



Parents with intellectual disability completed research

Support and services

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Understanding and Planning Support: A collaborative approach to assessing parents' support needs (2007)

Spencer, M. (2001). Proceed with caution: The limitations of current parenting capacity assessments. *Developing Practice: The Child, Youth and Family Work Journal*, 1, Winter, 16-24.

Spencer, M. (2000). Issues in assessing parenting capacity. *Journal of Intellectual Disability Research*, 44, 470-471.

Spencer, M. & Llewellyn, G. (2007). Working Things out Together: A Collaborative Approach to Supporting Parents with Intellectual Disabilities. In C. Bigby, C. Fyffe & E. Ozanne (Eds.), *Issues for Case Managers and Other Professionals* (171-190). London: Jessica Kingsley Publishers.

Background

Professionals in the human services sector struggle to understand and plan appropriate supports for parents with intellectual disability (Tymchuk, Llewellyn & Feldman, 1999). In the absence of specific assessment and planning tools, professionals rely on the approach they use with mainstream parents - that is essentially conversational and rely on parents taking the lead in defining their own situation and deciding what support they need. Such an approach is appropriate, and in keeping with client centred principles espoused in disability policies, however, there are a number of challenges in employing this approach with people with intellectual disability.

Firstly, the nature of intellectual disability often means that people with intellectual disability have difficulty conceptualising and communicating their thoughts and feelings. Secondly, they commonly demonstrate poor negotiation and choice making skills and have a tendency in the presence of professionals to acquiesce. Moreover despite their best intentions, most family support workers and other human service professionals are not skilled in working and talking with people with intellectual disability who are parenting, finding them a 'bit of a mystery' and unsure 'what they really understand or want'. Such difficulties obstruct client-centred practice and collaborative partnerships between professionals and parents with intellectual disability. Consequently, too often what eventuates is professionals second guessing and at times imposing support on to parents with intellectual disability or putting faith in assessment methods that are inappropriate (Spencer & Llewellyn, 2007).

Aim

The aim of this research was to develop a specific support needs assessment tool that professionals could use with parents with intellectual disability.

The research project, led by doctoral candidate Dr Margaret Spencer, was auspiced by the University of Sydney in partnership with NSW Family Services, with the assistance of an Australian Research Council Strategic Partnership Industry Research and Training Grant.

Method

The project employed a reflexive inquiry approach and had a development and trial phase. The development phase involved critical self-reflection (drawing on the researcher's own experience as a practitioner in the field) and extensive consultation with experienced family support workers.

The outcome from this phase was the development of the Understanding and Planning Support Approach (referred to as the UPS). The UPS adopts a collaborative approach to understanding to planning support. The approach is supported by a set of visual tool which facilitate conversation, comprehension and choice making by parents.

The trial phase involved 20 family support workers in New South Wales agreeing to use the

UPS in their casework practice with families where one or both parents had an intellectual disability. The aim of this phase was to evaluate the UPS's usefulness in actual practice settings.

Recruits participated in a face-to-face orientation and an information session about the UPS and its implementation. At the end of this session they were given some background reading, relevant literature and the UPS materials and asked to use it in their case work practice over a six month period. During this period workers were also provided with on-line and telephone support if requested.

Findings and implications

Results of the trial demonstrated that the UPS has utility. The findings suggest that the workers who found the UPS most useful were those who were internally motivated to change their practice.

The findings also draw attention to some obstacles that may be addressed if the UPS is to be used generally by family support workers in their everyday practice. For example, current work practices and pressures are potential impediments to implementing the UPS. For a number of workers, taking time to plan and or do anything different was perceived as a luxury not afforded them in their busy work schedules. For a number of workers the perception that using the UPS would require more time than they had served as an obstacle. Whether using the UPS with its collaborative conversational approach would in fact take more time or would be more time efficient in the long run (due to parents' engagement and ownership of the co-constructed support plan) needs further investigation.

Furthermore, the results highlight that if family support workers are to use the UPS in their everyday practice with parents with intellectual disability, they need to have the support of their agency. Although a number of coordinators were keen to have a worker represented in the trial or for their service to have access to the materials, these same coordinators did little to support workers in implementing the UPS in practice. Moreover some participants found adopting a collaborative approach problematic in the face of system imperatives to "fix the family up".

The UPS is now in the process of being published by NSW Family Services and will be available for use in the human services sector later 2009. Further research is underway to evaluate the training requirements of both novice and experienced practitioners in implementing the UPS.

In addition, further research is required to investigate ways of overcoming these obstacles as well as identifying the familial and environmental conditions that affect the effective implementation of the UPS in understanding and planning the support parents with intellectual disabilities need. Moreover the scope of this research focused only on workers experience of using the UPS. In order to improve of this resource it would be important that research be undertaken to gather first hand parents' perception of having their support needs negotiated using the UPS.

Human services and parents with a disability: working cooperatively in the best interest of the child (2004)

Background

This 3-year collaborative project (2001-2004), funded by the ARC Linkage scheme (APDI), the University of Sydney and the NSW Department of Community Services (DoCS) addressed two key practice issues for child protection and disability service workers. These were (1) establishing and sustaining a cooperative working relationship with parents with a disability,

and (2) negotiating with other government and non-government agencies to coordinate an effective response to the support needs of these parents and their children.

Aim

The two primary objectives were:

- To identify practices which promote and sustain cooperation between DoCS workers, parents with a disability and other service providers.
- To identify the explicit and implicit influences on the process of negotiating support for these parents and their children.

Method

This collaborative project took a Critical ethnographic approach grounded in the seminal work of Jurgen Habermas & the Theory of Communicative Action (1984/87). Communicative Action is the process through which parties arrive at consensus or a common definition of the situation as a basis for coordinating action. From this theoretical perspective what passes for 'ordinary case-work' is understood to be a thickly layered texture of struggles concerning power and authority, negotiations over identity, and social constructions of 'the problem at hand'.

This project looked in-depth and prospectively at the communicative process in which human service workers and parents with a disability engages to negotiate support for the family.

We recruited DoCS cases involving parents with a disability, drawn from metropolitan and rural areas. Case files were reviewed and regular interviews were conducted with the parents and their workers. Interviews addressed (1) participants' accounts of what had in fact happened, (2) what they thought should happen and why, (3) how they felt about the situation, and (4) what their understanding was of the views expressed by the other parties.

The qualitative data was analysed using the Critical method proposed by Forester (1992). This method looks at how attention is framed and 'the problem at hand' constructed; how participants act strategically and legitimate their actions; how relations of power are reproduced, and how claims are made to shape obligation, consent and patterns of future action.

Findings and Implications

The analysis resulted in:

- a rich description and critical analysis of the communicative process engaged in by DoCS workers, parents and other service providers.
- identification of practices that promote and sustain cooperative partnerships between the parties involved;
- identification of both the explicit and implicit influences on the process of negotiating a support plan, and;
- identification of effective ways of resolving conflict and misunderstanding between DoCS workers, parents and other service providers.

Related publications

McConnell, D., Llewellyn, G., & Ferronato, L. (2000). [Parents with a Disability and the NSW Children's Court](#). Sydney: The Law Foundation of NSW and the University of Sydney.

Llewellyn, G., McConnell, D. & Ferronato, L. (2003). [Prevalence and Outcomes for Parents with Disabilities and their Children in an Australian Court Sample](#) *Child Abuse & Neglect*, 27, 235-251.

Llewellyn, G., McConnell, D., Russo, D., Mayes, R., & Honey, A. (2002). [Home-based Programs](#)

for Parents with Intellectual Disabilities: Lessons from Practice *Journal of Applied Research in Intellectual Disabilities*, 15, 341-353.

Strike, R., & McConnell, D. (2002). **Look At Me, Listen to Me, I Have Something Important to Say** *Sexuality and Disability*, 20(1), 53-63.

McConnell, D., Llewellyn, G., & Ferronato, L. (2002). **Disability and Decision-Making in Australian Care Proceedings** *International Journal of Law, Policy and the Family*, 16, 270-299.

Llewellyn, G. & McConnell, D. (2002). **Mothers with Learning Difficulties and their Support Networks** *Journal of Intellectual Disability Research*, 46(1), 17-34.

McConnell, D. & Llewellyn, G. (2000). **Disability and Discrimination in Statutory Child Protection Proceedings** *Disability & Society*, 15(6), 883-895.

Tymchuk, A.J., Llewellyn, G., & Feldman, M., (1999). Parenting by persons with intellectual disabilities: A timely international perspective. *Journal of Intellectual and Developmental Disability*, 24(1), 3-6.

Tannous, C., Lehmann-Monck, V., Magoffin, R., Jackson, O., & Llewellyn, G. (1999). Beyond good practice: Issues in working with people with intellectual disability and high support needs. *Australian Occupational Therapy Journal*, 46, 24-35.

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.

McConnell, D., Llewellyn, G., & Bye, R. (1997). **Providing Services for Parents with Intellectual Disability: Parent Needs and Service Constraints** *Journal of Intellectual & Developmental Disability*, 22 (1), 5 - 17.

Llewellyn, G., & Brigden, D. (1995). Factors affecting service provision to parents with intellectual disability: An exploratory study. *Australian and New Zealand Journal of Developmental Disabilities*, 20, 97-112.

Llewellyn, G.M., (1995). Teachers and therapists as collaborators: A position paper. *Special Education Perspectives*, 3(2), 97101.

Llewellyn, G. (1994). **Generic Family Support Services: Are Parents with Learning Disability Catered For?** *Mental Handicap Research* 7(1), 64 - 77.

Llewellyn, G. (1990). **People with Intellectual Disability as Parents: Perspectives from the Professional Literature** *Australia and New Zealand Journal of Developmental Disabilities*, 16 (4), 369 - 380.

Look at Me, Listen to Me, I Have Something Important to Say (2002)

For an elaboration of this plan and a reading of this father's experiences, see Strike, R., & McConnell, D. (2002) *Look At Me, Listen to Me, I Have Something Important to Say* *Sexuality and Disability*, 20 (1), 53 - 63.

This paper, told from the perspective of a father with intellectual disability, outlines a seven-

point plan for workers supporting parents with intellectual disabilities. Both the father's experiences growing up and living with intellectual disability, and his recommendations for those working with people with disability, provide useful insights for anyone supporting or working with people with intellectual disabilities.

In summary, the seven-point plan is as follows:

1. Look beyond the disability label.
2. Talk to us, NOT at us, nor through others.
3. Hearing is not enough. LISTEN to us and RESPECT what we say.
4. Do things with us, not for us.
5. Explain things slowly and get straight to the point.
6. Talk to us face to face.
7. Be honest with us.

Parents with Intellectual Disability: Just the Same, Only Different (2002)

Strike, J., & McConnell, D. (2002) Parents with Intellectual Disability: Just the Same, Only Different Interaction 15 (4), 11 - 15.

With parenthood now being a realistic aspiration for people with intellectual disability, an increasing number are fulfilling their desire to have children. A recent SBS television program, Insight, featured the experiences of four parents with intellectual disability. The families shown included a couple who just gave birth to their first child; a mother whose child has always been in foster care; a couple with three children, two of whom were removed and later restored to their care; and another couple with three children in their care.

From this and their own research and experience, the authors explored some of the ways in which parents with intellectual disability are just the same as any other parents, as well as some of the ways in which their experiences are more extra-ordinary.

The common theme that emerged from their analysis was that "parents with intellectual disability are just the same, only different".

Parents with intellectual disability were found to be the same as any other parent group in so far as:

- Wanting to experience a loving relationship and raise children
- Finding that parenthood comes with trials and joys
- Having to learn how to parent well - experientially and from others
- Some succeeding, others faltering

However, parents with intellectual disability also encounter extra-ordinary experiences:

- Having to contend with the concerns, opposition, and scrutiny of others, this at times being to the extent of being advised to give their newborn up for adoption. Rather than the news of their pregnancy being cause for celebration, many parents with intellectual disability are discouraged and unsupported in their decision to have and keep their child. The doubt that they 'can do it' can easily be internalised.
- Restricted learning opportunities during childhood often lead to learnt dependency, and parents may continue to rely on others to make decisions and do things for them.
- Limited support networks.
- Fear derived from the fact that one in three children born to parents with intellectual disability are removed. Research has shown that in this process parents are subject to prejudicial views (eg., that parents with intellectual disability are unable to learn, adapt

and overcome parenting difficulties; that intellectual disability per se is the cause of perceived parenting problems and cannot be 'fixed') and are placed in the hands of ill equipped child protection workers and legal representatives. In turn, parental non-compliance may become an issue, where parents suspicious of professionals, are wary of seeking help and reluctant to engage with services.

In spite of these extra-ordinary experiences and with great resilience, many parents with intellectual disability and their children are thriving. A new way of working with this client group that counters these experiences can be adopted so as to make the parenting road one that many more are able to embark and stay on. At the heart of this approach is:

- A belief that these parents can succeed;
- A focus on personal growth as opposed to skill acquisition;
- A readiness to learn from them;
- A commitment to a person-centred approach in which the parents participate in setting the agenda;
- A flexible and responsive program, allowing parents to participate on their own terms and learn at their own pace; and
- A focus on peer mentoring and narrative learning, that is, by ways of stories shared.

Mothers with Learning Difficulties and their Support Networks (2002)

This research was funded by an Australian Research Council (ARC) grant and a University of Sydney (Faculty of Health Sciences) grant. For a complete reading of the study, see Llewellyn, G. & McConnell, D. (2002) Mothers with Learning Difficulties and their Support Networks *Journal of Intellectual Disability Research*, 46 (1), 17 - 34.

Background

Mothers with intellectual disability are regarded as the most socially isolated group of parents in our community. Within this context however, little attention has been paid to the support that these mothers may or may not receive from family, friends and the service system.

Aim

This study aims to build on preliminary research into the nature of support networks of parents with intellectual disability. Specific objectives were:

1. to identify whom mothers turn to for support;
2. to test the hypothesis that support network characteristics will vary with mothers' household living arrangements;
3. to examine the relationship between support network characteristics and sources of support i.e. family members, formal ties and significant others (friends and neighbours);
4. to examine whether the characteristics of the support provided by formal ties, family members and significant others varies with mothers' household living arrangements; and
5. to examine the relationships between support network characteristics

Method

70 mothers with learning difficulties and with preschool-aged children (i.e. < 6 years) were interviewed. A support interview guide was used, and the resulting identified 496 supportive ties analysed in terms of the 5 objectives.

Findings and implications

The research findings support and build upon those identified from the authors' 1999 study:

1. Family members were found to be central to the support networks of mothers with intellectual disability;
2. Service providers were identified as being the second largest group of supportive ties, providing mothers with primarily information support and advice;
3. Mothers identified few supportive ties with friends and neighbours. One in four in fact identified no such ties;
4. Mothers' support networks were shown to vary considerably according to their household living arrangement. Generally, mothers living alone with their children had widely dispersed family ties and accessed service centred supports. In contrast, mothers living in a parent household primarily had stable, local family centred supports. Those living with their partners had a high proportion of relatively dispersed family ties.
5. Mothers living alone were the most socially isolated and the most at risk given their heavy reliance on service workers who did not remain constant in their provision of support.

Implications for those working with mothers with intellectual disability are as follows:

- Service providers can promote stable, long term support networks by providing opportunities to establish and develop supportive ties with neighbours and friends. This is of particular importance for those mothers living alone.
- To facilitate participation and belonging in the community, practitioners can engage mothers living in a parent/parent figure's household in activities outside the family home
- Service providers need to be sensitive to mothers' living arrangements when considering the nature of their intervention

Proceed With Caution: The Limitations of Current Parenting Capacity Assessments (2001)

Spencer, M. (2001) Proceed with Caution: The Limitations of Current Parenting Capacity Assessments Developing Practice, Winter, 16 - 24.

Parental capacity assessments play a big part in what happens for families, particularly families in which a parent or parents have an intellectual disability.

Generally requested for two reasons - to inform and to justify intervention - assessment outcomes however, can be problematic. This is because what is being assessed - parenting and family life - are essentially subjective and dynamic, and therefore open to many variables.

There are multiple limitations inherent in current parenting capacity assessments which have serious implications for families headed by parents with a disability. These are:

1. Poor Conceptualization of Parenting

Workers undertaking assessments lack clear definitions as to "what is parenting?" and "what is good enough parenting?". Without clarity and consensus on these questions, parenting capacity is open to debate and likely to be seen through a normative lens. This has particular implications for parents with intellectual disability whose lives and life experience often place them outside the norm. For example, their generally interdependent functioning, in being in stark contrast to the normative individualized and independent view of parenting, may be negatively judged and viewed as an example of their incompetence.

2. An Inappropriate Use of Assessment Tools

- Currently there is no standard means of assessing parenting capacity
- There is also no one comprehensive assessment tool available
- What is used depends on the qualifications and experience of those undertaking the assessment and the economic and time constraints on the assessment process
- Often assessment instruments are developed and applied without due consideration to the purpose and uses of the test

- Some of these tools have not been psychometrically evaluated nor been standardized on parents with intellectual disability. As such, they would be invalid and unreliable in their interpretation

3. **Over-reliance on IQ Testing**

- Despite intelligence assessment per se having been shown to be a poor predictor of parenting capacity, IQ testing nevertheless remains as the common measure used to assess parents' with intellectual disability fitness to parent
- Although IQ testing can provide information on adult adjustment problems and capabilities, these measures are not designed to evaluate competence in parenting
- Moreover, IQ testing tends to be summarized and interpreted through a single composite measure. The danger of this is that an IQ score is treated as a unitary concept rather than as a reflection of performance over a range of tasks
- In child protection cases involving parents with intellectual disability, decisions are made on the basis of IQ scores that are ill-informed and at times mischievous and unjust
- A preoccupation remains with the parent's intellectual disability as the reason for any difficulty in parenting, over and above other factors such as poverty, emotional distress, social isolation and harassment

4. **Assessments Undertaken in Inappropriate Contexts and Circumstances**

- Ideally, assessment should take place in the family's own home and environment. However, due to time constraints and the fact that assessments are commonly conducted by psychologists and psychiatrists who work in clinical settings, home-based assessments are more the exception than the rule
- For parents with intellectual disability, the conditions under which they are assessed will have a significant bearing on their performance and not truly represent their usual parenting behaviour. This is particularly the case when the stakes are high eg., in cases where assessment findings will determine whether children will stay at home or be placed in care

5. **Lack of Predictive Validity**

- Commonly, predictions about parenting capability are based on correlation of risk factors to parenting capacity. Given that risk assessment protocols are based on items correlated but not causally linked to child maltreatment in "at risk" populations this is clearly poor practice with no empirical basis
- Predictive claims also fail to respect the dynamic nature of parenting and the multiple factors that can influence child-rearing practices
- In cases involving parents with intellectual disability predictions often are based on prejudicial beliefs about parents with intellectual disability; such as they can't learn, that the children will end up parenting the parent; or that parents with intellectual disability abuse and neglect their children - none of which are legitimate or factual

6. **Failure to Link Assessment Findings to Intervention**

- In responding to the question of whether a parent is or is not capable of parenting, important insights into how a parent functions or may learn best get lost and fail to be translated into specific recommendations about how and what supports need to be put in place

Within the context of these limitations, assessment needs to take place in accordance with the following principles:

1. **Conditions**

Assessments need to be

- Purposeful i.e. both the referrer and the assessor need to clarify and be clear about what is wanted from the assessment
- Carried out by an independent professional who does not have divided loyalties or biases that will influence assessment results
- Open, transparent and consensual - parents should be informed about what the assessment will entail and what is expected of them. The process should be inclusive and collaborative. It is also important that the views of all family members and those involved with the family are canvassed

2. Methods

- Naturalistic. Assessments need to be conducted in the family's home and community
- Conducted across time and family routine. The assessment must take more than a snapshot of the family. It needs to be conducted over multiple visits, preferably at different points in the family routine
- Multidisciplinary. Regard should be given for the expertise that a range of professionals, including workers who provide in-home support and are involved with the family on a regular basis, can contribute to the assessment process
- Use valid and reliable instrumentation. Because different tools focus on specific aspects of parenting, professionals need to be au faux with what tools are available; be able to access them; be proficient in administering them; and use them in a combination that appropriately covers all areas of parenting

3. Scope

- Multi-dimensional/ecological approach. The assessment approach needs to take account of the interplay between the multi-systems that impact on the family
- Functional/performance base. Assessing what parents understand, do and are capable of doing in terms of their care responsibilities. McGaw's Parent Assessment Model provides a useful tool that investigates different functional dimensions of parenting
- Resources and Constraints. In addition to deficits the assessment needs to identify strengths and potential resources and supports that are found in the family's environment
- Linked to therapeutic intervention and support. Assessment findings need to be translated into intervention strategies and inform individualized support planning
- Specific limitations reported in findings. Assessors need to be clear about what can and cannot be concluded from their assessments. Given the current limitations of assessment tools and the lack of consensus regarding minimal parenting standards, assessment findings should be interpreted and reported conservatively

Support Network Of Mothers With An Intellectual Disability: An Exploratory Study (1999)

A full account of this study can be found in Llewellyn, G., McConnell, D., Cant, R., & Westbrook, M. (1999) Support Networks of Mothers with an Intellectual Disability: An Exploratory Study *Journal of Intellectual & Developmental Disability*, 24 (1), 7 - 26.

Background

Mothers with intellectual disability are, as a group, among the most socially isolated in Australian society. This is of concern, particularly as it has been widely demonstrated that the availability of social supports directly benefits the well-being of mothers and consequently, of their children.

Current knowledge about social supports for parents with intellectual disability is primarily limited to the perspective of service providers. Nor has the impact of household living arrangements been taken into account.

Aim

This study was conducted in an attempt to develop the beginnings of a typology of the support networks used by mothers with intellectual disability. Five variables were considered from the perspective of the participating mothers: proportion of informal to formal supports, frequency of contact, proximity, reciprocity and type of assistance provided. Each was considered within the context of the mothers' household type.

Method

25 mothers of mild to upper moderate intellectual disability participated in the study. All had children under 6 years of age, were current users of a social service and spoke English. Semi-structured interviews were conducted with each participant and an analysis of the qualitative data made.

Findings

Three distinct forms of support networks were identified according to the mothers' living arrangements: mothers living in a parent/parent figure household (type 1), mothers living alone with their child/ren (type 2), and mothers living with a partner (type 3). Each group had approximately the same mean number of supportive ties.

However, significant differences were found between the support networks of types 1 and 2. Those living in a parent/parent figure's household (8 mothers) generally experienced frequent face-to-face contact with familial supports of close proximity. In contrast, those living alone with their child/ren (7 mothers) tended to use formal, service-centred supports, though this tended to be of a low frequency. Other supports in the form of friends and family tended to be semi-dispersed, that is, they were not geographically close to the mothers. Those mothers living with a partner in their own household (10) tended to lie between these two groups, having used a mix of formal and informal supports that tended to be dispersed, with a medium frequency of face to face contact. This group also had significantly more children and a greater fortnightly income than mothers of categories 1 and 2.

These findings carry several implications:

1. That household living arrangements critically affect the nature of support received by mothers with intellectual disability.
2. That one should not automatically interpret the fact that mothers living in a parent/parent figure's household having fewer ties with professionals and service agencies to be a positive sign of well-being. Whether such mothers have a desire to be more independent and part of the community needs to be considered.
3. That mothers living alone experience loneliness and depend on formal networks for emotional support, coupled with their having less practical assistance and fewer reciprocal relationships, requires further investigation in terms of how support services can best meet the needs of these women.
4. That further research with a larger sample of type 3 mothers - those living with a partner in their own household - be undertaken so as to distinguish subgroups in this network type.
5. That the perceptions of partners and the support networks of fathers with intellectual disability also provide the basis of future research.

Perception of Service Needs by Parents with Intellectual Disability, Their Significant Others and their Service Workers (1998)

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.

Background

Studies have shown parents with intellectual disability reluctant to access support programs such as parent education, especially when these are perceived as being interlinked with care and protection services. One way of overcoming this barrier is to break the traditional practice of professionals themselves determining course design and content, and instead, inviting and

incorporating the views of parents. This is of particular importance given that parents and their service workers have been found to hold different perspectives on parents' service needs.

Significant others - family and social networks - have also been shown to play a critical role in the lives of parents with intellectual disability. As such, they too can influence parents' real and perceived support needs.

Aim

This study sought the views of parents with intellectual disability, their significant others and service workers on parents' service needs in the areas of child care, social and community living, and domestic skills.

Method

Using government and community service contacts, 52 parents in metropolitan and rural areas in NSW were interviewed. Most fell within the mild to upper moderate range of intellectual disability. Nominated significant others and helpful service workers were asked to complete a questionnaire pertaining to the same need areas incorporated in the personal interviews: child care (child development, stimulation, discipline, hygiene, medical emergencies and home safety); domestic needs (nutrition, food shopping, meal preparation, home cleaning and money management); and social and community issues (assertiveness, marital relations, vocational skills/training, using community resources, friendships and leisure activities).

Results were analysed to determine whether there were any differences between the perspectives of parents and workers, and parents and significant others.

Findings and implications

Overall, a greater percentage of workers identified parents as needing help than did parents themselves on the majority of items. Moreover, the perceptions of parents, workers and significant others as to the help parents with intellectual disability needed were found to be significantly different.

Service providers most commonly identified needs in the child care area - child development, discipline, stimulation and activities. This was followed by parents perceived to be in need of assistance using community resources.

The most common need reported by parents was help with child care (esp. discipline) and child development. Activities for their children and respite were areas they also identified as needing assistance with. Their reported greatest unmet needs however lay in the community participation area: exploring work options, knowing what community services are available and how to access them, and being assertive, meeting people and making friends.

The authors raise the question of whether agencies that offer vocational, social, and communication skills training are willing and able to provide services for parents with intellectual disability. To do so in this way would do much to reduce the vulnerability often experienced by this client group because of their socio-economic position.

Interestingly, identified service needs incorporated both parent and child-focused skill areas. Consequently, services need to adopt a family-centred approach to ensure that the interests of both parents and children are served.

Parents also offered suggestions as to how support and services should be provided:

1. Be based in the parent's home;
2. Focus on short-term achievable goals;
3. Positively and in ways that encourage the service user;
4. Be practical and involve demonstration and repetition; and

5. Linked into mainstream services for parents and children.

Clearly then, providing support to parents with intellectual disability needs to extend well beyond helping them understand and more competently raise their children. Meeting parent-identified needs for social and community skills remains an ongoing challenge to those agencies working with this client group.

Parents With Intellectual Disability and Mainstream Family Agencies (1997)

For a full review of this study, see Llewellyn, G., Bye, R., & McConnell, D. (1997) Parents with Intellectual Disability and Mainstream Family Agencies International Journal of Practical Approaches to Disability, 21 (3), 9 - 13.

Background

In the absence of social policy that addresses the needs of parents with intellectual disability, the question of whether mainstream or specialist disability services are best suited to meet such needs remains. In Australia, there are in fact very few programs specifically designed for parents with intellectual disability, with mainstream agencies by and large being the only potential source of community support for this client group.

Of concern however, is the already established fact that only a minority of mainstream family support agencies in NSW actually provide services to parents with intellectual disability. Twelve factors have been identified as affecting service delivery to these parents: client knowledge of the service, client motivation to receive services, degree of client disability, client level of trust of service and staff, acceptance of the client by the service and other clients, client access to and ability to use transport, worker skills and training, funding levels, program content, time constraints on workers, involvement of other services with the parents, and other agencies' knowledge about and referral to mainstream family support services.

Aim

This study aimed to examine which of the twelve factors noted above were most influential in limiting service provision, and, on the basis of the findings, to make recommendations for policy and practice to overcome these limitations.

Method

Questionnaires were mailed to coordinators of the 157 Family Support Association's member services. For each factor, respondents were asked to indicate whether this affected their service delivery to parents with intellectual disability, and if so, how. They were also asked to identify any alternative factors that were also thought to be at work. In total, 109 (69.4%) of questionnaires were returned and the results analysed.

Findings and recommendations

66 (60%) services were currently working with parents with intellectual disability. Nearly a third of service coordinators (29.4%) indicated that they were no longer or that they had never serviced this client group.

Of the twelve factors only five were identified by more than 70% of respondents as

significantly affecting their ability to provide services to parents with intellectual disability. These were

- *Client motivation to receive services* (82%). This was more likely to be high when parents voluntarily received services as opposed to being court-ordered to do so.
- *Time constraints* (80.2%). Parents with intellectual disability were often regarded as "time-consuming" and/or generally received group work services with minimal attention, follow up or long term support.
- *General funding level* (78.9%). Limited funding severely restricted staff's ability to offer individualized and ongoing support.
- *Degree of parent's disability* (77.6%). Service providers acknowledged that they lacked the resources to adequately meet the needs of those parents with more severe disabilities.
- *Involvement of other services* (71%). Multiple service involvement at times did not follow a cooperative approach. Further, the criteria of some services meant that those with intellectual disability were excluded.

Other issues highlighted by respondents were the perceived inability of family support services to provide services for parents with more severe disabilities or multiple problems, and the need for additional specialist training.

Current family support service practice therefore needs to address the constraints that hinder their effectiveness with parents with intellectual disability. Recommendations to assist family support agencies in this process include:

1. Lobby for and target funds that allow for the provision of individualised, ongoing and ideally, preventative support
2. Adopt an individualized service planning approach which encourages and includes parental input
3. Be as "user-friendly" to parents with intellectual disability as possible
4. Undertake training that will enhance a greater understanding of people with intellectual disability, and that will allow for more effective inter-agency collaboration

This study was funded as part of the Parent Support and Services Project by the Disability Services Sub-Committee of the Standing Committee of Community Services and Income Security Administrators, Commonwealth Disability Services Program, Department of Human Services and Health, Canberra.

Providing Services for Parents with Intellectual Disability: Parent Needs and Service Constraints (1997)

For a more extensive reading of this study, see McConnell, D., Llewellyn, G., & Bye, R. (1997) *Providing Services for Parents with Intellectual Disability: Parent Needs and Service Constraints Journal of Intellectual & Developmental Disability*, 22 (1), 5 - 17.

Background

Although under certain conditions parent education programs have been effective in developing the skills of parents with intellectual disability, it is often the case that these parents access such programs only after a crisis has occurred. Crises such as suspected child neglect precipitate court intervention, a common outcome being mandatory parent attendance at family support or parent education services.

In a desire to break this crisis/intervention/crisis cycle, ways to effectively support parents with intellectual disability are being explored.

Aim

To investigate the support and service needs of parents with intellectual disability from the perspective of specialist service providers.

Method

40 professional service providers employed by agencies specifically designated for people with a developmental disability or by a care and protection service participated in a focus group or phone interview. Using a qualitative approach, their views on the support and service needs of parents with intellectual disability, and the major issues faced in meeting these needs, were explored.

Findings and recommendations

The support and service needs of parents with intellectual disability were found to fall into three key categories:

1. Parents' special needs - parenting skills; living skills; self esteem and assertiveness skills; informal social support; access to mainstream services; and advocacy.
2. Desirable service characteristics - tailored to individual parent's needs; provided over the long term; be home-based, empowering, pro-active, and at a level parents can understand.
3. Constraints on service delivery - lack of time, staff and funding; lack of educational resources; parent reluctance to use services; difficulties with transport; limited mainstream services; service providers' skills and attitudes; and agency and community expectations.

That the special needs of parents with intellectual disability extend beyond a learning of parenting skills warrants further attention. Fundamentally, the resource constraints faced by these agencies must be removed if they are to effectively and comprehensively meet the needs of this parent group.

Moreover, the authors outline four principles from which service providers are encouraged to model their service provision. These are:

1. Respond to each individual parent's situation, adopting a family centred approach so that the interests of parents and children are served
2. Provide flexible long-term, ongoing support to parents as their needs and the needs of their children change
3. Take into consideration the special learning needs of parents when designing and implementing programs
4. Actively assist parents to become part of their local community so as to lessen the physical and social isolation experienced by parents with intellectual disability

Finally, inter-agency collaboration is also called for, in particular, that which promotes the following:

- A family-centred focus in contrast to a parent-only or child-only focus;
- Preventative work as a priority rather than crisis intervention; and
- Access to mainstream services for parents and their children rather than reliance on specialized support services

This study was supported as part of the Parent Support and Services Project by a research and development grant from the Disability Services Sub-Committee of the Standing Committee of Community Services and Income Security Administrators, Commonwealth Disability Services Program, Department of Human Services and Health, Canberra.

Relationships and Social Support: Views of Parents with Mental Retardation/Intellectual Disability (1995)

Llewellyn, G. (1995) Relationships and Social Support: Views of Parents with Mental Retardation/Intellectual Disability *Mental Retardation* 33 (6), 349 - 363.

Background

Despite concerns about the ability of parents with intellectual disability to adequately care for their children, rarely have these parents been consulted as to their views on parenting education and what their support needs are.

Aim

This study aimed to explore experiences of parenting from the perspective of parents with intellectual disability. Specifically, parents' views about their social relationships and the support they receive, and seek, with the tasks of parenting, were examined.

Method

Data collected from six couples as part of an ongoing study on the shared experience of being a person with intellectual disability and a parent were used. In depth interviews, telephone calls, informal visits and observation of family outings were conducted to extract parents' perceptions. Information gathered was then coded and analysed.

Findings and implications

In contrast to the literature that presents parents with intellectual disability as primarily requiring and accessing substantial family support, those parents involved in the study were shown to have support that was more multifaceted:

- Most emphasis was placed on the support received from and given to their spouses or partners. This was in terms of practical assistance and moral support.
- Family members also rated highly, though not all parents had family support available to them. Assistance was particularly welcomed when it served to boost the confidence of parents and when their input was consistent with parents' values and ideas. At times however, family members were regarded as intrusive, dogmatic and ultimately unhelpful.
- Significantly, most parents did not have friends or neighbours they could call on for assistance
- Parents reported that they do seek the support of professionals, pending the type of help required, the urgency of need and confidence in those who might give help. Interestingly, parents exhibited a preferred sequence in seeking help, beginning with their partners, then family members, and finally, professionals. Assistance received was not experienced as useful when conflicting advice was given and when parent's learning difficulties were not taken into account.

Several issues raised by this study are pertinent to policy and practice:

1. The parents involved in this study are testament to the ability of those with intellectual disability to be competent parents. As a population group these parents should not be judged a priori; rather, their personal histories and unique parenting and family experiences ought to be taken into account.
 2. The study findings challenge the traditional concept of parenting, that it is the prerogative of relatively autonomous and independent individuals. The significant presence of other people in the lives of parents with intellectual disability requires consideration of the more collective and communal aspects of parenting.
 3. How 'family' is traditionally perceived needs also to be questioned. Families have to be understood as they are and not in relation to perceived ideals. The study findings of variation and diversity in the parenting experience affirms the need for policy developers to take into account family relationships and preferred family styles.
 4. That family members can serve as resource or constraint must alert policy makers and service providers to do more than merely assume or propose that parents can call on kin networks to provide support with the tasks of parenting. Rather, it behoves service providers to individually assess the support available to parents, taking into account the parents' views of this support as promoting or inhibiting their competence as parents.
 5. Providing opportunities for these parents to acquire friends by initiating parent-to-parent support groups and by teaching parents skills in developing friendships appears to be an appropriate support intervention.
 6. Worthy of further investigation is the parental viewpoint on services and whether these provide resource benefits or impose constraints on their family lives. Viewing professional support in this differentiated manner would allow the development of a user-centred framework to guide practice.
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Living Proof: Being a Parent with Intellectual Disability (1993)

A Llewellyn, G. (1993) Living Proof: Being a Parent with Intellectual Disability. Proceedings from the 29th Annual Conference of ASSID - the Australian Society for the Study of Intellectual Disability - "Quality and Equality". November 30 - December 5, 1993, Newcastle University.

Background

Parents with intellectual disability are often presumed incapable of competently caring for their children. Thus any support available to these families is assumed to be beneficial and welcomed.

Little attention in the research literature has been paid to the place of family, neighbours, and friends in the lives of these parents. Moreover, parent views on social support (or lack thereof) have been neglected.

Aim

This study aimed to explore the views of parents with intellectual disability on social support in their daily family lives. In particular, it aimed to examine the presence of others in their family lives and the ways in which they attempted to manage this involvement. All aspects of the parents' social support networks were to be considered.

Method

Over a two year period, seven family units consisting of ten parents participated in the study. Field notes were taken and data collected from initial, informal meetings, observations of family life/outings, and in depth interviews. These were analysed using constant comparative analysis.

Findings and implications

Three case study accounts are presented to provide a sense of the range of the social support networks of parents with intellectual disability. As with all families involved in the study, these parents experienced the significant presence of other people in their family lives, including family and professionals from service agencies. This involvement varied along a number of dimensions: short to long term involvement, relevant in specific instances only or as part of all aspects of the parents' lives; readily available to not easily accessible; highly intensive or low key; restrictive or freeing; practically and/or emotionally based.

Parents involved in this study were shown to manage the involvement of others in their family lives by using three key strategies:

1. **Accepting**

Whilst the involvement of others was generally accepted as being inevitable, this took the form of either complying without question, complying despite disagreeing with the other person's contribution, or disagreeing and not complying despite seeming to accept the contribution of others.

2. **Seeking Assistance**

Assistance was sought from

- partners - mainly for child care and household management task
- family members - for personal support and for ideas about how to care for the baby and later, how to manage the child
- professionals - for assistance in unexpected/frightening situations; to monitor the child's progress; for ideas on managing their child's behaviour. Professionals were generally thought to be trustworthy, however, the manner in which they contributed was not always welcomed, and not always perceived as helpful, particularly where the parents' difficulty with understanding and learning new concepts were not taken into account, or conflicting advice was given.

Of note was the absence of friendship ties to each of the family units. Thus asking other parents or friends for assistance was rare.

Assistance was sought in a particular sequence: families first, followed by those with recent child care experience and lastly, professionals. This sequence was affected by factors such as type of assistance required, urgency of need of assistance, and confidence in those who might give assistance.

3. **Getting and Giving**

The notion of reciprocal social support was observed with the partner or another family member (often acting as an adjunct parent). It was expressed through the provision of physical assistance, support being provided for the other persons' views or wishes, and through the provision of moral support.

Overall, the parent viewpoint illustrated in this study presents a broader perspective than the previously conceptualized picture of social support in the lives of parents with intellectual disability as merely being a family affair that either promotes or inhibits parental competence. Parents were shown to be more than simply receivers of support from a delineated group of people. Rather, parents played an active role in determining what support they want, from whom, and in what way. Getting and giving support, particularly with their partner, played a central role. In addition, whilst receiving help from family members was preferred, this was regularly supplemented by seeking assistance from professionals. Notably absent from the parents' lives was any presence of friends, neighbours and community acquaintances.

These findings suggest that parenthood for adults with intellectual disability needs to be viewed in a fresh light. Investigating their perspectives of whether support is regarded as a resource or a constraint in their environment offers more promise than a continuing focus on the individual parent's potential or realized competency level. Particularly worthy of further investigation are the ways in which parents do provide support (or do not, as the case may be) to each other and the role of professionals as resources or constraints in their family lives.

Finally, this study serves as a poignant reminder of the little that is known about the views of people with intellectual disability. The literature on parents with intellectual disability, dominated by the professional perspective, has concentrated on assumed parental inadequacy and ways by which individual parental competency can be enhanced. This has resulted in parents with intellectual disability being regarded as having little agency in their own lives. The parents in this study, by their own accounts, give lie to this view. Parents with intellectual disability do actively determine and manage the presence of others in their family lives. The challenge is now to incorporate this parent perspective into research and practice.

Parenting: A Neglected Human Occupation. Parents' Voices Not Yet Heard (1994)

Llewellyn, G. (1994) Parenting: A Neglected Human Occupation. Parents' Voices Not Yet Heard *Australian Occupational Therapy Journal*, 41, 173 - 176.

This article attempts to stimulate interest in the occupation of parenting and, particularly, in the exploration of parents' perspectives on parenting. This is of particular importance to the practice of occupational therapists who play a key role with parents of children with special needs. Their professional perspective focuses on what parents do and how they do it.

What is lacking in this process however is an engagement in parents' own views on parenting. When parents are consulted, this is usually limited to their attitudes to child rearing. The roles and everyday activities of parenting, as perceived by parents themselves, and how people perceive becoming and being a parent is usually neglected.

Why is incorporating parents' voices so important? Firstly, it is in keeping with one of the core values of occupational therapy, the belief that every individual has intrinsic dignity and worth. This implies that each individual's 'voice' is worthy of attention.

Second, practitioners can learn much about parenting as a human occupation when the participant perspective is sought. Studies for example, have highlighted:

1. contrasting views held by mothers and their therapists about physical and occupational therapy, and the impact this has on how mothers actually implement the home programs prescribed;
2. role strain to be an issue for mothers of young children. This is of concern to occupational therapists who regard role balance as essential to health and well-being; and
3. the competing demands encountered by parents with an intellectual disability, these including having to implement a home-based therapy program

In taking into account the perspective of parents, practitioners will be more acutely aware of how to maximize the effectiveness of their intervention. But to do so requires several assumptions to be put aside:

1. the presumption that practitioners objectively know what constitutes adequate or inadequate parenting;
2. the equating of 'parent' with women, and usually unpaid carers; and
3. the viewing of 'family' as mother, father and children, without any attention being paid to family constellations, parent networks, and relational processes.

There is an untapped wealth of parental expertise in managing everyday parenting. With this in mind, occupational therapy practitioners and researchers are challenged to respond, to listen sensitively to the parent voice and, in so doing, to redress the neglect of the human occupation of parenting.

Generic Family Support Services: Are Parents with Learning Disability Catered For? (1994)

Llewellyn, G. (1994) Generic Family Support Services: Are Parents with Learning Disability Catered For? *Mental Handicap Research* 7(1), 64 - 77.

Background

As increasing numbers of adults with learning disability (LD) have children, specialist disability services are responding with the provision of parent education programs. Whilst positive outcomes are generally reported, the greater participation of parents with LD in society begs the question of whether their parent support needs can be catered for by generic services. Family support services for example, have a policy commitment to helping parents with learning disability, but how does this translate in practice?

Aim

This study aimed to determine if and how generic family support services in New South Wales provide assistance to parents with LD. Further, it also considered whether this assistance included components thought necessary for successful training outcomes for parents with LD.

Method

Co-ordinators of 89 identified state wide family support services that indicated they catered for parents with LD were surveyed, with three general areas being covered: service characteristics, types of services provided to the parents, and demographic information. Open-ended questions on whether parents with LD were specifically acknowledged in service policies

and whether programmes or funding specifically targeted the needs of these parents were also included.

Findings

Only 20% (28) of the 136 identified family support services in NSW catered for parents with LD. The most common profile of these parents is as follows: young (19 - 30 years), Australian-born non-Aboriginal with English as a first language, a mild learning disability, preschool or school aged children and one adult in the parent role.

On average, four parents per service were catered for, with the range of services offered being either direct or indirect:

- Direct: Information about community resources and services (89%), parent education and training (85%), intervening on behalf of the parents (78%), training for parents in getting help for themselves (75%), and referral to other agencies (67%).
- Indirect: Group activities for support (53%), fun (46%), and parent peer support (32%)

Parent education and training was done more on an individual than group basis (86% and 60% of services respectively), more at home than at the service (78% and 43%), and with illustrative materials in only 34% of services.

Certainly some services encompassed those components of training programs identified as being predictive of positive outcomes for people with LD i.e., interventions are matched to parental learning characteristics (eg., using illustrated materials), training is highly concrete using strategies to promote generalisation and maintenance, education programs are conducted by well trained staff, and interventions need to be initially intensive and then periodic over the long term.

The research provides two possibilities as to why many family support services are unable or disinclined to work with parents with LD. Firstly, staff and/or funding constraints may prohibit the provision of the individual, intensive and home based support that parents with LD require. Secondly, with services working with only a small number of this parent group, the feasibility of offering groups specifically designed for these parents is limited. Interestingly, many co-ordinators' responses also indicated that the needs of parents with LD could be more appropriately met by specialist intervention.

Of course, the parents' perspective on their involvement in family support services remains to be investigated. It cannot be assumed that parents will view the services, or hold preferences about specialist or generic services in like manner to the professionals working in those services.

Parents with Intellectual Disability: Facts, Fallacies and Professional Responsibilities (1993)

Llewellyn, G. (1993) Parents with Intellectual Disability: Facts, Fallacies and Professional Responsibilities *Community Bulletin* 17 (1), 10 - 19.

For people with intellectual disability, becoming a parent is often not greeted with the same level of excitement that others experience. Rather, family, friends and service providers may be ambivalent if not actively discouraging of their decision to have a child. Such fears and

concerns have been shown to stem from a mixture of facts and fallacies that portray people with intellectual disability as incapable of being competent, loving parents.

In comprehensively reviewing research on parenthood for people with intellectual disability, a range of presumptions are identified:

- intellectually disabled parents will have significantly more children than other parents;
- they will give birth to intellectually disabled children;
- if the children are not disabled at birth they will quickly become so;
- they will abuse or neglect their children;
- they will provide inadequate child care; and
- they are unable to learn and apply adequate parenting skills.

Each of these opinions is explored, again in light of available literature, and shown to be by and large fallacy, not fact:

- parents with intellectual disability have the same or fewer numbers of children than other parents;
- the incidence of organic aetiologies among children of intellectually disabled parents is equal to that found in the general population;
- a clear relationship between parent intelligence and the child's educational achievement has not been established for any specified parent group. Further, a number of factors besides parent IQ, such as poverty, poor nutrition and school absence due to illness or high mobility, have been identified as contributing to poor educational achievement;
- no conclusive argument that parents with intellectual disability will abuse or neglect their children prevails. When such cases do occur, little consideration is given to predisposing factors such as social isolation and poverty. Indeed, whether the frequency or severity of abuse and/or neglect for these parents differs substantially from that found among other poor parents is yet to be determined;
- contradictory findings are common on the question of whether parents with intellectual disability function adequately as parents. What is clear is that most families require extensive assistance to fulfill the everyday needs of their children and that parents may struggle when this is not the case. Moreover, intellectually disabled people have been deemed by the courts to be incompetent parents often on the basis of diagnostic label and intelligence quotient alone. This is in contrast to the finding that above a minimum critical level of around IQ 60, there appears to be no clear relationship between parenting competency and IQ. Finally, factors such as family income, number of children in the household, and parents' childhood experiences of parenting warrant further investigation as to their impact on quality of care;
- parents with intellectual disability have been shown to learn parenting skills and behaviours. What facilitates this process is the provision of training that is specific, concrete, provides help in generalizing skills learnt to other situations, matches parental learning characteristics, is initially intensive and then periodic and long term, and is provided by a well trained practitioner.

These findings from the research literature hold numerous implications for those with professional responsibility for parents with intellectual disability. Most basic is the need for practitioners to develop and operate from a sound working knowledge of current empirical research, rather than relying on unfounded opinions about this parent group. Further, practitioners are urged to use this knowledge to raise awareness in the health, social services, education and legal sectors, and in the community at large.

Second, service professionals are encouraged to adopt a more macro approach to their clients, and consider the socio-economic and community context of parent. To do so would lead

to an introduction of much needed services other than parenting skills training, eg., social skills training and self advocacy. Irrespective of the service provided, the perspective of parents should also be sought in any planning, designing and evaluating of programs.

Continual lobbying for adequate resources clearly also needs to be undertaken, resources for social services and court system supports, and resources for professionals to undertake the specialized training they need to effectively work with this parent group.

Practitioners are encouraged to lead the way in developing a progressive and optimistic outlook about parents with intellectual disability, while realistically acknowledging their parenting challenges.

Talking with Parents with Intellectual Disability (1993)

Llewellyn, G. (1993) Talking with Parents with Intellectual Disability. In Johnston, C. (Ed) *Does This Child Need Help? Identification and Early Intervention* Sydney: Australian Early Intervention Association (NSW Chapter) Inc.

To date, the research literature on parents with intellectual disability has been entirely from the professional perspective. This chapter provides a timely reminder of the importance of paying attention to parents' points of view. Points of consideration are given to enable practitioners to most effectively communicate with these parents and uphold their dignity in the process.

Outdated stereotypes

- Contrary to popular thinking, understand that people with intellectual disability do sexually and personally mature
- Parents with intellectual disability are not inevitably incapable of caring for their children. Sometimes this seems to be the case because only those struggling with the tasks of parenting are known to support services

Life experiences

- Attempt to understand parents' life experiences and the impact of these on current behaviour. Consider their self-esteem, social skills, internal/external control, social role, and problem solving skills. Many have been encouraged to remain dependent on family or service providers, and so may not have had adequate preparation for adult life or the challenges of parenthood.

Parents as individual

- Focus on the parents' personal or parental needs. Often these are subsumed by attention placed on the needs of their children.
- Parents with intellectual disability are not a homogenous group. Remember that their needs and available supports will be unique.
- Give parents room to share information about themselves. At the same time, respect their right to privacy.
- Be wary of labeling. Many children who, whilst at school were labeled intellectually disabled, successfully integrate as adults into the wider community without needing specialist services for people with intellectual disability or attracting the intellectual disability label.

- Don't lose sight of each individual's ability in the face of their disability

Parents as parents

- Uphold their right to be regarded as the parent of the child
- Talk to these parents as adults, not children
- Encourage them to express their viewpoint and respect what they have to say
- Be wary of imposing your advice and/or giving overwhelming amounts of advice
- In addition to the practical tasks of parenting, offer assistance in other skill areas eg., assertiveness training and advocating for their child
- Provide information in non-ambiguous, direct short statements. It is often necessary to repeat the information, perhaps over several visits. Ask the parent to explain to you what they think the information means - this will help you to know whether they have understood.
- You may also need to ask the parent if they have a family member or friend to whom you could talk. When this is the case, ensure the parent is not denied their right to be the adult who is responsible for their child.
- Involve parents in any discussion or decision-making to the extent that they are able
- Acknowledge that there may be competing demands between the needs of parents and their children
- Remember that parenting is a socially determined process carried out within a family, social and community context

People with Intellectual Disability as Parents: Perspectives from the Professional Literature (1990)

Llewellyn, G. (1990) People with Intellectual Disability as Parents: Perspectives from the Professional Literature *Australia and New Zealand Journal of Developmental Disabilities*, 16 (4), 369 - 380.

The baggage of past policy and practice to prevent those with intellectual disability becoming parents remains despite increasing numbers choosing to have children. The question of whether one can be a competent parent and have an intellectual disability is both historical and current. In response then, this paper examines the various perspectives presented in the professional literature about parenting for people with intellectual disability.

The studies reviewed present an ambiguous answer to the question of whether people with intellectual disability can adequately function as parents. Various angles are examined:

1. Parenting after institutionalization - in terms of providing adequate child care, parents' competence ranged from satisfactory to neglectful
2. Parenting of those already identified as needing assistance - these studies frequently found this group of parents to be incompetent. These findings however, need to be treated with caution, with the majority being subject to methodological flaws such as inadequate sampling, poor definition of parenting behaviours, lack of validity and reliability in measures used to judge parenting, and poor design characteristics, specifically when comparison groups are used.
3. Outcomes for the children - low maternal intelligence was shown to be a significant predictor of low IQ in the offspring. However, a clear relationship between parent intelligence and their child's educational achievement has yet to be established for any specified parent group.

Rather, a variety of factors besides parent IQ have been identified as contributing to poor educational achievement. These include poverty, poor nutrition and school absence due to illness or high mobility.

4. Parenting in comparison with other parents - whilst some studies showed mothers with an intellectual disability to have fewer and/or less stimulating interactions with their children, socio-economic differences were largely ignored. When taken into account, mothers with intellectual disability were shown to make decisions about child care issues at least as good as those made by contrast mothers from similar backgrounds.
5. Parenting before the courts - on the basis of diagnostic label and intelligence quotient alone intellectually disabled people have been subject to court findings of general incompetence. This has been in stark contrast to research that has shown that above a minimum critical level, no clear relationship between parenting competency and IQ. Further, these outcomes were reached without due regard for usual neglect investigations and provision of support services.

One also needs to keep in mind that not all families in which one or both parents are intellectually disabled are known to health, welfare or protective agencies, and in consequence, to researchers in the disability field. Presumably there are parents with intellectual disability who are competent.

A review of the literature served to identify those factors that contribute to successful parenting and those that predispose to inadequate parenting. These factors are:

- Number of children - several studies reported quality of care to decrease as the number of children increased. However, these findings again need to be viewed in the context of biased samples
- Income level - care is questionable or unsatisfactory when parents had marginal incomes or were receiving financial assistance
- Additional health issues of the parents and the parents' own upbringing - both are likely to negatively influence adult parenting behaviour
- The availability of parent education resources - parental difficulties were unlikely to be addressed where service providers were unwilling or unable to tailor these to the specific learning needs of parents with intellectual disability
- Available familial supports - this was an element crucial to parental competence and which reduced the need for support from formal agencies

Given the contradictory and equivocal research findings, coupled with the considerable variance within the 'intellectually disabled' group and their social and family contexts, it is impossible to predict with certainty which people with intellectual disability will succeed as parents. What is clear however, is that against the skewed nature of parent groups studied, a substantial number of people with intellectual disability function adequately as parents.

Parents with Intellectual Disability and Older Children: Strategies for Support Workers (1998)

Llewellyn, G., McConnell, D., Grace-Dunn, R., & Dibden, M. (1998) *Parents with Intellectual Disability and Older Children: Strategies for Support Workers*. Melbourne: Victorian Government Department of Human Services.

Background

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. All parents of children 9 - 12 years of age face increased expectations to conform to social and cultural mores, for example, enforcing discipline, effectively communicating with their children, preventing anti-social behaviour, and assisting their children to achieve academically, and thus the task of parenting this age group is a challenging one for all.

This challenge is even more pronounced for those parents with intellectual disabilities. Aside from their cognitive limitations, this is owing more to family, social and environmental factors that shape the parenting success. Often parents with intellectual disability have a low socio-economic status, have not had 'good' parenting modeled to them, are socially isolated and have little or no experience of children's developmental needs.

Up until now most human service workers have only worked with parents with younger children. How to most effectively work with these parents to strengthen their family relationships needs to be explored.

Aim

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 this parent group.

Method

The contents of the resulting Resource Booklet were informed by informal interviews with parents with intellectual disability with older children; interviews and focus groups with human service providers with a particular interest in, and experience with parents with older children; a review of the literature on parenting of children in the middle childhood period; a review of literature on parents with intellectual disability; and a critical review of readily available parent education programs in terms of their applicability for workers supporting parents with intellectual disability.

Findings

A. Assisting Parents To Build Their Own Individual And Familial Resources

1. Housing and Money Matters

With many families living in circumstances of socio-economic disadvantage, survival and maintenance issues of housing, food, adequate clothing and bills need to be addressed. Attempting parenting training when these stressors are at the forefront of parents' minds is unlikely to lead to positive outcomes.

Strategies that support parents to be responsible for their own financial affairs and which allow them to set their own financial priorities were seen to be crucial:

- Assist parents with applications for housing and social security benefits
- Assist parents to obtain white goods and other household items at minimum cost

- Teach budgeting skills
Instruction needs to be as concrete as possible. Tasks need to be demonstrated, conducted with the parent, and practiced.

2. **Social Support**

Strong links exist between social support and positive outcomes for parents and children. Yet parents with intellectual disability are among the most socially isolated in the community. Support workers cannot artificially construct an informal support network for parents with intellectual disability. However, they can create opportunities for parents to form friendship ties eg., establishing a support group for parents with intellectual disability, supporting parents to join local groups.

3. **Parents and Service Providers**

Parents' needs for support services varied greatly, as did their experience of them. Advocacy, respite and just having someone to talk to were valued services. Less effective were services imposed by the courts, that undermined the abilities of the parents and which were provided inconsistently and by different workers.

The following principles and strategies were devised to improve the support services available to families headed by parents with an intellectual disability:

- 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
- Involve parents in all decision-making
- Respect the parent as the parent of their child
- Identify, acknowledge, and build on parents' strengths, always offering encouragement
- Keep in regular contact and be contactable. If conducting a home visit, let parents know beforehand that you are coming
- When more than one service is involved, coordination and communication is critical. An attitude of working together in the best interests of the family must be fostered

B. Promoting Parents' and Children's Health and Wellbeing

1. **Parents' and Children's Expectations**

Middle childhood is a period of rapid transition. A common issue raised by parents and workers was the need for parents to develop an awareness of appropriate developmental expectations, and how to meet their children's changing needs. Strategies that may be useful to support workers for this process centre around educating parents about age appropriate expectations and managing new behaviours. Staff are also encouraged to work with the children, helping them understand their parent's disability and offering support/counseling.

2. **Parents' and Children's Communication**

Effective communication between parents and their pre adolescent children is particularly important in this 'testing time'. Yet communicating with their children was identified as being particularly difficult for many parents with intellectual disability. Their previously restricted life experiences and ongoing social isolation may have led to poorly developed communication skills.

Support workers are encouraged to adopt the same practical strategies used to assist any family i.e.

- Initiate a family conference when a parent-child relationship has broken down. Provide space for both the parent and child to voice their points of view in a controlled, safe and mediating setting
- Help parents develop positive communication habits, such as not using 'put-downs', asking their child about their day, and using meal times as talking time
- Encourage parents to pursue or develop common interests with their children to further enhance their relationships

3. **Promoting Independence and Helping at Home**

Parents of 9 - 12 year olds face the ongoing challenge of negotiating the levels of freedom, independence and responsibility given to their children. To assist parents with intellectual disability manage this task, support workers can teach the following strategies:

- Encourage children to take on jobs around the home. Assist this process by setting realistic tasks, giving children choice in the jobs they take on, and showing appreciation for what they do
- Assist parents to deal with any fears their children may experience when taking on new responsibilities

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. Thus support workers may be faced with the dual tasks of building the parent's self esteem so that they in turn can build that of their children. To this end they can:

- Teach practical strategies to parents, eg., give children responsibilities and help them set realistic goals; point out to their children what they are good at, give their children positive feedback
- Use home visits to model self esteem building behaviours
- Encourage parents to support their children's participation in sporting teams or interest groups
- Boost the self esteem of parents eg., involve them in decision making processes, listen to and respect their point of view, include them in support groups, set them realistic goals, encourage them to engage in purposeful activities

5. **Discipline and Sibling Rivalry**

The task of defining boundaries and disciplining children becomes even more challenging as children enter their pre-adolescent years. In this period, many parents with intellectual disability - like other parents - may feel uncertain about where to set limits and how to enforce them when their children are defiant.

Practical strategies aimed at assisting parents with intellectual disability with these issues include:

- Running parent education programs/support groups which focus on behaviour management
- Modelling for parents problem solving without using harsh discipline
- Teaching the following discipline principles:
 - 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 only once 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, holding a family conference
- Reassuring parents that they are not alone in their struggle to maintain discipline and sibling rivalry. Strategies parents could be taught to reduce sibling rivalry and encourage bonding include:
 - Promoting communication between the children, and mediate if necessary. Take the attitude of 'let's 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
 - Having fun together by engaging in games and activities that foster cooperation

6. **Healthy Bodies, Healthy Minds**

As children grow rapidly during middle childhood teaching them good eating habits, personal hygiene and the importance of exercise and fitness becomes an even greater parental responsibility. Parents also need to look after their own health and self esteem needs if they are to fully meet their children's needs.

These tasks may be difficult for parents with intellectual disability. Many are on low incomes and/or have poor budgeting skills; lack the skills to make nutritious meals, and/or have poor emotional health.

Support workers can assist parents in these areas through the following:

- 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. Emphasise the importance of emotional self-care and assist parents to seek out professional help if needed
- Encouraging parents to pursue their own interests and hobbies
- Supporting parents to become more assertive
- Empowering parents to take control and speak up for themselves through group processes
- Presenting material about health care 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 also need to be informed about the dangers of abuse and to learn strategies to protect their children

7. Learning and the School Environment

Middle childhood includes the transition from primary school to high school. In addition to the academic and social challenges this brings, children of this age group are also becoming increasingly aware of the differences between their parents and the parents of their peers. Having to cope with these issues can be difficult for parents with intellectual disability. Support workers can assist by:

- Advocating on behalf of parents and their children
- Exploring options re providing school and homework support
- Encouraging parents to engage in school activities
- Encourage their children to get involved in extra curricula activities
- Teaching parents the following strategies to assist their 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
 - Find out about school holiday activities
 - Encourage children to feel capable, independent, and responsible
 - Don't be upset if they make mistakes. Understand that these are a part of learning.

C. Parenting Education

Parent education through parenting programs, the media, written material and informal networking are all means which support parents and their families.

1. Running an Effective Parenting Education Program

The following factors have been identified in the literature as being essential to the effectiveness of parent education programs:

- The relationship between educator and parent should emphasise reciprocity and partnership, acknowledging that each person can be a resource to the other. 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. Parent education interventions should also be based on family identified needs, with parents being involved in the planning and implementation of the program.
- Be aware of operating value systems: workers need to be very aware of their own value base, and that of the program they are using. They should critically examine current/proposed programs in terms of their appropriateness and relevance to the needs and life situations of parents. Caution needs to be taken when using programs that have a distinct value base (i.e. middle class, American, Anglo-Saxon) with parents with intellectual disability, that the program does not compound parents' feelings of inadequacy, guilt, anxiety, and depression.
- Support needs to be long term, ongoing and consistent if parents are to integrate new parenting strategies over the lifespan of their children. Skills are more likely to be maintained if the teaching includes generalization training, where parents are given experience and tools to generalize their new skills in a variety of settings and situations. Unless there are

opportunities for parents to apply their learning to everyday situations, to learn, revisit and discuss successes and disappointments in their attempts, there is a risk that they will lose what they will have learned.

2. **Components of Effective Parent Education Programs for Parents with Intellectual Disability**

For parent education programs to be effective with parents with intellectual disability they need to be:

- Specific - programs must be specifically targeted to the parent's individual needs for learning;
- Situational - the tasks must be taught where the skill is needed i.e. in the home; and
- Structured - this involves incorporating behavioural principles into programs; teaching tasks and skills in small steps; modeling new tasks; giving feedback; and providing opportunities for practice and repetition.

Support and Services for Parents with Intellectual Disability: What? When? How? By Whom? (1997)

Llewellyn, G. (1997) Support and Services for Parents with Intellectual Disability: What? When? How? By Whom? Report prepared for the Australian Family and Disability Studies Research Centre, School of Occupational Therapy, Faculty of Health Sciences, University of Sydney.

Introduction

This monograph focuses on the five themes that provided the focus of discussions at the Parent Access Project Forum (1996) "Making It Possible: Supporting Parents With an Intellectual Disability in their Role as Parents". Convened by the Family Support Services Association of NSW, the forum aimed to provide participants with an opportunity to learn about recent Australian and international research and program development in the area of parenting and intellectual disability, and (ii) to assist participants develop strategies to improve access and support for clients within their agencies.

The five themes addressed are:

- Who are parents with intellectual disability and how can we try to understand their life experiences?
- How can we determine individual parents' needs and how can we plan appropriately to meet these needs?
- What types of parent programs work and what do these offer for parents?
- What are the outcomes we are trying to achieve and how may we measure parent achievements?
- How can inter-agency collaboration be fostered?

Theme 1: Parents' Life Experiences

Who are parents with intellectual disability? The most appropriate way for workers to determine this is to use an approach that is not just deficit and diagnosis-focused, but which formally recognizes the parent's intellectual disability and acknowledges their resource and support needs. This involves:

1. Using acceptable standardized tests of intelligent quotient and adaptive behaviours;
2. Assessing a person's strengths and weaknesses across four dimensions: intellectual functioning and adaptive skills, psychological/emotional considerations, physical/health/aetiology considerations, and environmental considerations (living situation, work, education); and
3. Assessing those areas in which the person is thought to need support (eg., personal resources, other people, technology and services) and the intensity of support required (intermittent, limited, extensive and pervasive).

Although parents with intellectual disability are a heterogeneous group, similarities can be found in their experiences: poverty; unemployment; limited extended family or social supports; apathy; lack of normal, family living experiences as a child; lack of stability in family circumstances; negative experiences with professionals or authority figures; and low self-esteem. Obviously such experiences will impinge on the behaviours and parenting competence of those with intellectual disability, particularly in the areas of self-esteem, social skills, internal/external control, social role comprehension, and problem-solving skills.

Findings in the research literature raise several points about the experiences of parents with intellectual disability receiving services:

- parenting proficiency of mothers with intellectual disability is relatively independent of officially assessed intelligence status
- there is a relationship between mothers' personal and social situation and the development of positive or negative parenting
- between 80 - 90% of the parents live on some form of benefits or pensions
- between one to two thirds of mothers have partners and live in relatively stable relationships
- between 15-30% of the children are placed away from home at some time. Those mothers with younger children are more likely to be in a relationship and their children at home; those mothers with older children are more likely to be single and be separated from their child or children.

Theme 2: Parents' Individual Needs

In determining parents' individual needs and appropriately planning to meet these needs, it is important to remember that the level of the parent's intellectual ability seems to bear little relationship to their parenting ability. Research has shown that how mothers manage their parenting role is influenced by their mental maturity and stability - having a positive and realistic picture of oneself, feeling valued as an individual, and feeling that one is an asset to one's children. In assessing parents therefore, service workers need to take into account more than parents' ability to perform certain parenting skills. They need to look beyond the parents' cognitive limitations and look at the parent as a whole: the mother's way of perceiving things, her judgement, her reflection, her interaction as well as her role in caring for the health and safety of her child.

How these needs translate into service provision can be viewed from a number of different perspectives: the parents themselves, their partners, their family members, neighbours, and the range of service providers involved with the family. Generally speaking, professionals and significant others focus more on the parents' needs for parenting skills whereas parents are interested in getting support with personal and community skills such as vocational training and meeting people and making friends. Clearly, in trying to understand the parent's individual needs for support and services workers must look more widely than a typical constellation of parenting skills.

The Wisconsin Council's Developmental Disabilities Supported Parenting Project provides a comprehensive model of four key assessment areas:

1. Family Environment - housing, basic physical needs, household organization, neighbourhood, social and other support network
2. Family Structure and Function - family roles, current status of the family, relationships within the family
3. Parent/adult - health status, capabilities, skills/knowledge, learning abilities
4. Child - pregnancy/birth/developmental history, health status, behaviour/emotional status, school history

This type of interactional approach to assessment acknowledges the complexity of families and parenting, and helps in identifying parental, child and environmental factors that individually and together may affect parenting capacity.

Theme 3: Planning Programs for Parents

Two considerations are worth thinking about here. The first pertains to the difficulties with learning that are frequently encountered by parents with intellectual disability and will obviously impact on the effectiveness of any intervention offered:

- Difficulty with learning parenting skills and applying new skills in general
- Tendency to overgeneralise instructions
- Difficulty following complex instructions, or modifying instructions
- Problems with long and short term memory
- Difficulty in correctly recognizing cues and responding to the child
- Difficulty in recognizing problems and problem solving
- Difficulty with reading or only able to read basic words
- Difficulty with judgement and decision-making
- 'Splinter skills' - parents may exhibit very good abilities in some areas and yet have a surprising lack of skills in others

The second area concerns those features of successful parenting programs that have been shown to work for parents with intellectual disability. The components of these programs are:

- Specific - programs must be specifically targeted to the parent's individual needs for learning
- Situational - the tasks must be taught where the skill is needed i.e. in the home
- Structured - programs need to incorporate behavioural principles; tasks and skills need to be taught in small steps, and modeled to the parent with simple instructions and physical guidance if necessary; feedback needs to be given; and the steps being taught need to be repeated.

Theme 4: Parent Outcomes

Thinking about what needs to be achieved when working with parents with intellectual disability can and indeed needs to go beyond developing the health and safety of parents and their children. The primary purpose of programs for parents with intellectual disability should be to reduce the gap between the parent's capabilities and the demands of their environment. This can be broken down into three broad outcome areas:

1. The level of independence of the parent in their community
Measures of change in dependency level include frequency of service use; frequency of requests for help; level of integration into services for other parents and their children; nature of living environment/place of residence; and participation in work or community activity.

2. The quality of performance in everyday parenting activities
How parents are managing their everyday parenting can be measured from the perspective of the parents themselves, significant others and service providers.
3. The parent's level of competence in relation to that of others in the same community
Some potential measures of parenting proficiency/competence in relation to existing normative community expectations include: reduced or zero frequency of maltreatment notification; increased positive ratings on child health, wellness and development; decreased problem identification to social service agencies and child-oriented agencies; and increased problem resolution in relation to social service agencies.

Theme 5: Inter-agency Collaboration

That the support and service needs of parents with intellectual disability span several service agencies presents a major barrier to effective service delivery. In Australia, the response to this has been to develop mainstream services such that they adequately manage the needs of families where there is a member with a disability. This approach however continues to require a well-informed mainstream system or education and training opportunities to upgrade generic workers' knowledge about disability and its implications for family life.

To conclude, the application of each of these five themes needs to be underpinned by the following assumptions:

- Parents truly want the best for their child
- The greatest impact on parent, child and the family comes when the support given is based on the needs, dreams and wishes of the family
- Parents are more apt to expand their skills and learn new skills when we build on their existing skills and strengths
- Informal support networks are a primary resource for families and should be strengthened as much as possible
- The fundamental goal of supporting parents is to help parents, family and friends enjoy the child and parenting as much as possible
- A good program must meet the needs of parents to meet the needs of their children

Parents with Intellectual Disability: Support and Services Required by Parents with Intellectual Disability (1995)

Llewellyn, G., McConnell, D., & Bye, R. (1995) *Parents with Intellectual Disability: Support and Services Required by Parents with Intellectual Disability*. Report to the Disability Services Subcommittee (DDSC) of the Standing Committee of Community Services and Income Security Administrators, Department of Human Services and Health, Canberra. Copies of this report are available from Gwynnyth Llewellyn, Sesquicentenary Professor, School of Occupation and Leisure Sciences, University of Sydney, PO Box 170, Lidcombe, NSW 1825. E-mail: g.llewellyn@fhs.usyd.edu.au.

Background

In Australia, the number of parents with intellectual disability is increasing. Like all parents, those with intellectual disability have a wide range of capabilities that vary according to their own experiences in a family setting, their knowledge and skills in caring for children, and their

personality style.

However, despite recent federal and state legislation that mandates that people with disabilities be given every opportunity to participate as full citizens in Australian society, their decision to have children may be questioned from the very start. Myths about parents with intellectual disability prevail, for example, that parents with intellectual disability will abuse or neglect their children. Moreover, this parent group may only access support services in the event of a crisis or as an outcome of child protection proceedings.

There is an unequivocal need to break the crisis/intervention/crisis cycle. In the best interests of parents and their children, services are looking for ways to identify parents' needs early and provide support before crises develop.

Aim

To this end, this project aimed to investigate the support and service needs of parents with intellectual disability. More specifically, it was designed to:

1. Investigate the views of parents with intellectual disability about the support and services they require;
2. Investigate the views of nominated significant others (i.e. family or friends) and service workers about the support and services that parents with intellectual disability require;
3. Identify types of support and services offered by specialist disability providers and factors affecting these services;
4. Continue investigating factors affecting mainstream service provision to parents with intellectual disability; and
5. To develop recommendations about provision of support and services to parents with intellectual disability.

Method

52 parents with intellectual disability in rural and metropolitan NSW were interviewed. In addition, nominated service providers and family members and friends were asked to complete a questionnaire on what they perceived parents' support and service needs to be. 112 mainstream family support agencies were also surveyed to identify factors affecting service provision. Finally, focus groups and interviews were conducted with 40 specialist service providers to address desirable service characteristics and constraints on service delivery.

Three key needs areas were explored:

- Child Care: child development, child stimulation, child discipline, child hygiene, medical emergency and home safety
- Domestic: nutrition, food shopping, food preparation, home cleaning, money management
- Social and Community: assertiveness, marital relations, vocational skills/training, using community resources, friendships, and leisure activities

Findings and recommendations

Key findings included:

- Parents, significant others and service workers all identifying child development as the area parents needed most help with

- Second to this, many parents also reported needing assistance in the following areas: using community resources, vocational skills/training, and help with friendships
- Specialist service providers identified a need not only for parenting skills, but more generally with social and community skills including living skills, self esteem and assertiveness skills, and for community support including informal social support, access to mainstream services and advocacy
- Six desirable specialist service characteristics were identified: tailored to individual parents' needs; provide ongoing, long term support; are empowering; are proactive; work with parents in their own homes; and are at a level the parent understands.
- Seven constraints were seen to impinge on service delivery: lack of time, staff, and funding; lack of educational resources; parent reluctance to use services; difficulties with transport; limited mainstream services; limited skills and inappropriate attitudes; agency and community expectations.
- Mainstream service providers identified several factors that influenced service delivery: degree of parent disability; client motivation to attend; general funding level; time; and involvement of other services.

Further, similar themes were raised with remarkable consistency in each part of the project:

- the need for support and services to be responsive to parents' individual needs
- the critical importance of providing support to parents over the long term
- the need to provide opportunities for parents to learn in their own time and their own way
- the identification of ways to help parents become part of their local community; and
- the confirmation of the principle that supporting parents supports children

The findings clearly demonstrated that parents with intellectual disability do have special needs and consequently, agencies providing services to these parents have special requirements. There is an urgent need for mainstream and specialist agencies to address, together, the needs of parents with intellectual disability. Inter-agency collaboration is essential to develop flexible and innovative approaches to service provision.

The recommendations from this research specifically target mainstream services and articulate what is needed for parents with intellectual disability to receive the support and services they require.

Recommendation 1 - Intensive, individualized support

Mainstream services must incorporate an individualized service planning approach in their work with parents with intellectual disability and ensure that parents are active partners in this process.

- Services need to incorporate procedures into their service planning which involve parents in selecting and setting personal parenting objectives. Parents learn best when their views about what they need to learn are taken into account.
- Services need to take into account the special instructional needs of parents with intellectual disability. People with intellectual disability learn best when tasks are demonstrated and when there is opportunity for ample repetition.
- Services need to plan instructional activities in naturally occurring situations. Parents learn best about parenting in the family home when the task is practical and is taught in the situation where it typically occurs.

Recommendation 2 - On-going funding

Mainstream services require the necessary funding to provide ongoing, long term support to parents with intellectual disability

- Services need sufficient resources, specifically allocated, to ensure that the long term needs of parents are met
- Services need sufficient resources, specifically allocated, to incorporate a preventative and proactive focus in their work to forestall a cyclical crisis orientation to working with parents with intellectual disability

Recommendation 3 - Family-centred focus

Mainstream services need to incorporate a family-centred focus in their planning for parents so that the needs of the family are met. Specifically, resources need to be devoted to not only meeting parents' parenting needs but also to meeting their personal development needs.

- Services need to continue to address child-related topics of relevance to parents, in particular, child development, child stimulation, child discipline and activities for children
- Services need to specifically address parent-related topics especially in personal development skills such as meeting people and making friends, developing literacy skills and vocational skills and training.

Recommendation 4 - Accessible, available services

Mainstream services must have adequate resources to make sure services are physically accessible, widely known about in the community and welcoming to parents with intellectual disability.

- Training for mainstream agency workers needs to incorporate information about other supporting parents agencies and help workers develop skills in advocating for parents in the wider community
- Services must be specifically funded to provide transport as necessary so that parents can attend
- Services must be specifically funded to develop and distribute plain English information and alternative forms of information for non-literate parents and those of non-English speaking background.

Recommendation 5 - Supportive environment for parents

Mainstream agencies must be specifically funded to undertake an educative role with parents to assist parents to create an environment that supports children.

- Training for mainstream agency workers needs to incorporate information about parenting, about intellectual disability and about the impact of intellectual disability on learning parenting skills
- Services must be specifically funded and designated to provide proactive parent education, particularly in relation to identified 'difficult' times such as the transition from home to school and primary school to high school
- Services need to allocate funding to developing parent support groups where parents can exchange information in a supportive atmosphere and practice alternative strategies for managing difficult behaviours

Recommendation 6 - Inter-agency collaboration

Inter-agency collaboration must be specifically acknowledged as an essential element in providing support and services to parents with intellectual disability.

- Inter-agency collaboration must specifically promote:
- family centred focus in contrast to a parent-only or child-only focus
- preventative work rather than crisis intervention
- access to mainstream services for parents and their children rather than reliance on specialised support services

Recommendation 7 - Data collection

The collection and dissemination of epidemiological and support and service needs data about parents with intellectual disability and their children must be commenced as an essential part of planning and providing services. Collection and dissemination of adequate data requires inter-agency collaboration to ensure that the data collected reflects not only those parents and their children known to specialist services (in particular, disability and child protection services) but also parents with intellectual disability and their children more broadly in the community.

Collection and dissemination of data must specifically address:

- the number of parents with intellectual disability in the community (prevalence)
- the number of people with intellectual disability becoming parents in any given year (incidence)
- the level of support needs of parents and their need for services
- the geographic location of parents, and
- the number of children in families headed by parents with intellectual disability, and their need for support and services

Recommendation 8 - Pilot project

Funding needs to be specifically allocated for a local community-based pilot inter-agency project to investigate the most effective way to develop and maintain inter-agency collaboration in provision of services to parents with intellectual disability.

In particular, this pilot project would focus attention on increasing the capabilities of mainstream agencies to provide services and support to parents with intellectual disability. It would also be designed and implemented according to the principles elaborated in the first five recommendations.

Modelling contextual influences on parents with intellectual disabilities and their children

Publications from this project

Wade, C., Llewellyn, G., & Matthews, J. (November, 2009). *Modelling risk in vulnerable families*. Paper presented at the Research by Higher Degree Students Conference of the Faculty of Health Sciences, University of Sydney, Australia.

Wade, C., Llewellyn, G., & Matthews, J. (July, 2009). *Novel approaches to the examination of risk in vulnerable families*. Paper presented at the Doctoral Students Conference of the Australian Pacific Rim Universities, Kyoto, Japan.

Wade, C., Llewellyn, G., & Matthews, J. (November, 2008). *Success indicators of effective parenting interventions for at-risk parents and their children*. Poster presented at the Cell to Society Faculty of Health Sciences Conference of the University of Sydney, Leura, Australia.

Wade, C., Llewellyn, G., & Matthews, J. (November, 2008). *Consideration of Context in Programs For Parents With Learning Difficulties: A Review of the Intervention Literature*. Paper presented at the 43rd Conference for the Australasian Society for the Scientific Study of Intellectual Disability, Melbourne.

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 351-366.

Wade, C., Llewellyn, G., & Matthews, J. (November, 2006). *Success indicators of effective parenting programs for at-risk children: Conclusions from a review of parenting theories*. Paper presented at the Cell to Society Faculty of Health Sciences Conference of the University of Sydney, Leura, Australia.

Wade, C., Llewellyn, G., & Matthews, J. (August, 2006). *An analysis of parenting theories: Implications for our response to parents with intellectual disability*. Paper presented at the 2nd International Congress of IASSID-Europe 2006, Maastricht, Netherlands.

Project team

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Background

While parenting interventions have demonstrated benefits for families headed by parents with intellectual disability, they can be costly, time consuming, and have moderate to high rates of drop-out. Furthermore, not all parents benefit from these interventions to the same degree. Little is known about how mediating variables influence learning and skill development in families where a parent has an intellectual disability. Such knowledge is essential to promote best outcomes for the increasing number of children being raised in these families.

The relationship between parent, child, family and contextual variables and intervention outcomes in 120 Australian families headed by parents with intellectual disability were examined in this project. A theoretical model was developed to explain the pathways between context, parenting practices and child well-being for the sample and structural equation modelling was used to test these pathways.

Aim

This project aimed to identify the direct and mediated pathways between family context, parenting practices and child well-being among a group of Australian parents with intellectual disability who has been recruited via the Healthy Start National Strategy

(www.healthystart.net.au). The influences upon intervention outcomes for these families were also examined.

Findings

Findings revealed that parenting practices had a direct effect on child well-being, that socio-economic disadvantage, parent health and social support were associated with child well-being via the mediator of parenting practices, and that parent mental health and access to social support had a direct influence on parenting practices.

Cluster analysis of families based on contextual risk indicators that the literature identified as influential to intervention outcomes, revealed two distinct and theoretically discernable groups of parents within the sample. The two clusters differed in parent mental health, partner support, the number of children living at home, child birth weight, child protection involvement and minority status of parents. However, intervention outcomes did not differ for the two clusters. Of the variables that contributed to the clustering of parents, only partner support was found to be associated with program completion. Structural equation modelling was also used to identify that partner support was associated with program completion.

Implications

The implications of the findings reveal that while the socio-environmental context in which the child is embedded is important to child well-being, the pathway via which a child's wider environment impacts on his or her well-being is via parenting practices. In addition, the findings indicate particular aspects of the contextual environment of families that influence parenting (access to social support and parent mental health), which points to ways in which parenting interventions may be targeted to promote optimal child well-being. Furthermore, it appears that parents with little or no support from a partner are at increased risk for early discontinuation from programs aimed at improving their parenting. Cumulatively these findings have implications for practitioners wishing to target interventions to better meet the needs of individual families. The potential impact of such evidence is threefold: to ensure the highest rate possible of intervention success for all families; to reduce the risk of drop-out from interventions; and to reduce the high rates of child removal from the family.

Related publications

Wade, C., & Sartore, G. (September, 2009). *A 'Healthy Start' for children of parents with learning difficulties: Applications for prevention strategies aimed at building capacity*. Workshop presented at the ARACY National Conference, Melbourne, Australia.

Wade, C., Mildon, R., & Polimeni, M. (November, 2008). *Using evidence based practice to improve family-practitioner partnerships: Case studies from the Healthy Start National Strategy*. Paper presented at the 43rd Conference for the Australasian Society for the Scientific Study of Intellectual Disability, Melbourne.

Polimeni, M., Wade, C., & Mildon, R. (November, 2008). *Lessons from Healthy Start, a capacity building initiative: Strategies used to promote training transfer*. Paper presented at the ACWA Conference, Sydney.

Polimeni, M., Mildon, R., Wade, C., & Mayes, R. (2008). *Sharing practice knowledge through Healthy Start Learning Hubs: An example of a whole agency approach*. Paper presented at the 43rd Conference for the Australasian Society for the Scientific Study of Intellectual Disability, Melbourne.

Polimeni, M., Wade, C., & Mildon, R. (2008). *The validity and implications of parenting capacity assessments for parents in vulnerable circumstances*. Paper presented at the Queen Elizabeth Centre Conference, Melbourne.

Mildon, R., Wade, C., & Matthews, J. (2008). Considering the contextual fit of an intervention for families headed by parents with an intellectual disability: A pilot program. *Journal of Applied Research in Intellectual Disabilities*, 21, 377-387.

Wade, C., Llewellyn, G., & Matthews, J. (November, 2007). *Families at risk: implications for intervention*. Proceedings of the Biennial Faculty of Health Sciences Postgraduate Research Student Conference, University of Sydney, Australia.

Wade, C., Mildon, R., & Matthews, J. (2007). Service delivery to parents with an intellectual disability: Family-centred or professionally-centred? *Journal of Applied Research in Intellectual Disabilities*, 20(2), 87-98.

McConnell, D., Llewellyn, G., Matthews, J., Hindmarsh, G., Mildon, R., & Wade, C. (Winter, 2006). Healthy Start: a national strategy for children of parents with learning difficulties. *Developing Practice: The Child Youth and Family Work Journal*, 16, 34-42.

Mildon, R., Wade, C., & Matthews, J. (2006). Intellectual Disability and Parenting. *Every Child*, 12(1), 12-13.

Mildon, R., Wade, C., Hindmarsh, G., McConnell, D., Matthews, J., & Llewellyn, G. (2005). *Healthy Start: A national strategy for children of parents with learning difficulties*. Paper presented at the ARACY National Conference: Closing the know-do gap, Sydney, Australia.

Mildon, R., Wade, C., McConnell, D., Matthews, J., Hindmarsh, G., Llewellyn, G. (2005). *Healthy Start: A national strategy to promote safe, supportive and stimulating environments for young children of parents with learning difficulties*. Paper presented at the 40th Australasian Society for the Study of Intellectual Disability Conference, Auckland, New Zealand.

Clayton, O., McConnell, D., Mildon, R., Hindmarsh, G., Wade, C., Llewellyn, G., & Matthews, J. (2005). *Healthy Start: A national strategy for children of parents with learning difficulties*. Paper presented at the 5th Annual Conference for Disability Support Workers, Melbourne, Australia.

Matthews, J., Mildon, R., & Wade, C. (November, 2004). *Development & Implementation of Parenting Supports for Parents with a Disability: Introduction*. Paper presented at the 39th Australasian Society for the Study of Intellectual Disability Conference, Adelaide.

Mildon, R., Wade, C., & Matthews, J. (November, 2004). *Development & Implementation of Parenting Supports for Parents with a Disability: Key findings*. Paper presented at the 39th Australasian Society for the Study of Intellectual Disability Conference, Adelaide.

Wade, C., Mildon, R., & Matthews, J. (November, 2004). *Parents' views on service delivery to parents with an intellectual disability*. Paper presented at the 39th Australasian Society for the Study of Intellectual Disability Conference, Adelaide.

Wade, C., & Mildon, R. (2004). *Parent-child interactions and parents with an intellectual disability*. Paper presented at the Sixth Biennial National ECIA Conference, Broadening the Vision, Building Cohesive Communities for Children and Families, Melbourne, Australia.

Wade, C., & Mildon, R. (September, 2004). *Parenting and parents with intellectual disability*. Invited lecture at RMIT University to Intellectual Disability Students, Melbourne, Australia.

Wade, C., & Mildon, R. (June, 2003). *Parenting IDEAS program: Parents with special learning needs*. Invited presentation at the Kids in Care Conference, Melbourne, Australia.

Wade, C., & Mildon, R. (August, 2004). *Working successfully with parents who have an intellectual disability*. Invited workshop at the Eastern Metropolitan Region Student Disabilities Conference, Melbourne, Australia.

Wade, C. & Mildon, R. (July, 2004). *Working with parents who have learning difficulties: Issues and challenges*, half day workshop. O'Connell Family Centre, Melbourne, Australia.

Mildon, R., & Wade, C. (2004). *Embedding best practice skill development strategies into current family support practices: Working with parents with an intellectual disability and their young children*. Paper presented at the World Organisation for Early Childhood Education (OMEP) Congress 'One World: Many Childhoods', Melbourne, Australia.

This research was supported by project funding from the Australian Government through the Early Childhood - Invest to Grow Initiative and through a Post-graduate Primary Health Care Scholarship from the National Health and Medical Research Council, Australia.

Parent/Child Health and wellbeing

Becoming a mother: the experiences of women with intellectual disabilities (2009)

Mayes, R. (in press). Becoming a mother: The experience of women with intellectual disabilities. *Australian Journal of Occupational Therapy*.

Mayes, R., Llewellyn, G., & McConnell, D. (submitted). "That's who I choose to be": The mother identity for women with intellectual disabilities. *Women's Studies International Forum*.

Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: mothers with intellectual disabilities creating their social support networks. *Journal of Applied Research in Intellectual Disability*, 21(4), 341-350.

Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research*, 8(2&3), 120-131.

Background

The topic of women with intellectual disabilities as mothers has been explored in a discrete literature within the larger field of disability studies. In research predominantly conducted by disability scholars, concerns include:

- whether or not these women can adequately care for their children;
- how best mothering skills might be taught to women with intellectual disabilities.

Scholars have turned their attention from mothering as an individual pursuit to mothering within a social context, focusing on those in a mother's life who may aid or abet her mothering.

The focus of this research is largely about the tasks and activities women perform while caring for their children. Issues of gender and identity as they influence mothering by women with intellectual disabilities are yet to be considered. The meaning of motherhood for women with intellectual disabilities, and how they assume the mother identity are yet to be addressed. No study to date has examined the phenomenon of becoming a mother for women with intellectual disabilities.

Aim

The aim of this phenomenological study was to describe the phenomenon of becoming a mother for women with intellectual disabilities.

Findings and Implications

Seventeen women with intellectual disabilities were interviewed during their pregnancies, and accounts of their lived experiences of becoming a mother were sought.

Three essential elements of the phenomenon were identified:

- "recognising I am pregnant"
- "understanding my importance in my baby's life"
- "creating a family network for my baby".

The findings of this study make three significant theoretical contributions.

1. Women with intellectual disabilities, because they are women, become mothers. They dispel the myths that they are asexual or sexually promiscuous, passive and dependent.
2. Women assume the mother identity in relation to others in their lives. In developing a mother identity it is not only the woman and her baby who are involved. Others affirm her central place in her baby's life, thereby affirming her identity as mother of her baby.
3. Women negotiate support for the tasks of caring for her baby. In doing so, however each woman differentiates how she is involved in her baby's life from the way in which others are involved. Her role and identity in her baby's life is as mother.

Related Publications

Llewellyn G, McConnell D, Honey A, Mayes R & Russo D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomised controlled trial. *Research in Developmental Disabilities, 24*(6), 405-431.

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). [Developmental Profiles of Children Born to Mothers with Intellectual Disability](#) *Journal of Intellectual and Developmental Disability, 28*(2), 1-14.

Llewellyn G, McConnell D & Mayes R (2003). Health of mothers with intellectual limitations. *Australian and New Zealand Journal of Public Health, 27*(1), 17-19.

Llewellyn, G., McConnell, D., & Honey, A. (2001). [Healthy and Safe. NSW Parent-Child Health and Wellbeing Research and Development Project.](#) Report to the NSW Department of Ageing, Disability and Home Care Services. University of Sydney.

Tymchuk, A.J., Llewellyn, G., & Feldman, M., (1999). Parenting by persons with intellectual disabilities: A timely international perspective. *Journal of Intellectual and Developmental Disability, 24*(1), 3-6.

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.

McConnell, D., Llewellyn, G., & Bye, R. (1997). Providing services to parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability, 22*(1), 5-17.

Llewellyn, G., & Brigden, D. (1995). Factors affecting service provision to parents with intellectual disability: An exploratory study. *Australian and New Zealand Journal of Developmental Disabilities, 20*, 97-112.

Llewellyn, G. (1994). [Generic Family Support Services: Are Parents with Learning Disability Catered For?](#) *Mental Handicap Research, 7*(1), 64-77.

Llewellyn, G. (1990). [People with Intellectual Disability as Parents: Perspectives from the Professional Literature](#) *Australia and New Zealand Journal of Developmental Disabilities, 16*(4), 369-380.

Development Profiles of Children Born to Mothers with Intellectual Disability (2003)

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003) Developmental Profiles of Children Born to Mothers with Intellectual Disability *Journal of Intellectual and Developmental Disability, 28* (2) 1-14.

Background

With increasing numbers of adults with intellectual disability choosing to have children, concern remains as to the health and wellbeing of their offspring. One reason for this is the presumption that a causal link exists between parental intellectual disability and developmental delay in their children. Such parents are thought incapable of providing the stimulation children need to develop 'normally', to the extent that when a parent is identified as intellectually disabled, potential developmental delay of their child or children is often treated as a child protection concern.

Studies testing this hypothesis to date have reported findings of substantial variation with most children meeting age-norm expectations. Why some children experience difficulties and others do not has yet to be explained, though a number of variables are thought to play a part: genetic anomalies; antenatal and birth complications; parental health (physical and mental) and social support; the quality of a parent's own upbringing; the adequacy of support services; and the 'resilience' of the child.

Aim

This study aimed to contribute to the process of better understanding marked differences in the developmental status of children of parents with intellectual disability by:

1. assessing the developmental status of pre school aged children (i.e. 6 years and under) born to mothers with intellectual disability, and
2. examining the relationship between developmental status and selected child, maternal and home/environment characteristics.

Method

Data was gathered in the course of a randomized trial of a child health and home safety program for parents with special learning needs. The development of 37 children, each being the youngest in their respective families, was assessed by two occupational therapists and a registered psychologist. A number of assessment tools were administered and a combination of standardized measures and structured interviews employed. Data was analysed using the Statistics Package for the Social Sciences (SPSS). Descriptive statistics were computed and a series of univariate analyses conducted to examine the relationship between the dependent and independent variables.

Findings and implications

The developmental status of the children varied markedly in physical, self-help, academic, social and communication domains. Notwithstanding, in all developmental domains, between 35% and 57% of children showed a delay of at least three months.

No statistically significant correlation was found between developmental status and characteristics of the mother or home/environment. This is significant given the high rate of physical and sexual abuse experienced by the mothers, and their poor health relative to Australian norms. Such a finding suggests that the current emphasis on maternal and home/environment characteristics may be misplaced. It also implies that inadequate stimulation on the part of parents cannot be assumed. To do so is prejudicial and to cast assumed developmental delay as a child protection concern discriminatory.

Possible organic pathology was the only potentially explanatory factor that emerged from this

study for the observed variation in child development. Indicators used to identify organic pathology were as follows:

- the child having a diagnosed medical condition such as epilepsy and/or was regularly being seen by a specialist medical practitioner;
- the pregnancy being traumatic/difficult to the point of requiring hospitalization eg., due an accident/fall, Rubella infection or pre-eclampsia;
- premature birth (gestation period < 37 weeks) and low birth weight (< 2500 grams);
- a complicated birth that required emergency c-section, for example, due to anoxia;
- the child being admitted to intensive care after birth and/or having to experience an extended hospital stay (> 2 weeks); and
- since birth, the child having undergone a long hospital stay due to a serious medical condition, for example, related to heart or kidney function.

In this study sample, nearly half of the children were identified with one or more indicators of (possible) organic pathology. These children were also delayed in all of their developmental milestones. Children with no evidence of organic pathology were developing normally with the exception of an average slight delay in their communication skills.

The extent to which this high incidence of suspected pathology can be generalized is uncertain. Ideally a prospective study with a larger sample size and where the mothers are recruited as early as possible in pregnancy will provide the opportunity to obtain more sound epidemiological data and explore potential influences on good birth outcomes. Examining the type, quality and suitability of antenatal and maternity services for mothers with intellectual disability and exploring how these mothers care for themselves during pregnancy may lead to a better understanding of how best to prevent the developmental delay identified to date in studies of parents with intellectual disability.

This study was funded under the Best Practice Parenting Education Initiative of the Commonwealth Department of Family and Community Services and the NSW Ageing and Disability Department, August 1998 - November 2000.

Health of Mothers with Intellectual Limitations (2003)

Llewellyn, G., McConnell, D., & Mayes, R. (2003) Health of Mothers with Intellectual Limitations *Australian and New Zealand Journal of Public Health*, 27 (1), 17 - 19.

Background

A clear connection exists between a population group's health status and socio-economic circumstances. Parents with an intellectual disability can often be found in several of those groups that suffer marked socio-economic disadvantage - single parents, those who are unemployed, and those with a disability - and thus carry the risk of having poor health.

Rather than addressing these more fundamental issues however, policy and social programs have tended to support parents with intellectual disability and their children through the provision of parent education programs. This is surprising given the significant impact that early life experiences have on lifetime health and well-being, and the recognized relationship between living in impoverished circumstances and poorer health outcomes for adults and children.

Aim

In the absence of data on the health of Australian parents with intellectual disability this study was undertaken to investigate parental health status and health behaviours of parents referred to a home learning parent education program.

Method

The health status and health behaviours of 45 parents with special learning needs were assessed using structured interviews based on the Short Form 36 Question Health Survey (SF-36). Four additional health questions covering alcohol and cigarette consumption, exercise and participation in fun and relaxing activities were also included.

Findings and implications

Parents reported significantly worse health on all scales of the SF-36 compared to the general Australian population. Further, when controlling for socio-economic status, participants' reported health was significantly worse on seven of the eight health subscales. Single parents reported significantly worse health on the Physical Functioning and Mental Health subscales only. Surprisingly, parents in couple families reported significantly worse health on all but the two subscales of Role Physical and Social Functioning. Those parents who reported engaging in regular exercise and fun and leisure activities reported better health on four and one subscales of the SF-36 respectively.

Parents with intellectual disability are particularly vulnerable to poor health status. Given the association between early experiences of children and their health status in adulthood, the children of parents such as those who participated in the study may well be at risk for poorer health and adverse later life outcomes.

Factors such as shortfalls in system and practitioner expertise, and doubt as to the ability of these parents to learn and overcome parenting deficiencies mean that there is no simple way of addressing these core issues.

Home visiting programs however provide one avenue where an integrated approach to alleviating the difficulties experienced by parents with intellectual disability can be implemented. An urgent need exists for these program developers and service providers to pay particular attention to parent health status given the observed poor health status of parents and the associated high risk of poor long term health status for their children.

Being a Parent with Intellectual Disability: A Battle Against the Odds (1994)

Llewellyn, G. (1994) Being a Parent with Intellectual Disability: A Battle Against the Odds Community Bulletin, 18 (1), 9 - 13.

Written at a time when there was almost no Australian research about parents with intellectual disability, this paper provides a forum for the views of some of these parents to be aired. What is the shared experience of intellectual disability and parenting like?

A predominant theme quickly emerged: that parenting for those with intellectual disability is a battle against the odds. Factors such as restricted life opportunities and the perceived and often transferred expectations that people with learning difficulties are incapable of fulfilling

certain adult roles make the task of parenting more difficult.

Parents with intellectual disability also have to contend with unfounded presumptions that openly challenge their right to have a child. These myths are: that people with intellectual disability are incapable of learning adequate parenting skills, and that they will give birth to disabled children, have more children than other parents, and neglect or abuse their children.

The extent to which parents carry on satisfactorily with their family life depends directly on the support or opposition they experience. Parents involved in this study preferred to seek help from partners and family, and only occasionally turned to professionals for assistance.

Support given, whether formally and informally, will be most effective if:

- it is provided in the spirit of accepting that young adults with intellectual disability share the drive to procreate and dream of parenthood;
- it includes sex and relationship education early in schools;
- it allows adults with intellectual disability to talk about parenting, including their rights and responsibilities, not just practical matters;
- parenting education and home help is tailored to the specific needs of these parents; and
- if it recognises that no parent innately knows how to be a 'good' parent.

Service providers also need to practice being responsive to parents' needs; to find out how parents perceive their needs and then offer programs which:

- value parent input and support their decision-making;
- regard the parents as adult learners;
- provide opportunities for relationship building;
- provide informal support for families and for professionals; and
- promote and advertise successful parent and child outcomes

Intellectual Disability and Parenting: A Shared Experience

Llewellyn, G. (1994) *Intellectual Disability and Parenting: A Shared Experience* A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy. University of Sydney.

This study is set within the context of increasing opportunities for adults with intellectual disability to become parents. Currently there is no theoretical foundation on which to base policy and practice about parenting for intellectually disabled parents. The purpose of this study was to develop a theoretical formulation of the shared experience of intellectual disability and parenting.

This study differs from previous research on parents with intellectual disability in four major aspects. First, the study sample are all parents who live in the community without surveillance by child welfare and protection authorities. Second, the parents' views on their experiences of parenting constitute the empirical data. Third, the parents' everyday parenting experiences are explored from a sociocultural perspective. Fourth, a substantive grounded theory (Glaser & Strauss, 1967) of parenting for people with intellectual disability is developed from the parent viewpoint.

The theoretical orientation of the study is derived from symbolic interactionism (Blumer, 1969).

The study methods of ethnography (Agar, 1980; Spradley, 1979) and grounded theory (Glaser & Strauss, 1967) were chosen in keeping with this orientation. Ten parents with intellectual disability (six mothers and four fathers) participated in the study. The parent viewpoint was sought by indepth interviews and participant observation and recorded in field notes and a field work journal. Data analysis procedures were derived from the work of Strauss and Corbin (1990).

Eight conceptual categories of parents' experiences were generated from the empirical data: Experiencing Competing Demands, Holding Views on Parenting, Experiencing the Presence of Others, Getting to Know the Child, Managing the Child, Learning to Parent, Determining Others' Involvement and Implementing Parental Views.

The conceptual relationships within and between these categories yielded four theoretical constructs as follows: Assessing and Balancing, Perceived Questioning, Managing Parenting and Asserting Parenthood.

The theoretical formulation of the parenting experience - Building Family Life Against Outside Odds - was derived from the four constructs and the literature. Experience of parenting is determined by the perceived level of questioning and parents' views about their family life course. There are four potential parenting contexts: family life on course, questioning perceived as tolerable; family life on course, questioning perceived as high; family life off course, not critically so; and family life off course and under threat.

The methods used in this study provide a model for exploring the views of people with intellectual disability. The results of the study offer empirically grounded information on which to base policy and practice with intellectually disabled parents. In the future, the four theoretical constructs will be used to develop indices of parental concerns and learning needs. The theoretical formulation of the parenting experience will be elaborated with intellectually disabled parents with older children and those whose parenting is under threat from child welfare and protection authorities. Potentially, the theoretical formulation can be used to examine the parenting experience of parents other than those with intellectual disability.

Multiple risk families: the first year of life

Project team

[Professor David McConnell](#)

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Background

The most vulnerable families are those who, with limited internal (coping) resources, are exposed to multiple environmental risk conditions. Families headed by parents with intellectual disability (ID) are multiple risk families. With intellectual impairment (including borderline ID, IQ<79) and chronically poor health, these parents experience persistent poverty, social isolation and service systems that are poorly equipped to accommodate their support needs. The high incidence of developmental delays observed in their children, in the range of 30-50%, seems to support a bleak outlook. However, many parents with ID provide safe and

nurturing home environments, and many children are healthy and keeping pace with their peers. Given the multiple risk status of these families, determinants of child and parent resilience warrant investigation.

Aim

The primary aims in this study were:

1. To chart the health and developmental trajectories of infants born to intellectually disabled mothers through their first year of life.
2. To examine the relationship between birth outcomes, parental care and infant health and development and identify conditions (i.e. protective factors) that promote healthy infant development under multiple risk conditions.
3. To chart the health trajectories of intellectually disabled mothers.
4. To investigate adaptation to parenthood including the influence of their own upbringing, informal learning/support and utilisation of services.

Method

A cohort of 28 mothers who participated in a previous study of prenatal care and birth outcomes agreed to take part. These mothers were interviewed twice, usually in their own homes, and when their babies were 6 to 12 months of age. The interviews incorporated standard measures and open ended questions to explore each mother's experience and adaptation. Data collected included infant health and development; maternal health, warmth and responsiveness, social support, care experiences; and overall home environment.

Findings and Implications

This project was a cross-disciplinary collaboration, drawing together expertise in intellectual disability, perinatal and infant health. This multiple risk parent group has been identified as problematic to prenatal, early childhood clinic and family services due to lack of attendance, non-compliance and requiring intensive interventions. Some of the key findings include:

- No significant relationship between developmental status of the child and maternal IQ was found.
- A disproportionate number of the infants in the cohort were below the 50th percentile for length, weight and head circumference, at 6-8 weeks and 6-8 month follow-ups.
- 40% of the infants demonstrated a delay. of at least one month. across 4 out of 5 developmental domains. Delays were most common in the physical domain.
- Infants who had the poorest birth outcomes were also those most likely to be 'lagging' in their development.

The findings of this study, and the preceding study of prenatal care and birth outcomes, suggest that attention needs to be given to improving the health and health care of expectant mothers with intellectual disability. These findings supported a successful application to the Australian Government, under the Stronger Families and Communities Strategy (2005-2009), to implement a national strategy for young children of parents with learning difficulties – Healthy Start (www.healthystart.net.au). This national strategy, in partnership with the Parenting Research Centre (Victoria), included the development and evaluation of a health care resource, called Healthy Start for Me and My Baby, for pregnant women with learning difficulties.

Related publications

Llewellyn G, McConnell D, Honey A, Mayes R & Russo D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomised controlled trial. *Research in Developmental Disabilities*, 24, 405-431.

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003) [Developmental Profiles of Children Born to Mothers with Intellectual Disability](#) *Journal of Intellectual and Developmental Disability*, 28(2), 1-14.

Llewellyn G, McConnell D & Mayes R (2003). [Health of mothers with intellectual limitations](#). *Australian and New Zealand Journal of Public Health*, 27, 17-19.

Llewellyn, G., McConnell, D., & Honey, A. (2001) [Healthy and Safe.NSW Parent-Child Health and Wellbeing Research and Development Project](#). Report to the NSW Department of Ageing, Disability and Home Care Services. University of Sydney.

Tymchuk, A.J., Llewellyn, G., & Feldman, M., (1999) Parenting by persons with intellectual disabilities: A timely international perspective. *Journal of Intellectual and Developmental Disability*, 24(1), 3-6.

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.

McConnell, D., Llewellyn, G., & Bye, R. (1997). [Providing services to parents with intellectual disability: Parent needs and service constraints](#). *Journal of Intellectual and Developmental Disability*, 22(1), 5-17.

Llewellyn, G., & Brigden, D. (1995). Factors affecting service provision to parents with intellectual disability: An exploratory study. *Australian and New Zealand Journal of Developmental Disabilities*, 20, 97-112.

Llewellyn, G. (1994) [Generic Family Support Services: Are Parents with Learning Disability Catered For?](#) *Mental Handicap Research* 7(1), 64 - 77.

Llewellyn, G. (1990). [Parents with an intellectual disability: Perspectives from the literature](#). *Australia and New Zealand Journal of Developmental Disabilities*, 16(4), 369-380.

Parent education programs

Home Based Programs For Parents With Intellectual Disabilities: Lessons From Practice (2002)

A more detailed list of important practice points for parent educators can be found in Llewellyn, G., McConnell, D., Russo, D., Mayes, R., & Honey, A. (2002) Home-based Programs for Parents with Intellectual Disabilities: Lessons from Practice Journal of Applied Research in Intellectual Disabilities, 15, 341-353.

Background

The use of Home Learning Programs (HLPs) has been identified as a useful parenting education strategy. However, those variables conducive to enabling these home based parenting programs to be effective, particularly when being delivered to parents with intellectual disabilities, have yet to be pinpointed. This provided the focus of a research project - the NSW Parent-Child Health Wellbeing Project - conducted by the Australian Family and Disability Studies Research Collaboration, School of Occupation & Leisure Sciences, University of Sydney, in 1998 - 1999.

Aim

To develop process guidelines for practitioners implementing a home-based parenting education program with parents with an intellectual disability

Method

45 parents with intellectual disability and who had children under 4 years of age were randomly chosen to participate in a home-based education program that addressed issues of child health and safety.

Case notes documented by the parent educators, as well as parent evaluation surveys, provided the focus of data analysis.

Findings and practice implications

1. The Home Learning Program

Key process factors that enhanced the program's effectiveness revolved around a practitioner's willingness and ability to:

- Make good use of pictures that are realistic and concrete
 - Allow for the active and practical participation of parents
 - Provide opportunities for learners to monitor and reinforce their learning
 - Set activities that are achievable within the context of the person's home
 - Incorporate repetition of information using various methods
 - Present material that is useful/relevant to the parent's needs and experiences
 - Be flexible
 - Take into account individual learning styles and personalities
2. More broadly, practitioners are asked to consider:

- Individualising generalist home learning programs so as to make each parent's home as ideal a learning environment as possible
 - Giving priority to parents' immediate concerns before moving on to the program's learning activities
 - Applying effective teaching principles in the context of past learning experiences
 - If and how they might influence those in the home who have the power to facilitate or impede learning
-

Parents with Intellectual Disability: Learning to Parent: The Role of Experience and Informal Learning (1997)

An overview of study findings can also be found in Llewellyn, G. (1995) First Hand Experience: Parents with Learning Difficulties *Disability, Pregnancy & Parenthood International*, 11 (July), 10 - 12.

Background

Concern as to whether people with intellectual disability can be capable parents continues to be widespread in our society. Formal parent training, usually developed from the perspective of service providers, is frequently presumed necessary to teach competent parenting. The question of whether parents with intellectual disability can also learn through everyday family experiences has yet to be thoroughly researched.

Aim

To explore the role of informal learning and experience in parenting using an ethnographic study of family life with six parent couples.

Method

All participants were considered by their referring agency to be managing their parenting role adequately. Further, none were suffering significant socio-economic disadvantage.

Descriptive accounts of each couple's family experiences were drawn from family outings, informal home visits, telephone calls and in-depth interviews. Interviews were transcribed and the method of constant comparative analysis applied.

Findings and practice implications

Parents were seen to develop their parenting skills through informal learning. Firstly, they were able to learn from the experience of others - through their own upbringing and family traditions; from their experience with siblings or as a baby-sitter; and/or from the example set by significant others, usually family members.

Secondly, learning was able to take place from the mere practice of daily parenting. Parents were able to learn from their mistakes; change their or the child's routines in an attempt to achieve better outcomes; try alternatives; and do 'it' their own way and work out for themselves what the 'better way to go' was.

Thus in addition to professional assistance and training, parents with disability may also learn about parenting as they experience and practice it. The extent to which this is the case of course, will depend on parents' individual historical and current profiles.

These findings lend to four policy and practice implications:

1. That the significant effects of parental childhood experiences and respect for family traditions be considered when assessing parent knowledge and skill prior to formulating parent training programs;
2. That the commonly held view that parenthood for persons with intellectual disability is beset with problems be challenged;
3. That parents' views on parent training programs and whether these are perceived to help or hinder their learning to parent be investigated; and
4. That in supporting parents with intellectual disability, service providers individually assess what parents already know, how this was learnt, and how they learn best.

The challenge remains for practitioners to develop service models that provide effective structured teaching whilst at the same time capturing the opportunity, in everyday family life, for informal parental learning and experience.

For a full account of this study, see Llewellyn, G. (1997) *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.

Healthy and Safe. NSW Parent-Child Health and Wellbeing Research and Development Project (2001)

Llewellyn, G., McConnell, D., & Honey, A. (2001) *Healthy and Safe. NSW Parent-Child Health and Wellbeing Research and Development Project*. Report to the NSW Department of Ageing, Disability and Home Care Services. University of Sydney.

Background

Parents who are seen as having limited cognitive abilities are disproportionately represented in child protection services. Their children are thought to be at risk of injury at home or from serious illness from potentially inappropriate parental responses to the child's health care needs. Usually a crisis such as declining health or suspected abuse or neglect occurs, leading to court intervention and a subsequent order for parents to attend parent education services as a condition of keeping the child or proving parental competence to regain child custody.

These services however usually lack the time and resources to appropriately address the learning needs of parents with intellectual disability and other cognitive limitations. Service providers of mainstream family support and specialist disability services have identified the lack of suitable educational resources as being a major constraint in providing the specialized support required by this parent group.

Research has shown that parents with special learning needs, including those with intellectual disability, can indeed learn the parenting skills necessary to maintain their children's health, safety and wellbeing. Critical to such success however is the way these programs are designed. Rather than incorporating group instruction and written materials, programs are

more effective if they are specific to the parent's learning needs and suit their learning style; if they are structured around a variety of teaching methods and incorporate behavioural principles; and if they are delivered in the situation where the parent is to use the skills learned.

Aim

The NSW Parent-Child Health and Wellbeing Project was developed in response to this identified problem. Specifically, it aimed to:

1. Evaluate a parent education program - the NSW parent-Child Health and Wellbeing Project - for families headed by parents with special learning needs in terms of its effectiveness in equipping these parents to take responsibility for their child's health, safety and wellbeing;
2. Develop recommendations about the provision of designated parent educator training and the feasibility of adopting the project model and materials in mainstream and specialist service agencies in NSW.

Method

Based on the UCLA Parent Wellness Project and adapted for the Australian context, the study addressed three main areas: children's health care needs, child safety in and around the home, and parent-child interaction.

45 parents from 40 families with special learning needs participated in a randomized control trial whereby the effect of the Home Learning Program could be compared with three other conditions: parents receiving current services only, parents receiving only one informal home visit, and parents who only received lesson booklets from the Home Learning Program. Assessors who were blind to each parent's group membership conducted baseline, pre and post intervention and follow-up assessments. Outcome measures included a range of curriculum-based variables, and a range of standardized and non-standardised assessments were employed to gather demographic data and information on child development, parent health, parent IQ, parent literacy, the home environment and social support networks. Qualitative data was also obtained from parents, referring agencies, general practitioners, and parent educators in an attempt to better understand the process of conducting a parent education program in parents' homes and to gather parent and parent educator perspectives on this type of parent education program.

Findings and recommendations

The findings of this study demonstrated the significant effectiveness of the Home Learning Program for parents with special needs. These parents not only learned, but maintained the acquired child health and home safety knowledge and skills at three months follow up. Moreover, this was the case regardless of parents' health, literacy skills, IQ, perceived motivation, support network type, and home environment.

Essential components of the Home Learning Program were shown to be as follows:

- The use of pictures - the more the better
- Interactive learning - parents being invited to participate in a practical way
- Opportunities to monitor and reinforce progress
- Achievable activities
- Repetition of information in a variety of ways

- Material that is relevant to the participant's individual needs and experiences
- Delivered according to individual capabilities (eg., lesson lengths, concepts), learning styles and personalities

Four key themes pertaining to home-based education programs also emerged:

1. The home environment as a place for learning

Although this offers parents individualized, context-specific learning, there is the reality of a home with young children to contend with. Practitioners needed to be flexible in managing these frequent distractions eg., schedule home visits during school hours/term or when the baby was sleeping; provide children with food and entertainment prior to the lesson starting; include children where possible.

2. First things first

This relates to the competing needs and priorities of parent participants and educators. For parents, the relationship with their educator and the opportunity to offload their immediate concerns often proved to be more highly valued than the home learning activities. For parents it was a case of needing to air personal issues before they were able to concentrate on the task at hand. This required parent educators to allow plenty of time for the home visit and to become good listeners and provide practical support, advice and information. Further, given the high number of missed or cancelled appointments, educators needed to be extremely flexible to fit into the parents' sometimes hectic routines.

3. Parent readiness to learn and apply knowledge

Parents varied greatly in their readiness to learn and apply knowledge and past experience seemed to be an important factor here. When previous learning experiences were characterized by failure and negative judgements, and/or parents' behaviour was being monitored by child welfare authorities, educators need to be particularly encouraging in helping these parents get started on the learning activities.

4. Parent ability to make changes

Some parents had little or no control over the home environment and felt quite powerless to apply the knowledge they had learned. Thus the effects of home visiting programs will be moderated by the parent's degree of control over the household.

In light of these issues, parent educators need to be aware of the following practice points to ensure that parents are ready and able to participate fully and freely in a home-based learning program:

- Be prepared to listen to and if possible address the concerns of parents before commencing a teaching activity
- Be flexible in planning to take into account individual parents' immediate needs and priorities in their everyday family lives
- Be aware of parents' previous experiences with learning (either in the school system or informally) and be prepared to adapt strategies and offer plenty of positive reinforcement
- Be prepared to reflect critically and in an ongoing way on personal values and assumptions and to guard against falling into the trap of 'knowing what is best for all parents
- Be open to and interested in parents' life experiences and those of their family and friends so that these can be used in teaching and learning activities
- Be open to and aware of parents' home situations particularly of others who influence the parent. Be prepared to work with and engage significant others in assisting the parent to learn if at all possible

Parent educators also need to demonstrate the following fundamental requirements in order to work effectively with parents with learning difficulties:

1. Being able to build good rapport and to develop knowledge about parents' lives and experiences in order to effectively relate these to the home learning program
2. Being knowledgeable about child health and safety issues beyond the necessarily restricted items covered in a time limited home learning program
3. Being familiar with theories and sequences of child development
4. Being able to assess parents' abilities and tolerance levels for learning 'on the run' and being flexible enough to adapt the lessons accordingly
5. Being sensitive to the individual learning styles and preferences of parents and able to adapt the lessons accordingly
6. Being aware of the influences of cognitive limitations on learning as well as the social experiences of people with learning difficulties and the effects of these on their attitudes towards learning
7. Being flexible enough to adapt to and/or work around the disruptions and distractions of the home environment
8. Being respectful, as a guest, of parents' authority in their own homes and their differing priorities and immediate needs
9. Being patient and flexible, to fit into the routines, or non-routines of parents with learning difficulties
10. Being able to assess the impact of the attitudes and behaviour of significant others and to utilize these when helpful to parents' learning and help parents work around them when these are a negative influence
11. Being able to work with significant others to help them understand the importance of the program and the information and skills it teaches
12. Being able to assess parents' abilities (including utilisation of social supports) to make the required changes to their homes and to offer practical assistance where necessary.

The report concludes with three key recommendations:

1. *That the identified gap in appropriate parent education programs for parents with special learning needs be addressed.*
Further to this, it was recommended that the Ageing and Disability Department convene a Working Party in collaboration with the Department of Community Services, the Department of Education and Training and NSW Health to work with the Australian Family and Disability Studies Research Collaboration, University of Sydney and the Parent Access Project, Family Support and Services Association to design and implement a strategy to ensure that the Home Learning program is available on a system wide basis by 2003.
2. *That the immediate need to make available the Home Learning program lesson materials and training program (in prototype format) to mainstream and specialist service providers with significant experience with parents with special learning needs be addressed.*
To this end, it was also recommended that the Australian Family and Disability Studies Research Collaboration, University of Sydney in collaboration with the Parent Access Project, Family Support Services Association conduct a number of training workshops on the Home Learning Program in 2002 for workers who have significant experience with parents with special learning needs. This training workshop would be in prototype format prior to finalisation of learning materials and training content to be included in statewide training to commence in 2003.
3. *That the empirically demonstrated requirement that parent education training be specific, structured and situational be addressed.*
Thus it is further recommended that the Australian Family and Disability Studies Research Collaboration, University of Sydney in collaboration with the Parent Access project, Family Support Services Association work with the Ageing and Disability Department and potential

accredited education and training providers to identify the necessary experience and/or training required by service workers prior to or gained concurrently with undertaking the training module on the Home Learning Program.

Related Publications

Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003.) Promoting health and home safety for children of parents with intellectual disability: *A randomised controlled trial Research In Developmental Disabilities 24(6) 405-431.*

McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual and Developmental Disability, 28(2), 1- 14.*

Llewellyn, G., McConnell, D., Russo, D., Mayes, R., & Honey, A. (2002). Home based programs for parents with learning difficulties: Lessons from practice. *Journal of Applied Research in Intellectual Disabilities, 15, 341-353.*

Child Protection

Prevalence and Outcomes for Parents with Disabilities and their Children in an Australian Court Sample (2003)

Llewellyn, G., McConnell, D., & Ferronato, L. (2003) Prevalence and Outcomes for Parents with Disabilities and their Children in an Australian Court Sample *Child Abuse & Neglect*, 27 (2003), 235 - 251. This study was funded by the Law and Justice Foundation of NSW.

Background

Knowledge about parents with disabilities and their children has increased substantially over the last decade. Nevertheless, old myths about parenting and disability remain. A particularly persistent myth is that parents with psychiatric or intellectual disabilities are perpetrators of child abuse. This is contrary to good evidence that abuse is rare among parents with intellectual disability (mental retardation). Nor has "psychopathology" or "mental disturbance" consistently been found in child maltreatment perpetrators.

Despite this evidence, high rates of child removal from parents with psychiatric disability and parents with intellectual disability are reported in both Australian and international research literature. In sum, these studies suggest a removal rate of between one third and just less than half of all children of parents with intellectual disability. For children of parents with psychiatric disability, these rates have varied from almost 50% to 78%.

Aim

The aim of the present study was to provide a current determination of the prevalence of parents with disabilities by disability diagnosis in an Australian court sample. A second aim was to determine whether court outcomes varied for parents in the diagnostic groups and whether the outcomes experienced by these groups differed significantly from those for families headed by non-disabled parents.

Method

The court files of all 285 care and protection matters (involving 469 children) initiated by the statutory child protection authority and finalized in a nine month period at two Children's Courts in NSW, Australia were reviewed.

Statistical comparisons were made between the following groups of cases:

1. Group 1: Parents without a disability and no mention of drug and/or alcohol use
2. Group 2: Parents without a disability with suspected drug and/or alcohol use
3. Group 3: Parents with psychiatric disability and no mention of drug and/or alcohol use
4. Group 4: Parents with psychiatric disability with suspected drug and/or alcohol use
5. Group 5: Parents with intellectual disability

Findings

Parents with disabilities featured in almost one-third of the cases (29.5%). Parental psychiatric disability was most prevalent at 21.8% (84 cases) followed by parental intellectual disability at 8.8% (25 cases). These figures represent a substantial over-representation based on general population estimates of parents with psychiatric and intellectual disability, these

respectively being 2.6 - 5.4% and less than 1%.

Significant associations were also found between parental disability and court outcome. Children of parents with a psychiatric disability were more likely to be subject to short-term supervision in their family home. In contrast, more than half of the children with intellectual disability were made state wards, and most often placed out-of-home with non-family.

Further in-depth research is required to adequately explain these patterns of association. However, it seems feasible to suggest that the relationship found between parental disability and court outcomes is related to the court's perception of whether the child's situation can be changed for the better. For parents with intellectual disability, this lends to possible court pessimism about their capacity to overcome their parenting difficulties. Such pessimism may stem from pervading stereotypical beliefs about intellectual disability, such as parents being unable to learn, apply and retain new skills, and/or from a perceived lack of appropriate support services.

Stereotypes, Parents with Intellectual Disability and Child Protection (2002)

McConnell, D. & Llewellyn, G. (2002) Stereotypes, Parents with Intellectual Disability and Child Protection *Journal of Social Welfare and Family Law*, 24 (3), 297 - 317.

In reviewing how parents with intellectual disability fare in child protection and court processes this paper provides an empirical and legal critique of frequently encountered presumptions about their parenting capacity.

The incidence in which children of parents with intellectual disability are removed is unusually high. However, a survey of available international research reveals that such rates are unnecessary and unwarranted. Rather than the protection of the child, grounds for removal may in fact stem from misguided or prejudicial ideas about parents with intellectual disability. Of note are two presumptions. First is the idea that parents with intellectual disability will inevitably maltreat their child/ren or put them at risk of others. Second is the view that any perceived parenting deficiencies are irremediable and that there is therefore little point in offering such parents support.

How well founded are these presumptions? Not very. Empirically, the dominant view in the literature is that intellectual disability per se is not an adequate indicator of parenting capacity or an insurmountable obstacle to learning. Moreover, children with developmental delay and of parents with intellectual disability have been shown to experience behavioural and other difficulties for reasons beyond the disability of their parents. Consequently, the developmental delay of these children should not automatically be treated as a child protection concern, and to do so constitutes discriminatory practice.

Legal care and protection proceedings are also the site of prejudicial decisions and discriminatory practices. These include:

- The denial of parents' legal rights;
- The denial of appropriate supports and services to parents before their children are permanently removed;

- In the absence of clear guidelines as to what constitutes adequate care, child protection workers and courts imposing their own biases on proceedings;
- The enormous weight given to the assessment of 'experts', particularly when this rests so greatly on IQ tests. This is despite substantial findings which show IQ to be a poor predictor of parenting capacity;
- Evidence contrary to parental incompetence being disregarded; and
- Inadequate legal representation eg., court proceedings not clearly explained, legal representatives not having an understanding of the issues faced by people with intellectual disability

A series of strategies aimed at addressing this discrimination and disadvantage are outlined:

1. A training module for child protection workers, lawyers and judicial officers, based on up-to-date empirical research, be developed and implemented;
2. Video and accompanying plain English resources for parents with intellectual disability that explain the child protection process step-by-step and the rights of participants be developed;
3. A network of volunteers/advocates under the auspices of an independent third party to provide support to parents with intellectual disability during the child protection process be established;
4. Additional funding to support adequate legal representation of parents with intellectual disability be made available, given that these parents require significantly more time both to be informed about the process and to provide their legal representatives with sound instruction;
5. 'Expert' assessment practices be reviewed and the development of guidelines which clearly specify the limitations of diagnostic-prognostic assessment and the need for functional assessment developed; and
6. Regional internet web sites that provide listings of potential support services for parents with intellectual disability and their children be developed.

Disability and Decision-Making in Australian Care Proceedings (2002)

This study was funded by the Law and Justice Foundation of NSW and can be found in McConnell, D., Llewellyn, G., & Ferronato, L. (2002) Disability and Decision-Making in Australian Care Proceedings *International Journal of Law, Policy and the Family*, 16, 270 - 299.

Background

Parents with intellectual disability are subject to higher rates of state intervention in the care of their children than parents of any other group. Moreover, their children are more likely to be removed and placed in out of home care. International research has demonstrated that this is due to factors far more complex than an individual's limited parenting skills. At work are political, social and institutional factors that discriminate against parents with disability and deem their children to be at risk.

Aim

This study aimed to explore the over-representation of parents with intellectual disability in child protection proceedings and the high incidence of their children being placed in out-of-home care within an Australian context. How court outcomes are determined and why these parents and their children are subject to more intrusive court outcomes was investigated.

Method

An observational study of court and decision-making processes, together with a review of court files and one-to-one and group interviews with children's magistrates, legal representatives and child protection workers, was conducted in two New South Wales Children's Courts in Sydney over a 9 month period. Data was analysed with a view to illuminating those assumptions and influences underpinning the court setting and impinging upon the decision-making process.

Findings and implications

A number of factors were highlighted as significant contributors to both the high incidence of parents with intellectual disability in care and protection proceedings, and the high removal rate of their children. These were:

- entrenched preconceived views about parental (in)capacity
- the diagnostic-prognostic rationality of decision makers
- the need for parent compliance in an adversarial system
- the lack of suitable support services
- poorly resourced legal representatives

Given the multitude and macro nature of these influences, together with the limited political clout parents with intellectual disability have, how to redress the disadvantage these parents face over the course of care proceedings is far from simple. Nevertheless, the authors make several recommendations:

1. That initiatives which provide an alternative to court intervention eg., family group conferencing and alternative dispute resolution, be prioritized and their appropriateness/effectiveness for people with intellectual disability be evaluated;
2. That web-based resources, including those with a support services directory, continue to be developed and maintained;
3. That public legal aid funding be increased to levels that allow parents with intellectual disability to have access to the best possible representation;
4. That the use of expert assessment practices that rely heavily on IQ tests be reviewed;
5. That those professionals involved in child protection proceedings - magistrates, child protection workers, psychologists/psychiatrists, and legal representatives - become familiar with current empirical research that clearly demonstrates that intellectual disability per se is not an adequate predictor of parenting competence or an insurmountable barrier to learning;
6. That the participation of parents with intellectual disability be actively promoted eg., having an independent third party acting as a support person; developing interactive media, video and plain English resources that explain the court process and empower these parents; and
7. On a more fundamental level, that the negative and widespread presumptions about parents with intellectual disability be challenged and the social disadvantage that lends to children's suffering be repoliticised.

Parents with Intellectual Disability and Justice in the Child Protection Process (2001)

McConnell, D. (2001) Parents with Intellectual Disability and Justice in the Child Protection Process. A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy. University of Sydney.

Many parents with intellectual disability have their children removed by statutory child protection authorities and courts. Scholars in North America, the United Kingdom and Australia suggest that, in at least some cases, this may not be justified or in the child's best interests. This study examined the child protection process, how decisions are made and outcomes determined in the jurisdiction of NSW, Australia.

The child protection process is conceptualized as one of reaching understanding about what is in the child's best interests. The theoretical framework underpinning the critique of this process is derived from the Critical theory of Jurgen Habermas. Habermas analyses the process of reaching understanding and derives criteria for a just discourse. The criteria comprise 'the ideal speech situation': the conditions necessary if a dispute is to be resolved on the basis of rationally motivated and undistorted understanding.

The author focused on the reasoning and actions of child protection workers, lawyers and magistrates and examined three conditions for justice in the child protection process. One condition is that child protection authorities and courts are open to the free and equal participation of parents with intellectual disability in the process of reaching understanding about what is in the child's best interests. Another condition is that child protection workers, lawyers and magistrates are motivated only by the pursuit of understanding and in this connection, desist from strategic action. The third condition is that all conceivably relevant features of the child's situation are taken into consideration.

The study had three discrete layers. The communicative layer was concerned with reaching a shared understanding with 'system-insiders' of how decisions are made. The dialectical layer involved analysis of explicit influences shaping the process and decision making of system insiders. These layers provided the foundation for the normative layer in which three conditions for justice in the child protection process are addressed. The data collection methods included a review of court files at two Sydney children's courts, interviews with child protection workers, lawyers and magistrates, and observation of courtroom proceedings.

The study findings demonstrate that the process of reaching understanding about a child's best interests is not just with regard to parents with intellectual disability. The child protection process is not open to the free and equal participation of parents. The scope of inquiry is narrow and does not take into account parents' individual capabilities and unique circumstances. Further, the child protection process is distorted by system imperatives such as the need to ration resources and ward off public criticism.

Four changes would need to take place to address the injustice documented in this thesis. Decision makers must recognize that determining what is in a child's best interests involves interpretation and therefore requires genuine discourse. Secondly, the impact of social and environmental constraints on families need to be given due consideration. Thirdly, the individual qualities and capabilities of these parents must be taken into account. Finally, communicative rather than system imperatives such as the need to critically reflect on one's own presuppositions, to listen with empathy and grasp the other's particularity must drive the process.

Disability And Discrimination In Statutory Child Protection Proceedings (2000)

McConnell, D. & Llewellyn, G. (2000) Disability and Discrimination in Statutory Child Protection Proceedings *Disability & Society*, 15 (6), pp. 883 - 895.

In the context of high removal rates of children from parents with intellectual disability, this paper surveyed primarily North American literature written by legal scholars on child protection proceedings for people with intellectual disability. Compelling evidence of widespread discrimination was found.

Discrimination was seen to take the form of children being removed:

- despite a lack of evidence of abuse or neglect, or where evidence to the contrary existed, or when the evidence of neglect was refuted
- even when the court acknowledged the person with intellectual disability to be an adequate parent
- prior to parents having the opportunity to access appropriate support services.

A mix of political, social and institutional factors are shown to underlie the discrimination that parents with intellectual disability encounter in the course of child protection proceedings:

1. Political and Social

- The widely held assumptions that intellectual disability equates with parenting incompetence, that parenting deficiencies are irremediable, and that children of people with intellectual disability will inevitably be harmed
- The shift from a culture of social to individual responsibility. For parents with intellectual disability this has meant a withdrawal of support services, coupled with a keener mandate of the state to protect those most vulnerable in society (by implication, children of people with intellectual disability fall into this category). Trying to parent in a context where families are expected to be autonomous and self sufficient, where using familial supports is scrutinised as dependence, where broader sociological impediments such as poverty, poor housing and social isolation are not taken into account, serves to give those with intellectual disability a clear message that they are incompetent and a burden - not only have they failed their children but they have failed society as well.

2. Institutional

- Child protection legislation in some US states categorically deem those with 'mental disability' to be unfit as parents
- Contrary to the process applied in cases involving non-disabled parents, the establishing of child neglect/maltreatment is not required for those with intellectual disability - it is already presumed
- Within the courts, parenting competence is assessed only as a function of innate ability
- Disadvantages inherent in the adversarial process eg., difficulties experienced by people with intellectual disability in adhering to imposed rehabilitation plans; legal representatives usually being court appointed and having limited understanding of disability issues.

Given the equally and unusually high rates of state intervention in Australia, these findings may shed much light on whether parents with intellectual disability are similarly being disadvantaged and discriminated against in Australian child protection proceedings.

Parental Disability and the Threat of Child Removal (1998)

McConnell, D. & Llewellyn, G. (1998) Parental Disability and the Threat of Child Removal *Family Matters*, 51 (Spring/Summer), 33 - 36.

In a review of literature on the experience of parents with intellectual disability in care and protection proceedings, the authors note with concern high rates of notification and child removal. What is also disturbing is the fact that this high incidence is not merely a reflection of an inability to parent. Rather, parents with intellectual disability are shown to be subject to discriminatory treatment that makes state intervention and subsequent out of home placements all too common. Factors that contribute to this discrimination are:

- the presumption that children of parents with intellectual disability will inevitably be neglected or abused
- the presumption that parenting deficiencies are irremediable
- false attribution, that is, parents' difficulties being attributed to their disability, when in fact they derive more from poverty, poor housing, social isolation, harassment and the lack of appropriate support services
- the vulnerability of parents with intellectual disability - a failure to understand the implications of how they present and difficulties understanding and engaging with the legal process
- inadequate legal representation, both in terms of resources and ability to understand and work with people with intellectual disability
- the reliance on familial or other significant supports being construed as weakness on the part of the parent
- the misuse of intelligence tests as a predictor of parent incompetence

As a start to redressing this situation, the authors maintain that parents with intellectual disability need to have access to parenting skills training. Contrary to popular thinking, research clearly states that parents with intellectual disability are capable of learning new skills and unlearning negative patterns of behaviour.

Further, support for such parents needs to extend to addressing the environmental pressures that can make the task of parenting so difficult.

In the interim, professionals working with parents with intellectual disability are encouraged to take the following steps to ensure that they themselves are not contributing to parents with intellectual disability being disadvantaged in child protection proceedings:

- Be aware of prevailing stereotypes that paint people with intellectual disability as being inherently incompetent as parents
- Examine their own beliefs and assumptions
- Empower parents with disability as much as possible eg., explain court proceedings in simple language, invite parental participation
- Assess parenting competence in the broader context of social constraints
- Advocate for more appropriate support services

Parents with a Disability and the NSW Children's Court (2000)

McConnell, D., Llewellyn, G. & Ferronato, L. (2000) [Parents with a Disability and the NSW Children's Court](#) Report to the Law Foundation of NSW. University of Sydney.

Background

This report cites international and Australian literature that shows parents with intellectual and psychiatric disability to be over-represented in care and protection proceedings. Rather than being indicative of inevitable parenting incompetence, research suggests that these parents are in fact subject to prejudicial treatment in care and protection proceedings. Examples of such discriminatory practice include:

- child protection agencies and courts intervening and removing children without evidence of maltreatment
- children being removed with little or no effort to remedy parental deficiencies
- children being placed in out of home care primarily on the basis of their parent's IQ
- failure by child protection authorities to take into account contributing factors such as poverty, poor housing, harassment, social isolation and lack of appropriate services. Often these are dismissed whilst parental difficulties are attributed entirely to the disability.

Aim

In this context this study aimed to identify the prevalence of parents with a disability appearing in care proceedings in two NSW Children's Courts, outcomes for these parents as compared with those of non-disabled parents, and processes involved. Of critical importance was the question of whether these parents were disadvantaged or discriminated against in care proceedings.

Method

For the purposes of this study, parents with a disability were defined as having an identified impairment documented in their court file, including intellectual, psychiatric, physical, or sensory disability. Data was extracted from a review of court files in the NSW Children's Court; interviews and/or focus groups with magistrates, legal representatives and officers from the Department of Community Services (DOCS); and courtroom observations of care proceedings.

Statistical comparisons were made between the following groups of cases:

1. Group 1: Parents without a disability and no mention of drug and/or alcohol use
2. Group 2: Parents without a disability with suspected drug and/or alcohol use
3. Group 3: Parents with psychiatric disability and no mention of drug and/or alcohol use
4. Group 4: Parents with psychiatric disability with suspected drug and/or alcohol use
5. Group 5: Parents with intellectual disability

The study found almost one-quarter of all care matters to involve parents with a disability. Moreover, when considering DoCS' care applications alone, this figure rose to nearly one-third. These figures reflect a substantial over-representation of both parents with a psychiatric disability (18.4% of cases compared to mean general population estimates of 4%) and parents with an intellectual disability (7.1% compared to mean general population estimates of 0.6%).

Court outcomes in terms of type of court order, length of order and placement type for families headed by parents with a disability were also found to differ significantly from those of families with non-disabled parents. Specifically, the children of parents with intellectual disability were more likely to be subject to wardship orders over the medium term with a disproportionate number of children being placed out-of-home with non-family. This is in keeping with the Court's generally pessimistic view of the capacity of these parents to overcome parenting deficiencies as perceived by DoCS workers. The children of parents with psychiatric disability on the other hand were more likely to be placed back home with a short term supervision order. This is consistent with the view that care concerns can usually be resolved with appropriate medication.

Further, when the ages of the children of parents with a disability were examined, these children were shown to be significantly younger than children of parents without a disability. Thus not only were parents with a disability appearing more frequently in the Children's Court, their children were found to be removed at a younger age.

These outcomes were seen to be the result of numerous influences at work throughout care and protection proceedings. These are:

1. **DoCS and Court Personnel 'Thinking' About Parents With A Disability**

These are based on outmoded and pejorative beliefs, such as people with intellectual disability being eternal children and as parents, incapable of taking responsibility for their children. Such prejudicial beliefs give rise to serious concerns as to how parents with a disability will be perceived and treated in the courts:

1. Any parent with intellectual disability may be labelled incompetent on the basis of their disability alone and without any evidence of incompetence;
2. With presumed incompetence, child maltreatment may be anticipated, again without any evidence and based on parental disability alone;
3. With presumed immutability of their 'condition', they may be thought incapable of learning and therefore overcoming parenting deficiencies if these exist;
4. Parenting deficiencies may be blamed on the parent's disability rather than on social constraints eg., poverty, social isolation, poor housing, inadequate support services.

2. **The Concept Of 'Risk'**

Risk assessment was generally promoted as a quasi-objective means of determining the potential of the parental situation to provide for the health, safety and well being of the child. This is of major concern given the lack of a sound theoretical and empirical basis to the concept of, and current measures in, risk assessment. For parents with a disability, judgements made in the courts about the degree of risk for their children will undoubtedly be influenced by the perceptions of their abilities (or otherwise) as parents.

3. **The Reliance on Expert Opinion**

A highly significant relationship was found to exist between expert opinion and Court outcome (home vs out-of-home placement) in cases featuring parents with a disability. However, the diagnostic-prognostic rationality as seen to be used by the court and the consequent reliance on the opinion of psychiatrists and psychologists in determining whether parents with psychiatric or intellectual disability can lift their game invites serious questioning. In the first instance a diagnosis can provide neither an adequate explanation of parenting deficiencies or a valid prediction of parenting potential. The use of these 'expert' reports to make such predictions is likely to result in empirically invalid and prejudicial judgements. Secondly, parents with a disability may be denied individual review and adjudication. Thirdly, Australian and international research has shown that intellectual (dis)ability per se is a poor predictor of

parenting competence and there is good evidence that when parenting deficiencies do exist these are to a large extent remediable. Fourthly, the diagnostic-prognostic rationality used by the Court inevitably results in the mistake of false attribution i.e. parenting deficiencies are attributed to the disability rather than from social constraints such as poverty, social isolation, poor housing and the inadequacy of support services. Finally, psychiatric and psychological assessment conducted during care proceedings are of doubtful validity. Stress and confusion aroused by care proceedings and the threat of permanent separation from their child or children may undermine the mental state of parents and consequently impair/diminish their performance.

4. The Lack Of Suitable Support Services

This pertains to the extremely limited availability of suitable support services, and the misperception that parents with disability will only be able to care for their children with support that was intensive and ongoing. Once again, there is clear evidence in Australia and internationally that parents with intellectual disability do not as a group require such support. Nevertheless, rather than being due to the failure of these parents per se, their current over-representation in care applications is more likely a result of health, disability and welfare services failing to assist parents according to their individual need for support in performing the tasks of parenthood.

5. System Constraints

These were observed to be as follows:

1. Constraints on DoCS workers who do not have the time, training, or resources to adequately support parents with a disability
2. Constraints on legal representatives who have not the time, training or resources to adequately represent parents with a disability
3. Constraints on the court system which creates an environment in which the process of establishment can be 'washed over' as legal representatives work to negotiate a compromise solution to keep the system 'moving'.

6. The Court Environment

The court environment was shown to be alienating and disempowering for parents with a disability on several counts:

- Little opportunity throughout the court process being given to parents' voices
- DoCS holding the dominant position throughout
- Negotiations being conducted in a manner incomprehensible to parents and particularly, to parents with intellectual disability
- Lawyers feeling ill-equipped in both training and time to adequately represent parents with a disability

In sum, the court environment was seen to breach the requirements of the Disability Discrimination Act 1992 (Cth) and the Anti-Discrimination Act 1997 (NSW).

The report concludes with 5 key recommendations:

1. Address the marginalisation of parents with a disability in the court process

The report recommended that the Attorney General's Department (NSW), in consultation with the Senior magistrate of the Children's Court and court personnel review court environment, procedures and processes to ensure appropriate accessibility by people with a disability as required under the Disability Discrimination Act 1992 (Cth) and the Anti-Discrimination Act 1997 (NSW).

Further to this, it was recommended that urgent attention be given to the marginalizing and disempowering nature of court procedures and processes detailed in the report, and strategies put in place to remedy this situation as soon as practicable. These strategies include:

- The development of a video and accompanying plain English resources which explain the court process step-by-step and the rights of participants to a fair hearing
- The development of an Internet site listing potential support services to assist the Court in establishing what community supports and services are available and with hotlinks to other sites including those which contain up-to-date information about disability and parenting performance
- The development of a network of volunteers/advocates under the auspices of an independent body to provide support persons to assist parents with a disability
- Additional funding to support adequate legal representation of parents with a disability

2. Address the outmoded inaccurate beliefs and pejorative attitudes held by departmental and court personnel involved in care proceeding.

The report recommended that the Attorney General's Department (NSW) in collaboration with the Department of Community Services develop a joint training module for departmental and court personnel to inform and educate based on up to date empirical research and the broad range of community experiences of parents with a disability

3. Address the over-representation of parents with a disability in care proceedings

It was recommended that the Department of Community Services develop a professional development module on disability and parenting and implement a training program for district officers and assistance managers as a matter of urgency. This professional development module needs to pay particular attention to:

- Up to date empirical research on parental disability and the broad range of community experiences of parents with a disability
- The inappropriate use of risk assessment as a proxy measure of parenting performance
- Appropriate measures of assessing parenting performance in relation to identified concerns
- Appropriate measures of identifying parents' support needs
- Suitable supports and services to overcome identified concerns in the context of ensuring the safety, welfare and well being of the child

4. Address the inappropriate reliance on a clinical diagnostic-prognostic model in determining outcomes in cases involving parents with a disability

The report recommended that the Attorney General's Department (NSW) develops and implements a professional development module to inform magistrates of the inappropriateness and limitations of using clinically determined diagnoses and prognoses to determine current and/or future parenting performance. This module needs to pay particular attention to:

- The use and misuse of clinical diagnoses with regard to current and future parenting performance
- The appropriate measures for assessing current and estimating future parenting performance.

From this, it was further recommended that:

- the Children's Court clinic develop policies and procedures in relation to the appropriate assessment of parenting performance with particular attention to cases involving parents with a disability
- the Children's Court work collaboratively with the department of Community Services to assist in the implementation of appropriate methods of assessment of parenting performance as part of all child protection workers' professional practice

5. Address the lack of suitable support and services for parents with a disability

As a matter of urgency it was recommended that the Attorney General's Department take a lead role in addressing the shortfall in suitable services. This would require:

- Advice from relevant government departments on services available to parents with a disability and the geographical location and support provided
- Information based on national and international expertise as to the appropriate formulation of suitable supports and services for parents with a disability
- The development and planning and/or modifying of current services as appropriate to ensure the establishment of a network of suitable support services for parents with a disability and widespread dissemination about the availability of these services to legal representatives and court personnel

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