

# ‘LOOK ING AT THE WORLD DIFFER ENTLY’

THE EXPERIENCE OF HAVING A  
CHILD WITH ADDITIONAL NEEDS



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Prepared for Noah's Ark Inc by Dr Gay Ochiltree and John Forster



Much has been written about children with developmental delays and disabilities and their learning needs. Less is heard about the ripple effect that a child with a disability can have on their family. Relationships on many levels can go through adjustments. There are extra demands on time and resources.

At times the media reports on situations in which the stresses of having a child with a disability becomes too much. These often sensationalised stories do not reflect that, out of love and necessity, families more often keep going, building the additional demands into their daily routines.

In developing this report Noah's Ark was conscious that this story, the efforts by so many families to keep going and enjoy life together as best as they are able, needs to be told and told frequently. The services and supports that exist currently to offer help are too few and too difficult to access.

Making these stories known is important in building community awareness.

The second reason Noah's Ark needed this report was to help provide the context in which we provide Early Childhood Intervention Services. These services are focussed on creating learning opportunities for children with disabilities. The scientific evidence, such as that presented in the influential 'From Neurons to Neighbourhoods' has highlighted how important supportive carers are during the vital early years. Families play the key role in their child's learning. We need to understand how what we do supports the way families are already tackling the additional demands.

We would like to express our appreciation to the mothers who were willing to share their experiences. It is their stories which fill the following pages and help us understand the joys and challenges of raising a child with a disability.

John Forster  
CEO

# CONTENTS

<b>INTRODUCTION</b>	<b>1</b>
Why Noah's Ark is undertaking this project:	1
Overall objectives of the project	2
<b>FAMILIES WHO HAVE CHILDREN WITH ADDITIONAL NEEDS: WHAT THE LITERATURE HIGHLIGHTS</b>	<b>3</b>
Social inclusion of children with disabilities	3
Family life in the preschool years	4
Life for families with children with additional needs	5
Stigma and social exclusion	5
A lack of resources exacerbates social exclusion	6
Support from services	6
Recent research on family adaptation	7
<b>PROJECT DESCRIPTION</b>	<b>8</b>
Selection of sample families	8
Family characteristics	8
Child characteristics	8
The Process of sample selection	8
The families in the sample	9
The interviews	9
The Diagnosis	10
What changed after diagnosis?	11
Where did you turn for help?	13
Family support	13
Support of friends and social networks after diagnosis	14
Experience of other families with a child with additional needs	15
Experience with Noah's Ark services	16
Experience of child care and kindergarten	17
<b>PARENTING</b>	<b>18</b>
What does having a child with additional needs means to you as a mother?	18
What have you learned as a parent?	19
Aspirations for the child with additional needs	20
The Community	22
The parental relationship	23
<b>DISCUSSION</b>	<b>24</b>
Experience of children's services	25
Parenting and personal development	25
Conclusions	26
<b>REFERENCES</b>	<b>27</b>
<b>APPENDIX 2</b>	<b>28</b>
Project Interview – cue questions	28
Employment	28
The child	28
Parenting	28

## INTRODUCTION

### WHY NOAH'S ARK IS UNDERTAKING THIS PROJECT:

A wide range of factors, such as family income, mother's employment and how close the family is, affect family wellbeing, but families with a child with additional needs have additional demands and complexities to deal with (Noah's Ark 2002, 2003). Having a child with a disability can impact on parent's perceptions of themselves as a parent, their family life, their social networks, and their relationships within the wider community. It will also affect their goals for the child. The most recent information available from the Australian Bureau of Statistics indicates that 8 per cent of Australian children under the age of 15 years have a disability and 4 per cent of these children are under 5 years of age.

Recent research emphasises the importance of the early years for the development of all children including those with disabilities. It is now recognised that children's development in all domains: physical; cognitive; social; and, emotional, is not simply dependent on maturation and factors within the child but is influenced by factors within the family, within the community, and within the culture into which they are born and are brought up (Centre for Community Child Health 2001). This recognition of the significance of the early years has led to appreciation of the importance of appropriate services to support not only the child but also the family.

Over the past three decades our understanding of what promotes the development of young children with disabilities has evolved from a focus on the child and the educational and therapeutic activities that can extend his or her abilities, to a more social and ecological approach.

The later view recognises the importance of the child's family and the broader community in providing learning opportunities, emotional support and a healthy environment.

This approach recognises that much of what a child with disabilities needs is the same as any child.

Our new understandings of what supports a child's development has a significant implication for how we provided services. Early models of early childhood intervention often replicated the kindergarten model when family and child or the child came to a 'class' during which specific activities were undertaken. A second stage involved highlighting the role of the parent as the child's "first teacher" with take home activities. Some services evolved into home visiting services, although the focus remained on similar activities. As the importance of family life has become more evident, greater emphasis has been placed on setting goals that are high priorities for families and on activities that are useful for everyday living.

Entering into these new relationships with families is a complex task that is taking services into as yet uncharted waters. It involves understanding the complexity of families, the realities of family life and the sources of concerns that families have.

Only on this basis is it possible to start work with families to identify priorities for action. It broadens the focus from the child's well being to the family's well being, particularly the well being of the child's principle carer. At Noah's Ark this emphasis on the role of families has seen the development of the 'key worker' role, where the worker works closely with both the child and the family in a strengths-based manner. This project has been undertaken to raise some of the issues in working more closely with families who have a child with a disability.

The project involved talking with a selected group of mothers (principle caregivers) using Noah's Ark services not only to hear about their experience of having a child with additional needs, but to find out what has affirmed them as parents and what has supported their wellbeing. It builds on an earlier Noah's Ark report on 'The social dimensions of disability'. (CCH, 2003)

# 'LOOKING AT THE WORLD DIFFERENTLY'



The report is in two major sections:

- The introduction of the report describes the project and its objectives and includes the methodology and literature relevant to the project.
- The second part of the report is an analysis of the interviews with the twelve mothers focusing on the objectives of the project followed by discussion of the findings.

It must be remembered that this is an investigative study only, which illustrates the complexity of family life in families that have a child or children with additional needs and to examine the pathways taken by these mothers. The focus is on the processes involved in adapting to the additional needs of the particular child and of accommodating the needs of the rest of the family. Any positive changes that have occurred are also discussed.

### **OVERALL OBJECTIVES OF THE PROJECT**

- To inform policy makers about the complexity of family life with a child with a disability.
- To inform practitioners (particularly new staff) about the range of factors they need to consider when working with families.
- To examine what supports the wellbeing of families who have a child with additional needs.
- To inform further research.

The project will explore the factors associated with well being in families with a range of different family and child characteristics. While it has been mothers of children with additional needs who have been interviewed, the focus is on the family and not just on the child. The project has attempted to move beyond a focus on grieving to the ways in which families reconcile the needs of the child with the needs of the family as a whole and of family members. This project looked at:

- How the parents, and in particular the mother, negotiate the changes involved in their child's development;
- What changed when they realised that they had a child with a disability;
- Where they turned for help and who supported them;
- What affirmed them as a parent and as a family;
- What their goals and aspirations are for their child and for the family;
- How they perceive community acceptance of disability and additional needs; and,
- Which services have been helpful?



## FAMILIES WHO HAVE CHILDREN WITH ADDITIONAL NEEDS: **WHAT THE LITERATURE HIGHLIGHTS**

Families of children with additional needs have challenges which are extra to those of families with typically developing children as they cope with the emotional and practical issues that arise. The care-giving demands are usually greater and take up more time and energy and there are greater financial costs. These families experience more strains than other families but they vary in their responses and in the nature of their adaptations. It is possible for parents in these circumstances, particularly mothers, to become isolated if their life is entirely taken up by caring for the child with additional needs and they do not have the range of relationships that most parents have. The well-being of all families including those with children with additional needs can be affected by a number of factors including low income, poor housing, lack of social support, lack of connections and ill health. The well-being of the family as a whole is important for the well-being of children.

Research evidence has shown that the greatest and most enduring influence of children's development is the family and in particular the parent-child relationship. Children's development is also influenced by the community within which they are raised. These community influences include the availability of children's services and support for parenting, the safety of streets and parks and the general feeling of trust among residents.

Culture also plays an important part as it influences parenting styles, beliefs and values and views about how children should behave and be educated (Shonkoff & Phillips 2000).



### **SOCIAL INCLUSION OF CHILDREN WITH DISABILITIES**

In most developed countries, including Australia, current government policies support the inclusion children with disabilities in the provision of services, keeping with the United Nations Convention on the Rights of the Child Article 23, to which Australia is a signatory. This Article '...recognise(s) that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate the child's active participation in the community' (UNICEF 1990). In other words, all children have a right to feel that they belong in the community regardless of race, culture, disabilities or any other attribute.

These days the inclusion of children with additional needs is important not only in early childhood services such as child care and kindergarten but in broader aspects of community life such as leisure services, swimming classes, playgrounds and playgroups, as it affects the opportunities of these children for optimal development and learning and for social interaction (Centre for Community Child Health & Noah's Ark 2003). However, the greater participation of young children is dependent on the capacity of their family to support such involvement. This means that there is a need for services and policies that support families as a whole in order to enhance their capacity to maintain young children in inclusive activities. Understanding how to support families adds a different layer of complexity that is different from supporting children as individuals.

Understanding families involves considering family roles and relationships and the perspectives of family members as well as professional perspectives. Families come in many forms that go beyond the usual definitions of partner and 'blood' relationships (Morris, Hughes, Clarke, Tew, Mason, Galvani, Lewis & Loveless 2008). Nonetheless, all families remain the most important source of individual support, mutual interdependence and wellbeing. For family focused services to be effective, understanding the diversity of families is of great importance in order to prevent some families from facing barriers to the use of mainstream services just for being different.

For services to be family focused there must also be recognition of the realities of family life and the sources of problems must be understood. It must also be recognised that some of the difficulties faced by 'at risk' families will also be shared with families who belong to less marginalised groups.

One way to consider families is within an ecological framework where family relationships are seen within a series of interacting settings and relationships, starting firstly with the micro setting of the home and family, secondly extending to the neighbourhood and educational and service settings, and thirdly the macro setting of society (Bronfenbrenner 1986). This ecological approach includes the influences of cultural and linguistic diversity and the interactions between the different settings, for example, between the parent's workplace and family life. When the development of children with disabilities is framed in ecological terms it takes account of the wide range of influences on child outcomes.

## FAMILY LIFE IN THE PRESCHOOL YEARS

In order to understand how having a preschool child diagnosed with a disability can affect families, it is useful to reflect on this period of family life more specifically. Family life is not static and is ever changing as children are born, grow, start school, leave home and so on. Families with babies and small children in the preschool years have different experiences, different

stresses, and different joys, from families with older children. The birth of the first child is the first major life course transition in any family and although it is usually anticipated with pleasure parents must make major adjustments to their everyday lives (Ochiltree 1998). These changes are, as a rule, greater for mothers than for fathers as they usually involve giving up paid work, physical changes in their bodies, and change in their everyday social contacts as well as care of their baby. The early years, as children are growing and changing rapidly, are not always easy for parents as they cope with lack of sleep, learning how to be a parent, and adapting to a changed life style. However most parents enjoy watching their children's developing capacities and anticipating their developmental milestones and parents often compare their own child's development with that of other children (Guralnick 2004). Sometimes parents worry unnecessarily if their own child is slower than others in some aspect of development or are pleased if they are ahead. The birth of second and subsequent children changes the family dynamics once again and the parents and siblings must adjust their lives to the new family member. The suspicion that a child may have a disability and additional needs adds another dimension to the common everyday stresses of this period of family life.

When their child is diagnosed with developmental problems that '... are likely to be substantial and life-long' parents are usually stressed as their fears are confirmed and their expectations of the future for their child are overturned (Guralnick 2004, 120). However, they must come to terms with their additional responsibilities as they and their children interact with the community, extended family, specialist services and professionals, and with the preschool services and the education system as they seek assistance and support for the child. This is not easy for parents.

Guralnick (2004) points out that all parents invest considerable effort and resources that are both psychological and material in the development of their children whether they are developing typically or have disabilities and additional needs. There are three categories of these family investments. The first is the quality of the parent-child relationship, including the sensitivity and responsiveness of the parent; the second is family arranged experiences for the child which include not only the provision of appropriate toys and social experiences but also a suitable child care environment; and, the third is the health and safety factors provided by the family, including proper nutrition, immunisation, the accessing of health care as needed and avoiding the experience of emotional hazards such as the

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witnessing violence. However, where children have disabilities it often affects each of these three areas of family investment: parent-child interactions, the types of family arranged child experiences including social experiences that are available, and health and safety provisions for the child's additional needs.

### **LIFE FOR FAMILIES WITH CHILDREN WITH ADDITIONAL NEEDS**

In order to cope with additional demands associated with having a child with additional needs families must adapt their daily routines to fit in the extra care required and to make time for any extra appointments with professionals and services as necessary (Berheimer, Weisner 2007). These adaptations or accommodations change over time as the demands of family life change not only in regards to the child with the disability but to other family members also. These changes can affect the well-being of the family as a whole; sometimes for the better and sometimes negatively. For example, an Australian study of primary school aged children with disabilities and high support needs found over time that the well-being of some 'thriving' families could suffer a down turn that was associated with events or circumstances that upset established family routines (Llewellyn, Thompson, Whybrow & McConnell with Bratel, Coles & Wearing 2003). On the other hand, up turns in the well-being of some families were associated with improvement in financial resources, satisfaction with the child's school situation and progress, additional help for the family and other factors which improved family life. Family well being, like family life, is not static but can be affected by changes in circumstances over time.

There is the potential for three common forms of family stressors that can affect the family's ability to accommodate and adapt to the needs of the child with a disability and to the needs of other family members (Guralnick 2004). The first is **the need for information** about the diagnosis and an ongoing need for information that goes beyond the everyday as parents seek supports and services and as they interact with their own social network and family. However, many researchers both in Australia and overseas have found that searching for information is one of the most difficult tasks that families undertake (Owen, Gordon, Frederico & Cooper 2002). The second potential stressor is **the effects on family relationships** including sibling relationships and sometimes there is a feeling of stigma which can lead to social isolation. The third category of potential stressors is **the resources needed by families** including financial and time resources such as, the increased costs associated with professional services for the child, disrupted daily routines and additional time demands. In combination these stressors can undermine the confidence of the parents and change the family's patterns of interaction.

### **STIGMA AND SOCIAL EXCLUSION**

One of the major difficulties reported by parents of children with additional that can make them feel excluded from the community is the insensitivity of people in relation to their child. This insensitivity can be present even where inclusive policies are in place. As far back as 1986 Fullwood and Cronin wrote *Facing the Crowd* about this issue for parents of children with disabilities. Fullwood herself had a child with a disability and had experienced the insensitivity of people to her child. Unfortunately, this



insensitivity can occur with professionals that families come in contact with including the medical profession. It can occur in the intimacy of the family and with friends as well as strangers. Even people that the parents come into regular contact with can be insensitive. Although this insensitivity is usually the result of people's feelings of discomfort in the presence of children with additional needs it is sometimes due to a lack of knowledge that children actually have a disability in the case of children with certain conditions such as autism. This inconsiderateness can cause parents both anger and pain and may cause them to withdraw from activities that they and their child would otherwise take part in. Ultimately, in some families, this can lead to isolation. A 2004 Victorian Department of Human Services survey confirmed this when it found that a third of people were 'active avoiders' responding with fear and uncertainty to people with disabilities.

## A LACK OF RESOURCES EXACERBATES SOCIAL EXCLUSION

Exclusion can result from lack of information and lack of understanding that some families, including those who have children with disabilities, need extra support to access services. Exclusionary factors can include poverty, cultural differences that extend beyond simply language differences, lack of information about what is available, lack of transport and so on (Hayes, Gray & Edwards 2008). Parents, but particularly mothers, have limited opportunity for employment when caring for children with additional needs. Access Economics (2005) estimated that overall the employment rates of primary carers (42.8%) was considerably below the Australian average (59.2%) although it must be remembered that these estimates included carers across the life span and that the employment of carers is predominantly part time (Gray, Edwards & Zmijewski 2008). Employment not only improves the financial situation of the family but it also prevents the social isolation of the primary caregiver (generally mothers). The single most important feature of the experience of families with children with additional needs is lower family income and sometimes poverty (Owen, Gordon, Frederico & Cooper 2002). The time demands of caring for a child with additional needs are also greater than in other families and this is exacerbated if there is more than one child with additional needs.

‘LOOKING AT THE WORLD DIFFERENTLY’

Families from culturally and linguistically diverse communities that have a child with additional needs have been found to use services less, find that many services are not culturally appropriate and lack linguistically appropriate information and it has also been found that these families are rarely represented on the management committees of services (Owen, Gordon, Frederico & Cooper 2002).



### SUPPORT FROM SERVICES

An Australian study, ‘Listen to Us’, that examined issues in supporting the families of children with disabilities aged up to 18 years of age reported that many parents were frustrated with the lack of responsiveness of services to their needs (Owen, Gordon, Frederico & Cooper 2002). It was found that the services available for families with a child with a disability were fragmented and that parents with children who had profound or severe disabilities had to negotiate a complex service system. Many families had difficulty in accessing services and a priority for many of the parents who were consulted was for locally coordinated and integrated services that were provided in a culturally sensitive way.

The ‘Listen to Us’ study found little evidence of long term planning in Australian services and it was suggested that taking an individual and family life cycle perspective is valuable in both service and policy planning. A wide range of different kinds of support are needed over the life cycle of a family and such an approach at state policy and planning level could address some of the issues involved in transitions from one service sector to another. It was also found that families are under-represented in the various bodies which involve stakeholders. There is a need to hear their point of view and where possible the views of children with additional needs themselves. It was recommended that parents, children and young people should be engaged in a ‘genuine partnership with service providers’ at all levels including regional and state levels.

The ‘Listen to Us’ research also found a need for parent education materials appropriate for parents of children with disabilities and especially information about challenging behaviour and general behaviour management.

## RECENT RESEARCH ON FAMILY ADAPTATION

There are two recent studies which examine the patterns of adaptation in families that have a child with additional needs that are worth examining more closely in relation to the Noah's Ark study. A Canadian study of 50 mothers of school aged children with disabilities looked at both the negative and positive aspects of their parenting experiences (Roehr Institute 2000). Eighty per cent of the mothers were the primary caregivers with fathers providing limited support only. More than half the mothers in this study reported that they had suffered from anxiety, depression, or



**‘LOOKING AT THE WORLD DIFFERENTLY’**

stress at times, and three quarters of these had sought help to deal with these concerns. Inadequate support affected all family members and also had an

effect on the marital relationship. Nevertheless, mothers also reported positive experiences.

They believed that they had grown in strength and also in awareness of a wide range of issues. Many mothers (70%) were involved in voluntary work, usually in a service or organisation that was relevant to the inclusion of their children in the community. Mothers also reported developing a range of new skills and confidence, despite the difficulty of balancing this work and the needs of their children. However, it was also found that support from extended family, friends and neighbours was at best only once a week or a few times a month.

Another Canadian study that went beyond a narrow focus on the negatives of having a child with additional needs examined the views, values, and priorities of families with a child with autism or Down Syndrome. A strengths based approach was taken using information from three focus groups, interviews with 15 parents, and interviews with four staff members (King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates 2005). The theoretical basis for the study was previous research that had indicated that the most important factors affecting adaptation and resilience in families are their belief systems as these enable people to create a sense of meaning, purpose and control over continuing life events.

The researchers in this study found four themes in parent's responses to their child's additional needs which indicated adaptation and resilience:

- That the diagnosis was **a life changing experience** and that the original dreams of the parents for the child were lost.
- **They adapted over time:** Parents were motivated to examine their beliefs, to sort out priorities, to justify the decisions that they made and to identify what was really important to them. They also found that hope was important to the parents. Seeing possibilities in the future and creating new dreams enabled them to gain a sense of control. Parents were empowered by realising that they had choices about the way they viewed their situation.
- **Changes in views and values:** Parents developed stronger values in relationship to not only their own families and but for all children. There was also personal growth such as greater understanding of themselves, patience, acceptance, tolerance, perseverance, compassion and unconditional love. They appreciated small joys and learned to respect others more.
- **Changed priorities:** Parents gave up trying to 'fix' the child and focused on what their children could do and in supporting the child to be happy.

## PROJECT DESCRIPTION

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### **SELECTION OF SAMPLE FAMILIES**

Twelve families who were using Noah's Ark services were selected by staff. The families were those where staff thought the principal caregivers, mothers, would be prepared to be interviewed. A reference group of staff discussed the selection of the sample and the characteristics of the family and the children that were important for this project. In selecting the sample an effort was made to represent a range of families supported by Noah's Ark. The following are the family and child characteristics thought appropriate for the study.

### **FAMILY CHARACTERISTICS**

- Eight families from metropolitan locations and four from country areas.
- Families needed to represent, as far as possible:
  1. Those on low incomes - for example families in receipt of Government income support or low income earners;
  2. Those who are comfortably off on good incomes (four families); and,
  3. Those between middle range incomes (four families).

It was not necessary to know exact incomes for purposes of this study.

- The families should be past the initial diagnosis of their child and the accompanying distress stage.
- As far as possible the sample should include some families from culturally and linguistically diverse backgrounds.
- A mixture of two parent, single parent and step-families.
- Families where both parents are employed full or part time, families where only one parent is employed, and those where neither parent is employed.

### **CHILD CHARACTERISTICS**

- Child's condition: a range of physical, behavioural, intellectual, and communication disability.
- Varied number of siblings and position of the child with an additional need/sin the family.
- Mix of boys and girls.
- Only child with an additional needs, or child with siblings who also have an additional need.

### **THE PROCESS OF SAMPLE SELECTION**

Key staff members at the various Noah's Ark services in metropolitan and rural areas were asked to select a number of families attending their service based on the above criteria. These key workers discussed the project and the characteristics of families with staff members who were working directly with suitable families and asked for the names and descriptions of children and families who might agree to be interviewed. These names and descriptions were then sent to the researcher. However, in some services there was actually little choice given.

After selection, the staff member working directly with the families then discussed with each family the possibility of an interview. All families selected agreed to take part in the project and a letter from the CEO of Noah's Ark formally inviting them to take part was given to each family by the staff member. The letter explained the project and told the parents that the researcher would ring them and arrange a time for an interview at a place and time of their choosing.

## **THE FAMILIES IN THE SAMPLE**

Seven of the mothers had children diagnosed with autism, three had children with developmental delay, one had a child with cerebral palsy, and another had a child with a rare genetic syndrome.

Six of the mothers already had an older child or children with additional needs. In two families both the first and second child were autistic, in two families there was an older child with Asperger's Syndrome, and in two families where the subject child had developmental delay an older child or children had the same diagnosis. Nine of the children were the second child in the family and three others were the youngest in a family of more than two children. One child was adopted. There were nine boys and three girls in the sample.

Ten of the mothers were married and two were single parents. Two of the married mothers were in second marriages so the families were stepfamilies but only one of the children with additional needs had a stepfather, the other was the child of the second marriage. Four families lived in rural areas and the rest were spread across different Melbourne metropolitan areas

The majority (7) of mother's perception of their family's financial situation was that they were just getting by financially with little to spare, two families were financially comfortable while three others, two single parents and one whose husband was unemployed, were having a struggle on government benefits. One single parent rented in public housing and the other lived with her sibling. Nine of the families were living in their own home, while another family lived in rented accommodation. Four of the mothers were employed but only one was in the equivalent of full-time work: two mothers did occasional part-time work, one did regular part-time work, and one worked full-time by working at hours that were different from her husband so that he could care for their children when she was at work and she was thus able to run a business.

## **THE INTERVIEWS**

In depth interviews were held with the 12 mothers who were the principal caregivers of a child with additional needs. Ten of the mothers were interviewed in their own homes and two chose to be interviewed in a Noah's Ark location. Most of the interviews took about 30 to 35 minutes and were recorded and later transcribed so that the exact words of the mothers could be used wherever possible.

As the concern of this study was with the experience of the mothers interviewed this research used a qualitative approach and the questions asked were open ended. The interview schedule focused on:

- Family members names and ages and includes information on employment and a broad overview of the financial situation;
- The child with the additional needs, the diagnosis and the experience of diagnosis;
- What changed with the recognition that the child had additional needs and where the family turned for help;
- Family and community support;
- The help of services including Noah's Ark;
- The experience of kindergarten and child care;
- Parenting including what confirmed them as mothers;
- Aspirations for the child with additional needs and how they saw the child's future;
- Perception of community acceptance of children with additional needs and what mothers thought could improve things; and,
- An overall view of the parent's relationship (where appropriate).

The interview was flexible. Because the questions used in the interviews were open ended sometimes the mothers answered later questions in response to earlier questions so the interviews varied to some extent but covered the same content. (See Appendix 2 for interview questions.)

## ANALYSIS OF THE INTERVIEWS

### THE DIAGNOSIS

For the mothers, the diagnosis of their child's disability or additional needs was generally a slow process. Usually the mother first noticed problems with her child's development, often their speech development. If an older sibling of the child had already been diagnosed with a disability or additional needs mothers were more aware of the signs and sought not only a diagnosis but assistance from services more quickly than those where the child was the only one of their children with additional needs. For example:

- *Jared is the third of Carol's five children to be diagnosed with developmental delay but because she already had children who had received early intervention support she was quick off the mark to obtain assistance. She enrolled Jared with Noah's Ark when she was pregnant because of her history, because he was a boy, and because his brother was already there. 'If he had been fine I would have cancelled. I know how hard the services are to get to'.*

Sometimes mothers became aware that their child was developing differently from other children and their typically developing siblings.

- *Ahn's daughter Emma was diagnosed when she was about 18 months old. Emma has a typically developing older sister and her mother could notice the difference. She noticed that Emma 'didn't talk and she didn't look at me'. She took her first to the general practitioner and then a specialist at the Royal Children's Hospital. After a search through various agencies Ahn was supported by early intervention services from when Emma was about two and a half years old.*

The period of diagnosis is not easy for the mothers as their hopes and fears are often in conflict. Some mothers went through periods of recognition that something was wrong but also denial of the problem.



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→ *Judy's son Jack was a different child from when he was a baby but she thought that he was just a serious child that did not smile much. 'I just thought of him as very special and very gifted and very choosy about who he wanted to be around, so he was always a very precious child from the moment he was born'.*

*Because of this, when it was first suggested that she should get him checked out she did not do so. However, he was eventually diagnosed as autistic after many visits to a variety of specialists and other professionals. Although Judy has experienced some wonderful help and support along the way she also found some professionals were quite insensitive.*

Maria, one of the mothers interviewed, described the long and inconclusive process to try and diagnose her son from when he was a baby. The ups and downs of the process were very distressing for her.

- When Maria's son Glen was 6 or 7 months old the parents noticed a problem with his eyes so they took him to their general practitioner and he was sent to the paediatric unit at Monash. This started an ongoing investigation because the doctors feared he might have fluid around the brain causing pressure. He was put into the hospital through emergency but all the tests were negative and all results were normal. He was then sent to the genetics department to see if there was some sort of syndrome present, but again all test results were normal. 'They took pictures, they held conferences, and they could not find anything whatsoever. It was a good thing in a way. They did an MRI scan and it showed the intelligence part of the brain was fine but the nerve part may not have been fully developed yet. They said it was a "wait and see". It was very worrying always having appointments to go to and you have to keep up with everything else. Then we came to a decision. Because he wasn't regressing I got to a point where I didn't want to see anybody, I didn't want to see doctors, and one doctor said he was doing great and the MRI scans were OK. He had to wear a brace for one joint for about 6 months and this delayed him as well. But otherwise after that he kept developing really well and he was getting older and all the doctors were becoming very optimistic so all we know is that he is delayed. He has had several minor surgical interventions



including more recently grommets for his ears (this may assist his language development which at present is delayed). We have reached a point where even his neurologist is very optimistic. He may eventually catch up with his age group. We try to do things'. Glen is now two and a half and attends child care three times a week and Maria is optimistic about his development and his future.

### WHAT CHANGED AFTER DIAGNOSIS?

While the process of the diagnosis has its stresses, and can be drawn out over time, when the diagnosis is actually made the parents have to face the reality of having a child with additional needs and come to terms with what that will mean, not only for the child but for the whole family.

There were two themes in the mother's responses when asked what changed after the diagnosis. The mothers who had no previous experience of siblings with additional needs or disability were shocked and often went through a period of distress as they came to terms with the diagnosis. Where the mother already had a child with additional needs, often with the same diagnosis as the child in this study, the mothers took the diagnosis more in their stride but they also indicated that they had been very shocked at the diagnosis of the older sibling. At this stage of the interview many mothers cried or had tears in their eyes as they remembered the experience and their feelings at the time. But some of the mothers also explained how it had also had positive effects such as becoming more confident and/or accepting of things.

- Val, whose youngest child Lily was diagnosed with a very rare genetic syndrome, revealed the emotional turmoil of this phase. 'Initially our world was turned upside down. What does the future hold for her? All you ever want really is a healthy child. Initially I went through a period of thinking why did this happen to me. Why us? But Lily has probably taken us to a place where I never thought that we would go. I'm on more of an even level and that is the way it should be. The other thing about having Lily is that each milestone that she reaches is an achievement and part of her personality is very social and very accepting of things. You just have to learn to deal with it'.

- When he was around three Bronwyn's younger child Matt was diagnosed as autistic and with ADHD. 'So that started it. I didn't know what autism was. I hadn't seen Rain Man. I was thinking I don't know what it is but I know it is really bad and where do we go and what do we do. That was hard and then, I'm a reader, I love books, love reading but I don't know what a novel is any more. I'm forever reading autism books'.
- For Ahn, who is a Vietnamese refugee, the diagnosis of her second daughter with autism at 18 months was very difficult for her. 'It was a very big change, very hard. Every child is different but with additional needs it is very hard. Her older sister is very close in age so it was very hard for me as she did not understand much. Everything changed a lot. I had not heard of Autism before and I wanted to know what happened'.
- Patricia, whose second child Jon was diagnosed with autism when he was four, explained: 'When you get the diagnosis even though you have had an instinct you get a horrendous shock because you don't know what it means for him and for your family. I was very grief stricken. The feedback I was given was that I was going to look at Jon differently and it's true. My impulse was to tell people because I didn't want to keep it under wraps but I have moderated that now to a "needs to know" basis'.
- Helen, whose second child Miles was diagnosed with autism and global developmental delay when he was around three, explained the changes that happened to her. 'Your mind just changes. Our family life didn't really change because we had always had Miles and he was always different. It changes in your head. I don't know how to explain that. I never took Miles out anyway because he was always too hard to handle, so we spent a lot of our time at home. I'm more accepting now about Miles being who he is in front of other people and not worrying about what other people think of us and how we are managing. Having Miles has made me more confident. Initially it set me back but it has brought me out more. I'm more happy with who I am in my life and I'm not worried about anybody else whereas before I was more insecure but I have had to deal with people and get my point across for Miles and to speak for him. It makes you more out there'.

Mothers who already had a child with a diagnosis of disability or additional needs were much more matter of fact about the diagnosis of the second child although they often referred to the shock of the first child's diagnosis.

- Jelena said: 'Nothing changed when I realised David had special needs as I was used to it from first child with developmental delay. I have to use a different way of teaching him – every child is different'.
- Andrea's son Justin was diagnosed with autism the same as his sister, when he two years of age. Andrea explained that what changed was: 'Double the work and I wasn't shocked because I knew what to expect. I was more shocked with the first one. He was not talking, not babbling at 18 months, and I thought these are the same signs and took it from there. I knew how to deal with it. You just do what you have to do'.
- Carol has five children, three of whom have developmental delay. When her third son showed the same signs as his older brothers by the time he was 12 months old she was prepared and had already enrolled him with Noah's Ark.



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## WHERE DID YOU TURN FOR HELP?

When mothers were asked where they turned for help at the time of diagnosis, most mentioned early intervention services and/or a professional in the field who guided them and occasionally, they mentioned a family member. The answers to this question were limited as it appeared to be tied to the diagnosis stage rather than seen as a separate thing. At the time of diagnosis one mother, who had a sister with an intellectual disability, returned to a counsellor who she had seen previously for some personal help. A number of mothers mentioned that their husbands were not helpful at first because they processed the information about their child's diagnosis differently or were in denial. For most, but not all, this difficult stage in the relationship eased with time.



A few mothers reported needing to adapt their house to cope with their children's additional needs. These were mothers who had very active children with autism. The changes involved putting locks on windows and doors, putting electrical switches and plugs higher on the walls and sometimes putting barriers on doors and balconies.

## FAMILY SUPPORT

Eight of the mothers had received some family support when their child was diagnosed. Of the four mothers who received no family support it was either because their parents had died or because they lived too far away. In the case of Ahn, the refugee, her sister has been a great and ongoing support as she and her children live with her. However, most of the mothers recognised that the support family, mostly parents and parents-in-law, can provide is limited for one reason or another. Mothers see themselves as taking the real responsibility.

- *Maria: 'Really just my husband and my parents. But really it is just 'you'. These people come and go and make time for you but it's you by yourself. You are alone!'*
- *Bronwyn: 'Mum's in Melbourne. The in-laws are here but they really don't understand. They will take my daughter but they won't take him. They don't accept him. You read all the things about it (autism) and then you've got to explain and some people just don't get it'.*
- *Jelena: 'My parents and in-laws provide ongoing support. But I don't want to bother them too much with my problems as they have their own problems. The kids are hard for them to handle as they are so hyper. They see the differences as a problem with this generation of children and they don't realise that these children have additional needs. They occasionally have them overnight and give us a "little break".'*
- *Val: 'We were very fortunate with both sides of our family, my husband's family live around here and his parents live next door. They were terrific and my family live several hours away. But my Mum and my sisters were all very supportive. Not so much now but earlier there would be frequent visits. I tend to be reasonably independent so I find that asking for help hard'.*

## SUPPORT OF FRIENDS AND SOCIAL NETWORKS AFTER DIAGNOSIS

When asked about the ways in which friends and their social network supported them, some mothers reported that it was Noah's Ark that provided most support for them and others reported that they had difficulties as they and/or their child/ren were not accepted or welcomed. On the other hand some mothers found friends and acquaintances were supportive and accepting. Some of the mothers found that the opportunity to talk to their friends was enough and all that they wanted. They did not expect them to provide practical support because their child did not like social occasions or meeting other people.

- *Andrea: 'Friends are not necessarily helping out but just to talk to them is supportive. I wouldn't take him to functions because I knew he couldn't handle it - the noise and so on. He just doesn't like social things'.*
- *Patricia: 'People love him. He is a very lovable boy. Everyone was really supportive. People have been great. Samantha (his older sister aged 12) and Jon are very close'.*
- *Judy: 'Friends helped. I had friends that would come and would watch my younger child for me so I could take Jack to therapy and that was an enormous support. Another girlfriend used to come every day and check that I was OK. Our social network was the same people and accepting but the wider community stands back. People are not helpful if he has a meltdown and they do not realise there is something wrong until I started signing and then you get the pity look but I would actually rather get the pity look at that stage'.*
- *Helen: 'Friends have been good but they see him for an hour and most of the time Miles doesn't want to spend time with these people and he goes into his room on his own so they don't really see him in real life. For example, at Christmas time at my mother's, we have a huge family, lots of grandkids, lots of brothers and sisters, wives, nephews with girlfriends, lots of people, but he spent the whole day in the bedroom on his own. He didn't come out for presents; he just wants to be in a room by himself. We just let that happen because it is easier than forcing him into a situation that he is really uncomfortable with. We didn't go anywhere initially but family and we didn't go into it with our friends. We have friends that know he has autism and we try and explain what it is so most of them are very accepting. There is no choice. If you want to be friends with us you are going to accept our child'.*

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## EXPERIENCE OF OTHER FAMILIES WITH A CHILD WITH ADDITIONAL NEEDS

The majority of mothers found that the parents in families that have children with additional needs are very accepting and supportive and that they enjoy meeting them. Some have made ongoing friends, while others just enjoyed meeting them at Noah's Ark activities or support groups and some have kept in touch by phone. Only one mother was critical of other mothers because she felt that they did not do as much as she did and said that they asked for her advice because her child was making noticeable gains.

- *Patricia: 'It's like you join a club'.*
- *Carol: 'They are accepting – fantastic! I only meet them at Noah's Ark, not otherwise'.*
- *Andrea; 'You know what they are going through and you can feed back with each other about things that are coming up and literature or call each other. I'm doing the program for parents and you get to talk and so on. I do have mothers of kids who were in my older child's class that I keep in contact with sometimes, but not on a regular basis. It's good because you find that you have more in common and you have things to talk about. It's different with parents of normal kids'.*
- *Ahn: 'I had not heard of autism before and I wanted to know what happened and why. So I contacted a couple of Vietnamese people and they were happy to share. They were the same when they found out about their child. They got very stressed, they cried the same as me. They couldn't go out because they were very depressed. Also there was an Australian group. They tried to find out and share problems and they are the same. They shared ideas on how to cope and what to do – try this – there was support'.*
- *Val: initially made contact with a group that supported and informed parents with children who have the same condition that her daughter has (a rare genetic syndrome). However, at that time she was not ready for what it offered and only now when her daughter is older is she making contact again and feels that it will be helpful. She was told from the beginning that people turn to the group at different times and get different things out of it. Val has had plenty of support from the extended family and community.*

# LOOKING AT THE WORLD DIFFERENTLY

The children did not always enjoy contact with other families in the way that their mothers did because some of them had difficulty with social contact but the mothers still benefited.

- *Helen: 'We haven't had really a lot to do with other families. My child has been to social skills groups with other kids in the area but all the kids are so different. He doesn't want to be with the other kids anyway and it's very hard to get the kids to interact with each other. The parents are great because we have a common thing in our lives. You can get on well with someone because they are going through a difficult thing as well. You have an instant connection'.*



## EXPERIENCE WITH NOAH'S ARK SERVICES

Nine out of the twelve mothers interviewed were put in touch with Noah's Ark quite early. The six mothers that already had a child who had been assisted by Noah's Ark had a head start as they already had contact. The others were put in touch with Noah's Ark through professionals that assisted them in the process of diagnosis of their child's additional needs. Four of the mothers used other early intervention or support services before they changed to Noah's Ark, sometimes because a staff member that was working with them changed employment to the Noah's Ark service in the area.

Unanimously the mothers found Noah's Ark staff a great help and spoke highly of them. When asked if Noah's Ark staff could have done anything differently, mothers were quite satisfied with the support and information they had received. The only suggestion was that a case manager could be a good idea for one mother and another mother had had some difficulty with funding for equipment and had missed out on something that would have helped had she known.



- **Andrea:** *'I find their strategies very helpful and they have good ideas and they come to the home and discuss things'.*
- **Tina:** *'Noahs Ark has been great for chats and they gave me strategies to work with. For example when Zoe was falling to the floor in shopping centres. I understand that they only have a set number of hours but I think that it should be a bit more flexible and I know that currently that someone has left so they have staffing issues. They are only allocated a certain number of hours and sometimes it should be more – it's probably the government'.*
- **Carol:** *'They are the greatest support for me. Even when I turn up in tears someone will take me to a room and talk to me. They ask what I need, etc'.*
- **Patricia:** *'By and large they have been fantastic. I have wondered if there should be more case management. You need someone to help through, especially the transition to school – it would be good if there was one person to help you'.*
- **Judy:** *'The staff member who had worked with Jack moved to Noah's Ark and I wanted to follow her. The hardest thing with early intervention is staff turnover. You find that most of your therapists are fresh out of Uni and they then go into private practice. And the kids find that difficult, especially routine oriented kids who are funny about who they like and who they don't, and everybody has a different approach'.*
- **Helen:** *'They've done a fantastic job from the moment they made contact, everything has been wonderful. She's (staff member) brought me games for him to try and different ways of teaching him computer. He shouldn't be on it all the time and we try not to, but it is the best learning tool - educational things like word games and to make sentences to copy them so he understands speech a lot more'.*

## EXPERIENCE OF CHILD CARE AND KINDERGARTEN

- All of the children, except a child with cerebral palsy, had experience of child care and/or kindergarten. For most mothers the experience was positive for their children, although it was not always straightforward. Children who had difficulty in socialising with other children did not find it easy when they first went to the kindergarten or into child care, but settled down after a time. One mother found that the first child care centre that her child attended was not suitable and had to change to another.
- Andrea: 'Justin was very unsettled when he started child care. You would assume that if the director of a child care centre accepted a child with autism that they would try to do things with him, but the Noah's Ark staff member would go out there and show her things to do with him but they just weren't doing it. They didn't listen and they were quite rude to her. I changed child care centres and this one is excellent and it has a smaller class size'.
- Patricia: 'Kinder experience has been wonderful. The teacher was new and has been very interested in Jon and very supportive. There have been no issues with the other parents'.
- Judy: 'The Family Day Care person was gorgeous and she has been with me through the whole process and he has always enjoyed going there. I've been so fortunate with some of the people I've met along the way. With kindergarten I asked around a lot and I stayed with him for all of first term until he was really settled. He has had an exceptional teacher over the two years probably one of the most dedicated teachers you could ever come across. She always asks is there anything she can put into the program that will support him. She actually got a teacher of the year award. She is working with us now to make sure that Jack has a smooth transition to school'.
- Helen: 'Miles goes to kinder 2 days a week this year. He doesn't like going there. He went to 3 yr old kinder last year and screamed the joint down. Even now he'll go one day and be quite happy and then this morning he was climbing up the gate screaming "get me out of here"! He is fitting in well as far as I can tell. Once I go he calms down. He is still not into big group play or sitting on the mat with all the children listening to a story. He prefers one child activity on his own. He is allowing 1 or 2 children to play near him now, whereas before he would go crazy. It's working well and they have been great. There is one assistant there that helps him and she has a beautiful understanding and she is just wonderful'.
- Jelena: 'I love the kinder because the teachers there are so wonderful they go to courses about additional needs kids and they are actually out there helping the kids'.
- Maria: 'Glen goes to child care about 3 times a week, six hours a day. It's great. It gives me a bit of time to do the things I have to do'.
- Bronwyn: 'Last year started with Matt going to child care for two hours and I have now extended it as I want him to have that length of day ready for school – the special development school here - and the other three days he has kinder. With kinder I have to take him late to avoid all the crowd and I have to pick him up early'.
- Shirley: 'She will start kinder next year and we would have liked to get her in for the final term this year to get her familiar, but we couldn't as they had no vacancies. She will start next year.

However, I am not sure if I will send her. I don't feel that confident about her going. I'll feel much better about it when she goes to school – a special school – I've worked there and I know that people there are more experienced and she will be more supervised and everything. It will be a lot tougher at kinder probably'.

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## PARENTING

The mothers were asked what confirmed them as mothers and they all said that the main thing was the love they felt for their children. Love was the crucial element. A number also said that it was seeing their children make progress, even though it was only small steps and took a lot of time, it made them feel good and confirmed them and their efforts.

- *Helen: 'Seeing Miles make little gains. Seeing what we are doing for him is working. We set a goal and he can reach it, not always of course, and that is a great feeling. It makes you feel good as a parent'.*
- *Maria: 'When you see your kid developing. That's the biggest thing. You just love your kids and you want the best for them'.*
- *Val: 'When I was a little girl I always dreamt of having 4 children so the sexes and ages and everything was in a box and as you get older you find that the world just doesn't happen like this. I do feel blessed that we have been able to have children. It came quite easily and that is fortunate. I had a dark period a couple of weeks ago but the reassuring thing is that everything happens for a reason. I have a child with a disability but I don't want that to impact on me as a poor thing! This has happened and it has made me a stronger person in lots of ways. I think that I will be a better in my job because of being a mother. I know that already'.*

### WHAT DOES HAVING A CHILD WITH ADDITIONAL NEEDS MEANS TO YOU AS A MOTHER?

Some mothers did not answer this question, presumably because they felt their response had been covered in earlier questions. However, the mothers who did answer were quite philosophical about the experience of having a child with additional needs. While they acknowledged that it is a challenge, they also believe that they have become more compassionate and understanding and that as individuals they have changed for the better. They also see their children as giving something back to them.

- *Patricia: 'I look at the world a bit differently. It has given me back my compassion. I see people on public transport and I look at people and observe them and wonder. There is a sadness in me and a heightened awareness. I do some comparisons with other children. I can't step into the future and I have learned not to. I don't know what is going to happen to Jon. We are older parents and I feel confident that he will be OK. He has a lot of good skills. It really is not the end of the world although I have had to work really hard to actually believe that. I've met so many wonderful people'.*
- *Bronwyn: 'It's taught me that people carry on about the little tiny things that don't matter and I was a lot like that anyway. I'm a more patient mother now. My mother doesn't know who I am. She says "you look like my daughter but I don't think you are her!" That's because I was never patient. Now it is OK. I don't get upset about little things because there are bigger things bigger worries'.*



- ‘You get a lot extra from them. They are so special. Harder work in a lot of ways. I find the emotional stuff a lot more draining’.
- Val: ‘It was unexpected. It means that there are challenges in place but it doesn’t have to be a negative experience. I think differently about it than I would have once. Life would probably be easier if I didn’t have this but the normal road would not have taken me off on a different journey. Although a lot of times are very challenging she has really made us value simplicity. Our world is very much a material place but it doesn’t have to be. Not to say that there are not a lot of times when you wish that things were just normal. I don’t ever think that I was an extremely judgemental person but it has made me aware of thinking about being judgemental and more accepting and less patronising because neither of our families have ever had a disability. So while I never looked down at these people sometimes now I realise that I was being patronising to them’.
- Judy: ‘I don’t see my kids as having a disability. I think that all children have additional needs because all children are different but I think my children have different abilities. My children see the world differently to everyone else and I think that it is beautiful the way that they do look at the world. I think that they will get knocked around more than other people because they are not so far along the spectrum that the world won’t affect them but I think that they see more of the world. In many ways I think that I have



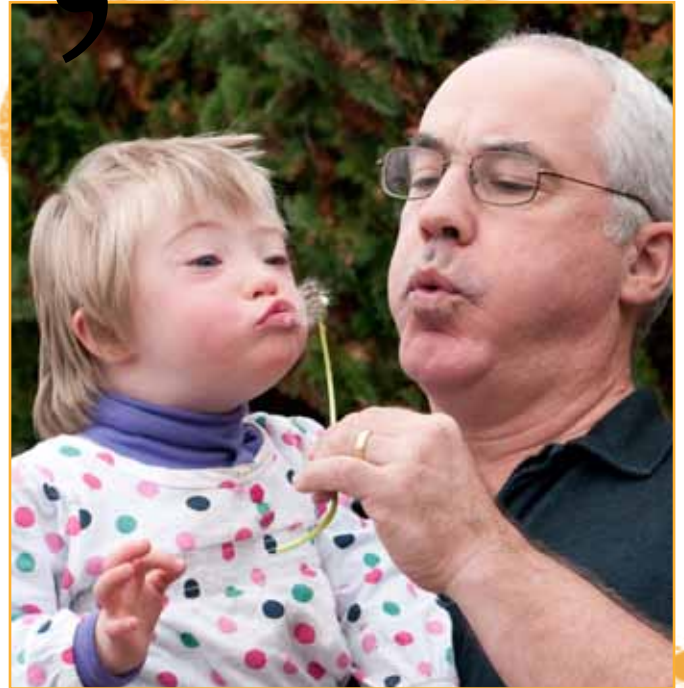
been given a gift because I get to be caretaker of these children and to show them that while their way is different it is not always the wrong way. They have taught me that my way of looking at the world is not always the right way either. Where they will end up I don’t know but as long as they enjoy the journey. You can’t experience the sunshine if you never experience the rain’.

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### WHAT HAVE YOU LEARNED AS A PARENT?

- Most of the mothers, but not all, focused on the child with additional needs when asked what they had learned as a parent, but a couple talked more generally. Judy: ‘I’ve learned to take nothing for granted. I have learned that even when you believe that a situation is hopeless it is not. Any gain, no matter how small, is still a gain. Normal kids are actually pretty boring because you don’t learn all the things about why children are doing the things that they do at kinder etc and the different fields of development – language development, motor skills, etc’.
- Bronwyn: ‘To be more understanding of other people’s children. I used to be so judgemental of other parents in my earlier years - not considering that there could be some other reason for the behaviour. I have a greater understanding of other people’s situations and of being more tolerant of other children that may or may not have a disability that you can’t see. Not a visual thing. When you see a child that has a physical disability you know what’s wrong but when you see a child acting badly you can’t see if they have autism or ADHD or any of those other unseen things. I have a greater understanding and respect for other people’.

- Jelena: *'Don't judge every kid by its cover. Get to know the child, talk to them like a child, don't talk to them like their adults'.*
- Maria: *'I have learned what other parents who have children with additional needs go through. Being a parent with a child with additional needs is another thing to just being a parent. Through being a parent of a child with additional needs I understand these things. When I see other people I don't just shrug it off. They didn't make a choice to have a kid like this. You have to deal with it. You can't run away from it you can't just hand it over to someone else - it's you! You've been picked to do this job and that's it'.*
- Patricia: *'For me it is very important that I don't get swallowed up in it. That I do things for myself whether it is going to a movie or catching up with friends. Talking about other things, it is part of my life but it is not my whole life and I'm lucky that Jon is not physically so dependent on me. Sometimes I hear stories about people with kids with additional needs who are physically dependent and I don't know if I could cope with that - but you do cope with it'.*
- Val: *'I have learned to be patient. I have learned that it is not an easy job. I have learned as a mother just how fantastic my mother was. Mum was faced with a farm and a daughter and no husband (he died young) and I never missed out on anything, although we didn't have a great deal of money. It's teaching your kids good family values. Being there for the kids, they come first and I am happy to come second. I don't take them for granted. I love my kids, I give affection very easily. I talk to my children and I feel that I have given them structure and routine'.*
- Tina: *'There are a lot of sacrifices. I think as soon as you become a parent you are not as selfish - you feel responsible for your children. They rely on you for everything'.*



## **ASPIRATIONS FOR THE CHILD WITH ADDITIONAL NEEDS**

All parents want their children to be happy and eventually to lead an independent life. The mothers of children with additional needs are no different. However, they recognise that their children may have a more difficult time in achieving these goals. Although a couple of mothers saw aspirations for their child in terms of short term goals for things like starting school, most had aspirations for their lives in the longer term. Nevertheless, when asked how they saw the child's future they were well aware of the challenges that their children face.

- Carol: *'What every parent wants – for him to be happy and do well at school but I can't predict the future'.*
- Ahn: *'I hope that she will be a normal person. That she can understand the things in her life that she can, otherwise I have to be with her for her whole life. You don't know because they change. I want her to be independent, so I do as much as I can'.*
- Patricia: *'That he's OK that he feels OK about what happens to him in life'.*
- Judy: *'I just want him to be happy and balanced and to be able to achieve his potential. At the moment that is an unknown quantity. I don't think that it is going to be easy. I can imagine him having a lot of difficulty. Kids can be cruel but as long as he is supported. Teachers teach for a year and I am his mother for life. But it's an unknown quantity at this time'.*

- Helen: *'For him to be happy and to be able to live in society like everybody else. I see a really bright future for my daughter, she's just that kind of person, and with him I see the future with fear. I don't know what is going to happen. The fear is that he's not going to be able to cope, that he won't have friends, he won't interact with people in the right way or that he is not going to be happy and that his life isn't going to be fulfilled (but that can be any child!). I try not to go there in my thinking. In the beginning I was having all these horrible thoughts that people would pick on him and he would have a tormented life. I try not to go that far now. I don't have that fear with my daughter. I don't have that fear about her fitting into society'.*
- Bronwyn: *'I would like him to be able to live independently but I don't know and that is one of the biggest worries. Something that has changed is that I don't take anything for granted, even holidays, I can't get on a plane. I hope that he will be able to live a happy independent life but I don't know if that is possible. I don't know whether or not he will have to go into residential care. He's moderate to severe (autism) and I accept that but my goal is that he learns to live as happy and independent life as he can but as long as he's happy'.*



Only a couple of the mothers made suggestions about what could help in their aspirations for their child. One mother was afraid that when her preschooler became older and did not look as 'adorable and gorgeous' as he does now as a preschooler, that he will be rejected. Due to this fear she suggested that the community needs to recognise when children need extra support and acceptance. Another mother believed that the community needs more information about conditions such as autism so that there is more tolerance. She also suggested that there is a need for special education teachers in primary schools because teachers do not always know what to do when there are difficult episodes with children with additional needs.

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## THE COMMUNITY

As in other studies which have asked about the community's acceptance and inclusiveness of children with additional needs mothers replies indicated that reactions varied. Mothers who had children with no physical indications of their additional needs, such as autism, reported acceptance in the community was more problematic.

- Bronwyn: *'Where they can see the disability I think they are more accepting and if that child has a tantrum in the supermarket they don't come up and say give him a wack yet I have had that with my son (autistic). They think that he is just a naughty boy. So in some respects they are not accepting. When you can see the disability they are accepting. People need more knowledge to be accepting in regards to autism and Asperger's syndrome. People don't know what it entails and there is no information for the community'.*
- Shirley: *'Sometimes they are accepting but there are places I find hard to access (child has cerebral palsy and cannot walk). For example, when wheel chair access in a supermarket is closed. I had to go and find someone to open up the register. When people realise she has a disability they either back off or they are sorry for her. I had a woman in the supermarket who wanted to pray with me. She kept on and on about how terribly sorry she was for me'.*
- Val: *'Everybody in town knows Lily and everybody looks out for her and it is a wonderful thing. Lily is a bit of wanderer and she is quite curious. I might be in a shop and Lily will disappear but I won't freak out initially. I'll be worried about the road but I pretty much know that she will be somewhere having a chat and that everyone will look after her. That is a support element that is not characteristic of all communities. It's one of the wonderful aspects of these little rural towns'.*
- Carol: *'When you had a child with a disability, especially years ago (with first child), it's different now because more is known, people treated you like their kids were going to catch it so although some people are still a bit funny about it there is more understanding. When my first child was about 12 months the Department of Human Services, child protection, was blaming me for his condition. They said I deliberately isolated my child and blamed me for his delayed development. A neighbour reported me. When I took Jared to play group (with normal kids) the other mothers all knew each other and were very friendly but were cold to me although they were polite. It was hard because all the kids were crawling around and my kids were not and other parents are looking at me and wondering why. I felt out of place. I didn't feel right there. I felt like I was judged although they may not have been but that is how it felt. No-one said anything but that is how I felt. Some of the parents were nice to me but they were not welcoming. They might all have come from a mother's group and then I came in. I felt the outside person. I stopped going because I couldn't handle it'.*



## THE PARENTAL RELATIONSHIP

It was not originally planned to ask about the parent's relationship but the question arose when mothers indicated that their husbands had processed the information about the diagnosis of their children very differently from themselves. Some fathers were in denial, at least initially, and some just did not want to talk about it and the mothers felt unsupported. With the passing of time most situations had changed. One marriage had broken down at the time of diagnosis but the mother said it was not good anyway and she has since re-partnered. A couple of the marriages were obviously unhappy and in one case there had been some violence that was dealt with appropriately at the time. The following are comments from the mothers:

- *'Now there is a much better understanding of each other's feelings about our son. Now that he has accepted the fact that his child does have autism we're quite good with each other. We're more supportive of each other and we did struggle with the work arrangements for a while but it is great now. He works hard and he spends time with the children and he'll make that time for them. As a family we are more supportive of each other. It is difficult to make my daughter (typically developing) understand why things are different. We struggle with that'.*
- *'Takes a lot out of you and you don't have much time. The relationship has been on and off (cries). We've talked about a divorce'.*
- *'In a way it does strengthen you because you are supporting each other and you are in this together. And you understand that you have this in common. Although I'm the one who is mainly dealing with it all and I go to the appointments and have the accurate knowledge of what is going on, but we talk about everything'.*
- *'I have a good marriage I have a very good patient husband. Certainly it has affected us that we can't go out that we don't go on holidays and we are very isolated in that regard. I'm the one that does the research (about autism) and I relay it and he accepts it'.*
- *'Our child (who was adopted) enhanced our relationship. My husband adores her and she is a daddy's girl. The foster children put a strain on us but she doesn't'.*
- *'My husband was probably, to an extent, in denial. At that time I just felt that things were not gelling for us. Initially there was a lot of confrontation and I didn't feel supported, but I could see that was the way that he was dealing with it. I think sometimes I have been compromised because of him so we might go out and if our daughter is difficult to manage then we have to pack up and go home and I feel cranky, but he is generally very accepting. I'm a bit of a homebody now but he is quite involved in the local community. We go out together and a niece babysits and we pay them. So it is OK. It has had its ups and downs but we are in a pretty good place'.*
- *'It can be hard because we have our own business and that is hard because he is under a lot of pressure and stress. It is hard to go on holidays and sometimes he just needs a break. Sometimes he will go out and if I want some time to catch up with girlfriends he will look after the kids and that's fine. I have a lot of good friends'.*
- *'Initially he processed it very differently to me. He acted like everything was fine. I can see why relationships don't last because of this. But I have so much faith in him. But he is very hands on and he is home now and he does so much - he helps'.*
- *'She did more testing, my marriage fell apart, and that was the end of it. The marriage wasn't good before that and my husband's response when I came home from the paediatrician was "I don't like that idea and I don't want to talk about it". And that was it'. This mother has since remarried and says of her new husband: 'He is fantastic with them (her children) he would do anything to help any one of them. I was really lucky to meet him and I never thought that I would. He just takes it in his stride. He's amazing'.*

## DISCUSSION

All children in the preschool age group are more dependent on their parents both physically and emotionally than when they are older. The preschool years are often challenging for any family. However, there are additional challenges for parents who have a child or children with additional needs and family life is more complex, as the mothers who were interviewed have found. There are challenges not only for the parents but also for siblings, and several mothers mentioned this. Sometimes siblings are too young to understand why their brother or sister behaves the way they do and as they get older some siblings may feel that most of their parent's attention goes to the child with additional needs.

It was clear during the interviews that all mothers had experienced some degree of depression, anxiety and worry that affected their well being and to some extent family well being during the drawn out process of diagnosis. Some, possibly most, continue to experience down times on occasion. When the diagnosis was actually made the mothers had to cope with their worst fears being confirmed. This was an exceptionally difficult period when their lives were turned upside down as they came to terms with the situation. They also reported that they had difficulty absorbing information at the time of diagnosis and then spent considerable time and effort finding further information about their child's condition (See the case studies for more information). It appeared to be made more difficult for the mothers because nearly all the fathers were reported as having processed the information in very different ways from the mothers and at least in the beginning they were sometimes in denial.



Despite the obvious distress at diagnosis all mothers moved on over time and adapted to the situation, although it was not easy. Most of the mothers immediately sought professional assistance from early intervention services or from specialist staff who guided them in seeking appropriate services and with managing the child. This again was not easy thing as the pathways were not clear, and to a great degree it depended on the advice they received. Nevertheless, the help they received was greatly appreciated and the mothers and families adapted.

Family support for the mothers at both the early stage and later is a mixed. In some families, the grandparents, parents and parents-in-law, provided support but in other families the grandparents did not understand the condition or were not willing to help. In some families the grandparents had died or lived too far away to help. In the refugee family it was the sister of the mother who has provided ongoing practical support. Similarly to mothers in the Roehr Institute study (2000) of Canadian mothers of children with additional needs these mothers were aware that family support was for short time periods only and that in fact the care of the child is really up to them.

Some mothers reported friends were accepting, and a couple of mothers had friends that were more inclusive and practical in their help, but others were happy just to be able to keep in contact with friends without involving their children. Other mothers were more isolated from friends and some found them rejecting.

A major source of support and comfort for most of the mothers, other than professional services, were other families that had children with additional needs. These families were very accepting and supportive. Some of the mothers had made ongoing friends, some only saw these mothers at arranged meetings such as groups for the child or at Noah's Ark, while others kept in touch by phone. Mothers shared information and strategies on how to cope with different situations and child behaviours. Most importantly of all the mothers felt that families which had a child with additional needs understood what other mothers and their families were experiencing. One of the mothers in a rural area had become the leader of a support group for parents whose children had autism. Another mother in a very accepting community has only recently turned to a support group with experience of her child's condition as she had not felt the need until recently. As one mother said meeting other parents of children with disabilities was like joining a club.

## EXPERIENCE OF CHILDREN'S SERVICES

The services that mothers had used for their children were early intervention services, mostly Noah's Ark, family day care and centre based care, and kindergarten.

The mothers were universally happy with Noah's Ark services and could suggest little that would make them better. They spoke glowingly of the assistance and ideas that Noah's Ark staff had provided for them. For some, Noah's Ark was the centre of their world in terms of assistance, not only for their child, but also for themselves when they were having difficulties. However, a couple of mothers mentioned problems with staff turnover and the need for more time.

**‘LOOKING AT THE WORLD DIFFERENTLY’**

All but one mother had used child care or kindergarten services for their child and this parent was in a relatively isolated rural area. Although one mother had had to change her child from one child care centre because it was not helpful, nor cooperative with the Noah's Ark staff member, overall mothers were happy with the care. A number of mothers reported at least one especially helpful staff member at the service their child attended. Whether it was family day care or centre based care mothers found that it was good for their child. A number of mothers were especially happy with their child's kindergarten experience and some were keeping them in kindergarten

for an extra year because they did not feel they were ready for school as yet. Mothers of some children who did not like too much social contact found that the children took time to settle in to both child care and kindergarten and sometimes were upset when they first arrived but settled down gradually.

Nevertheless, some mothers reported that on occasion that staff did not listen to what they were saying or take notice of what they suggested and it took them some time to get their message through.

## PARENTING AND PERSONAL DEVELOPMENT

All the mothers said that love for their children was what confirmed them as mothers. Seeing them developing, even though the gains were small, gave them satisfaction as mothers. Having a child with additional needs was a challenge and hard work for these mothers but most said that they believed it had made them stronger, more compassionate, and more understanding and patient. They believed that they themselves had changed for the better because of it. They were more tolerant and no longer took things for granted or worried about small things. This is very similar to the findings of the Canadian (King, Zwaigenbaum, King, Baxter, Rosenbaum and Bates 2005) study which found similar themes in their research of parents adapting over time, changing their world views and values, and changing their priorities for their children with additional needs.

These mothers, like all mothers, wanted their children to be happy and live independent lives but they were also aware that this was not easy and that the future was not as predictable for their children with additional needs. They believed it would be much easier for their typically developing siblings.

Mothers had varied experiences of community acceptance, inclusiveness or rejection. Some had experienced criticism, especially when their child had no physical signs of their disability, and these mothers felt that they were viewed as bad parents. Others felt more accepted, but most felt that the community needs more information about children with disabilities and additional needs so that people can be more understanding.

The mothers felt that they had become stronger because they had experienced challenges beyond the usual learning experiences of parenting and some had become more confident. They were both more realistic and more thoughtful, not only about their own family and children, but also about the community and other families. They had developed patience and tolerance and a greater acceptance and understanding of other people's children than they had had in the past.

## CONCLUSIONS

All the mothers had accessed early intervention through Noah's Ark and other services and their children had been included in child care and kindergarten services. Nevertheless, a number had experienced some exclusion and discrimination in the community, and in one case in child care, due to lack of sensitivity rather than direct exclusion, from services or support. For example, one mother who has an older child with developmental delay who has already started school as well as a preschool child with the same condition, has found that although the school the older child attends is technically inclusive there is, in fact, discrimination. She believes that mothers who are volunteers in the classroom to assist with reading have seen her child's behaviour and are critical of him. She feels that she is rejected by most of the other mothers because of this and is very angry and upset. (For more examples of this insensitivity in the context of the families read the case studies of Bronwyn, Helen, Shirley, Andrea, Ahn, Carol, Judy and Jelena in Appendix 1).

Some of the mothers (see the case studies) were facing the first transition to a different sector of education and support as their children are due to start primary school in the new school year. This transition is not always easy for any family, but for families with children who have additional needs it is especially difficult as they have to negotiate a different set of expectations and different supports for children with additional needs in the primary school sector.

The mothers in this study were devoted and dedicated mothers but one of the things that was most upsetting for them was the attitude of people in the community, particularly those that they thought were critical or not accepting. This is not new as other Noah's Ark have found the same thing (Centre for Community Child Health & Noah's Ark 2003). It was not only strangers who were insensitive or critical, but sometimes people within the extended family circle, often grandparents. This was a painful experience for these mothers who love their children dearly, who have done their best to accommodate their additional needs and to support their learning in ways that go beyond what most parents experience in family life and parenting. Being seen as a poor mother in the eyes of the community is not only a painful experience but it made mothers angry and frustrated. Many of the mothers expressed the need for more information to be made available to the public so that other people can understand conditions, such as autism spectrum disorders and developmental delay, which are not immediately apparent. The mothers did not want pity either, although it is preferable to criticism, what they want is understanding, respect and community education.



To truly carry out the United Nations Article 23 in regards to the rights of the children with disabilities in order to '...facilitate the child's active participation in the community' the public needs education. Simple information about the various conditions experienced by children with disabilities, especially those which are not apparent at first glance, is not readily available at present. An education campaign with some uncomplicated messages would go some way to removing some of barriers to inclusion which are caused not only by insensitivity but also by lack of knowledge.



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## APPENDIX 2

### PROJECT INTERVIEW – CUE QUESTIONS

Who is in your family? Names and ages?

Financially, would you say that as a family you are:

- Comfortably off
- Just getting by with little to spare
- Or having a financial struggle?

Do you own your own house or are you renting?

Do you own a car? (for country parents: is the cost of petrol an issue?)

### EMPLOYMENT

Can you tell me a little about your family's work situation?

Do you receive any government benefit or pension? If yes which do you receive?

Is your husband in paid employment FT /PT or unemployed

Are you in paid employment? FT or PT or not at all

If both parents or a single parent are employed: How do you manage the care of your children including the child/ren with a disability?

Are you able to pay for any additional supports or treatment for your child with a disability?

If yes, what are they?

Are you able to pay for any additional household help such as cleaning, babysitting etc?

How does your overall financial situation affect family life?

### THE CHILD

Could you tell me about your child/ren with the additional needs?

When was the child/ren identified/diagnosed?

What is the diagnosis?

What changed when you realised that you had a child with a disability?

Where did you turn to for help?

Who in your immediate family or extended family supported you at that time?

Who in the community supported you (friends, neighbours) at that time?

Was your social network accepting when your child was identified?

Do the same people continue to provide support and/or acceptance or have there been changes?

What has been your experience with other families who have a child with a disability?

In what ways did you have adapt your home and family life to accommodate your child with additional needs?

When did you get in touch with Noah's Ark?

Do you have your child in child care or kindergarten?

How have you found that experience?

Is there anything that Noah's Ark staff could have done differently?

What has been the greatest help for you as a mother?

When have services been helpful?

### PARENTING

What has confirmed you (made you feel good) as a mother?

What does having a child/ren with a disability mean to you?

What have you learned as a parent?

What are your strengths as a parent for (child with a disability)?

What are your aspirations for (child with a disability)?

How do you see the future for (child with a disability)? Your other children?

What would help you in your aspirations for (child with disability)?

Is the community in which you live accepting and inclusive of children with disabilities?

Is there anything that could make it better?

Parental relationship?



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