

Parents with Intellectual Disability and Older Children

Strategies for Support Workers

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Introduction

There are increasing numbers of parents with intellectual disability in Australia and more of these parents are continuing to parent their children into the primary and high school years. Up until now most human service workers have only worked with parents with younger children. As workers and researchers, we need to turn our attention to families where there are parents with intellectual disability and school aged children and young adolescents.

This Resource Booklet was commissioned by Disability Services, Department of Human Services Victoria to address the child care and management issues and strategies relating to older children (9 years to early adolescence) whose parents have an intellectual disability. The aim was to produce a practical and informative booklet to assist human service workers in their work with our parents. Our team from the Family Support and Services Project, Faculty of Health Sciences, University of Sydney undertook this task using four inter-related methods.

First, we talked with parents with intellectual disability with older children. This was by way of an informal interview that included questions derived from the general literature on parenting and the literature on parents with intellectual disability. Second, we met with—individually or in a series of focus groups—human service providers with a particular interest in, and experience with parents with older children. All of the parents came from metropolitan Sydney, as did the majority of the workers. One focus group was held in Melbourne in April 1998 arranged by the Department and included key personnel from disability, education, advocacy and family support agencies. Third, we reviewed the literature on parenting of children in the middle childhood period and the literature on parents with intellectual disability (which is almost silent on the issues facing those parents with older children). Finally, we critically reviewed readily available parent education programs and analysed their applicability for workers supporting parents with intellectual disability. A fuller account of the background to the project and the project methods is contained in the Project Report (Llewellyn, McConnell, Grace-Dunn, & Dibden, 1998).

The results of these four methods inform this Resource Booklet. To the best of our knowledge this is the first time that issues affecting parents with older children have been specifically addressed. The practical strategies that we present are suggestions to assist workers as they support

these parents. We make no claim for the empirical validity of these strategies. As yet, there are no studies to demonstrate which strategies are most effective, when and with whom. That research clearly needs to be done. In the absence of research we must rely on the experience of those most closely involved. The information in this Resource Booklet represents the views of parents themselves, experienced workers and the literature on parenting. The practical strategies included in this Booklet come from these sources. Many of these strategies have been tried and tested by parents and workers. Others are good ideas just waiting to be implemented. We trust workers will find this Booklet thought provoking and a useful resource when working with parents either individually or in small groups.

We begin by discussing some ideas about parenting, about middle childhood and about parents with intellectual disability and then we introduce the structure of the Resource Booklet.

What determines how parents 'parent', whether or not they have cognitive limitations?

Beliefs about good parenting play a part. Our own parents play a part—how we were parented becomes the 'default mode' when raising our own children. Parents also strive to do better with the next generation.

Family factors also influence parenting. Each child is treated differently—despite parents' best intentions—and each child affects their parents in different ways. Parenting behaviours also change over time. Parenting a twenty-four year old is very different to parenting a four month old, a four year old, and a fourteen year old. There is speculation but little hard data about which parenting behaviours are needed when. There is even less evidence about how to prepare parents—in advance—for the next stage of parenting.

Environmental factors such as parental depression, marital discord, and low socio-economic status play a part in parenting but their role is not straightforward. For depressed mothers the extra demands of parenting may result in less responsiveness and less engagement with parenting. Similarly, the stresses associated with marital discord may result in parenting difficulties. In reverse, dysfunctional parenting can create child problems that in turn challenge the parents' relationship. The effects of low socio-economic conditions are multiple. The degree to which life affects parents adversely is strongly related to their capacity to parent effectively.

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What are the implications for parents with cognitive limitations? First we need to recognise that parents with cognitive limitations are parents first and people with a disability second. Their parenting is shaped by influences that are common to all parents and often more so. Parents with cognitive limitations may be challenged by several, or all of the factors listed above: inappropriate or non-existent parenting role models, little or no experience of children's developmental needs, relationship problems, and, in most instances, poor financial, living and employment situations.

Often, however, others focus on the parent's disability, not their life situation. This attention to parental disability leads to at least three false conclusions. The first is that all parents with cognitive limitations have similar problems. It is nonsense to suggest that parents are alike in this way. False conclusion number two is that all parents with cognitive limitations will need help and furthermore, the same kind of help. In our experience, supporting parents requires tailoring that assistance to meet each parent's individual needs. The third false conclusion is that by understanding disability, we understand parenting by people with cognitive limitations. This is false because there is no direct relationship between cognitive ability and parenting competence. Personal, family, social and environmental factors are far greater forces in shaping parenting success. The importance of each of these factors will shape the strategies needed to support parents.

Middle childhood—9 to 12 years of age

Between 9 and 12 years of age children make the transition between childhood and adolescence. It is a time that is often confusing and challenging for both parents and children. Many parents do not know what to expect of their older children, and many older children do not know what to expect from themselves. Many changes are taking place.

Children's physical bodies change quite dramatically. They get bigger and, with the influence of hormonal changes, develop sexually. They ask difficult questions about sex, giggle about sexual innuendo, and compare and compete for boyfriends and girlfriends. They begin to develop their own sexuality—this is often uncomfortable for parents (Gorzka et al., 1991; Waters & Kennedy, 1993).

Behavioural changes also occur. Children at this age have regular emotional outbursts or moody behaviour. These are due to hormonal changes, as well as social pressure and their own insecurities.

Older children need to assert their independence: rebellious behaviour is one sign of this (Bennett, 1987; Waters & Kennedy, 1993). The tone of the family home may be very different as change in children's behaviour affects their parents' behaviour and vice versa (Kendziora & O'Leary, 1993; Coates et al., 1985).

In middle childhood cognitive ability rapidly develops. Children become more curious about their world and are keen to solve problems (Berlin, 1990). They develop abstract reasoning skills, learn to see meanings and intentions, and to express their emotions and feelings (Waters & Kennedy, 1993). Children at this stage also develop socially. As well as having at least one best friend it becomes more and more important to be accepted by ones' peers (Berlin, 1990; Bennett, 1987).

Despite these rapid and often challenging changes it is well established that their parent's continuing interest is of fundamental importance to the growing child's healthy development (Berlin, 1990). The most important ingredient is the giving of parental love, along with unqualified acceptance and respect (Friedman, 1993).

Prior to middle childhood, household and family activities mainly define the child's world. When children start school, this changes dramatically. Parents and children are now part of a much wider community with increased expectations to conform to social and cultural mores. For parents with cognitive limitations these expectations can present major challenges. In this introduction we briefly mention three overarching issues. These issues are academic, social and community expectations. Later in the Resource Booklet we expand on these issues and introduce others.

By academic we mean the expectations placed on children's learning. Society values academic achievement. Parents are expected to support and engage in their children's learning. This translates into helping with homework, encouraging reading, stimulating interests and providing opportunities for learning out of school time. Parents with cognitive limitations are hit hard by these expectations. With low educational levels and literacy and numeracy difficulties, often there is little they feel they can do to help their child. Their living situation may also mitigate against academic learning with limited access to reading material, restricted space or time for quiet reading or number work and little concern for routine or regular bedtimes.

Community expectations of parents of 9 to 12 year old children are high. The community expects that

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parents will enforce discipline, stimulate learning, help their children develop friendships, communicate with their children, help develop self-esteem, keep their children healthy and prevent anti-social activities such as drug taking, gambling and criminal behaviour. This is a tall order for all parents. For parents who rarely have appropriate past or current role models, few financial resources and friends and limited work opportunities undertaking these tasks alone may overwhelm them. All parents need some support with parenting; parents with cognitive limitations need support with parenting to meet community expectations.

What about parents' needs? First and foremost, parents with intellectual disability need to be acknowledged as their child's parents. This is particularly important when several others are involved with supporting the child. Mandatory consultation with parents, respect for their wishes, and promoting their involvement in every matter affecting their child—even when the child is primarily residing elsewhere—is fundamental to successful parent-worker relationships. In foster care or shared parenting, the parent's advice on matters ranging from getting a hair cut to picking the child up from school to organising residential and holiday arrangements must be sought. It is easy to slip into subconscious denial of the biological parent. However, no matter what the future holds the child will always remain the biological parents' child; conversely, the parents remain the child's mother or father.

Many parents with intellectual disability are socially isolated (Llewellyn, 1995). For some their living situation has been an across generations experience of being a 'welfare' family. By definition, being on welfare places parents in a subordinate and passive role and shapes others' attitudes to the extent that parents are given less information and receive poorer quality services or none at all on the grounds that they are non-compliant or unlikely to benefit. Advocating for and empowering parents with cognitive limitations is, therefore, a fundamental task for service providers. Putting yourself in their shoes to identify how you would like to be treated is a powerful strategy to ensure that parents are not disenfranchised.

This brief introduction serves to remind us that parents with intellectual disability are parents first—and as parents of developing children they are faced with the same challenges and rewards as all parents with children in their primary and early high school years. Many of the factors known to

influence parenting may be even more pronounced in the lives of parents with cognitive limitations. This highlights the need to work with parents to strengthen their family relationships. Supporting parents in their everyday family life provides the foundation for successful engagement with the wider community for parents with intellectual disability and children as they take their place in Australian society.

Organisation of the Resource Booklet

The Resource Booklet contains three main sections. Part 1 deals with family resources. Topics include housing and money matters, social support, and relationships between parents and service providers. In Part 2, we focus on promoting parent and child health and well-being. In this section we include parent and child expectations; the parent-child relationship; promoting independence and helping at home; self-esteem; discipline and sibling rivalry; health, hygiene & nutrition, and learning and the school environment.

In these first two sections, the material is arranged as follows. First we present the parent's point of view as told to us by those whom we interviewed for this project. Not all parents identify the same issues: we present those issues most pertinent to the majority of families. We then discuss issues raised by workers and suggest strategies for workers to use. These strategies come from a variety of sources: from parents, from workers who took part in this project, from the literature and from our own experience. Workers' views draw on their experiences with a number of different families. These views therefore represent a collective and general view of issues facing parents with intellectual disability and older children. No one worker presents all of these concerns for any one family. Several parents with intellectual disability interviewed for this project have children with a disability. Issues such as promoting independence and parental authority take on a different meaning when the child has an intellectual, physical or sensory disability.

In Part 3 we provide information on resources thought useful when working with parents with intellectual disability and older children. We also include some notes on how to run a parent education program and what makes an effective parent education program for parents with intellectual disability. Following this we include a bibliography so that readers may turn to the literature for additional information.

Part 1: Building Family Resources

Section 1.1 Housing and Money Matters

Parents with intellectual disability commonly raise their children in circumstances of socio-economic disadvantage. Most families live in public housing. Social security benefits are often their only source of income. With such limited resources, it is a difficult task ensuring that children are fed and clothed, and the bills paid. This is especially so in middle childhood when children are perpetually hungry, growing rapidly and 'rough on clothing'.

Parents with intellectual disability may be stretched providing for their family's basic needs. The cost of school excursions, recreational activities, and items for the home may mean all these items are out of reach. White goods, television and other household appliances may be rented, or bought on hire-purchase. As children get older and become more aware of what their friends have and they do not, they may pressure their parents for the latest craze, expensive items such as a Sony Playstation or roller blades. Not surprisingly, many parents with intellectual disability are faced with rising debt.

Parents with intellectual disability may not have the telephone connected, or the funds available to travel to visit family and friends, or simply to 'get out of the house'. Social dislocation can result from having to move away from family or friends to take whatever housing is offered. Parents may move house frequently making it difficult to keep or make new friends. For many families, poverty and isolation are not temporary but enduring features of their lives.

Parenting efficacy is affected by socioeconomic status to the extent that 'socioeconomic disadvantage is likely to be the common denominator for many of the correlates of negative outcomes in parent training' (Kendziora & O'Leary, 1993, p. 190). Survival and maintenance issues of housing, food, adequate clothing and bills have to be addressed before mothers can attend to parenting and health issues (Hardy & Streett, 1989). Practicing good communication and self-esteem boosting strategies come a long way down on any priority list when mothers are struggling to keep their family fed and clothed.

Parents' and Service Workers' Views

Housing

Parents' voice concerns about needing more space for their children to play, as they grow older. There is a long wait for alternative accommodation, to move from an apartment to a house. Lack of heating, leaky taps, faulty (or non-existent) appliances and vermin make parents' lives

uncomfortable. Their neighbourhoods may be unsafe. Experiences of verbal and physical harassment are not uncommon.

Julie was separated from her daughter while waiting for housing. Julie left her husband when she discovered that he was sexually abusing her daughter Angela (8 years). Julie moved in with her own mother and took her youngest child Terry (2 years) with her. Angela went to stay with her paternal grandmother. This arrangement was thought best at the time, but Julie missed Angela, especially as they were now living six hours apart. Julie pleaded her case to the housing department and was told that she would have to wait approximately 3 years. Julie continued to call them 'every single day', and they found her a home after six months.

Kim says that people are regularly beaten up just outside her door. Kim is also troubled by young people 'hanging around the street', who yell and throw things at her (Kim did not want to say exactly what they said to her). Elisha (11 years), Kim's daughter, often defends her mother, saying 'don't talk to my mother like that'. Kim would like to move one day and maybe buy a place of her own, but feels that this is a long way off or may never happen.

Money matters

Often, parents with intellectual disability report that they have difficulty with managing money and making it stretch far enough. Workers agree that parents are poor money managers, most often spending their money unwisely on frivolous items and forgetting to budget for necessities. Dealing with banks, social security and the Housing Department are daunting tasks. Many parents shy away from such encounters; some do not. Others lack the necessary literacy and numeracy skills. Reading and filling in forms may be impossible tasks.

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Melissa says that she is a poor money manager, and would like to get out debt. Most of her debt is as the result of the many appliances she rents, such as a TV, Video, Hi Fi, and Sega Mega-drive. 'I just get so frustrated because there's a lot of things I'd like us to do, like go out. We never have any money to go anywhere. That's what frustrates me more than anything!'

Practical Strategies

Handling one's own finances is critically important to a sense of autonomy and responsibility. All strategies therefore need to support parents to be responsible for their own financial affairs. Families have different financial priorities. The worker's task is to help families set their own not to impose personal priorities on families' situations.

- To assist parents with applications for housing and social security benefits, support workers could offer the following kinds of support:
 - Help to explore their options and understand their entitlements.
 - Assistance to fill out written applications.
 - A letter of support to accompany written applications.
 - If parents are seeking a private rental property, accompany them to visit real estate agents.
 - Accompany parents to visit departmental offices of housing and/or social security.
- To assist parents to obtain white goods and other household items at minimum cost, a range of innovative alternatives to 'hire-purchase' and rental could be explored:
 - Help parents take advantage of interest free loan schemes.
 - Support agencies could offer parents an interest free loan to cover a proportion of the cost of an item.
 - Ask local manufacturers or retailers for in kind support. One support worker succeeded in securing a new washing machine—free of charge for one of her clients. Making a specific request for a specific family is worth a try!
- Set up not-for-profit fruit and vegetable co-ops to purchase basic items in bulk at reduced rates.

Pass the saving on to the parents who purchase what they need from the agency.

- When money is in short supply, budgeting is a necessity. Here are several suggestions for teaching budgeting:
 - Use a weekly rather than fortnightly budget. It is easier to manage smaller amounts of money.
 - Advise parents to only withdraw the money needed—as determined by the weekly budget.
 - Use envelopes for different expenses. Prior to visiting the bank, write each expense and the sum required on separate envelopes. Encourage the teller to put the required amount in each envelope.
 - Suggest parents pay bills (electricity, phone) on a fortnightly basis to avoid big outlays. Automatic fortnightly withdrawals may be possible.
 - Encourage parents to put aside the family allowance for children's requirements.
 - Advise parents to have a separate account for big items such as school and excursions.
 - Help parents identify goals—things they will be motivated to save for.
 - Educate parents about interest rates and the pros and cons of hire-purchase.
 - Inform parents about the relative costs of alternatives such as 'take-away' versus 'home cooked' meals.
- Instruction must be as concrete as possible. One support worker suggests using monopoly money for demonstration.
- A one-off lesson is unlikely to be effective. An 'apprenticeship' approach is preferable. Demonstrate the task, do the task together with the parent, then offer many opportunities for the parent to practise and get feedback.

Section 1.2 Social Support

Family and friends can be a great resource for parents by providing emotional support, information, advice, material aid, and practical help. There are strong links between social support and positive outcomes for parents and children. Social support is thought to buffer the impact of stress and negative life events. It is a strong predictor of personal adjustment and health (see House, Umberson & Landis, 1988 for a review). There is also a strong link between social support and parenting behaviours. For example, Kendziora and O'Leary (1993) found that mothers who are very insular and isolated display more 'aversive' behaviour towards their children. Social support has been shown to be related to child outcomes in families from low socio-economic backgrounds (Hanson & Martin, 1991) and in families of parents *without* intellectual disability raising children with disabilities (Dunst, Trivette, & Cross, 1986). Empirical and anecdotal evidence from specialist disability and community-based service providers including Home-School Liaison Officers in New South Wales suggests that parental social isolation appears substantially related to difficulties experienced with parenting (McConnell, Llewellyn, & Bye, 1997; Home School Liaison Officers Conference, 1995).

Parents with intellectual disability are among the most socially isolated in the community. An unusually high proportion of parents with intellectual disability are estranged not only from their immediate family but receive very little, if any, support from extended family, neighbours or other community members (Andron & Tymchuk, 1987; Llewellyn, 1995; Rosenberg & McTate, 1982; Whitman & Accardo, 1990). Even where other family members are on the scene, support cannot be assumed. The involvement of family members can be both a restraint and resource for parenting (Llewellyn, 1995; Tucker & Johnson, 1989).

When parents are socially isolated their children are also. Opportunities for children to develop friendship ties may be very limited. Parents may not have friends with children of the same age. Families may live in neighbourhoods that are intolerant or inhospitable. Recreational activities for children may cost too much. Children may be reluctant to invite friends home due to the stigma associated with their parent's disability. As well as having friends, children need an adult role model, someone that takes an active and ongoing interest in them. They need someone who is 'there for them', encourages them, and recognises their potential and worth. This adult may or may not be a child's parent. When a family is disadvantaged

and under pressure, another adult may be needed to perform this vital role.

Parents' Views

Even when some support is available, parents talk about feeling isolated in coping with the challenges of parenting. Many parents do have the support of family members. Sometimes, however, these family members are seen as interfering. Service workers are the only source of support for some parents.

Partners and spouses can be a great source of support. Alternatively, they may be distant, non-supportive or even abusive. When conflict is hard to resolve a great strain is placed on the family. Single parents—typically the most isolated of all—are often lonely and wish to have the help of a partner to back them up.

One parent to whom we talked had developed a 'shared parenting' arrangement with another couple. This couple looks after her son on weekends and for parts of the school holidays. They offer this parent and her son practical help, advice and advocacy. From this parent's point of view—'They are always there when we need them'.

Several mothers have established supportive and lasting friendships with other mothers attending a group coordinated by their support worker. An older and more experienced mother in this group has become a role model—and the first port of call—for mothers in a crisis. Another mother has been warmly accepted into a local church congregation, where she has formed several close friendships. Most parents however, talk of few, if any friends. Some parents experience rejection when they reach out in friendship. Others feel they have too many problems to offer reciprocal support and friendship. Some parents are wary of becoming too involved with their neighbours because they fear that if friendships turn sour they may 'turn them in' to the welfare department.

Melissa rarely leaves her home and feels very alone. She does have a boyfriend, but she sees him no more than once every couple of weeks. The only person that Melissa was able to list as a support person was her Support Worker who visits weekly. Melissa says 'I get so lonely, I talk to myself sometimes. I'm too much of a hermit.'

Part 1

Mary's son, Jamie, attends a special school. One time a mother, whose child attends the same school, announced that she would like to meet with other mothers. Mary thought she seemed nice, and so approached her, said that she would like to meet for coffee one day, and gave the lady her phone number. The lady never called. Mary is very disappointed, and wonders what went wrong. Mary also talked about 'a couple across the road that we are friendly with, but I find them frustrating when they come over because they are always complaining about their own problems. The man hits her and pulls her hair, and when she starts on about it I say, "You've gotta solve it yourselves, 'cause I can't solve it for you. I've got my own problems to look after"'.

Catherine's greatest frustration is that she feels all alone and has no support. She does not have a friendship network at all, and all of her extended family lives a long way away. She is grateful that both Grandmothers will often take her son, Tim, for a week or so during the school holidays. Catherine is glad for the break, but also finds the experience very frustrating. Tim behaves well for the grandmothers, but very badly for her. When Catherine tries to tell the grandmothers about Tim's bad behaviour and the help she needs, they simply will not believe her. Catherine has tried to rally some support from the teachers at school, but has experienced a similar difficulty there. Tim does not behave as badly at school as he does at home. Catherine suspects that the teachers do not believe her either. She feels alone. She feels as though she has nobody to talk to because nobody will believe her.

Josie feels very alone. She does not feel that her husband has any interest in her or her children, and she misses the fun times that they used to have together. Their relationship has become more and more strained as the children have grown older. Mostly this is because the children are more demanding, and because he does not help in their care or the care of their home. Josie is also frustrated that she and her husband never spend any time alone together anymore. He believes that

now that they have children they should not go out anywhere without them. Even on the days that he is home from work and the children are all at school, he will disappear in the morning and not return again until the evening. Josie does not know where he goes. Josie says—'It's been years and years since he's taken me out to dinner anywhere . . . but I don't see just because you have children you have to stop living, you have to stop going out . . . just because I have kids doesn't mean my life has to stop'.

Workers' Views

Support workers agree that parents are isolated and do not seem to make friends. It is difficult to sustain friendships when parents move house frequently or live in neighbourhoods where there is a lot of conflict. Parents with intellectual disability may become the 'scapegoat' of such a neighbourhood. 'When people need to blame their own unhappiness on others, these parents are a soft target'.

Support offered by family and friends is sometimes more hindrance than help. Family members can make parents feel small and incompetent. Advice from neighbours, offered with the best of intentions, often succeeds in confusing parents. Many friendships are thought suspect by workers who emphasise parents' vulnerability to manipulation and exploitation.

Practical Strategies

Support workers cannot artificially construct an informal support network for parents with intellectual disability. Rather, they may need to create opportunities for parents to form friendship ties. This might be achieved by:

- Establishing a support group for parents with intellectual disability. This has been done successfully in several states, sometimes under the auspices of women's services, in other instances, with the help of the local family support services or neighbourhood centre.
- Supporting parents to join local clubs or groups. A weekly visit to a club provides contact with other people that may lead to friendships developing.
- Exploring with parents any programs offered by local churches. One mother joined a craft

group run at a local church. Phoning, and speaking with local church ministers or pastors is a good place to start and to explain the level of support the parent may need to become involved in church activities. Local church members may also respond to isolated families by taking the initiative in offering friendship.

- Encouraging and supporting parents to join and participate in any recreational leisure services for people with disabilities (where these are available). One mother plays T-ball with her son on weekends, and enjoys the company and friendship of the other parents.
- Establishing a volunteer 'buddy' program. One support service in NSW has been successful in recruiting and training volunteers from the local community to visit parents regularly to help with any mundane tasks, take them shopping, or simply to chat.
- **To enable parents to attend support groups or other activities, workers need to consider access. Parents with young children may not be able to attend unless child minding is provided. Providing transport will probably also be necessary. Local councils may offer a community bus service. Where costs are involved, these may be prohibitive. Helping parents' budget for such costs will be important.**
- **Parents may need help learning skills in communicating with their partner/spouse. Both may need to be included to nurture their relationship. Where parents are involved in abusive relationships they need to be made aware of the support services available to assist.**
- **Parents may need to spend time with their partner or spouse. The demands of childcare often prevent this. The organisation of respite or child minding on an occasional basis gives parents the opportunity to 'get away'.**
- **Children may need support to make friends:**
 - Determine what opportunities are available, and what a child's interests may be. Consider local sporting teams, recreational clubs, church youth groups, cubs or scouts, and school holiday 'rec' programs that are often run at local schools.
 - Assist parents to budget for school excursions and the cost of additional activities.
 - Organise transport for children.
- Children also need an adult to take an active and ongoing interest in them. With their parents' consent, several programs, such as 'Aunties & Uncles' and 'Big Brother-Big Sister' may be able to link up children with an adult figure. These programs may offer the additional benefit of weekend respite for parents. Introducing another interested adult needs to be done in such a way that a significant difference occurs for the child without disregarding or challenging their parent's authority.

Part 1

Section 1.3 Parents and Service Providers

Parents' needs for support services vary greatly. Many require long term and ongoing support to raise their children from infancy through to adulthood (Llewellyn, McConnell & Bye, 1995). Others require short-term support at times of transition, for example, immediately after birth, when children start school and when adolescence looms. Support workers can fulfil many roles, often simultaneously.

Parents' experiences with support services also vary greatly. Many parents have numerous support workers from an array of service organisations (Booth & Booth, 1993). For these parents keeping track of 'who's who' is no mean feat. In contrast, other parents would desperately like support but are not able to identify and/or access community resources (Kaatz, 1992).

Support services are not always welcomed. Parents commonly speak of living under constant scrutiny and fear of 'welfare' taking their child away (Andron & Tymchuk, 1987; Booth & Booth, 1993; Llewellyn, 1997a; McConnell & Llewellyn, in press). These parents may be reluctant to seek out services and be resistant when services are offered. As Ray, Rubenstein, and Russo (1994) note 'Accustomed to public questioning and sometimes blatant non-acceptance of their parenting roles, most parents who are mentally retarded (sic) do not welcome social services with open arms, and many are suspicious of staff persons from service programs, especially if these individuals plan to spend time in their homes'.

Support workers may be resented as an invasion of privacy. This is particularly so when many service workers from multiple agencies are involved. A lack of coordination between services can lead to confusion, with multiple appointments and contradictory advice. Frequent changes in staffing can undermine the trust established between agencies and parents. Parents with intellectual disability can feel disempowered when services fail to consult them in decision-making. As Pomerantz et al. (1990) noted 'We cannot expect parents with disabilities, or any other persons, to enter a trusting relationship if their helper does not fully believe in their ability to succeed as individuals and family units'. Friedman (1993) recommends that 'for action to be relevant, useful, and effective, the people for whom it is intended must be involved in planning, implementation, and evaluation to the greatest extent possible'.

Parents' Views

Parents like some aspects of the services they receive. They are glad for the advocacy that some service workers provide. Parents report there are some workers who can be relied upon to act as advocates for them at the school, at the doctor, or in dealing with government services. Respite care is a highly valued service, particularly during school breaks. Some service workers are appreciated as teachers, as a source of good advice, and as good listeners. These workers make parents feel understood. For many parents, these service workers are the only people that they have to talk to.

Parents also dislike some aspects of the services they receive. Inconsistency in service provision upsets many parents. Support workers often change without notifying the family. A new worker simply arrives and the parent has to start all over again, to tell their story and to learn to trust this new person. Workers are also inconsistent when they make promises and do not follow through. Often parents do not know when the worker is coming next. They may not see a worker for months, and then suddenly they will show up. Worse still, some workers try to force their ideas and values on parents without consulting them about what they think is best for their families.

Kim feels that all the DOCS workers want to do is criticise her parenting, and watch to catch her out. She believes that they are just looking for an excuse to take her daughter away from her. She sees them as the enemy. She also holds DOCS responsible for all of the young 'hoodlums' who hang about in her street. Kim asks—'*Why don't they do something about that, rather than pestering poor single mothers*'.

Mary is very frustrated that her support workers never give her any notice before a visit. They simply show up, and expect her to drop everything to talk to them. They always seem to show up when it is most inconvenient, like when she has guests over, and then Mary feels that she has to ask her guests to leave.

Workers' Views

Many workers feel frustrated by parents' lack of initiative in seeking out and using services. Parents need to be informed about what services are available and then encouraged and actively prompted to go ahead and use these. Workers sometimes find it is hard to get parents to cooperate and they become frustrated when parents fail to follow through with services. For example, a parent may say they need help, so the worker goes out of his or her way to organise the needed assistance and then parents do not take advantage of this help.

Support workers view advocacy as a vital role. Parents need advocates when dealing with medical and other professionals as well as community and government authorities. Advocates are also needed to educate parents about their rights and responsibilities. Workers acknowledge that their intrusion into the everyday lives of families may be difficult for some parents to accept. However, in the experience of many workers, most parents are not that disturbed by the continuous presence of a support worker.

From the point of view of several workers, parents with intellectual disability appear to have little vision of a better life. Parents living situations add to this as many live in small enclaves where many others also have disabilities or significant disadvantage in their lives.

Many support workers often find it difficult to know when to withdraw and allow families the opportunity to function independently—to allow them the dignity of risk. They are concerned that if parents are not ready for this, something terrible may happen and they might be held responsible. Other support workers suggest that slow and steady withdrawal and being easy to contact is the key to success.

One worker talked about her frustration with a mother who kept making excuses for why her child was not attending school. One excuse was that it was difficult to get them breakfast and get them ready on time. The worker started a breakfast club, arranged for a taxi to pick the children up and take them to the club and then on to school. However, this strategy failed, as the children were never dressed when the taxi arrived and the taxi could not wait.

Another worker talked about a mother who needed advocacy with the police. *'Her son attacked her, and I took her to the police station to make a statement. This mother found the whole situation very distressing, and found it incredibly difficult to give a comprehensive statement. It took well over three hours. The next time she was attacked by her son she didn't want to go to the police and go through the same process. I sat down with her and told her about her right not to be attacked, and then I helped her write out her statement before we went to the police station, and so this second experience wasn't quite so distressing for her.'*

Practical Strategies

Much can be done to improve support services for families headed by parents with intellectual disability. Incorporating the simple but challenging principles and strategies outlined below would be a leap forward.

- Practice seeing problems and circumstances from the parent's perspective.
- Believe in the parent's competence, or capacity to be competent.
- Be frank and honest to ensure parents understand your role and intentions.
- Take time for small talk, spend enough time with a family to get to know them and understand their interests and priorities.
- Address any concerns and needs raised by the parent first. Parents will be more highly motivated to achieve the goals that are most important to them.
- Involve parents in all decision-making.
- Respect for the parent as the parent of their child must never be compromised.
- Identify, acknowledge, and build on parents' strengths, always offering encouragement.
- Keep in regular contact and be contactable. When planning a home visit, support workers should always let parents know beforehand when they are coming.
- When more than one service is involved, coordination and communication is critical. One agency may take the role of primary coordinator. An attitude of working together in the best interests of the family must be fostered.

Part 2: Promoting Parents' and Children's Health and Wellbeing

Section 2.1 Parents' and Children's Expectations

Middle childhood is a period of rapid transition as adolescence looms. Many parents find it difficult to keep up with changing demands. Clothes, especially shoes, are quickly outgrown. Parental authority may be challenged, as children demand greater freedom and independence to explore their own interests. This can be a time of confusion, loss, and reward for parents. Many parents with intellectual disability adjust and adapt to meet their children's changing needs. Others need ongoing support to do so. Parents' life experiences—such as segregation, the absence of a role model, and low expectations from significant adults can leave them disadvantaged from the start. Poverty and social isolation as discussed in Section 1.1 may compound this disadvantage. Some parents may lack insight, have difficulty with problem solving, and lack the skills required to assist their children with tasks such as homework.

Children of parents with intellectual disability also have to come to terms with their parent's 'difference' and disability. During middle childhood, they may discover that in reading, writing and maths, they are more capable than their parents and that they will not get help with their homework. They may be required to assist their parents with literacy and numeracy tasks, such as completing forms; reading letters and paying bills. Some children may be embarrassed by their parent's disability. Others may seek to protect their parents from jeers and harassment. Either way, children may be reluctant to invite friends home, or inform parents about social events at their school. Support workers may need to help children deal with negative feelings (for example, resentment, anger and burden) about their situation and help them understand the nature of their parent's disability.

Parents' Views

Knowing what to expect of one's children is one of the most difficult things for all parents with intellectual disability. Parents we talked to asked questions like, 'Shouldn't he be old enough to control his bad temper?' and 'Isn't she too young to be interested in boys?'. As children develop 'a mind of their own', and demand more freedom and independence, parents are often frightened for their child's safety and uncertain about where to draw the boundaries. At the same time, parents are glad that their children are more able to entertain themselves.

Louise reported how pleased she was that 'Mark can keep himself busy for longer now you know. He can stick at doing something for longer. All I need to do is give him some bits of wood and nails, and he's out there for hours. He likes to make things that are useful, you know. Like he made a bird table, so now we can put out seeds for the birds.'

Increasing interest in the opposite sex evokes varying responses in parents. Parents describe crushes on peers as well as teachers, giggling on the phone, teasing, and a growing obsession with fads and teenage idols. Some parents accept the situation and others turn a blind eye.

Here are some comments from different parents about their children's beginning interest in the opposite sex.

'I've met her boyfriend already. He picks her up and they walk to school together. He's nice.'

'She loves the Spice Girls, and has posters of them all over her room, and she really loved the Spice Girls movie. I must admit that I think they're pretty good too.'

'I anticipate she is interested in the opposite sex. I don't want to know about it really. She is still my little baby.'

The parents we consulted care a great deal about what their child is doing and going through and want to know how best they can help their child. Some parents have very definite ideas about their parenting responsibilities. Others are keen to ensure their children do not grow up in ignorance as they had done. For some parents, their views brought them into conflict with support workers.

Kim lives alone with her 11-year-old daughter, Elisha. Elisha has not yet started menstruating, but Kim has spoken very openly with Elisha about periods and sex from the time that she was a little girl. Kim feels that she had been kept in ignorance about these issues as she was growing up. She does not want her daughter to experience the same panic that she did at the first sign of menstruation. Kim

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speaks openly and hides nothing from her daughter, including her handling of her own periods, and the sharing of her own sexual experiences. Kim says that the workers from DOCS (child protection) do not approve of her openness, but she feels strongly that nothing should be hidden from her daughter.

Workers' Views

Support workers are often concerned that parents with intellectual disability are not aware of appropriate developmental expectations for their child. Sometimes parents may not know how to instruct or guide their children or know where to draw the line. As a consequence, 'children may run riot'. Many children begin to challenge their parent's authority and many of them work out how to 'get around' their parents. A lack of supervision and parental control in some families can result in premature independence or serious child behavioural problems. The implications of this for discipline and supervision are discussed in Section 2.5.

One worker commented that 'Children walk all over parents. In one instance this girl, who was in grade six, she'd worked out that both her parents had a disability, and she made them quite depressed by calling them names like "retard" and "stupid". This had a big impact on the parents. They weren't expecting it to come from the children. In another example, the children didn't know their parents had a disability, but sensed there was something different about them. The daughter would get away with things more. Like, she'd go out and not say where she was going, sort of get around saying where she was going.'

Practical Strategies

Parents with intellectual disability have beliefs and ideas of their own that must be respected. In this area, support workers need to be especially careful not to impose their own values and beliefs on parents.

- Parents need help to learn what to expect of children this age and how to manage new behaviours when these occur.
- Giving each parent information individually is useful and provides an opportunity to 'test out' the parent's understanding. Discussion needs to be concrete and to start with the parent's concerns.
- Group discussions are invaluable as parents can share their experiences, ask questions and hear other parents' coping strategies. Sharing experiences with other parents with similar challenges helps make the information more meaningful. Parents—with and without intellectual disability—trust those 'who have been there and done that' and are able to draw on their own experiences.
- Video documentary type programs can be excellent tools for parent learning.
- Children need to learn about their unique circumstances, and to develop esteem for their parents. This may be difficult if the only feedback they get is a negative cultural stereotype about disabled parents.
- Support workers, with parent permission, can initiate a frank and open discussion with the child to help develop understanding about their parent's disability.
- Support workers need to keep in mind that some parents are sensitive about, or do not perceive they have a disability. A great deal of sensitivity and respect is required when broaching this topic with these parents.
- Children need to feel that the support worker is approachable so and they can discuss how they feel at any time.
- Some children may need more formal counselling over an extended period of time
- Setting up a support group for children of parents with intellectual disability is one strategy that, to the best of our knowledge, has not yet been tried but is worth exploring.

Section 2.2 Parents' and Children's Communication

Middle childhood is a 'testing time'. Children test boundaries, their skills and abilities. As children develop their capacity for reasoning, they may question their parents, demanding more from them in terms of explanation.

During middle childhood, children's interests increasingly extend beyond the home and family to peers and the opposite sex. Children become more aware of their bodies and their sexuality, as 'hormones begin to take effect'. Privacy is increasingly sought after, as children often prefer to be alone with their developing bodies, fragile egos and powerful feelings.

At times, parents may feel shut out. Communicating with children as they approach adolescence is difficult for most parents, and an area in which they may seek advice and support. Yet the quality of the parent-child relationship depends at least in part on open, effective communication. Children need to be listened to and understood. Parents need to be heard and obeyed. Communication skills do not always come naturally. For many parents, they are difficult to acquire. Friedman (1993) argues that effective listening courses should be compulsory for everyone in contact with young people, including parents, teachers, health professionals, and service workers.

Communicating with their children during middle childhood may be particularly difficult for parents with intellectual disability. Their previously restricted life experiences and ongoing social isolation may mean they have poorly developed communication skills.

Parents' Views

For some parents, their relationship with their child becomes more like one between adults. On the positive side, some parents are glad of someone to talk to. On the negative side, children may compete with parents for the attention of adult friends or service workers. Some parents express concern that their children are becoming 'little adults' too quickly.

Some parents are concerned that communication in their household is not all they would like it to be. Parents frequently mention the amount of yelling that goes on. They report among other things, children talking over the top of others, not waiting their turn, being impatient and demanding immediate attention. Sometimes parents feel that their children only speak to them when they want to complain, or when they do not want to do things they are asked to do. Parents acknowledge

that often the communication difficulties stem from their own limited communication abilities.

Communication is particularly difficult when a child has speech difficulties. One mother told us about her son—on a waiting on a list for speech therapy—who is 'still not able to tell me what he wants and he gets very frustrated and throws things and gets upset. I get cranky at him because I don't understand what he wants, and then I shout at him'.

Several parents identified strategies they use to enhance communication with their children. For example, one family plays Yachtzee together because 'When we play games together we can get talking about all sorts of things'. Other parents find it is easier to talk to their children when it is quiet (such as at bedtime) or when they are doing relaxing things together like going for a walk. One father looks forward to walking his daughter to school each morning, as this is a time when they can talk more easily.

Kim and her 11-year-old daughter, Elisha, love to watch the wrestling together. Kim says 'we don't really talk much, but at least we can always talk about the wrestling'. They love to read wrestling magazines and watch it on TV or video. The walls of their apartment are plastered with posters of wrestlers. Wrestling is one of the few things that they both enjoy and are able to talk about together without arguing.

Catherine is trying hard to put the advice of her support worker into practice when communicating with her son Tim. 'I try to explain to Tim how I feel all the time. Like, he'll say, "I really hate you", and I say "Look, if you really hate me all the time how do you think I'm going to feel? Eventually I'm going to think, well why should I like you if you don't like me? And then what's going to happen? You know, we've got to live here for a long time together. You need me, and I need you." So he went very quiet and didn't say anything, but then later that night he came out and said that he was sorry, so I suppose it got to him eventually.'

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Kim's daughter often accuses her of not loving her. . . . *But that's the way I am, I do, but it's a bit hard for me to show emotion and all that sometimes. When you've been hurt so many times you virtually say "Oh to hell with this", and you virtually have no feelings half the time. I do love her even though I fight with her. She might get a cuddle sometimes, but I'm a difficult person to please at the best of times.'*

Workers' Views

Workers regard communication between parent and child as a major issue for many parents with intellectual disability. Parents may not always pick up on problems or things that need talking about with their children. Children who are aware that their parent is different may choose not to communicate information to their parents. This is illustrated in the story told by one service worker about a boy who was continually in trouble at school for refusing to complete his spelling homework. The teacher began to see this child as obstinate and uncooperative. In truth, he did not want to ask his mother to test him because he knew that she could not. He wanted to protect himself and his mother from embarrassment and did not explain this difficulty to his teacher.

Parents may have difficulty expressing emotions such as grief and may 'act out' or shout. For example, one mother became physically abusive to her son after his father died. Not knowing how to express her grief she took this out on her son. When parents' communication skills are poor, this can be psychologically and physically damaging for parent and the child. Workers generally agree that parents with intellectual disability often need help to improve their communication skills and counselling to manage their negative emotions.

Practical Strategies

Many families in the community have difficulty with communication. Parents need help to learn how to engage in regular 'round table' discussions with their children. Practical strategies to use with parents with intellectual disability are the same as those used to help any family.

- When a parent-child relationship has broken down, a family conference or series of conferences need to be initiated by the support worker. Both parent and child need to voice their points of view in a controlled, safe, and

mediated setting. An action plan or contract agreeable to both parent and child could be drawn up at this meeting.

- To help parents develop positive communication habits, the following strategies can be taught.
 - Use meal times as talking time. For some families this can mean developing the habit of eating together around a common table
 - Ask children about their day, and tell them about your own.
 - Talk to children in their own space, such as in their bedroom. Children are more likely to open up in a private place where they feel secure.
 - Respect children's boundaries, and let them talk in their own time.
 - Talking is more effective than shouting if you want to get a point across.
 - Don't use 'put-downs' and other comments that belittle a child.
- Encourage parents to pursue or develop common interests with their children to further enhance their relationships.

Section 2.3 Promoting Independence and Helping at Home

Middle childhood is a time when many children want to be more independent, to take on responsibilities and pursue their own interests. Parents respond differently to these demands. Some encourage their child's growing independence. Others set strict limits, often out of fear for their child's safety. Middle childhood is also a time when parents may want their children to help more around the home. Children demanding more independence and not helping at home frequently leads to family conflict. Parents with intellectual disability may not manage negotiations in these areas very well. These parents are often accused, somewhat contradictorily, of both 'giving too much freedom and independence' and 'expecting too much from a child'.

Parents' Views

Some parents with intellectual disability expect more of their children than in the average household: some expect less. Some parents to whom we talked do not expect their children to help at all. For some this is because they feel they can do a much better job themselves and so they would rather just 'get on with it'. Other parents do allocate tasks to their children but find they argue, refuse, fight with their siblings about 'turns' or forget to do the tasks. Often then, parents decide to avoid conflict by not enforcing assigned chores.

Some parents with intellectual disability realise that their children want independence and responsibility, but only on their own terms. For example, one mother said her daughter was thrilled to be able to go alone with her friends to the shopping mall, but failed to live up to her promise to complete her homework and household chores before she left. Some children may be seen as inconsistent, only fulfilling their responsibilities when they want to: other children may refuse to take on any responsibilities at all.

For several parents in this project, the fear of 'welfare' and their power to remove a child overshadows their interest in promoting their child's independence. These parents are frightened that neighbours may report them if, for example, they see that they allow their children to walk together to school without a parent. To combat any disapproval, one parent always phones DOCS (child protection services) to request permission before granting her child any freedom.

Colleen expects her 13-year-old daughter, Amy, to help as much as she can with the housework. Her chores include washing the dishes after dinner, sweeping the verandah, running her own bath each night, cleaning her own room, making her own bed, and helping with the care of her younger brother. If she does not complete all of her chores, Colleen punishes her by assigning her more tasks to do on the following day.

Catherine decided that she would give her son, Tim, \$2 pocket money each week, so that he could learn the value of money. On the very first week Tim went to a toy store and picked out a \$50 toy. He took it to the counter to pay with his pocket money. Catherine tried to explain that he did not have enough, and that he would have to save before he could afford it. Tim threw a temper tantrum, and threw the expensive toy on the floor. For the next couple of weeks Tim spent every cent of his money on lollies the day he received it. Catherine felt that he was not learning the lesson she had hoped, and so discontinued the pocket money.

Workers' Views

From the workers' perspective, independence generally comes too early for the children of parents with intellectual disability. These children need to get themselves ready for school, take responsibility for their own homework, and make decisions about what they tell—and what they do not tell—their parents and others about their life situation. In some families, children often fail to attend school because they are busy taking care of household responsibilities and younger siblings.

Some parents are thought to 'disengage' themselves from their children and lack awareness of the fears their children may have as they experiment with increasing independence and responsibility. This may happen because for some people with intellectual disability it is difficult picking up on subtle messages or indications of fear or unhappiness.

'Parenting the parent' is a phrase frequently used by workers when children care for the house, their siblings, read letters for their parent or write notes for them. This phrase oversimplifies a complicated

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situation. Certainly, many children take on numeracy and literacy tasks that are usually the responsibility of parents. These tasks may also be done by children in families where parents do not have cognitive limitations, such as families for whom English is a second language, or where parents have physical or sensory disabilities. When a child takes on such tasks, does this mean that they have, in effect, become the parent? If parenting could be reduced to such tasks the answer would be yes. Parenting however is also about authority, unconditional love, and about adult experience in the face of the child's developing engagement with the world. It is uninformed to suggest 'role reversal' when we know so little about how parents and children experience their changing roles during middle childhood. Tim and Wendy Booth's helpful new publication *Exceptional childhoods, unexceptional children* (1997) sheds some light on this issue by reflecting on the lives of adult children of parents with cognitive limitations.

One worker commented that 'Children are expected to be older than they are. When parents realise they are capable, they expect them to take over the household chores disproportionate to their age and what other children their age would be doing at home. One parent was happy to let her 9 year old go to the bank and collect the pension. In another instance the child had been using the parents keycard and taking money out for himself because he knew the pin number. He had been buying things for himself and his friends at school.'

Practical Strategies

The question of how to promote their child's independence was an important issue for all the parents we consulted. Grose (1997) suggests a range of strategies that can be taught to parents. These are summarised below:

- Encourage children to do routine household chores.
- Encourage children to be responsible for their own homework tasks.
- Watch for your child's readiness to do things for themselves, and then let them take over.
- Encourage them to get themselves up for school and prepare their own breakfast.

- Show them how to operate the washing machine and microwave.
- Identify purposeful tasks for which that you can give them responsibility.
- **When children fear taking on new responsibilities, the following strategies may be helpful:**
 - Distinguish between caution (taking into account possible dangers) and fear.
 - Listen to your child and investigate the source of fear.
 - A sense of security comes from routine, so make sure there are as few changes as possible in their daily routines.
 - Teach them and show them ways to cope with their fears.
 - Show them your own confidence and positive attitude.
 - Find someone to talk to about your child's fears and swap ideas.
- **To encourage a child to take on responsibilities around the home, Grose (1997) recommends the following strategies:**
 - Give children realistic jobs, rather than jobs that just keep them busy.
 - Balance personal chores with family jobs.
 - Involve children in choosing their jobs.
 - Place unpleasant jobs on a roster.
 - Ensure that jobs are completed before meal times and pleasant activities, like watching TV.
 - Avoid doing the jobs for the children.
 - Show that their help is appreciated.
 - Keep chores and pocket money separate. It is reasonable to expect children to help around the house without reward.
 - Try using a different word to 'chore' or 'job' if it seems that these words turn them off helping.

Section 2.4 Self-Esteem

Raising children with healthy self-esteem is an important goal for any parent. Some parents with intellectual disability may have difficulty meeting this goal. Indeed, many parents with intellectual disability have low self-esteem themselves after years of experiencing failure, segregation and abuse (Llewellyn, 1997b). Several authors suggest that children of parents with intellectual disability will need other relationships, for example, an adult outside the home, or peers to assist in developing healthy self-esteem (Barnes, 1996; Coates et al., 1985; Booth & Booth, 1997; Tymchuk, 1992). Strategies to facilitate such relationships are discussed in Section 1.2. Helping parents to develop self-esteem cannot be neglected, as many parents with intellectual disability are motivated to learn how to build their child's self-esteem.

Parents' Views

For some parents, their children seem to lack self-confidence. Others appear not to really notice their child's self-esteem, except to say 'he/she seems happy enough'. Most however try to help their children combat things that are damaging to their self-esteem, such as teasing from peers.

Sue is concerned that David is picked on.

'...Called chicken legs. We tell him to show his legs and say "this one is KFC, and this one is Red Rooster". "Say it", we say. He won't do it. I say to David, "we can't help you if you're not going to do it. If they do it tell them, 'stop, I've had enough"'. He's not that confident to stand up for himself. . . . If only he would say stop, I've had enough.'

Julie talked about how Angie tries hard at school, but she gets discouraged because she isn't as good as everyone else. She says to me all the time, "I don't want to grow up dumb, Mum". The kids at school tease her and call her a "stupid, fat pig". She's as skinny as anything, but she took it to heart, and she believed that she was too fat. For a couple of days she just wouldn't eat anything, and I was so worried. I was scared for her, but I was also scared that they'd come and take Angela away if someone reported that she wasn't being fed properly. So I had to speak really firm to her. I didn't like to say it, but I had to, so I said "If you don't eat, you'll get

sick. You may even have to go into a home, I don't know". Angie got really frightened that she might be taken away, and so she started eating again.'

Workers' Views

The major concern of workers is that poor self-esteem makes the children of intellectual disability vulnerable to abuse. Another potential danger is peer pressure. Children with low self-esteem may seek the acceptance of a 'bad crowd' who encourage them to do inappropriate, illegal, or dangerous things. Some children with low self-esteem may also be a danger to their parents. Feeling powerless, children may attempt to dominate their parent emotionally and physically. This is illustrated in the following story:

One worker talked about one family where the son rules the household. 'He tells his mother, who has an intellectual disability, what to do. He even moved his girlfriend and a couple of other friends into the home, to be financially supported by the mother. He hits his mother when she tries to exert some control. One day he and his friends 'jumped' his mother in a park, then stood in a circle and cheered while his girlfriend and some of her friends beat her up'.

Practical Strategies

It is important to remember that parents are usually keen to help their children; they simply lack knowledge of how to do so. These parents need guidance and support to play an active part in fostering their own child's self-esteem and feelings of worth. The following strategies can be taught to parents with intellectual disability:

- Give children responsibilities and help them set realistic goals.
- Point out to your children what they are good at.
- When you do have to correct your children, point out a strength first.
- Take an interest in what your child likes to do and play—make them 'the expert' in these activities.

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- Say at least one positive thing to your child every morning before they leave for school.
- Don't compare children with their siblings.
- Tell your child that you love them regularly, perhaps when they are saying good night.
- Home visits provide support workers with the opportunity to model self esteem building behaviours.
- Encouraging and supporting children to participate in sporting teams, recreational clubs and other interest groups such as the scouting organisation or local church youth groups, can also have the effect of building a child's self esteem.
- Some children will require the unconditional support and regard of an adult outside the home. Suggestions to facilitate this are mentioned in Section 1.2.
- A parent's own poor self-esteem may hinder their capacity to put into practice strategies to help their child. Several strategies to boost the self esteem of parents include:
 - Involve parents in decision making, respecting their wishes and concerns.
 - Listen and respect what parents tell you.
 - Give parents the opportunity to help you and reciprocate your support. For example, ask parents to watch or videotape a television program for you—and to tell you about it.
 - Set measurable and realistic goals in collaboration with the parents. Regularly discuss parent progress toward meeting these goals helps to offer positive encouragement.
 - Acknowledge parents as the experts on their child and in other areas. For example they might be an expert on the Rugby League, an expert gardener as well as their child's likes and dislikes.
 - Include parents in support groups with other parents. If at all possible, give parents a role in organising and running the group (see *Out of the mainstream: A parenting group for parents with intellectual disability and their children*, Department of Human Services publication, 1998).
- Encourage and support parents to engage in purposeful activities such as: recreation, hobby groups, or attending a course; getting a job or volunteering; or, helping in various ways at their child's school such as working in the canteen or library.

Section 2.5 Discipline and Sibling Rivalry

Discipline is the means by which parents establish a loving and supportive environment in which what is acceptable behaviour and what is not is clear to all. During middle childhood, parents have to redraw boundaries to keep pace with their child's development. For parents with intellectual disability, knowing where to set limits may be particularly problematic (see Section 2.1). As children grow in size, disciplinary methods formerly used may be unproductive and difficult to enforce. Parents must adapt their methods. At the same time, sibling rivalry—a normal part of family life—can also become more ferocious (Bennett, 1987). As Marris (1996) notes, 'All children need secure, constant and well defined boundaries to their lives. This is the crucial role of parents, for it is their adult knowledge, their greater wisdom and their better experience of the world that allows children to explore, to experiment and to push into new frontiers without being at risk'.

Appropriate discipline is essential in promoting happy and emotionally healthy children (Campbell, 1992). Children learn social parameters through discipline. They need the security of clearly stated rules before they can explore freedom. Appropriate discipline also enhances a child's self-esteem by teaching natural consequences of actions. The outcomes of inept discipline can be serious. Inept discipline is the best predictor of antisocial behaviour in children and in adolescence (Patterson, 1986; Patterson & Chamerlain, 1988).

Parents' Views

Most families list fighting between children as a major issue—in some families—a daily issue.

In Catherine's family, nine year old Tim knows exactly the right thing to say to 'set off' his four year old sister, Rebecca. From the moment he gets into the car after school he will poke her, and say things that he knows will make her cry. At home he takes things from her, such as her toys and lollies, and pulls the heads off the dolls that she loves. No afternoon tea goes by without tears and distress from Rebecca. One time Rebecca saw a boy with no hair on the TV, and asked her mother what was wrong with him. Her mother explained that the boy had cancer, and might die. Rebecca said, 'I wish that Tim would get cancer and die. It would be great here without him.'

At these times parents with intellectual disability—like other parents—often feel powerless. They may be uncertain where to set limits, and how to enforce them when children are defiant. The parents we consulted use a range of disciplinary methods. Some parents believe the best method is a good smack. Others feel as if they constantly have to yell. Another popular parental strategy is sending children to their rooms. However, for many parents this becomes more difficult as children get older and can no longer be physically forced to go. Several mothers said that their children listen more attentively to their father and so they rely on their husband or partner to discipline their child.

Here is a range of ways in which mothers dealt with disciplining their children:

'When the children fight or backchat they get sent to their rooms to cool down. They are fine after. Except now my daughter won't go. I can't make her go to her room.'

'Their father takes on more of the discipline. After he's sent them to their room he talks to them and tells them not to shout at me. He stops Amy back-chatting.'

'It is difficult to keep consistent and do the same thing or give the same punishment every time they misbehave. They get away with things once, and the next time you're down on them.'

'You have to keep a step ahead. As they get older they get tough, smarter, then pick things up from the older ones. They get harder to control and want to be in control and tell you what to do.'

'When they do something well we give them a dollar. We tell them if they finish high school and do their best we'll buy them something big like a Hi Fi.'

Some parents prefer to deal with child management problems 'on the spot'. Others focus more on positive preventive methods. For example, one parent uses a star chart to reward good behaviour. Food treats, verbal praise and money are also widely used. Parents' report how difficult it is to stay one step ahead, not knowing what to expect as their children get older. This concern was often exacerbated by parents' fear of 'child welfare' and being reported by their neighbours if they hear any yelling or smacking.

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Mary talked about 'Next door, she puts her two cents in whenever I try to discipline my kids. She tries to tell me how to bring up my kids. She's got problems. She tried to do me in! She's the one with the problems. Her little girl runs around in her nightie all day and comes and asks for food because her mother doesn't feed her. I don't think the girl goes to school even. The welfare rang me mother and asked her if it's true about me neglecting my children, and my Mum told her no'.

Catherine felt that her own mother had been a 'dragon' when she was growing up, and she started to realise that sometimes she behaved in the same way. She was always yelling and smacking her children. Her son, Tim, has Aspergers Syndrome and particularly had behaviour problems. Catherine approached her family support worker and asked for some help. He sat down with her and explained that you have to 'link consequences with the crime'. Catherine listened as he explained, and then tried very hard to put his advice into action, even in some extreme circumstances. For example, on the way to school one morning, Catherine stopped and popped in to the local shop. She told her children to stay in the car. She was gone for only a couple of minutes, but when she returned she found that Tim had defecated into his own hand and rubbed it all over the inside of the car door. Catherine was furious and disgusted, and she said that she really wanted to yell, but she stopped, and tried to remember what her support worker had told her about linking punishment to the crime. She jumped in the car and drove to a petrol station. She requested a bucket full of water and a rag, and then stood there and insisted that Tim clean up his mess all by himself. Catherine says that she does still yell and smack sometimes, but much less than she used to.

Workers' Views

Workers agree that behaviour management is one of the biggest problems for parents with intellectual disability. Parents are thought not to have the skills or know how to discipline their children. Children are seen as 'walking all over their parents'. Some parents with intellectual disability may not recognise inappropriate disciplinary methods, sometimes relying on harsh physical discipline.

One worker commented that 'In this one family, the daughter wouldn't let the mother brush her hair before she went to school because she had long hair and it took too long. On one occasion the mother ended up biting the child with the brush, she got so frustrated. She felt so bad afterwards, she called her support worker, she knew she'd gone too far. The support suggested to the daughter that she brush her hair before she goes to bed at night, and take responsibility for her own needs. It would then be easier to brush her hair in the morning. She also showed her how she could plait her hair and look after it so it wouldn't get so tangled. In this way good discipline, and promoting independence were modelled for the parent'.

Practical Strategies

Parents want less conflict at home; they want their children to grow up to become good adults and they want to do the right thing by their children.

- A parent education program/support group focusing on behaviour management is an effective way to teach skills at the same time as reducing isolation (a major factor in inappropriate discipline with children). Smylie and Price (1994) from South Australia have effectively used sharing problems and solutions in a group setting supported by a structured behaviour management program. Details of their program are included in Section 3.1 Parent Education Resources.
- Workers can set a good example of problem solving without using harsh discipline. However, a genuine relationship of trust and respect is necessary, and parents need to know that the support worker is on their side. For many parents, the service worker is the last person they tell about mistakes because they fear their power to take their child away.
- Parents can be taught the following strategies suggested by Grose (1997) to help them understand discipline and develop effective methods. To be successful, these strategies need to be individually tailored for each parent using examples from their everyday lives.
 - Discipline means teaching children appropriate behaviour, not punishment.
 - Discipline also means teaching children to be responsible for their actions.

- Establish clear boundaries and limits for children.
- Stop, think, and go against your first impulse when children misbehave, so if you feel like exploding or losing your temper, take a walk, phone a friend, or count to ten.
- Cue children once only when asking them to do something, repeating yourself encourages them to ignore you.
- Pinpoint the reason for the child's misbehaviour, work out if it is attention seeking, and then try to change the way you respond.
- Encourage children whenever you get the chance.
- Consistency, rather than severity, is the key to discipline.
- In more extreme circumstances, a family conference as discussed in Section 2.2, may be a necessary first step. At this conference, discussion about developmental expectations can go hand in hand with implementing a behaviour modification scheme designed collaboratively and agreed to in the family contract. Such contracts need to be individually drawn up to reflect each family's circumstances, to include incentives for the child, and to be reinforced by all workers involved.
- Where parents have concerns about sibling rivalry, they need to be reassured that they are not alone in their struggle to deal with it. Assisting the parent to see what is good about their family and the way they work together relieves some of the pressure. Strategies to reduce sibling rivalry and encourage bonding include:
 - Promoting communication between the children, and mediate if necessary. 'Take the attitude of 'lets work this out together'.
 - Encouraging the children to verbally air their ideas and feelings.
 - Taking a long term view, and addressing each issue on its' own.
 - Encouraging children by example of how to reason with each other.
 - Accepting each child for who they are and value their differences.
- Encouraging children to take an interest in each other's activities.
- Ensuring that acceptance of children is not conditional upon their success.
- Emphasising children's effort, improvement, and enjoyment in activities, rather than praising them for good results.
- Staying out of children's disputes, and avoiding opportunities for blame, as this often reinforces the notion that one child is favoured above the other.
- Having fun together by engaging in games and activities that foster cooperation.

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Section 2.6 Healthy Bodies, Healthy Minds

As children grow rapidly during middle childhood they need a balanced, nutritious diet in order to develop and remain healthy. Eating and health habits developed at this time will continue into adulthood. Teaching children good eating habits and personal hygiene are parental responsibilities. Older children also need to learn the importance of exercise and fitness (Bennett, 1987).

Parents must also take care of their own health. Parenting is a demanding task and requires a healthy body and a healthy mind. Parents' capacity to fully meet their children's needs is compromised if their own health and self-esteem are poor. Being healthy can be difficult when money is in short supply and parents feel isolated and lonely and are unable to take 'time out' for themselves.

Parents' Views

Some parents will be concerned to make sure that their children eat well. Others will not and appear not to care what kinds of food their children eat.

Josie is proud to say that her children always have fruit in their school lunches. Her children do not always like to eat healthy food, and that frustrates Josie, especially when they fill up on lollies before dinner. She tries to hide the lollies from them, and insists that every night they try at least one vegetable on their plate.

Kim commented that *'I sometimes ask Elisha what she wants for dinner, and she always says "two-minute noodles", but I say "No way!" 'Cause that's not good for her.'*

Mary and her two boys love McDonalds, and so she regularly takes them to McDonalds for breakfast, or as an after school treat. They eat at McDonalds at least a couple of times every week.

Kim is satisfied that Elisha is eating some healthy meals, because for dinner Elisha generally opens a can that has sausages and vegetables in it. Elisha sits and shares this meal with the cat. Kim says that she admits they are both over-eaters, and eat too much junk.

Some parents with intellectual disability do not appear to care too much about their own health. Others are well aware of the need to look after themselves both physically and emotionally. For example, one mother we spoke to enjoys taking walks and talking to her support worker as stress reducing strategies. Another mother finds shopping helps her to 'escape' and is calming when she is upset.

Some parents may trust their local doctor as someone whom they can frequently visit: for ear infections, colds, sore eyes and so on. Others may be very reluctant to take their child or themselves to a doctor for any reason at all. Doctors can be difficult to understand and parents can become confused by their instructions. Parents may be too shy or too embarrassed to let the doctor know that they did not understand or to ask questions. This may also happen with other professionals. One mother was given written instructions that she could not read. Her family support worker had to step in to mediate between her and her child's speech therapist.

Kim has a very twisted and deformed elbow. It is very painful, and she says that it prevents her from doing anything around the house, or anything that she would like to do other than watch TV. This injury is the result of a fall in the backyard. Kim hates doctors because she feels that they are too bossy, and that generally things get better on their own anyway. She believes in 'self-healing.' For these reasons, she did not go to see a doctor until five months after the fall. She had been hoping that the bruising and swelling would go down, but when things did not get any better after five months, she decided that she had probably better see a doctor. She now regrets seeing the doctor because he lectured her and told her that she should have come sooner. Also, he booked her into hospital for an operation on her elbow without asking her if that's what she wanted to do.

Managing children's medication can be difficult but with some thought beforehand this can be overcome. One mother hides her children's tablets in their food or cordial so that they do not spit it out. Another goes out to buy more of her child's medication the minute the school tells her that it is starting to run out.

Parents with intellectual disability—like all parents—value the time they have to themselves when children are at school or in bed. This is a time for doing housework or watching TV or other tasks that are more easily done without children around. Some parents like to get out of the house and do the things they enjoy most. One mother goes to fabric-painting classes while her son is at school. Another goes shopping and meets her sister or a friend for lunch and to talk about fashion and the children. A third mother loves to go out to play lunchtime bingo. Activities like these help parents to feel better about themselves and happier with their lives.

Workers' Views

In general, workers think that children of parents with intellectual disability are poorly nourished. Children are often sent to school with an inadequate lunch or no lunch at all. This often follows a no breakfast or a non-nutritious one. Poor budgeting may mean there is no money to buy food. Some parents may have food in the house but lack the skills to make nutritious meals.

Workers consider that parents with intellectual disability do not adequately care for themselves. They may be heavy smokers or in some instances engage in drug and/or substance abuse. They may have poor dress or hygiene standards. When parents are not able, or unwilling to care for their own personal hygiene, it is unlikely they will care for their children's health or teach hygiene and healthy living skills to their children.

Parents' emotional health and their ability to manage stress are also a concern. When parent's emotional needs are not being met and they have low self-esteem, they are more vulnerable to exploitation and abuse. Under such circumstances their children are also placed at risk. Poor stress management usually means difficulty dealing with conflict and anger. When anger is poorly managed there is always the potential for harsh discipline.

Practical Strategies

- Helping parents learn about good nutrition, their child's dietary needs and how to prepare basic and 'tempting' meals for the family. This can take place in a group setting or one-to-one in the parent's home. Meal planning can be worked into budgeting skills training.
- Helping parents learn how to care for their own health. When parents live unhealthy lives, they set a poor example to their children as well as being unable—due to their own poor health—to care adequately for their children. The importance of emotional self-care also needs to be emphasised and parents assisted to seek out professional help if needed.
- Encouraging parents to pursue their own interests and hobbies. Parents often need reassuring that it is OK to take 'time out' and that this will help them be better parents. Parents may need a lot of encouragement to choose activities they would like to do. For parents too frightened to leave the house, a support person can accompany them to do a liberating activity like taking a walk or going to a movie.
- Supporting parents to become more assertive. Self-assertiveness training assists parents to make choices about the treatment they receive from others as well as professionals. Parents need support to accept that nobody has the right to speak to them in a devaluing way and to learn strategies for dealing with these situations when they arise. For example, parents need to know that they do not need to stay with a doctor whom they do not like or who treats them without respect. It is fundamental that parents find and continue to go to a doctor whom they like and trust to ensure their own health and that of their children. A support person may be needed to help locate the right doctor for them and other suitable health professionals.
- Empowering parents to take control and speak up for themselves can be best facilitated by the group process. In Australia, several group programs have been successful in not only helping parents to manage difficult behaviours in older children but also to seek support from each other and relevant community personnel. A successful Danish program uses the group process for parents with cognitive limitations to air their feelings, to share experiences, to learn skills, to provide support, to develop competence in social relationships and most

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importantly to build hope and strengthen their ability to act on their own behalf. Finally, the group process provides a sense of community for parents and children with holiday camps, family nights, and child minding clubs. Other suggestions for boosting parents' self esteem are in included Section 2.4.

- When presenting material about health care this must be done in structured, specific presentations and with many opportunities for discussion. Health care information should include symptom recognition, the treatment of non-serious illness or injury, and the administration of medication and healthy eating patterns. If necessary the material may need to be adapted specifically for the parent and the worker will need to check regularly that not only has the parent understood but also remembered the important points. Parents are entitled to have essential information about good health care. Informed parents are the best protection for the safety and well being of children. Although there is no evidence to suggest that abuse is more common among the children of parents with intellectual disability workers report they believe this to be so. It appears that when abuse does occur this is more likely to come from others (including the mother's partner) rather than from the parent with an intellectual disability (Tymchuk & Andron, 1990). Like any parent, parents with intellectual disability need to be informed about the dangers of abuse and to learn strategies to protect their children. Most information on abuse and neglect is written and, therefore, not easily accessible to parents with intellectual disability. This information must be adapted to be easily understood at the same time as their children are taught about stranger danger and protective behaviours.

Section 2.7 Learning and the School Environment

Middle childhood includes the transition from primary school to high school. For most children primary school is a highly structured, predictable and low-pressure environment. In contrast, high school means new subjects, many teachers, frequent moving between classrooms and a change in status from senior student back to the most junior. Children cope with this transition in different ways. Some make the transition smoothly; others do not. Children can become bored and disruptive at this time or make an extra effort only to 'fail', lose their confidence and their self-esteem (Bennett, 1987). Bullying which is frequent at this time (around one in ten children are bullied) can add a further pressure.

There is general agreement that the more involved a parent is in their child's education, the better this child will do at school. Parents can offer support and help their child in their homework tasks by providing a quiet and uncluttered place for their child to work, encouraging good study habits, and actively assisting with homework (Bennett, 1987). They also play a pivotal role in their child's cognitive development by the way they interact with their child and how they structure their children's experiences. Parents also can serve as 'mediators' in helping their children interpret and learn from their experiences.

Only one study has explored how older children of parents with intellectual disability fare at school. Feldman & Walton-Allen (1997) investigated the effects of maternal mental retardation and poverty on intellectual, academic and behavioural status of school-age children. In general, their findings demonstrate that the children, particularly the boys of mothers with intellectual disability were more likely to demonstrate cognitive, academic and behavioural difficulties than children of similarly poor mothers without intellectual disability. More research is needed, however, to determine whether child behaviour problems are related to inadequate parental knowledge and skills in basic child management strategies, such as positive reinforcement, supervision, limit setting, and consistent discipline (Fantuzzo et al., 1986; Tymchuk & Andron, 1992).

Parents' Views

Most parents want their children to do their best, and better than they did at school. Parents expect that if their children finish school they will be able to get a good job. To help their children they want to know how their children are going at school as well as when there are problems. Some children

may be particularly vulnerable to peer pressure and very easily led into mischief at school. The parents who participated in this project reported difficulties in communicating with their children's schools. For example, reading school reports or notes sent home by their child's teacher.

Mary has a communication book that comes home with her child. She can read it only as long as the teacher writes in printing. She has told the teacher this, and the teacher usually remembers to do that for her. When she does not remember, Mary is frustrated and disappointed. Mary always has problems reading the school report, and generally asks a friend or extended family member to read it for her.

On the other hand some parents have very positive interactions with their children's schools. They really like the school concerts and look forward to them as much as their children do. Some like to go and help at the school. One mother goes every week to help in the craft class where she loves helping the children and seeing her own child with the others.

Parents with children with a disability have additional problems. Fighting for help and services for their child is especially taxing when few parents have the skills to do this. Some parents in NSW report being very unhappy about not being consulted by the NSW Department of School Education and Training about their child being sent to a special school. Other parents are quite happy to trust the judgment of the department.

Kim talked about how her daughter Elisha, who is in sixth class, has attended three different schools. She is in a special education program. Each time that she has moved schools, it has been a decision made by the NSW Department of School Education and Training. Kim is very upset that nobody has ever discussed the moves with her. She is simply notified when the move is to take place. Kim is also concerned that Elisha is not learning enough, and should know more than she does. *'These teachers obviously aren't trained to deal with learning disabilities. I get so angry at the system for not helping us. See . . . I don't think they help the kids enough.'*

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Parents acknowledge they cannot always help their children with their homework. They may not have the time, nor know how to help. For many parents, their child's academic ability outstrips their own. One mother knew that other mums went to the library to get books to help with their children's projects but she did not know how to look up the right books. Other mothers find different ways to help their children. One mother tells her daughter's teacher when the homework seems too hard so that the teacher will explain it again. Another mother who reads but with difficulty began reading classes. Her son's teacher helps by setting homework tasks that they can work on together.

Tracey talked about how 'Thomas comes home after school and has something to eat before he starts his homework. I have a bit of a problem with the writing, but if I do understand it I'll try and help him as much as I can. Or he'll wait till his father comes home. If he thinks it's too hard and he doesn't understand it and he knows Mummy can't understand it, he won't worry till his father gets home.'

Getting children to do their homework is nearly always a struggle. Parents are often unsure how to make children do homework particularly if they simply refuse or demand to do other activities such as playing computer games. Parents talk about their children not seeing their school friends outside school. Friends are rarely invited home. Some parents understand that this may be because 'our family is different'. Others do not understand why except that their child may have seen enough of their friends at school during the day and want family time at the end of the day.

Workers' Views

Workers focus on the fact that children become increasingly aware of the differences between their parent and other parents. They may feel that their own home life is painfully different from the outside world. Their peers' opinions also become very important. They usually do not want their friends to know about their parent's disability for fear of being made fun of. They may not want to bring their friends' home and instead sneak away to their friends' houses after school without telling their parents. As they begin to understand their parent's disability they realise they are 'smarter'. They can read better, calculate better, write better,

and understand better. They know they cannot get homework help: they may resent the fact that their schoolmates can get this help while they have to work things out on their own.

Getting children to attend school may be a problem. Some parents may not even know if their child is at school or not. Children may 'forget' to pass on notes about non-attendance or lie about the content of the note. For some parents it is difficult to get their children ready on time especially when families do not have an efficient morning routine. Other parents may know that their child is not at school but feel unable to force them to attend and allow their children to make their own decision. Children may choose not to go to school when they do not have any friends or are not achieving or when they are being bullied. Potentially the children of parents with intellectual disability are more vulnerable to these unhappy situations.

Coping with children's issues at school can be difficult for parents with intellectual disability. Thinking through what to do or thinking about what is likely to happen next can be beyond the parent's ability. It may be that the parent simply does not understand that their child and school demands change over time. They may think in terms of 'tomorrow is the same as today.' Some parents may 'want a quiet life', with as little hassle as possible. For some, there may be little value placed on education. This results in a high rate of truancy, and a general lack of respect from their children for their teachers, homework or school learning. Parents' isolation contributes to the stress resulting from the expectations put upon parents by school personnel. Parents can feel very alone in trying to meet these expectations.

Teachers may not be aware of the limitations associated with parental disability and the impact of these on children's learning and homework. Teachers, as with other professionals, may expect parents to conform to their own predominantly middle class values and may not be prepared to tolerate another perspective. Not surprisingly, some teachers may carry the attitude 'Do these children belong in a school like this?' When informed of a parent's disability, teachers may respond with community stereotypes about disability and assume only the worst, look for problems, and over-react to any difficulty. The following examples illustrate this problem.

One worker told the story about one young girl who had made a friend *'...and she didn't want her to know her mother had a disability, so she used to go to her house all the time after school. The mother of this friend became concerned and rang the mother one-day to let her know where her daughter was. She felt it was important for the parents to know where their own daughter was. That's when it all came out that the young girl was worried that her friends would reject her because of her parents and so didn't want them to meet them.'*

Another worker told the story of a young boy who did not want to go to school. *'He was quite defiant about the school, the people, etc. His mother got him moved to another school and after six months he was unhappy at the new school so he wanted to move or not go. The interesting thing is that the school didn't ask a lot of questions because they knew the parents, and they knew the parents were always asking the school to do something, and I think they thought it might be easier to let them go. The parents don't have a lot of skills to approach the school in the appropriate way.'*

Practical Strategies

- Advocacy is needed to support parents and their children at school. Parents may need someone to attend parent-teacher interviews with them; to help explain the differences between school now and when they attended, and to ensure parents understand their responsibilities in getting their child to attend school and why non-attendance is bad for their child. A parent and child advocate could be formally assigned or personally chosen. They could be a service worker or a concerned friend or relative. Most importantly, they will need to be someone to whom school personnel will listen. Not all families will need such an advocate. However, many will. Support workers first need to check whether the parent and child have a positive relationship with school or need an advocate to be 'their voice'. In one of the interviews, a support worker stated this clearly as follows: 'The role of the advocate is to help the child understand his choices and the parents their choices. The advocate needs also to advocate for the child at school. All these families need someone to work with the parents to construct an overall plan, help with important decisions. Help is needed with intellectual choices, understanding of choices, what leads to what. There is a role for the support workers to construct longer-term plans. They need a 'crusader of justice'. Someone who can distinguish what is different and what is bad'.
- Children also need someone who can help them make choices such as subject selection. They need a supportive adult or teenager who can provide homework assistance over a period of time. With parents often unable to understand schooling options, children need support as a 'safety net' to avoid being labelled as 'special needs children'. This frequently happens. However with early, carefully planned, forward looking and consistent support this can be avoided.
- Opportunities for parents to learn the skills and behaviours expected by the community. One of the best ways is to support parents to engage in school activities. This could include serving in the canteen, working in the school library, assisting in the playground or whatever other activities the school offers. In this way parents get to see other children—and parents—in action. The child's classmates also get to know his or her mum or dad. Younger children thoroughly enjoy their mother—or father—being part of school although as children get older this may change. Negotiating parents' appearances at school then needs to be done with parents and children together.
- Opportunities for children to be helped with their schooling. When children enter school there is a general expectation that they will listen, do as they are told, be quiet on request and take turns. Learning these behaviours at home is more difficult for children who come from isolated families—and mothers with cognitive limitations are often among the most isolated in the community. For the school-age child, active involvement in after-school activities, recreation camps and neighbourhood programs is usually necessary to supplement the home environment.
- Support workers may need to explore options for homework support. This may come in the form of a homework club, homework help at after-school care or a personal tutor such as a neighbourhood teenager. Several strategies are useful for homework and learning dilemmas. A

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family member, friend or an older neighbourhood child may be happy to take on this role with the parent's consent. Supporting the parent to recognise their difficulties without recrimination is essential. It is critical that the school is sensitive to getting the parent to fill in forms, hear reading homework, or preparing items for show and tell. The parent-teacher relationship works well when teachers take the time to listen to parents—most parents with cognitive limitations will want to share information about their child orally. Some parents have no one to offer homework support to their children. A successful program in Los Angeles offers after-school homework assistance at their centre in small groups to the children of their parent clients.

- Grose (1997) suggests the following strategies may be usefully taught to parents to assist children with homework:
 - Set aside regular times for homework and other educational activities, such as reading.
 - Provide children with a broad range of opportunities they can then talk and write about at school, such as going to the beach, or going for walks.
 - Find out about school holiday activities being run by the council.
 - Encourage children to feel capable, independent, and responsible, it all promotes learning.
 - Don't be upset if they make mistakes. Mistakes are part of learning.

Part 3: Parenting Education

Section 3.1 Parent Education Resources

Parent education through parenting programs, the media, written material and informal networking is now an accepted way to support parents and their families. In this section we describe some parenting education packages that are useful for support workers working with parents with intellectual disability. No single package claims to cover all topics of interest. Workers will need to adapt ideas from several packages to develop appropriate individual or group programs for parents.

Grose, M. (1997). *Parenting Ideas*. Melbourne, Victoria, The Australian Council for Educational Research.

This package aims to provide parents with help and guidance about some of the issues and problems they encounter. It can be used with any parent group in the community. The philosophy underlying this package is to build and improve relationships between parents and children.

The package contains twenty-four cards with a brief background on each of the topics that are a particular concern for parents with school age children. Each sheet covers a different topic such as talking with kids, encouraging children, discipline, bullying, helping children learn and promoting independence. The sheets are in point form and can be used in group discussion or as take home material. This package does not purport to offer solutions rather it offers ideas and new ways of looking at issues, stimulates thought and challenges some existing habits.

The main advantage of this package is the concise, clear format with practical everyday ideas that can easily be used for parents with intellectual disability and applied to their everyday situations. It is user friendly both for parent and workers. The topic cards can be introduced individually as particular concerns arise for parents. These cards can be used to trigger brainstorming of further ideas on a one to one basis or in a group context. They can also be used as reminders and placed on parents' fridges or notice boards. The topic cards serve as a useful additional resource for workers with little experience with parents with older children or those who are stuck for ideas!

Linke, P. (Eds). (1994). *Practical Parenting. Leaders Guide*. Melbourne, The Australian Council for Educational Research.

Linke, P. (1994). *Practical Parenting. A Parents Handbook*. Melbourne, The Australian Council for Educational Research.

This package aims to support leaders with course planning and implementation and parents by way of a handbook with developmental and parenting information. The package focuses on managing issues related to 6–12 year old children including the development of social roles, age appropriate responsibilities and developing sexuality. This program was developed by a group of parent educators and modified by use with parents over a number of years. The package takes a developmental approach based on the assumption that children's needs and abilities change as they develop and that parents need to adapt to these changes as they occur. It also reinforces that children develop as part of a family and that these relationships are fundamental to their development, therefore relationship building and problem solving processes are encouraged.

The leader's guide systematically addresses everything that needs to be considered in setting up parent programs with photocopy masters that can be used as visual aids for discussion. The parent handbook allows parents to choose topics from the package that are most relevant to them. Numerous examples are used to help explain the knowledge and skills required and practical strategies to use. Topics range from communication with children, sibling rivalry and discipline to self-esteem, sexual development, childhood fears and friendships. The authors encourage workers to build on parents' own experiences and to support each other's learning by setting homework tasks and discussing the outcomes.

The advantage of this package is its development in Australia for Australian parents either working individually or in groups. A variety of activities are provided with each topic to provide choices for parents and opportunities to practice the skills required. The activities and visual material provided in this package make the package easily adaptable to individual or group work. The sessions may be a little long for parents with intellectual disability; several sessions may be needed or the worker could focus on and repeat aspects of particular relevance. For example, parents may need several short sessions to practice and learn alternative methods of disciplining

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children with follow up sessions for review on how they are managing the tasks practiced at home.

Peterson, L. (1992). *Stop and Think Parenting*. Hawthorne, Victoria, The Australian Council for Educational Research.

This manual aims at providing all parents with a clearly structured approach to managing day to day interactions with their school age children as well as a method for children to be taught how to control their impulses and learn from their mistakes. The manual is based on cognitive behavioural theory and applying this to everyday interpersonal exchanges.

The method suggested is 'stop, think and do' with graphic visual cues to act as reminders when learning to do this. The three steps are repeated with specific examples relevant to the parents of school aged children such as managing pocket money, watching television, and cooperating with chores. The last section in the manual outlines how parents can teach their children to use the method in daily encounters with others. The manual also includes practical exercises parents can do to learn to apply the method. A bright, tear out traffic light poster at the back of the book can be put on the wall as reminder to parents and children of the steps involved in managing problem situations.

This approach offers a great advantage for parents with intellectual disability because it is a simple concept that can be readily applied to parents' everyday situations. For example, a child comes home and tells their parent that they will have to give their books back at school if they do not pay their school fees by the next day. The stop and think approach can prevent an 'off the top of the head reaction' that might be inappropriate and ineffective. This approach can be used equally well in a group parent education program as on an individual basis. Parent educators, support workers and teachers can use it to support parents and children through primary school. This stop, think and do approach could be adapted to help parents having difficulty with interpersonal relationships with their partners and friends. It could be introduced in parent group work in community living skills programs with other adults.

Sanders, M. R. & Markie-Dadds, C. (1996). *Triple P: A Multilevel Family Intervention Program for Children with Disruptive Behaviour Disorders*. St Lucia, University of Queensland.

This program is targeted at parents who have children with behavioural difficulties and aims at identifying and subsequently managing risk behaviours early in the child's life. It also aims to increase parent's sense of competence in their parenting abilities, improve marital communication about parenting and reduce parent stress. The Triple P program is an Australian designed family intervention program based on research that has established the effectiveness of intervention strategies for reducing disruptive children's behaviours. It has been evaluated independently with mild and moderate intellectually disabled children (Harrod, Lutzer, Campbell & Touchette, 1992)

This program is based on applied behavioural analysis, developmental models of social competence in children, social learning theory and developmental psychopathology. It involves five core parenting skills:

- Creating a safe engaging environment with adequate adult supervision for children.
- Creating a positive learning environment where parents are observant and accessible to their children.
- Using consistent discipline with clear rules and boundaries for particular situations.
- Developing age appropriate expectations and beliefs about their children and their behaviour.
- Taking care of oneself as a parent.

The main features of the Triple P are that it allows the intensity of the intervention to be tailored to the assessed needs and preferences of individual families. The package presents a table with levels of the Triple P which range from low cost self-help programs to brief supported interventions, training and intensive family intervention programs. These address additional family problems such as marital conflict and parental depression. Guidelines are provided to help the worker decide the level of intervention required. Problem behaviours that may occur in school age children are listed in tables and possible ways to weaken or reduce the behaviours are identified.

The potential advantage of this program is workers can assess the level of intervention necessary in families where children have minor or more

substantial behaviour difficulties. Workers can readily adapt some of the strategies used at each level in their programs without having to use the whole program. To date this program has been mainly used by clinical psychologists receiving weekly supervision. Workers are advised to receive the training and supervision necessary to design and implement this program effectively.

Dennison, S.T. (1995). The E.S.SE. Group Model: Group Model: A Twenty First Century Approach for Families at Risk. *Journal of Family Social Work*, 1(2), 57–69.

This program aims to support and educate single parents and teenagers for healthy and successful parenting. It is an American program with objectives and activities for eight sessions. This program was developed from four core concepts—to educate, strengthen, support and empower (ESSE)—parents and families attending a family support program. The advantage of this program is that it addresses the needs of single parent families regarding issues concerning the transition to becoming a teenager and young adult. It provides a framework and step by step planning for eight sessions with specific objectives. Initially there are separate sessions for the children and parents and towards the end the sessions are combined. Strategies for overcoming the common concerns for single parent and their families are discussed reinforcing the principles of the program of education, strength, support and empowerment.

Chapman, P., Brewer-Eiszella, D., & Stevenson, L. (1994). *Challenge, Choice & Change. A Guide to Developing Skills in Parenting, Communication and Living*. Hobart, Tasmania, Centacare.

This structured learning program aims to use creative and challenging learning opportunities to improve interpersonal relationships and life skills of parents and children. The Endeavour Model used in this program is based on concepts from family systems theory, cognitive and behavioural theory, role theory and adult learning principles. It states that to become a self-actualising person needs must be met at the cognitive, social and intellectual levels. For some families some or all of these needs have never been realised and their life skills may be underdeveloped. The holistic approach that the Endeavour Model advocates acknowledging the difficulties experienced in interpersonal relationships, decision making and general social functioning.

Originally this program was targeted as a group work program for families at risk but has proved to be successful with training group workers and with other families. The package includes five manuals: 'Overview', 'Energisers & Terminators', 'Leaders Manual', 'Workshop Manual', 'Handouts' and an 'Organisers manual'. Each manual contains comprehensive information and practical activities, role-plays and other ideas for workers who are working in the area of parent education with diverse groups.

The program is recommended for use in a recreational atmosphere where groups of families with parents and children can together learn new ways of dealing with daily family interactions. This could be adapted for families with parents with intellectual disability. The advantage of the Endeavour Model is that it incorporates group methods that address the whole person and assist personal empowerment by learning effective strategies based on individual life goals. Programmed activities are designed to work on all aspects of life with other families. A significant advantage is that families get to see that many parents and families share the same day to day issues and concerns and that there are many ways to overcome these. Families can learn from each other and be supported to choose and try different approaches. Topics include: consequences/discipline, anger management, assertiveness, communication, stress management, values, conflict resolution and dealing with past memories.

This program could be adapted so that families choose particular topics according to their own needs, with more time being spent on these areas of greater concern. This could be done on an individual basis before the families begin the program. Stories and role plays given in the package could be readily adapted by encouraging families to generate their own examples of situations relevant to them. The handouts provide supplementary explanations. However, for parents with intellectual disability some of the more text-based ones would need to be modified to incorporate more graphics. Another advantage of this package is that workers who do not have much background group work experience are not disadvantaged. The package includes detailed group work plans in the sections with rationale and explanation of theory base.

Part 3

Smylie, T. & Price, B. (1994). *A Model of Parenting for Use in Groups with Parents with Intellectual Disability*. Carelink, South Australia.

This model is aimed at changing parents' attitudes to parenting by providing them with a tool to analyse their parenting style and a method to apply to meet their children's needs more effectively. This program was developed from the author's involvement in a pilot project as part of the services provided by Carelink. Carelink's preventative therapeutic program targets families with children in the 0-12 year age range and is aimed at families where there is a danger of children being separated from their families due to abuse. Many of these families have limited literacy skills and learning difficulties. This is presently the only package available that specifically targets this group of parents with children in the 0-12 age range.

The program outlines a specific ten-week program with practical ideas of activities that can be done each session with parents and includes a family camp at week seven that includes the parents and their children to improve their families' experiences. Games are suggested which enable parents to practice the skills and concepts in a supportive environment. The package includes handouts with visual illustrations that can be photocopied to supplement parent education of possible ways of overcoming difficulties and make parenting more positive. The model presented in this package places parenting along a continuum- the Giant at one end, the Doormat at the other and the Juggler in the middle, with the juggler being the 'ideal' parenting type. At either end of the continuum, there exists the potential for children to be at risk and in this model this is defined as the 'Danger Zone.'

This package is recommended for parents with intellectual disabilities in a segregated skill-training course where workers can address their specific learning needs without parents feeling anxious about their level of understanding. The advantage of this package is that it is primarily group focused and offers families the opportunity to get support to learn new strategies. Parents' individual needs are acknowledged by providing separate sessions, sessions with other parents as well as joint sessions with their children. It provides parents with a language to describe their own parenting styles and that of others. It also provides a framework within which parents can discuss their everyday parenting responses and how they can change to meet the demands of their particular situation.

This program can be readily adapted to individual parent group needs as the program begins by spending time ensuring the parents develop trust and comfort with each other. The family camp is not introduced till the seventh week allowing time for parents to build and learn new skills they can apply during the camp. Workers might need to repeat individual sessions in response to observations of parents' needs as required. It may also be necessary to provide opportunities for parents to practice the skills learnt individually or in groups.

Section 3.2 Notes on How to Run a Parenting Education Program

Workers interested in running a parent education program should note the following suggestions from the parenting education literature.

Reciprocity and partnership in learning

In a survey of Australian parent education programs conducted by Allan (1994), a number of key factors were identified as essential to the effectiveness of parent education. Firstly, the relationship between educator and the parent should emphasise reciprocity and partnership, acknowledging that each person can be a resource to the other. All parents bring to the learning situation their own experiences. They bring their experience of how they were parented, their experiences of observations of others, what they have learned from the media, and their community experiences in general. Parents can teach the worker about their experiences, and workers can teach the parent how to use these experiences in a way that is positive for their own parenting. Allan (1994) therefore argues that programs should emphasise parents' own experience and knowledge rather than stress the teaching and acquisition of new techniques.

Often overlooked is the fact that not all parents with intellectual disability will have grown up in nuclear families and so may bring to the parenting role an array of experiences with multiple parent figures in their lives, some of which may be good and some not so good. Parenting programs assume a middle class approach to family life will not be comfortable for many parents with intellectual disability. Programs need to be open-minded and able to accommodate the experiences and family values of all parents.

To be empowering, parent education interventions should be based on family identified needs rather than needs identified by professionals (Gorzka et al., 1991; Dunst & Trivette, 1988).

Parents are entitled to be involved in the planning and implementation of the program. For each group of parents, the concerns may be different. Commercially available programs may need to be broken down into smaller stages with some sections expanded and others repeated when necessary. New ideas need to be presented in a supportive rather than authoritarian way

Value systems

Workers need to be very aware of their own value base, and that of the program they are using. They

should never assume their own value system is superior to that of the parents. Many programs have been found to have a distinct value base (i.e. middle class, American, Anglo-Saxon). This value base should not be disguised. For example, some programs assume without question that the mother should stay at home as the full time carer of her children (Allan, 1994; Friedman, 1993).

There is some concern that parenting programs are inclined to impose a white middle-class stereotype on what constitutes 'good parenting.' It is worthwhile critically examining any program you are thinking of using, and questioning the extent to which the program is appropriate and relevant to the needs and life situations of your parents. Whyte (1996) suggests questioning the extent to which the program is truly empowering for parents or whether it is another form of social control encouraging conformity and reinforcing stereotypes. Caution needs to be taken when using such programs with parents who have intellectual disability that the program does not compound parents' feeling of inadequacy, guilt, anxiety and depression.

Ongoing support and skill maintenance

Parents need long term, ongoing and consistent support in order to integrate new parenting strategies over the lifespan of their children through adolescence (Llewellyn, McConnell, & Bye, 1995). Strategies and skills learned in parent education classes may not be maintained over a long period of time. There is generally an immediate positive change after parent education, but this change is difficult to sustain (Kendziora & O'Leary, 1993). Skills are more likely to be maintained if the teaching includes generalisation training, that is, that parents are given experience and tools to generalise their new skills in a variety of settings and situations (Dadds & Sanders, et al. 1987). Unless there are opportunities for all parents to apply their learning to everyday situations, to learn, revisit and discuss successes and disappointments in their attempts there is a risk that parents will lose what they have learned.

Pomerantz et al. (1990) suggest that, perhaps, another way of providing support for parents and helping them maintain their skills is to build a support network into their own neighbourhood. For example, 'mentor parents' could be employed as support people. Good candidates for this role may be older parents in the community whose children have grown up, and who have much to offer from their own parenting experiences.

Part 3

Section 3.3 Components of Effective Parent Education Programs for Parents with Intellectual Disability

Feldman (1994) described the three components necessary to ensure that such programs are effective: specific, situational, and structured. Further information on teaching and learning strategies can be found in Llewellyn (1997b).

Firstly, programs must be specifically targeted to the parent's individual needs for learning. Identifying parent concerns may involve, for example, observing the parent carrying out the everyday activities of parenting in their home with special attention to the areas most likely to be difficult at different stages. For example, for newborns, there will be more emphasis on feeding, changing, bathing, dressing, playing, and handling the child as well as parent-child interactions that stimulate physical, language, and social development. For pre-school and school age children, home-safety, nutrition and parent-child interactions that promote development and appropriate social behaviour are more relevant.

The second component is situational. This means that the tasks must be taught where the skill is needed—in the home. Most parenting in the early years is predominantly carried out in the home and this is where parents need to learn the necessary skills. With older children, many parenting tasks also take place outside the home. Again, parents will need to learn the skills in the relevant setting.

The third component of successful parent education programs is structure. Teaching methods must incorporate behavioural principles. Tasks and skills need to be taught in small steps. The way in which the task is to be done needs to be modeled to the parent with simple instructions and physical guidance if necessary. Feedback to the parent is essential. This may be praise, touching or physical reward. Frequent and sincere feedback helps to maintain interest and motivation. The steps being taught need to be repeated as people with intellectual disability take longer to learn, and learn best when taught in small steps with frequent opportunities for practice and repetition.

Bibliography

- Allan, J. (1994). Parenting Education in Australia, *Children & Society*, 8(4): 344-359.
- Andron, L., & Tymchuk, A. (1987). Parents who are mentally retarded. In A. Craft (Ed.), *Mental handicap and sexuality: Issues and perspectives* (pp. 238-262). Tunbridge Wells: Costello.
- Barnes, G. G. (1996). The mentally ill parent and the family system, In M. Gopfert, J. Webster and M. V. Seeman (Eds.) *Parental Psychiatric Disorder: Distressed Parents and Their Families*, (pp. 42-59). Cambridge: Cambridge University Press.
- Bennett, D. (1987). *Growing pains: what to do when your children turn into teenagers*. Sydney, N.S.W: Family Issues, Doubleday.
- Berger, D., Inkelas, M., Myhre, S., & Mishler, A. (1994). Developing health education materials for inner-city low literacy parents, *Public Health Reports*, 109(2), 168-172.
- Berlin, I. N. (1990). The Role of the Community Mental Health Center in Prevention of Infant, Child and Adolescent Disorders: Retrospect and Prospect, *Community Mental Health Journal*, 26(1), 89-106.
- Booth, T., & Booth, W. (1997). *Exceptional childhoods, unexceptional children. Growing up with parents who have learning difficulties*. London: Family Policy Studies Centre.
- Booth, T., & Booth, W. (1993). Parents with learning difficulties: Lessons for practitioners. *British Journal of Social Work*, 23, 459-480.
- Booth, T., & Booth, W. (1994). *Parenting under pressure. Mothers and fathers with learning difficulties*. Buckingham: Open University Press.
- Booth, T., & Booth, W. (1995). Unto us a child is born: The trials and rewards of parenthood for people with learning difficulties. *Australian & New Zealand Journal of Developmental Disabilities*, 20(1), 25-39.
- Booth, W., & Booth, T. (1993). Accentuate the positive: a personal profile of a parent with learning difficulties. *Disability, Handicap & Society*, 8(4), 377-392.
- Bowes, J. M., & Chalmers, D., et al. (1997). Children's involvement in household work, *Family Matters*, 46, 26-30.
- Bradley, R. H. (1987). Providing a stimulating and supportive home environment for young children, *Physical and Occupational Therapy in Pediatrics*, 7(4); 77-89.
- Butcher, L. A. & Gaffney, M. (1995). Building Health Families: A Program for Single Mothers, *Clinical Nurse Specialist*, 9(4), 221-225.
- Campbell, J. M. (1992). Parenting classes: focus on discipline, *Journal of Community Health Nursing*, 9(4), 197-208.
- Chapman, P, Brewer-Eiszelle, D., & Stevenson, L. (1994). *Challenge, choice & change. A guide to developing skills in parenting, communication and living*. Hobart, Tasmania, Centacare.
- Coates, D. L., Vietze, P. M., et al. (1985). Methodological issues in studying children of disabled parents, In S. K. Thurman (Ed.) *children of handicapped parents: research and clinical perspectives* (pp. 155-180). London: Academic Press, Inc.
- Dadds, M. R., Sanders, M. R., et al. (1987). The generalization of treatment effects in parent training with multidistressed parents, *Behavioural Psychotherapy*, 15, 289-313.
- Dennison, S. T. (1995). The E.S.S.E. group model: a twenty-first century approach for families at risk, *Journal of Family Social Work*, 1(2), 57-71.
- Dunst, C. J., Trivette, C. M., & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency*, 90(4), 403-417.
- Dunst, C. J., & Trivette, C. M. (1988). A family systems model of early intervention with handicapped and developmentally at-risk children. In D. Powell (Ed.), *Parent education as childhood intervention: Emerging directions in theory, research and practice* (Vol. 3, pp. 131-179). Norwood: Ablex.
- Fantuzzo, J. W., Wray, L., Hall, R., Goins, C., & Azar, S. (1986). Parent and social-skills training for mentally retarded mothers identified as child maltreaters. *American Journal of Mental Deficiency*, 91(2), 135-140.
- Feldman, M. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies, *Research in Developmental Disabilities*, 15, 299-332.
- Feldman, M. A., & Walton-Allen, N. (1997). Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children, *American Journal on Mental Retardation*, 101, 352-364.

Bibliography

- Franks, P., Campbell, T. L., & Shields, C. G. (1992). Social relationships and health: the relative roles of family functioning and social support. *Social Science & Medicine*, 34(7), 799-88.
- Friedman, H. L. (1993). Promoting the health of adolescents in the United States of America: a global perspective, *Journal of Adolescent Health*, 14, 509-519.
- Gorzka, P. A., Blair, C. L. et al. (1991). Parenting: categories for anticipatory guidance, *Journal of Child and Adolescent Psychiatric and Mental Health Nursing*, 4(1), 16-19.
- Grose, M. (1997). *Parenting ideas*. Melbourne: Victoria, The Australian Council for Educational Research.
- Halvorson, V. M. (1992). A home-based family intervention program, *Hospital and Community Psychiatry*, 43(4), 395-397.
- Hanson, M. J., & Martin, A. C. (1991). Perceived hopelessness and level of social support among economically disadvantaged mothers and grandmothers. *Virginia Nurse*, 59(3), 14-17.
- Hardy, J. B. & Streett, R. (1989). Family support and parenting education in the home: An effective extension of clinic-based preventive health care services for poor children, *Journal of Pediatrics*, 115(6), 927-931.
- House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual Review of Sociology*, 14, 293-318.
- Kaatz, J. L. (1992). Enhancing the parenting skills of developmentally disabled parents: a nursing perspective, *Journal of Community Health Nursing*, 9(4), 209-219.
- Kendziora, K. T. & O'Leary, S. G. (1993). Dysfunctional parenting as a focus for prevention and treatment of child behavior problems, *Advances in Clinical Child Psychology*, 15, 175-206.
- Linke, P. (Eds)(1994). *Practical parenting. leaders guide*. Melbourne, The Australian Council for Educational Research.
- Linke, P. (1994). *Practical parenting. A parents handbook*. Melbourne, The Australian Council for Educational Research
- Llewellyn, G. (1997a). Parents with intellectual disability learning to parent: The role of experience and informal learning. *International Journal of Disability, Development and Education*, 44(3), 243-261.
- Llewellyn, G. (1997b). *Support and services for parents with intellectual disability. What? When? How? By Whom?* Sydney: University of Sydney.
- Llewellyn, G. (1995). Relationships and social support: views of parents with mental retardation/intellectual disability. *Mental Retardation*, 33(6), 349-363.
- Llewellyn, G., & Brigden, D. (1995). Factors affecting service provision to parents with intellectual disability. *Australia & New Zealand Journal of Developmental Disabilities*, 20(2), 97-112.
- Llewellyn, G., Bye, R., & McConnell, D. (1998). Parents with intellectual disability and mainstream agencies. *International Journal of Practical Approaches to Disability*, 21(3), 9-13.
- Llewellyn, G., McConnell, D., & Bye, R. (1998). Perception of service needs by parents with intellectual disability, their significant others and their service workers. *Research in Developmental Disabilities*, 19(3), 245-260.
- Llewellyn, G., McConnell, D., & Bye, R. (1995). *Parents with intellectual disability. Support and services required by parents with intellectual disability*. Sydney: University of Sydney.
- Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1998). *Parents with intellectual disability and older children: Strategies for human service workers. A report to Disability Services, Department of Human Services, Victoria*. Sydney: University of Sydney.
- McConnell, D., & Llewellyn, G. (in press, 1998). Parental disability and the threat of child removal. *Family Matters*.
- McConnell, D., Llewellyn, G., & Bye, (1998). Providing services to parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability*, 22(1), 5-17.
- Marris, M. (1996). *Teenagers: A parents' guide for the 90's*, Sydney, NSW: Millennium Books.
- Out of the mainstream. A parenting group for parents with intellectual disability and their children*. Department of Human Services Victoria, 1998.

Bibliography

- Patterson, G.R. (1986). Performance models for antisocial boys, *American Psychologist*, 41, 432-444.
- Patterson, G.R., & Chamberlain, P. (1988). Treatment process: A problem at three levels, In L.C. Wynne (Ed.), *The state of the art in family therapy research: Controversies and recommendations* pp. 189-223, New York: Family Process Press.
- Peterson, L. (1992). *Stop and think parenting*. Hawthorne, Victoria. The Australian Council for Educational Research.
- Pomerantz, P., Pomerantz, D. J. et al. (1990). A case study: service delivery and parents with disabilities, *Child Welfare*, 69(1), 65-73.
- Ray, N. K., Rubenstein, H. et al. (1994). Understanding the parents who are mentally retarded: guidelines for family preservation programs, *Child Welfare*, 73(6), 725-743.
- Rosenberg, S. A., & Mc Tate, G. A. (1982). Intellectually handicapped mothers: Problems and prospects. *Children Today*, January-February, 24-27, and back cover.
- Sanders, M. R. & Markie-Dadds, C. (1996). *Triple P: A multilevel family intervention program for children with disruptive behaviour disorders*. St. Lucia, Queensland: University of Queensland.
- Sanders, M. R., & James, J. E. (1983). The modification of parent behavior. *Behavior Modification*, 7(1), 3-27.
- Simons, R. L., Wetback, L. B. et al. (1991). Intergenerational transmission of harsh parenting, *Developmental Psychology*, 27(1), 159-171.
- Smylie, T. & Price, B. (1994). *A model of parenting for use in groups with parents with intellectual disability*. Carelink, South Australia.
- Tucker, M. B., & Johnson, O. (1989). Competence promoting vs. Competence inhibiting social support for mentally retarded mothers. *Human Organisation*, 48(2), 95-107.
- Tymchuk, A. J. (1992). Predicting adequacy of parenting by people with mental retardation. *Child Abuse and Neglect*, 16, 165-178.
- Tymchuk, A. J., & Andron, L. (1992). Project Parenting: Child interactional training with mothers who are mentally handicapped. *Mental Handicap Research*, 5(1), 4-32.
- Tymchuk, A. J., & Andron, L. (1990). Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect*, 14, 313-323.
- Tymchuk, A. J., & Andron, L. (1990). Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect*, 14, 313-323.
- Umeh, D. C. (1995). Helping parents communicate effectively with children about preventing acquired immune deficiency syndrome (AIDS), *Journal of Health Education*, 26(5), 303-304.
- Waters, B., & Kennedy, L. (1993). *Every kid: Parenting your five to twelve year old*. Sydney, NSW: Family Issues, Doubleday.
- Whitman, B. Y., & Accardo, P. J. (1990). *When a parent is mentally retarded*. Baltimore: Paul H Brookes Publishing Co.
- Whyte, A. (1996). Programmed for parenting. *Health Visitor*, 69(6), 211-212.