be unavailable (Maino, 1995). However, labelling can be detrimental if it results in over-medicalisation of the child's condition. There are problems associated with the labelling of impairments in explaining certain behaviours that may have alternative explanations (Hanks and Poplin, 1981). There is also evidence to suggest a restriction of opportunities for those who have received a diagnosis of an impairment (Gillman et al., 2000). A partnership approach between families, the individual family member with a disability and professionals is considered to be the best approach to this problem (Gillman et al.).

2.3 Holistic Approach to Family Needs

Llewellyn et al. (1996) found that families were concerned about aligning their child's needs with those of other family members; with the difficulty of integrating their child with a disability into day-to-day family life; and current and future effects on siblings. The authors identified the need for service providers to respond to families' experiences, caring responsibilities and capacity and resources for managing family life as individual and unique to each particular family. They also found that placement options should support family decision-making and take a holistic approach to their child's needs (1996: 3-4).

2.4 Information and Communication

Case found that '... families believe that they have only received useful help or advice from the parents of other disabled children. Consequently, parents view professional advice as inadequate, citing a lack of concern, support, information, knowledge and co-ordination' (2000: 282). This dissatisfaction was expressed in relation to the periods before, during and after assessment.

In particular, communication methods that are insensitive to the family experience '... can have a direct bearing upon parents' emotional recovery from the trauma of diagnosis' (Quine and Rutter, 1994, cited in Case 2000: 282). Such experiences may also influence choice of service providers, which means that if there are no alternatives, families may decide to bear the whole burden of care by themselves, which may not be in their best interests or the best interests of the child. If families feel their needs are not being heard and therefore, will not be met, it is not surprising that some may choose to live without service assistance.

Reports from families suggest that service organisations should encompass access to information (eg. seminars, counselling, alternative therapies) and availability of services (eg. speech therapy and respite care). Families respond positively to human, skilled intervention, rather than an abrupt, uncaring and negative manner (Case, 2000: 282).

2.5 Family Characteristics

There are a number of social factors associated with the experience of disability. For families with disabled children, these interact to produce ‘... unequal opportunities and outcomes in work, leisure, finance and quality of family life’ (Dowling and Dolan, 2001: 21). The effect of these can be far-reaching by impacting on family activities, relationships and future aspirations and plans.

The association between disability and poverty is well known. Fujiura and Yamaki (2000) discovered trends in childhood disability prevalence and interactions with economic status, particularly a greater risk of disability in single parent households and an increasing relationship between poverty and risk for disability. It is notable that they also found no additional risk associated with racial or ethnic status after controlling for income. One of the most comprehensive surveys of people with disabilities in Britain (conducted between 1985 and 1988) revealed that three quarters of parents with a disabled child said they did not have enough money to care for their child. Families with children with disabilities were also found to have significantly lower income than other families (Beresford 1994, cited in Dowling and Dolan, 2001: 23).

Closely associated with poverty is employment. In Britain, mothers with disabled children were found to be much less likely to be in employment than their peers. However, research shows that many would like to work and that maternal employment provides material and social resources and is associated with lower levels of stress (Dowling and Dolan, 2001).

2.6 Models of Disability

A variety of models of disability exist, reflecting the development of ideas since disability was first identified as a phenomenon in need of critical appraisal.¹ The two models of disability most often referred to are the *medical model* and the *social model*.

Medical model of disability

The medical model conceptualises disability as a quality of individuals and equates disability with impairment.

Case (2000: 274-275) neatly summarises the limitations of the medical model:

... the course of medical supervision focuses upon symptoms.
Therefore, medical professionals treat the symptoms of disability

¹ For a brief but thorough explanation of other models, particularly individual social and psychological models, refer to Case, 2000.

rather than the needs, concerns and problems of the disabled child and the parents, perpetuating a form of 'social oppression' (Oliver, 1996).

Social model of disability

The social model constructs disability in terms of social experiences and perceives disability as an outcome of the relationship between individuals and socio-structures. 'The individual is being disabled, not by their impairment, but by the failure of society to take account of and organise around difference (Dowling and Dolan, 2001: 24).' In this way, society is intolerant of the inability to walk, yet be perfectly accommodating of people who are unable to sing.

The strength of the social model of disability lies in having been developed by people with disabilities themselves. This '... has led to a transformation in our understanding of disability over recent decades (Campbell and Oliver, 1997, cited in Dowling and Dolan, 2001: 24).'

Social theory is not created in a vacuum; it arises out of people's experience and is reflective of their culture. As such, social theory pertaining to family experience of disability can be described as *evidence-based*. Models that are evidence-based can provide a framework for which policy makers and service providers can understand the experiences of families and thus assist to orient their position from which to work; and formulate goals and methods for service delivery.

The social model of disability is particularly applicable to the study of family experience of assessment, as the interactions between family members and assessment service providers are inherently social. This project endeavours to elicit the experiences of families in the Inner West by employing a framework based on the social model of disability.

3 Methodology

3.1 Interviews

Given the experiential emphasis of this project, a qualitative methodology was selected. This type of design has the advantage in that the themes and issues that are elicited take priority over representation and generalisation. This means that the method would be successful even with a small number of families (Miles and Huberman, 1994).

To maximise the utility of a small sample, a mixed methodology was designed. Of primary importance were interviews with families who have a child with a disability. Interviews were also conducted with other stakeholders (such as people who provide assessment, family advocacy group representatives) and service providers (Appendix C). Case workers were prioritised over managers, as they have direct contact with families. Case managers are thus expected to have an understanding of services and resources offered to families, barriers they face in accessing needed services, gained directly from the experience of the families themselves. Both focus groups and face-to-face interviews were employed, depending on what was preferred and convenient for the participants. Telephone interviews were also conducted with some service providers.

Sixteen families were recruited from diverse backgrounds including, culturally and linguistically diverse, Aboriginal background and diverse socio-economic status. The ages of children ranged from five months to eight years.

Interview schedules are in Appendix A.

3.2 Documentation

Service documentation was collected in order to enhance the information gained from interviews. They were analysed for evidence of acknowledgement of the importance of early and timely access to services for families. This component of the methodology was planned with the understanding that such documentation may not be available or comprehensive in all service agencies. As such, a detailed text analysis was not feasible in this project.

Two types of documentation were examined: public brochures to inform the public and service providers about the assessment process or how to access support for children with disabilities and their families; and policy and procedure manuals describing the processes that should be followed in assessing the needs of children with disabilities and their families.

4 Findings

For many families, it was not always possible to separate assessment from their experience of services designed to meet on-going needs. There is not always a clear delineation between assessment and ongoing support, since assessment can be a continuing process as a child develops and needs alter accordingly. Assessment has many purposes: to diagnose an impairment; to monitor developmental progress; to evaluate the effectiveness of initiatives introduced to manage impairment; to determine whether a child qualifies for a particular service or intervention; and for an organisation's programming purposes. Therefore, much of the information families gave relating to experiences other than assessment-based has relevance to the objective of this report.

4.1 General Issues

Understanding of disability

When asked to define 'disability', most service providers were primarily concerned with the direct implications of impairment to their work. Broader social disadvantages and needs that characterise the experience of disability appeared to be of secondary concern.

Within our setting, we think of all of our children as having additional needs. And we would see some of those children have a diagnosed disability, so they are labelled if you like, they have a name. And there's a mix of physical and intellectual disability. And I guess there's something therefore that hinders them from adjusting to mainstream programs. And particularly within the limits of staffing in mainstream programs. *(Service provider in education)*

This contrasts to the broader and more inclusive definitions offered by a number of parents, particularly those with older children who have had time to develop a relationship with their child that is distinct from their child's impairment.

He doesn't see the world the way we do, he doesn't understand the way we do. He thinks differently and acts differently. *(Mother of a four year old)*

Family characteristics

Whilst none of the families interviewed felt that issues of ethnicity, socio-economic or familial characteristics impacted on their assessments, much of what they said reflected cultural differences in the way they experienced the assessment process. Service providers and advocacy groups on the other hand, explicitly raised this as a major issue. The disparity is most likely due to the fact that individuals tend not to define themselves in terms of broader macro structures, rather than the absence of culture as an influencing factor.

We're good at doing rapid assessments, because low socio-economic families tend to drop out. They have a threshold of coping – you assess, start doing some work and then they reach above their threshold and drop out. When they come back later on, they'll say 'oh, we were OK last time', but by OK they can just cope. *(Service provider in clinical practice)*

Newly arrived refugees and some migrants have been through trauma. So it takes a long time to unravel what's gone on before that in terms of disability. Considering their emotional state, it's not always appropriate to find out. Building trust takes time and practical issues can take precedence. *(Service provider in clinical practice)*

I had all these tests done privately. I'm lucky, I was working. I had the money. *(Mother of a four year old)*

This has been extremely traumatic, but we're lucky. We're lucky we've got each other, so in terms of external support, we've got a great family, we've got a very tight group of two or three friends who are unbelievably supportive. And we're no better than anybody else, but we're fortunate in the people we're surrounded by and the upbringing we've had, which has obviously given us the ability to assess and deal with situations. *(Father of a five month old)*

One service demonstrated just how effective it is to operationalise cultural awareness in practice:

In the past, we had funding for a Vietnamese-speaking worker and that had a huge impact. At that time, the service was not only open to children with special needs, it was open to the wider community. And we had lots of Vietnamese-speaking families there and all the time she was with us, the momentum grew and it was absolutely fabulous. And from that we got to know a few children who hadn't been identified as having issues but in fact did. And we were able to offer help. We don't have that worker anymore and I think we all stood here and said 'yeah, look at the demographic of who we have here now, they're predominantly English-speaking people again, gosh, we've lost the very people who probably need it most of all!' *(Service provider in clinical practice)*

However, an Aboriginal support worker identified the need for culturally specific workers to have a thorough understanding of disability:

They still talk to you like you're deaf, you know? Culturally specific services have got good communication skills, but the problem is they don't have an understanding or they're limited in their approaches to disability. *(Advocacy group member and father)*

Early intervention

Much of the experience of childhood disability is characterised by waiting – waiting to see how an impairment manifests, waiting for test results, waiting for vacancies to become available. The primary concern of parents here was that their child is missing the window of opportunity to help their kids be all they can be.

Early intervention is really important and you do get the best of your child. If they're going to improve dramatically, the key is to put a lot of work in the child when they're young. *(Mother of a six year old)*

Quite often they're a real conduct disorder, but we don't put that label on kids at an early age, but we know that the intervention is much more successful if we intervene at an earlier age. *(Service provider in clinical practice)*

With autism you need to do things early, not to cure, but to give them a chance at a normal life. *(Mother of a four year old)*

My wife will spend two hours a day on specific things that the physio has said 'if you do this, he will do that'. And he's in the game, he's doing what other babies his age do. *(Father and mother of a five month old)*

Policies and procedures

For many service providers, no formal policies or procedural guidelines were maintained about their standard practices.

There's not policy on that as far as I'm aware. I'm just used to doing that so that's the way I structure my working relationships. *(Service provider in clinical practice)*

Many service agencies had a commitment to verbal communication with families and as a result, had very little printed material. As many workers were in small teams, they preferred to communicate verbally with each other as well.

This may pose problems for families at times, as the experience of the following mother suggests:

When she was diagnosed with Downs Syndrome with the amniocentesis, I was offered an ethics committee hearing to look at the possibility of letting me have an abortion. They said, when I found out on the Thursday, that they wanted to call me at 10 o'clock on Monday morning and I'd have to have decided by then. So I did feel quite a bit of pressure on the time thing. I had an appointment with the hospital psychiatrist on the Monday morning and I told him that I left my mobile phone on and I explained to him that they would be calling me to see if I'd made up my mind. And he was horrified. He was really angry that that sort of pressure had been put on me. And they're all at the same hospital. *(Mother of a five month old)*

4.2 Key Issues and Suggestions from Participants

A number of key issues were raised by parents as being of importance to them and reinforced by many service providers. The qualitative approach used in this study allowed participants to make suggestions about these issues. This section describes these issues in turn.

Holistic approach

Families expressed the importance of a holistic approach to their needs. This means that, in order for families to maintain family life, services that target impairment in isolation of other needs may do little to enhance families' coping abilities. It is important to note that families did not require services to meet all of their family needs. Most of the needs families reported required minimal outlay.

A holistic approach is essential given that other family members, particularly siblings, can feel neglected and isolated from the family.

My youngest got very upset about it and she just stayed away from me, I guess because she just felt left out. Because we were focussing a bit on our daughter with the disability. She was always sitting on my lap in the evening, but she just stopped that. I know she was feeling inside, she was hurting. *(Advocacy group member, reflecting on her adult child with a disability when she was diagnosed)*

The lack of generic or inclusive service delivery can also result in a disabled child being isolated from their own family.

The services tend not to be part of the ordinary places, like some sort of community centres or early childhood centres. They're off somewhere special, a spastic centre or DoCS office or whatever. So it doesn't meet the family needs. The families then have to rearrange their whole lives around it, rather than having the special support their child might need as part of other places where they're likely to be near children. *(Advocacy group member)*

Service providers noted the importance of including the whole family in consultations. This includes having all primary caregivers present and the importance of including siblings.

Suggestion: Parents and service providers frequently suggested better links and communication between service providers and awareness of the services offered by different agencies.

I think from the perspective of families, one of the problems is they're dealing with a whole bunch of separate little systems that are perhaps not as well connected as they could be. *(Clinician working for a government department)*

An example of where links between service organisations were evident reflects the benefit of this to the family:

We have said many times since our son was born, we cannot believe how well the system works. It is there, the communication – who needs a copy of this information? That one, that one, that one. They know each other. It's well integrated, it's fabulous. *(Father of a five month old)*

Suggestion: Many respondents mentioned transport as one factor that would make it easier for them to attend to the needs of their child with a disability as well as those of other family members. This included disability parking permits for those whose children had a behavioural impairment.

A lot of NESB families haven't got their licenses, so they're restricted to trains and travelling by bus. We're lucky in that we are on a direct bus route and we're near to a station. *(Service provider in clinical practice)*

We can't get the disabled parking permits because he has autism. So all these appointments we have to go to take so much longer and it's really hard when I have to pick my other kids up from school and sport stuff. And it's so stressful, because you know, you have to cross the road with him and he runs off, it's not safe. *(Mother of a five year old)*

Suggestion: Respite was often mentioned as a way for families to maintain family life and alleviate stress. Family support and advocacy group representatives raised this as an important issue, particularly in the early days before families receive services.

We could have really done with some respite. That would have been just fantastic. I don't need it so much now because I have her at preschool three days a week. When she was unwell, you wanted to be with her when she was sick. But just to go out to the movies. *(Mother of a four year old)*

Suggestion: Service organisations able to provide some generic services for all family members was mentioned as being offered by some service providers. One service

found this to be particularly useful for families in juggling the disability-specific needs and the mainstream needs of all their children:

As far as the general needs go, we are able to respond to them if necessary. And that's particularly important, people use that for immunisations. We have children who have chronic ear problems. So we can intervene at that sort of level. *(Service provider in child care)*

Self advocacy and the process of seeking support

Many respondents across the different groups raised the issue of the pressure on parents and their varying capacity to continually lobby for the required tests, to receive a diagnosis and for support services they may need. A number of families said that they had to make a lot of noise in order to receive services. Many of them raised as a negative issue the necessity for parents to approach multiple agencies to receive one service.

So much of what you get depends on the degree of resolve families have to go through multiple services. Most people, if they're told there's a one-year waiting list, that's the last time they try. *(Advocacy group member)*

I think the nature of the problem for parents is, they have to look after the child and at the same time they've got to run around and find services. And it's absolutely exhausting, because you're trying to cope with the stress of having a child with a disability and you don't know where to go. And I can remember sitting with a telephone book and just ringing and ringing and ringing. *(Advocacy group member and mother)*

I asked the Department why the long wait. They told me that autism was not prioritised. So I went off my head and that's when I got homevisiting. *(Mother of a four year old)*

Most parents reported a convoluted process involved in assessment and in accessing services. A certain level of skill was expected of them in understanding and completing forms, which for some parents was a difficult and time-consuming task. This was especially the case for parents with an intellectual disability. Parents reported no support in helping them with this essential requirement. Many reported having to complete the same forms a number of times for the same support service or agency.

The degree of success families have in accessing services depends on how good you are on paper. *(Advocacy group member)*

If you get over a hurdle with a service like that, you get this siege mentality, you're doing this fight for your life. We've had a lot of good outcomes for our son, but only because we've had the resolve and the ability to deal with them, we're not intimidated. *(Advocacy group member and father)*

The amount of application forms you have to fill in, like to get after school care funding, I had to pay for a psychologist to do a behavioural management plan. Even though the school had one. It was like, this one's not a good one, so I had to chase around to different doctors. He already had a diagnosis and assessments, but he kept going through the process and it seemed like the person would read the form and he'd get so far and find something wrong and it'd get sent back. And then he'd read a bit further down and say 'now I need another thing'. It was quite an involved process. *(Advocacy group member and father)*

Suggestion: Both families and service providers suggested client support and centralised assessment to reduce the need to have the same tests for different services and agencies.

There used to be case workers, so each child would get a case worker. That's long gone. And that was a supportive person that got to know the child. *(Service provider in clinical practice)*

I've been here 17 years so I've got a longitudinal view and I think what's basically happened is 10 years ago, it was a coordinated service. Everyone in early intervention diagnosis working together. Now it's a whole bunch of separate little silos doing their own thing with not enough dialogue going on between them. *(Service provider in clinical practice)*

Negative experience

Many parents felt extremely dissatisfied with the emphasis clinicians and service providers placed on the deficits their child's impairment represented. Parents felt that they were given a bleak outlook for the future.

We find what families tell us in terms of diagnosis and assessment is it's usually an overwhelmingly negative experience. There's always the shock and there's never a right way to tell difficult and bad information. Families feel that it's all negative, negative, negative. People who have older children might have reasonably positive ideas about how this child really isn't so different to any of their older children. They're told they have unrealistic expectations, they're finding the system is trying to 'box' them, give them doom and gloom scenarios. *(Advocacy group member)*

Suggestion: Families urged that professionals delivering results of assessments should acknowledge the child and family's strengths and discuss how these strengths could assist the child and family manage the impairment.

Most impairments are likely to have a range of outcomes and varying degrees of restriction. Parents reported that they would have appreciated being made aware of the range of possible restrictions that may be associated with their child's impairment, rather than only the worst-case scenario. As the following example demonstrates, parents who were encouraged to focus on their child rather than on the impairment

felt less distressed and were willing to 'wait and see' what the future would bring for their child:

The doctor pointed to the cot and he said 'you focus there. Nowhere else. Just focus there. That's all you've got to do.' (Interviewer: So did that change the way you were thinking or feeling?) Well it changed my feeling a lot because the internet will frighten the life out of you, but my son looks just like any other baby. So I felt reassured. (*Mother and father of a five month old*)

Isolation and lack of emotional support

Parents often described the moment of diagnosis as 'a point of crisis' and 'complete shock'. The amount of information they were expected to take in at that time was for many overwhelming. Many parents felt at a loss as to what to do and where to go. Many parents felt they were left to deal with a very new and alien experience by themselves. Additionally, many families felt that professionals misinterpreted their emotional state and as a result they were not offered the emotional support they required.

I was absolutely devastated. You can't believe it's happening to you, you want answers – we don't smoke, we don't drink we're healthy, so why? Are my husband and I not compatible? So confused, you don't know where to go, where to look, what's right, what's wrong. You're lost, because it's a new thing to learn. (*Mother of a four year old*)

Parents can present as being neurotic and overwrought and really, they're not, it's a grief process, that's what happening to them. They'll come through it, they'll come out the other side, they are quite aware what's wrong with their child. They're quite aware that their child does have problems. Quite often when a child with a disability achieves something, when they've been told they won't walk, won't talk, whatever and they say one word they can be seen to be in denial, they're so excited at one word being spoken. (*Advocacy group member*)

Many parents reported that the initial information they received was inadequate and out-of-date, too technical and not designed for the purpose of informing parents. Many also reported the lack of an opportunity for follow-up. Many service providers were also found to be unaware of what was offered by other service agencies.

Suggestion: Family advocacy groups reported that contact with other families in similar situations was invaluable in providing emotional support, information, networking and the sense that they are not alone.

Opportunities for counselling needs to be looked into further, as the experience of this mother would suggest:

One of the big gaps I feel that's involved with amniocentesis and the diagnosis is that there's no counselling. There's absolutely no counselling around that period. So the amniocentesis happened a

couple of hours after I had the scan. It wasn't forced on me by any means, but nobody actually counselled me to say, there's going to be a period when you're waiting for the results, think about what you're going to do rather than fingers crossed, fingers crossed. In hindsight I would have kept my cards much closer to my chest if somebody had said to me, think about what the rest of the pregnancy is going to be like knowing about the disability. Because it put a huge dampener on the pregnancy. There was a lot of gloom and doom until I gave birth, so that whole period was very stressful, very depressing. (*Mother of a five month old*)

The following service provider made a further useful suggestion:

They need those opportunities to establish networks with families of children with disabilities, but not just sort of lumped in all together. They need the opportunity to meet families who have a kid with a similar disability; that's a real need. (*Service provider in education*)

Written information that is up-to-date and available from accessible locations (such as public libraries) is essential. This information needs to be provided in alternative formats such as Easy Language and audio tape.

One family focus group made up of mothers mentioned the difficulties their husbands experience in accepting their child's impairment, particularly as they were reluctant to attend information sessions during work hours or in the evenings. These mothers felt that public education via television and radio would not only benefit their husbands, but it would assist in community awareness and acceptance of people with disabilities.

Communication between families and professionals

Many families found it difficult to communicate with professionals, particularly medical staff, as the clinical setting is often a rushed and uncomfortable environment. Many parents also felt that their initial concerns were not taken seriously when they raised them with professionals. There were a number of examples where gaps in communication led to parents being kept in the dark and the outcomes for their children less than optimal.

People, especially the early childhood centre, should understand that babies sometimes have real problems and that it's not just a first-time mother thing.' (*Mother of a four year old*)

I listened in on a case conference. They were transferring information from one set of staff to the next and everybody else thought that somebody had told me and it's like 'excuse me'. And everybody went into denial. So it's just that, it's really basic, that somebody has to take responsibility. (*Advocacy group member and mother*)

The paediatrician did have the possibility of autism in his notes, but he didn't tell me because he needed some records. I had those

records! I didn't know they would help him! I could have had that diagnosis six months earlier. *(Mother of a four year old)*

Suggestion: Families asked for opportunities to meet with professionals outside the clinical setting. A representative for a family support group gave an example of this where families and professionals participate in seminars.

We have seminars where the professionals get to see patients outside a clinical setting. That means the families show a side of themselves the professionals don't get to see in a clinic. *(Advocacy group member)*

Lack of freedom to criticise and complaints procedures

If support services were received, many parents felt unable to complain if they were dissatisfied. This is linked to the long waiting lists for services that many of them experienced.

But with a lot of service providers you always felt like they lived by the creed that you should be grateful for the services that you receive ... in a lot of cases that's why people are quite often very reluctant to, not so much make complaints about service, but questions services. There's not a lot of money to go around and you're lucky to have the service type of thing and I've been in people's office and I feel like they're opening their own wallets and handing the money from their own pocket. And it's awful, humiliating. Where to me, kids with disabilities should expect the same rights as kids who don't have the disability. You wouldn't put up with certain standards with your other kids and why should you have to put up with them just because your child has a disability. *(Mother of a six year old)*

And they're fitting you into a box. You're not even getting to choose the box and a lot of services are offering a box and you take it or leave it. You take the way in which they offer the service or you don't get anything at all, rather than being able to kind of influence it. My personal experience and the experience of a lot of others is, if you ask for something different, you're treated in a very negative way. *(Advocacy group member and mother)*

You don't get the services unless you make a noise and if you make too much of a noise they gang up on you. *(Advocacy group member and father)*

I still needed to know what the cause was. So I went to see another paediatrician who gave her a blood test and tests on the chromosomes and hereditary factors. And after that, the paediatrician realised that I had seen another paediatrician and because of that she refused to see me. She discontinued seeing me. *(NESB mother of a two year old)*

Families find that in order to get support, they have to parade out everything, having to kind of put out there in the public domain in order to get any kind of assistance. And you have to be enormously grateful and all those kinds of things. (*Advocacy group member*)

At worst, parents reported that clinicians attributed their child's impairment related challenging behaviour to bad parenting and began proceedings to have families assessed by DoCS for the possibility of removing their children. Once these families opted out of the system, there were no alternative sources of support available to them.

They basically did an assessment of us and maybe we weren't up to looking after our son and maybe sooner than later would be a better time for foster care. And this was very close to our assessment. They tricked us into going to a hospital to get a psychological assessment about my wife which obviously made us very scared because we thought they had the power to take the child away from you. So we ended up saying we don't require any services any further and we don't want any further contact. So we were in the position where we had to deny my child services. So we have to do all our own advocacy stuff. We have to coordinate all the services that he gets, which has created a huge problem because we haven't got a case officer. And a lot of different types of funding dealing with government departments want case officers to sign off on things. (*Advocacy group member and father*)

I found out that the Director of the preschool, without my knowledge, behind my back, went to DOCS and made a referral for long-term residential care for a boy with an intellectual disability when he has cerebral palsy. So she's kind of misunderstood the whole thing and because I was so unrealistic, I was obviously crazy trying to get a child with cerebral palsy into a preschool. So she thought his interests would be better served in residential care and that's happening behind my back. (*Advocacy group member and mother*)

Suggestion: Parents asked for more direct involvement in the development of support services so the support is relevant and sensitive to their needs.

The following example of best practice was given by a service provider:

Our policy's very much about giving parents information about the assessment process and what their options are and then for them to say I don't feel comfortable about the fact you're going to use a formal tool that's going to give my child a standard score, or OK, yes the score system, we're going to need that. What we do in our process each year is we hold, offer, individual service plan meetings. It's offered biannually to every family, now that's a requirement by our funding body to document people's wishes and to make sure that we're setting goals, it's an accountability thing. But it's also a very valid thing in terms of the parents for them to sit

down and review how the last six months have gone and what they would like and whatever. In that process we say to them, what are your comments, what's the progress you've seen in Fred in the last six months, again it's driven by them, it's not driven by us. What do you see as being his strengths, what do you want to prioritise for the next six months and then out of those priorities, we also ask if we are the only service they use and we list all those they're using and we say out of the priorities, how would you like to achieve those? The programs that we have here are driven by the parents primarily by what they've said they would like to see. It's driven by the parents and their priorities are utmost. We may not necessarily agree with the list of priorities and we may say to them 'have you thought about this' or the impact of that is, we could deal with such and such but only when he's got this. Because they may not have thought about the process it would take. So in order to achieve the objective parents want, we have to say well we need to do this first. And they say OK, that's fair enough. They're asking us for a professional opinion and we're giving it. They may still not want to go down that track, but again that's their choice. *(Service provider in clinical practice)*

Context of assessment procedures

Many parents felt that clinicians had not gained an accurate representation of their child's abilities because assessment procedures isolated the child from their usual environment. Some parents were not allowed to be present for the assessment, which was distressing for both parents and children alike.

One of the downsides to the big developmental assessments is that it's done with people this child has never met before, in a totally foreign environment and it's often a very lengthy process for both child and parent. One of the things that's happened recently is that when some children have been going into the big assessment centres, we've just seemed to have had an incredible explosion of children falling into the autism spectrum disorder. And I don't know whether that's an assessment procedure that's happening, or it's because people haven't got the bigger picture, or our tools for assessment are better at detecting this. But there would be a good 25 per cent that we've received reports from and thought 'what? No way!' We would be in disagreement. We think 'this is not the child that we see, week by week.' *(Service provider in clinical practice)*

When they did the complete assessment, we weren't allowed to be there. And just the timing of it. We know that our children have low attention spans but they're able to do things, but because they were told to sit and do it right there and then, they automatically got assessed and it wouldn't have been right. *(Advocacy group member and mother)*

And how awful to put kids where they have to be assessed without their parents or with strangers. No one, with or without a disability, can function well in that situation. *(Advocacy group member and mother)*

Suggestion: Parents suggested revisiting options for assessing children in their own homes. They insisted that parents should be present. In the exceptional circumstances preventing this, they suggested that a full explanation of the reasons and the outcome of the assessment should be given.

Waiting lists and waiting times

Virtually without exception, parents reported experiencing waiting lists and long periods without any form of support service.

Then there was a big, big long gap of time, months and months. Which was a terrible gap for me in hindsight, just feeling more and more sick and tired but also in denial as well; that everything would be alright. We had been referred and I think we were just on a waiting list for months and months and months. And I didn't have any information about any services. I was just so struggling to survive that I didn't have any energy to look for services myself. *(Mother of a four year old)*

A lot of families experience serial waiting times – a couple of months at each referral. Nobody really supporting them through that process. *(Service provider manager)*

We really need to see kids within two and four weeks of referral and continue to see them while they're waiting for other services. *(Service provider in clinical practice)*

Suggestion: Parents suggested that to 'fill the gap' in contact that waiting lists involve for families, information needs to be given regarding other support services that are available. They thought peer support through informal support networks would be most suitable. They also emphasised that respite services to help families maintain family life would also help with the distress experienced during this period of isolation.

Labelling

Having a name for their child's condition was a major issue for both families and service organisations. Families reported that, even if they did not necessarily feel it was important to have a name, they either could not access services or found it extremely difficult to get the support they needed without it. Service providers understood the reason why families did not always want a label for their child, but most did not feel they could operate their services without the label.

It was brought up at a service meeting that even though DET prefer to have a psychometric score, families don't actually have to do that. It's just a longer, harder road to go without that score. *(Service provider in clinical practice).*

Suggestion: Families suggested that service agencies should communicate their assessment outcomes and service provision decisions to families based on the child's capacities rather than on the impairment. For the most part, clinicians interviewed talked about the impact of disability on the family in terms of the child's development and capabilities. This approach could be employed when communicating with families as well.

At young ages you're looking at child's development across a broad number of areas, not just their cognitive functions, development across all areas. And I think that there's the medical component as well, looking at, are there sort of disorders there medically that are causative or associated with it that need to be addressed in some way, because there's a high probability of those. Just looking at the child's needs in general, given that they have something that's gone wrong with their development. We also identify what the issues are for particular families and they can be as individual as there are families, so for one family toileting may be a major issue for them and I think to know that's a major issue for them and that comes out of an assessment of needs, you take actions to try to address that. Whereas for another family even though the child might be developmentally very similar, other things may be of issue. I think that's part of the issue as well. *(Service provider in clinical practice)*

I think we focus on identifying strengths as well as deficits. It's important to convey the information without stress as well as identifying weaknesses and their needs for ongoing support. We certainly try to look at all areas of need, as well as their strengths. *(Service provider in a family support service)*

5 Implications for Supporting Families

This section discusses possible implications for three of the major aspects of assessment that families experience: communicating assessment outcomes, principles of support during assessment and supporting families through the assessment process. The implications are relevant to assisting families who do not wish for an assessment, are in the process of receiving assessments or as follow-up to assessment.

The section draws on the range of suggestions from the research participants (discussed in the previous chapter and summarised in Appendix B) and interpretive analysis of the researchers. The suggestions further develop the principles of the Families First strategy and other service reforms.

5.1 Communicating Assessment Outcomes

Families and providers reflected upon the progressive path of disability assessment, whereby most children are involved in complex assessment over a prolonged period, with the possibility of ambiguous outcomes rather than clear results. It is important that families understand that there is no set path their child's impairment will take and that their child has strengths that will help them and their family manage the disabling impacts of the impairment.

There was a clear message from families about better ways to be presented with assessment outcomes. The steps below are complementary and combine to produce a five-step model for communicating assessment outcomes. Service providers need to respond to individual needs of each family, so the families have options about the level of information they need to know and the format they receive it in.

- 1) **Present brief information in the first instance.** Families cannot usually learn everything about their child's impairment when they are first presented with assessment outcome information. Their initial distress may mean that they are unable to immediately absorb large amounts of information. Families need to be given time to ask any questions, allowing the initial information exchange to be parent-led as much as possible.
- 2) **Give families positive information as well as the negative.** Focussing on the positive features of children with disabilities is not denying there is a problem or giving parents false hopes. It is being realistic.
- 3) **Give the family a fact sheet about the impairment.** Fact sheets about impairments specifically designed for families should be distributed whenever verbal information is presented. This should reinforce, not replace, verbal information exchange. Families can use fact sheets to refer to following an assessment when they are learning about the impairment. They also help in the process of informing family members, friends, schools and others in their networks. Fact sheets should be written in easy language, available in alternative formats and in a variety of languages.
- 4) **Provide opportunities for follow-up.** Families need opportunities to ask further questions following an assessment. At the time of communicating the outcomes, two appointments should be scheduled for follow up visits (families can cancel these appointments if they do not feel they need them). Parents

should also be given a contact number and be encouraged to make contact by phone as questions arise.

- 5) **Refer families to a peer support agency.** Service providers should provide a list of peer support services to families during the assessment and again at the time of communicating the outcome information. The Guide to Disability Services in the Inner West an example of a list designed for this purpose. The lists need to be kept up-to-date. Service providers need to be reminded regularly of its existence, have access to the lists and be familiar with the content.

5.2 Principles of Support during Assessment

This section describes the qualities that families would like to see in the support that assessment agencies provide and build on the principles of the Families First strategy.

Communication and connections

Families need to be recognised as the primary experts in the management of assessment and support for their children and family members. The implications of each step of the assessment process need to be discussed with families for them to effectively manage their child and family's needs. Information needs to be accessible in person, written and in alternative formats.

Families and children need assistance to make links to informal support and form new peer support networks to be able to make connections with people in similar circumstances. Access to additional information and support from counsellors is essential for some families to help them understand what each new occurrence means for them and how they will deal with its impact on their lives.

Holistic approach

An important aim of services should be to maintain the family unit. This represents the essence of early intervention and a core value of the Families First Initiative. This does not mean simply early specialised services, but inclusive or generic services that promote family life.

Family-centred perspective

Families need the opportunity to be partners in the directions of service delivery, program design, management design and connections with other participants in the assessment process. They need access to ways of having input into the way services are managed and into the programs in which their children participate. This means options for families such as family representation on management committees or a parent advisory committee. Other examples are regular reviews with parents regarding their child's progress and other mechanisms to enable family perspectives to be included in program delivery, respecting families as an expert in their children's lives.

Open door policy

It is essential that families can access support without a formal medical diagnosis.

Targeted services

Assessment agencies need to prioritise early intervention. This will assist families to gain an early understanding their child's impairment and manage the child and family's changing support needs. Families may need assistance to manage changes in both the child's development and the impairment. They may also need assistance with assessments that are progressively conducted over time. There are times when intensive support may be needed particularly while families learn how to navigate the service landscape.

Networked and coordinated services

Families may be assisted by connections between agencies, including common assessment instruments, information collection and information distribution. First points of contact for families, such as general practitioners and teachers, as well as clinicians and specialists in the disability field need to be familiar with disability support services. Disability awareness training conducted by people with disabilities should be considered as a professional development activity for workers in assessment and service delivery organisations.

Cultural awareness and inclusiveness

Service providers need to employ or have access to workers with culturally specific understanding, experience and skills.

5.3 Supporting Families Through the Assessment Process

Many families, services and support organisations expressed the benefit of having a single, first point of contact for families to assist them in navigating the service landscape and offer interpersonal support as they learn about and come to terms with their child's impairment.

The fact is that there's no sort of adequate case management type service that can really know what we want and be able to talk as a professional. I know that professionals are going to talk a lot more freely to each other than they necessarily will to a client. *(Advocacy group member and father)*

And I think that if we're going to help families, it has to be so that they can make one phone call and be referred around from there. *(Advocacy group member)*

What you need is a personal approach to it. And you need someone there to support you through that process, to be there as a mentor, as a counsellor, as an advisor. Rather than being transient, they're there until you're comfortable and they're comfortable that you've been through the grieving process. So that you're not going into panic mode, or you're not stressing out. *(Mother of a six year old)*

We recommend allocation of responsibility to support and inform families when their children are being assessed. Two parts to the models are proposed: responsibilities for supporting families allocated within all assessment services and an independent service for supporting families.²

² The experience of some families with formalised case management in the disability community is negative, having a passive role of being told what is best for them. In contrast, the basic premise of the proposed model of supporting families puts the family in the control

Responsibilities for supporting and informing families

Staff responsible for supporting families would focus on explanation, information and referral, counselling and family support. The primary responsibility would be to offer current, thorough and timely explanation, information and referral when families have questions and identify their needs.

An important component of the role would be to canvas both generic and disability specific organisations for products, services, peer support and other opportunities to enhance family life.

So that families can develop a trust relationship with a consistent person across an agency, the person with support responsibility would need to be adequately skilled to provide explanations about the process and outcomes, basic counselling and interpersonal support when required and have disability awareness training.

Responsibility for supporting families within assessment services

In the first part of the model, responsibility for supporting families could be allocated within government and non-government organisations involved in assessment, such as the Central Sydney Area Health Service Early Childhood Health Home Visiting Service and the Department of Ageing, Disability and Home Care Community Support Teams. Assessment service staff could be allocated the role or staff could be employed from the client support auspicing body as in the second part of the model. Principles of family-led decision-making and participation in the design of services would be more difficult to maintain in this part of the model. However, if responding to information needs and supporting families was seen by the assessment agency as an essential element of effective assessment, the model could have the advantage of greater access to support by more families.

Family directed service

The second part of the model would be to allocate complementary responsibility to an external agency with specific role of supporting families through the assessment processes. Not all families would require this level of information and support. A family directed organisation would need to be inclusive of the principles above that families deem important to disability service provision. These support services could be auspiced to non-government organisations throughout the Inner West, so that their geographical coverage could be maximised. The management committee would include a majority of parent representatives.

Criteria for award of the auspice could be based on an organisation's history of family-led decision-making and participation in the design of services, as well as other factors such as cultural awareness. Continued funding for this role could be based on the conduct of regular, individualised reviews with parents to assess the progress of children and to ensure that families' needs and expectations are being met.

of the support. In doing so, the model can be described as assisting families to meet needs as identified by the families themselves, rather than telling them what they need.

6 Conclusion

Assessment is an essential element for families developing a plan for managing the progression of their child's impairment. Families need to understand as much as possible about the challenges facing them and their child.

Of equal importance for developing a plan for the future is an awareness of the qualities children with disabilities share with all children and as such, they will be enjoyed and celebrated and loved. It is important in those early stages of learning about their child's impairment that parents are made aware of this as well as the challenges they face in the future.

Incorporating a family-centred perspective in the delivery of assessment and support services is the best way of ensuring that a balanced perspective is employed in identifying and meeting the needs of families with a child who has a impairment. Adopting such a perspective also provides a valuable opportunity for families to contribute to the development of a more inclusive framework for policy development. The families in this project have illustrated some of the difficulties that the disability experience can present. Yet many of them could relate to the sentiment of this father who so eloquently described his experience: 'We don't know what lies ahead. We can say, if this is as bad as it gets, heaven can't be this good. My son is an absolute delight.'

Appendix A Interview Schedules

Family Interview

Families First Inner West is seeking to investigate what happens for families who have a child with a disability at the point of assessment and identification of the child's disability. The research is examining this experience from the perspective of both the families themselves and the service staff who assess and diagnose children.

We would like to discuss your experience of assessment, your views on what works in the current assessment system and how it could be improved to better meet the needs of your family.

Themes

- How well services met the needs of their family through the assessment process
- How family characteristics affected the assessment process
- Beliefs and values re: disability and assessment

Schedule

1. Can you tell me a bit about [child's name]?
 - Age, disability, daily activities outside the house (school, childcare)
2. Tell me about the time when you first knew that something was 'different' about [child's name].
 - When, what happened, how you felt
3. Tell me about the process you went through from the first time you tried to get help, the assessment process, to the time that you received a diagnosis.
 - Who, how you found out, what happened, how you felt
 - Information given - written, oral, other; for whom in the family, how did you feel
4. Did the characteristics of your family have an impact on the assessment process, and were these taken into account? In what ways?
 - Cultural, siblings, health, other family members with disability, SES, extended family, sole parent, where you live - transport, isolation
5. What happened after the assessment process?
 - Referred to services? What kinds?
6. How well did those services meet the needs of your family (both as a family and individual members)?
 - MASTER NEEDS LIST: medical/therapy, social, childhood, family/parenting, educational, participatory
7. Was there anything else your family needed but didn't get?
 - Information, support, services; who in the family; MASTER NEEDS LIST
8. How would you describe [child's name] disability? What about other people?
 - Professionals, other family members, anyone else?
9. How is [child's name] doing now?
10. Is there anything else you feel is important about [child's name] assessment that we haven't covered?

Service Provider Interview

Themes

- How service providers perceive, determine and meet the needs of families
- Their understanding of disability
- Any connections, associations between assessment and support services

- How sole parent, low income, sole parent and culturally diverse families impact the way they do assessments.

Schedule

1. Can you describe what your role is in an assessment process for families of a child with a disability?
2. How do you define 'disability'?
3. Thinking about the families you come into contact with during assessment, what are their needs and how do you meet those needs?
 - Are there any other types of information and support you provide to families and for what purpose?
 - MASTER NEEDS LIST: medical/therapy, social, childhood, family/parenting, educational, participatory
 - Families' input in the assessment process; what sort of input, degree of importance
4. Are you aware of networks or connections between your service providing assessment and those providing support services? Could you describe your participation in them?
 - Information, structures, referrals, joint training, informal/formal, meetings etc.
5. How do the differences in family characteristics impact on your assessment process?
 - Cultural, siblings, other family members with disability, SES, extended family, sole parent, where you live - transport, isolation
6. What do you think works in the current assessment system and how it could be improved?
7. In your opinion, what does assessment achieve/what is the purpose of assessment?
8. Is there anything you think is important about the assessment process that we haven't covered?

Other Interested Groups Focus Group

Themes

- How well they think families are supported through the assessment process
- What they think assessment achieves for families
- Their role in supporting families

Schedule

- 1) Can we start with you each briefly describing what your service provides to families of a child with a disability?
- 2) How do you define 'disability'?
- 3) Thinking about the families you come into contact with, what are their needs during assessment and how are those needs met?
 - MASTER NEEDS LIST: medical/therapy, social, childhood, family/parenting, educational, participatory
- 4) Are you aware of networks or connections between your service providing support services and those providing assessment? Could you describe the participation of relevant groups in those networks?
 - Information, structures, referrals, joint training, informal/formal, meetings etc.
- 5) How do the differences in family characteristics impact on the assessment process?
 - Cultural, siblings, other family members with disability, SES, extended family, sole parent, where you live - transport, isolation
- 6) Finally, what do you think works in the current assessment system and how could it be improved?

Appendix B Suggestions from Respondents

- Parents and service providers frequently suggested better links and communication between service providers and awareness of the services offered by different agencies.
- Many respondents mentioned transport as one factor that would make it easier for them to attend to the needs of their child with a disability as well as those of other family members.
- Respite was often mentioned as a way for families to maintain family life and alleviate stress. Family support and advocacy group representatives raised this as an important issue, particularly in the early days before families receive services.
- Service organisations able to provide some generic services for all family members was mentioned as being offered by some service providers.
- Both families and service providers suggested client support and centralised assessment to reduce the need to have the same tests for different services and agencies.
- Families urged that professionals delivering results of assessments should acknowledge the child and family's strengths and discuss how these strengths could assist the child and family manage the impairment.
- Family advocacy groups reported that contact with other families in similar situations was invaluable in providing emotional support, information, networking and the sense that they are not alone.
- Families asked for opportunities to meet with professionals outside the clinical setting. A representative for a family support group gave an example of this where families and professionals participate in seminars.
- Parents asked for more direct involvement in the development of support services so the support is relevant and sensitive to their needs.
- Parents suggested revisiting options for assessing children in their own homes. They insisted that parents should be present. In the exceptional circumstances preventing this, they suggested that a full explanation of the reasons and the outcome of the assessment should be given.
- Parents suggested that to 'fill the gap' in contact that waiting lists involve for families, information needs to be given regarding other support services that are available. They thought peer support through informal support networks would be most suitable. They also emphasised that respite services to help families maintain family life would also help with the distress experienced during this period of isolation.
- Families suggested that service agencies should communicate their assessment outcomes and service provision decisions to families based on the child's capacities rather than on the impairment. For the most part, clinicians interviewed talked about the impact of disability on the family in terms of the child's development and capabilities.

Appendix C Service Types Included in the Research

Services that provide assessments to these children and families

- NSW Department of Ageing, Disability and Home Care
- CSAHS Community Child Health
- Department of Education and Training
- Tumbatin Clinic, Sydney Children's Hospital; Child Development Unit, Children's Hospital Westmead; Neonatal King George, Silver Star, Ingrid Gregan; Genetic and Radiology Services at King George V Hospital

Services that provide support to children and families following assessment or independent of an assessment

- Early intervention agencies
- Disability information and advocacy services: indigenous, family and genetic.

References

- Ali, Z., Q. Fazil, P. Bywaters, L. Wallace and G. Singh (2001), 'Disability, ethnicity and childhood: a critical review of research', *Disability and Society*, 16 (7), 949-968.
- Banks, P., N. Cogan, S. Deeley, M. Hill, S. Riddell and K. Tisdal (2001), 'Seeing the invisible children and young people affected by disability', *Disability and Society*, 16 (7), 797-814.
- Bhattacharya, M. and P. Sidebotham (2000), 'Parental and professional perceptions of the levels of disability in children with Down's Syndrome', *Ambulatory Child Health*, 6, 153-163.
- Brown, S. (1998), 'The orchestrated body: an anthropology of embodiment and experience in brain injured children', PhD, University of Edinburgh.
- Browne, G., C. Byrne, J. Roberts, A. Gafni and S. Whittaker (2001), 'When the bough breaks: Provider-initiated comprehensive care is more effective and less expensive for sole-support parents on social assistance', *Social Science and Medicine*, 53 (12), 1697-1710.
- Case, S. (2000), 'Refocusing on the parent: What are the social issues of concern for parents of disabled children?' *Disability and Society*, 15 (2), 271-292.
- Dowling, M. and L. Dolan (2001), 'Families with children with disabilities - inequalities and the social model', *Disability and Society*, 16 (1), 21-25.
- Families First Inner West (2002), *Providing Information, Education and Support to Families – Understanding Parent Needs*, Families First Inner West, Sydney, forthcoming.
- Fujiura, G.T. and K. Yamaki (2000), 'Trends in demography of childhood poverty and disability', *Ambulatory Child Health*, 6 (4), p. 286.
- Gillman, M., B. Heyman and J. Swain (2000), 'What's in a name? The implications of diagnosis for people with learning difficulties and their family carers', *Disability and Society*, 15 (3), 389-409.
- Hanks, M. and D.E. Poplin (1981), 'The sociology of physical disability: A review of literature and some conceptual perspectives', in M. Nagler Ed. (1990), *Perspectives on Disability*, Paolo Alto, CA: Health Markets Research.
- Katz, L. (2000), 'A developmental approach to assessment of young children', *ERIC Digest*, <http://ericae.net/edo/ED407172.htm>.
- Llewellyn, G., P. Dunn, M. Fante, L. Turnbull and R. Grace, R. (1996), 'Families with young children and disabilities and high support needs: Report to ageing and disability department', University of Sydney, Sydney.
- Maino, D. (1995), *Diagnosis and management of special populations*, Mosby, St Louis.
- McDonald, L., G. Kysela, J. Drummond, C. Martin and W. Wiles, *Assessment of the Clinical Utility of a Family Adaptation Model*, <http://www.quasar.ualberta.ca/cfrp/famadap.html>. Accessed 16/10/02.
- Miles, M. and M. Huberman (1994), *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd edn, Sage Publications, Thousand Oaks.
- Rosenau, N. (2002), 'The social construction of disability: Challenges to Counsellor Ethical Practice', unpublished paper.
- Sattler, J. (1992), *Assessment of Children*, 3rd edn, Jerome Sattler Publisher Inc., San Diego.