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Abstract

Gwynnyth Llewellyn, Senior Lecturer in Developmental Disabilities at the University of Sydney examines research on parenthood for people who have disabilities to clarify the facts and fallacies of commonly held opinions. Even among people who may wish to encourage community participation by people who have disabilities to the fullest extent, there exists ambivalent attitudes when they seek also to become parents. One of the concluding comments Llewellyn makes is that the lack of experience and opportunity to learn parenting behaviours may be the reason for poor child care standards, not a person's disability. **Keyword: Attitudes**

Parents with Intellectual Disability: Facts, Fallacies and Professional Responsibilities

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Editors Note: This paper has been updated from a presentation delivered at the Queensland Intellectual Disability Services Occupational Therapy Conference -Approaches in Developmental Disability", July 1991. Gwynnyth Llewellyn continues to do research in this area. The references listed provide an excellent overview of resources and articles dealing with the associated issues raised in this paper.

Species survival demands that a significant number of individuals engage in parenting. In Australia, despite time, money and career pressures to the contrary, parenthood remains a valued social role. Marriage and parenthood are expected life markers, signifying transition from childhood to adulthood (Cusick, 1990) The right to reproduce and freedom of choice to engage in or abstain from reproduction are generally regarded in our society as inalienable. Denial of parenthood, on the basis of disability alone, is an unacceptable infringement of the right to reproduce. As Greenspan and Budd (1986) note "allowing individuals labelled as mentally retarded to exercise their desire to participate in the life-giving process is the ultimate test of living in a free and humane society" (p 126).

When intellectually disabled people seek to become parents they may encounter ambivalent attitudes from family, friends and service personnel. On the one hand, significant others may wish to encourage community

participation to the fullest extent. On the other, they may be concerned that either the disabled person or their offspring will be disadvantaged in the parenting process. Expectant parenthood, an event generally greeted with joyful anticipation, may become a time of anxious uncertainty, concern for the future and fear of unknown consequences. What assumptions underlie these fears? And, on what facts or fallacies are such concerns based?

In this article, research on parenthood for people with intellectual disability is examined to elucidate what is known, and what is imagined. My aim is to bring some sobriety to a somewhat emotive topic. Further, I wish to stake out areas of professional responsibility: to intellectually disabled parents or those considering parenthood; to the education of personnel who have contact with such parents; and most importantly, to developing an educated awareness in the community at large.

A Cautionary Note

Much of the literature about parents with intellectual disability with the exception of some relatively recent North American writings comes from a time with less exacting scientific rigour. This presents several difficulties. The information was gathered when people with intellectual disability were devalued and restricted in all aspects of their lives; there were few trained professionals, few empirical studies and even fewer informed consumers of research able to discriminate between empirically derived and descriptive data (Tymchuk, 1990a).

Further, many of the parents described in the literature have experienced

institutional living, or at the very least, restricted home, social and community lives. Gath (1988) notes that these parents "are very unlikely to have had experiences in childhood that offered any model of good-enough parenting" (p 741). It is questionable how far findings from this population of parents can be generalised to parents living in the community. It may well be that we need to wait until a whole generation of parents has been living in the community before we can adequately comment on their parenting experiences.

A second difficulty is with definitions. Definitional problems are legendary in the field of intellectual disability. Definitions and labels vary from country to country and may also differ from state to state as is the case in Australia. In addition, definitions of mental retardation have changed over time. Previously a person with an IQ of 70 to 80 would have been considered mentally retarded. The literature must be viewed cautiously therefore to avoid extrapolation to broader group who may fit within some older definition of disability, delay or handicap.

Definitional problems also surround the concept of parenting. How should parenting be defined? Poor parenting seems obvious or at least clear in the *Judicia* sense, for example, when children are neglected or abused (Hayman, 1990; Hertz, 1979; Wald, 1975). There is debate in the general parenting literature, and for parents with intellectual disability in particular, about what constitutes parenting, and more importantly, what is adequate parenting. Despite a lack of consensus (and reliable and valid measuring instruments), parental adequacy has attracted considerable research

attention. Intellectually disabled parents have been compared to other parent groups on a number of dimensions of parenting. This has created a source of considerable error (Baumeister, 1967; Stoneman, 1989). One concern is the lack of adequately matched groups. Another is the lack of instruments sensitive to the specific characteristics of each group. Comparison groups have generally been middle class, yet it is widely acknowledged that parents with an intellectual disability are inevitably poor (Greenspan & Budd, 1986).

A final caution concerns the parents selected for investigation. Although parents include fathers, almost without exception (notably, Peck and Stephens, 1965) only mothers have been studied. Further most studies have not included children of all ages, but rather restricted their samples to children in the 0 to 3 years age range (Tymchuk, 1990a). As mentioned, previously institutionalised people have provided one readily accessible 'sample' group. Parents already identified as needing assistance have provided another. Common sense would suggest however that not all families in which one or both parents are intellectually disabled, are known to health, welfare and protective agencies. Presumably there are intellectually disabled parents who are competent to the extent that their parenting behaviours do not come to the notice of the authorities. These parents do not appear in the literature.

Notwithstanding these difficulties and my cautions, the professional literature does provide one view on parents with intellectual disability. Through examining this literature, the facts and fallacies of commonly held opinions can be identified.

Fact or Fallacy

Eugenic arguments and an assumed generalised incompetence pervade many of the opinions expressed about parents with intellectual disability. These opinions include:

- Intellectually disabled parents will have significantly more children than other parents (Goddard, 1912; Priest, Thurline, La Veck, & Jarvis, 1961);
- They will give birth to intellectually disabled children (Goddard, 1912; Penrose, 1938);
- They will abuse or neglect their children (Accardo & Whitman, 1990; Crain & Millor, 1978; Schilling, Schinke, Blythe & Barth, 1982; Seagull & Sheurer, 1986);
- They will provide inadequate childcare (Bowden, Spitz & Winters, 1971; Peck & Stephens, 1965; Scally, 1973);
- They are unable to learn and to apply adequate parenting skills (Accardo & Whitman, 1990; Whitman & Accardo, 1989).

Each of these opinions is discussed to clarify fact or fallacy, with the final two receiving more detailed attention. My analysis draws heavily on several recent reviews of the literature: from Feldman (1986), Llewellyn (1990), Tymchuk (1990a), Tymchuk (1990b), Tymchuk and Feldman (1991) and Tymchuk, Andron and Unger (1987).

The traditional ideas that the mentally subnormal are both prolific and likely to produce defective children persist, and arguments for and against have been carried on for more than a

hundred years (Laxova, Gilderdale & Ridler, 1973, p 193).

First, the view that intellectually disabled people have more children is generally not substantiated (Accardo & Whitman, 1990; Craft & Craft, 1979; Tyrnchuk & Andron, 1990). Haavik and Menninger (1981) reviewed 14 studies up until 1975 and showed that "retarded people have either approximately the same or fewer numbers of children when compared to normal families" (p 68).

Second, Laxova, Gilderdale and Ridler (1973) noted the incidence of organic aetiologies among the children as equal to that found in the general population. Further, Haavik and Menninger (1981), in a review of pertinent studies between 1945 and 1975, found a striking general trend toward higher IQ's among the children than the parents, despite some variability across study findings. They suggested this trend is a predictable phenomenon from a genetic or statistical perspective but cautioned against drawing conclusions about parental influence on child intelligence from this phenomenon. However, other authors (for example, Garber & Heber, 1977; Priest et al., 1961; Reed & Reed, 1965; Shaw & Wright, 1960) have shown the incidence of lower IQ among the children to be higher than expected in the normal population.

Third, some authors have expressed concern that children of 'slow' parents are at risk of developmental delay (Baroff, 1974; Me Candless, 1952; Reed & Reed, 1965). This concern presumes inadequate parental stimulation for the child's cognitive development. The educational achievement of children of parents

with an intellectual disability has been studied (Heber, Dever & Conry, 1968; Shaw & Wright, 1960). Heber, Dever and Conry (1968) noted a differential course of intellectual development for the offspring of mothers with different intelligence levels, suggesting that low maternal intelligence is a significant predictor of low IQ in the offspring. Importantly however, a clear relationship between parent intelligence and the child's educational achievement has not been established for any specified parent group. Rather, a variety of factors besides parent IQ have been identified as contributing to poor educational achievement. These factors include poverty, poor nutrition and school absence due to illness or high mobility. For many adults with an intellectual disability such conditions are part of their daily lives.

Fourth, abuse and neglect have been associated with parenting by intellectually disabled adults (Crain & Millor, 1978) however, the literature is equivocal on this point. Unfortunately, abuse and neglect are often grouped together indiscriminately for study purposes (for example, Accardo & Whitman, 1990; Schilling et al., 1982), and further, little consideration has been given to predisposing factors such as social isolation, poverty, single parenthood and so on. Recently, Tymchuk and Andron (1990) found other sources of abuse and neglect within the family, not necessarily by the intellectually disabled mother. The incidence of neglect, but not abuse, does appear to be substantial. It has been suggested by several authors including Tymchuk (1990a) that -where abuse does occur, it often occurs out of omission rather than commission ... and that neglect, appears to be as a result in part of not being trained, rather than as purposeful

on the part of the mother" (Tymchuk, 1990a, p 36). 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.

Parental adequacy is probably the uppermost concern. Currently there is not an authoritative answer to the question of whether parents with intellectual disability function adequately as parents. Contradictory findings are common. Much of this relates to flawed research design: inadequate sampling, poor definition of parenting behaviours, lack of validity and reliability in measures used to judge parenting and poor comparative characteristics (Gath, 1988, Greenspan & Budd, 1986; Haavik & Menninger, 1981 Mira & Roddy, 1980). As well as poor research design, many studies have relied on indirect means of assessing parenting competence such as case records, place of residence of child, or third party sources such as social workers and health care visitors.

On this question of parental adequacy, two groups of parents have received most attention: previously institutionalised people and those parents already identified as needing assistance. In 1947, Mickelson investigated 90 previously institutionalised parents, of these, 42% provided satisfactory care, 32% were rated as giving questionable care (inconsistent or inadequate care but not of a degree to judge the children neglected), while 26% gave unsatisfactory care (children were judged to be neglected and either removed from the home or removal had been considered). In a study of 54 couples (with 32 children) Floor, Baxter, Rosen and Zisfein in 1975 concluded that -although the care of

some of the children would be questionable by middle class standards, there are others who appear to be receiving proper medical attention and affection from both parents" (p 35). Similarly, of the 42 children of the 32 married couples interviewed by Mattinson (1970), 34 were with their parents receiving satisfactory care, with 6 committed to the care of the local authority. These six children belonged to only three families, in which, in Mattinson's words, "the standard of care fell below the threshold of community tolerance" (p 107).

Less positive findings on previously institutionalised adults have also been found. For example, in a study of 37 women Johnson (1950) found 26 (46%) of their children supported solely, and 24 (42%) supported partially, by public funds with only 7 (12%) supported by their parents or relatives. On these figures Johnson claimed few parents had little interest in taking responsibility for their children. Scally (1973) in a large scale Irish study reported---only 30% of the offspring were being reared satisfactorily in their own homes, whereas 62% had to have other provisions for them (p 193)

Mitchell (1947) reported inadequate childcare for the majority of 28 young intellectually disabled mothers who sought, or were referred to, casework services and 79% were reported as poor or indifferent housekeepers. Shaw and Wright (1960) studied 197 married intellectually disabled adults either previously institutionalised or under statutory supervision and reported many of the families providing poor child care. Sheridan (1956) studied 100 mothers who had been judged neglectful and

characterised them as incompetent housekeepers.

Relevant to both positive and negative findings is the frequent observation that the majority of families needed extensive assistance to supply everyday domestic and child care needs (cf. Berry & Shapiro, 1975; Floor et al., 1975; Johnson, 1950; Mattinson, 1970). This assistance came from within the family or from the wider community. Peck and Stephens (1965) reported the only study on fathers, of which there were five among 125 young adult intellectually disabled males. Several of the five lived with, and were financially and emotionally supported by, their parents. Assistance was also provided by social service or health agencies. The necessary and extensive assistance frequently observed may of course, be an artefact of the "already identified parent- samples selected for study. Whatever the case, the serious implication remains that some families can not manage without extensive assistance.

Intellectually disabled people have also been determined incompetent as parents by the courts often on the basis of diagnostic label and intelligence quotient alone (Hertz, 1979; Payne, 1978). In the legal sense incompetent parenting is that which results in a finding of neglectful status of the child. Three aspects of parenting are examined in neglect proceedings: love and affection, performing housekeeping tasks, and attending to the child's physical needs. In cases involving intellectually disabled parents some courts in the United States have added a fourth factor: stimulating the child intellectually (Hertz, 1979). Hertz (1979) noted that this difference suggests that -(these)

courts equated mental retardation with inability to care for children" (p 791).

The opinion that low intelligence is linked in some way to inadequate parenting also appears to be commonly held outside the courts (Crain & Millor, 1978). Yet, Mickelson noted way back in 1947 in her study of 90 parents that "the parents mental status did not appear to be the sole determinant of adequacy of child care; otherwise, all of the children would have been neglected" (p 517). A crucial task then, is to identify factors contributing to successful parenting and factors, which predispose to inadequate parenting. Potential factors, which have received some attention in the literature, include intelligence level of one or both parents, number of children, income level, additional handicaps of the parents and the parents' own upbringing. The findings however are rather sparse, of a preliminary nature and must be regarded cautiously. Each of these factors is discussed in turn.

Above a minimum critical level of around IQ 60, there appears no clear relationship between parenting competency and IQ (Borgman, 1969- Mickelson, 1947, Mira & Roddy, 1980). Whether the relationship between the IQ's of both parents is significant has, for the most part, been neglected (Mickelson, 1947; Shaw & Wright, 1960). However, Mattinson (1970) noted that paired, many (of them) were able to reinforce each other's strengths and established marriages which, in the light of what had happened to them previously, were no more, no less, foolish than many others in the community, and which gave them considerable satisfaction- (p 185).

Several studies (Mickelson, 1947; Shaw & Wright, 1960) have reported decreased quality of care as number of children increased. For example, Sheridan (1956) noted that beyond one or two children, the mothers became overwhelmed- as the responsibilities outgrew their capacity to manage. More recently, Zetlin, Weisner and Gallimore (1985) noted more extensive assistance was needed for parents with more than one child, particularly so if the children were close together in age

Not surprisingly, family income level appears to affect parenting. Mickelson (1947), Mattinson (1970) and Mitchell (1947) all reported questionable or unsatisfactory care when parents had marginal incomes or were receiving financial assistance. Further, Mattinson and Mitchell suggested inadequate income as a factor exacerbating the difficulties presented by increasing numbers of children. The effect of the emotional and/or physical health of the parents and their childhood experiences of parenting has received little attention. Yet experience of workers in this field would suggest these factors could be quite significant

Parental Learning

The sixth and final opinion discussed here, that intellectually disabled parents are unable to learn or to apply adequate parenting skills, is potentially the most damaging. This opinion is of paramount importance to service providers, policy developers and those responsible for implementation, to families and significant others in the lives of intellectually disabled parents and of course, to the parents themselves. Knowledge of empirical research rather than responding to, and accepting opinion about parents'

learning ability, is not only critical but an integral part of professional ethics.

This issue is indeed topical as the courts are being asked to decide "who is an adequate parent?" and more importantly, "can parents be trained to be adequate?" given that most may have lived in circumstances that provided little training or appropriate models for parenthood.

During the past decade the facts on the effectiveness of parent training have been accumulating. Overall, the findings are positive. Parents with an intellectual disability can learn parenting skills and behaviours. The results of training programs (although a relatively recent phenomenon) are promising (Feldman, 1986, Tymchuk, Andron & Unger, 1987; Tymchuk & Feldman, 1991). Evidence from early studies, in the late 1940's (Mickelson, 1947; Mitchell, 1947) had suggested that intervention and casework services had beneficial effects, but only for those already providing reasonably adequate care. Two 1970's projects, the Milwaukee Project and the Carolina Abecedarian Project both reported improvements for parents and children after training with either parents, children or both (Carber & Heber, 1977; Ramey & Campbell, 1984). Both these studies however, focused more directly on families at risk (low socio-economic status, some mothers with limited intelligence) so the training results may not be directly applicable to parents with an intellectual disability.

Several casework and counselling programs were also reported around this time, that is, late 1970's, early 1980's (Madsen, 1979, Rosenberg &

McTate, 1982; Wayne & Fine, 1986). All indicate that parents can be trained but caution that training must be specific, concrete and must provide help in generalising skills learnt to other situations. In the 1980's Budd and Greenspan (1985) surveyed 16 behaviourally oriented training programs for mentally retarded parents. In summary, the programs were determined to be "more elaborate, more directive, and longer than typical programs for non-handicapped clients" (Budd & Greenspan 1985, p 272). Slightly less than half of the families made substantial improvements on the referral problem however, respondents noted limited generalisation of effects. Most notably, some individuals benefited substantially from the training programs. This finding reinforces an important notion that intellectually disabled parents are not a homogenous group. One implication is that research efforts must be directed to investigating sources of variance within the parent group, rather than assuming all parents will either succeed or fail in learning parenting skills.

Recent findings from behaviourally orientated training programs support this view of a mixed group of parents. Some parents do very well indeed, whilst others appear to learn little (see Tymchuk and Feldman, 1991 for a review). Experience of researchers suggests (personal communication (1) Espe-Sherwindt, 1991, Feldman, 1991; Tymchuk, 1991) that those parents currently "dealing with- poverty, homelessness, the protective agencies and so on, have little time, energy or attention left to learn new behaviours or skills. Research is needed to identify not only the program components most relevant to teaming, but also participant variables which contribute

to the success or other-wise of training programs (Tymchuk & Andron, 1990). Some possibilities include individual parent characteristics, current living situation, family support, and age of children and mother's emotional health.

Some training programs have focused on basic child care and safety concerns, whilst others have directed efforts toward parent child interaction skills, problem solving and decision making. For example, mothers with an intellectual disability have successfully learned the following:

- child illness symptom recognition, understanding and treatment (Tymchuk, 1992),
- identifying home dangers (Tymchuk, Ilamada, Andron & Anderson, 1990a),
- responding to common home emergencies (Tymchuk, Hamada, Andron & Andersori, 1990b), and
- to discuss home dangers and emergencies with their eldest children (Tymchuk, Andron & Hagelstein, 1992).

Success has been reported in teaching the following:

- parent child interaction skills (for example, Fantuzzo, Wray, Hall, Coins & Azar, 1986, Feldman, Case, Towns & Betel, 1985; Feldman, Towns, Betel, Case, Rincover & Rubino, 1986, Feldman, Case, Rincover, Towns & Betel, 1989; Slater, 1986),
- dealing with child problematic behaviour (Tymchuk, Andron & Tymchuk, 1990), and

- problem solving and decision making (Tymchuk, 1985; Tymchuk, Andron & Rabbar, 1988, Tymchuk, Yokota & Rahbar, 1990).

Several training programs have demonstrated parents learning to make appropriate decisions about common parenting situations however, some parents continued to have difficulty making decisions "on the spot" (Tymchuk, Andron, & Rahbar, 1998). From these training programs, several components have been identified as necessary for parents to learn. These are:

- interventions need to be matched to parental learning characteristics, for example, by the use of illustrated materials (Feldman, Case, Garrick, & MacIntyre-Crande, 1989; Tymchuk, Andron & Tymchuk, 1990);
- training must be highly concrete using strategies to promote generalisation and maintenance (Andron & Tymchuk, 1982; Feldman, 1986; Feldman et al., 1986; Feldman et al., 1989; Kaminer, Jedrysek & Soles, 1981);
- staff must be well trained (Espe-Sherwindt & Kerlin, 1990; Lynch & Bakley, 1988); and interventions need to be initially intensive and then periodic over the long term (Tymchuk, 1990b).

Professional Responsibility

What do these findings from the research literature mean for those who have professional responsibility for parents with an intellectual disability? I think it is fair to say that misconceived opinions about parents with an intellectual disability are still prevalent, despite the increase in

empirical information. Personal experience in discussing this topic with a great number of people in health, education and welfare agencies suggests that two commonly held misconceptions remain; firstly, that the children will automatically be significantly 'retarded' and, secondly that the parents will be incompetent. Tymchuk and Feldman (1991) noted a poignant example of yet another frequent misconception:

A student at a major Canadian university wishing to write a term paper on mothers with mental retardation was queried by her psychology professor as to what could be written about this topic as lie assumed that any offspring would be immediately removed from the parents and that most women with mental retardation were sterilised" (p 1718).

There is evidence from the field of physical disability that health practitioners attitudes towards people with disabilities do not differ significantly from those of the general population (Yuker, 1977). Lyons (1991) demonstrated that the attitudes of freshman occupational therapy students did not differ significantly from those of their business major peers. Further, the occupational therapy students' attitudes did not vary with the years of undergraduate education completed. Interestingly, those students who had contact with disabilities beyond the context of the caregiver-client relationship, had significantly more positive attitudes than those students without such contact. If we assume the number of parents with an intellectual disability is relatively small, what opportunity exists then, for professionals, or professionals in training, or for the community at large to meet with, and

get to know, adults with an intellectual disability who are also parents?

Recently, Westbrook and Chinnery (1990) presented the view that negative attitudes toward physically disabled women having children created an additional handicap for these women. The negative attitudes fit well with the opinions that I have discussed here: namely, the genetic arguments, assumed parental incompetence and concern for effects on the children. These authors suggest that professionals and others adopt a coping perspective (Wright, 1963) to address some of the problems faced by parents with a disability, many of which are 'outside themselves'. The list includes the following:

Negative social attitudes, ill informed and prejudiced health practitioners, unavailability of information, lack of aids and suggestions that would make child care easier, lack of means of contacting mothers in similar situations, limitations of access to facilities and activities that mothers are routinely expected to attend, and lack of resources to transport (Westbrook & Chinnery, 1990, p 21).

Unfortunately, little is known about how parents with intellectual disability perceive their parenting and others attitudes towards them. There are life histories in intellectual disability, however, the majority are biographical and quasi -biographical accounts written from an 'outsiders' perspective, generally that of a family member (Langness & Levine, 1986). None are by or about parents with intellectual disability. Rarely have parents with intellectual disability been asked for their point of view

An exception is a recent study by Walton-Allen and Feldman (1991) who questioned parents and professionals about the needs of parents with mental retardation. A survey of 18 categories of parenting, domestic and psychosocial skills was used to compare the self-reported service needs of 22 mothers with mental retardation to the perceptions of their affiliated social service workers.

Results indicated that there was a significant difference in the perceptions of the mothers and their workers. The mothers and the workers disagreed on 83% of the skill categories. More mothers from the workers' view required intervention than the mother's assessments of their own abilities. Overall, the workers felt that the mothers needed more services than they were actually getting, while the mothers felt they were being over-serviced in some areas (e.g. child care training) and under-serviced in others (e.g. vocational and assertiveness training). In general, the professionals focused on the parents need to learn specific parenting behaviours and skills. On the other hand, the parents felt these areas to be adequately covered. Rather, parents identified needs more directly related to their personal well being, including wanting to become more part of their community through social and leisure activities. This finding may be due to the parents being satisfied with the level of direct parent training that they currently receive, or not being able to perceive ongoing needs for training, for example, as their children's needs change. Whatever the case, it is clear that their perceived needs relate directly to their involvement in community life irrespective of their children. Further, from both the

workers' and mothers' perspectives, the mothers' service needs were not filled.

Moreover, rarely have investigators considered parenting within the socio-economic and community context in which it occurs, despite recognition that the parental 'environment' plays a critical part in parenting, particularly for the first time parent (La Rossa, 1986; La Rossa & La Rossa, 1981). It is incumbent on professionals to consider the parent with an intellectual disability as more than a client requiring training in specific skills (although such training may be necessary). Other strategies may also be needed, for example, relationship counselling, community/ social skills training, self-advocacy and so on.

Disparity of professional and parent viewpoint is also apparent in data from my 1991 study examining parent and professional perspectives (Llewellyn, 1991). In brief, several themes emerged through analysis of a series of in-depth interviews with parents and professionals. From the professional perspective these were: firstly, that parenting for adults with intellectual disability is confounded by poor judgement, lack of appreciation of consequences and limited organisational ability and secondly, that these parents lack motivation to change, to be involved outside the home, or to take responsibility for their own actions. These perspectives are not surprising in light of the commonly held opinions noted above, and thus are not further elaborated here.

From the parents' perspective, the all pervasive theme which emerged from the data is best expressed by a parent quote, namely, that "you've got your own answers anyway". For some parents these answers came from

experience, for example, with their sibling or their siblings' children, or because their partner or parents set parenting standards that they were expected to follow. For others, it was just "common sense" or "what you learnt from your mum".

For some parents, in addition to their own ways of doing things, there was a determined desire to be left alone. One mother noted "To agree to them (to get custody of her child) I'd say yes I'd do that (attend the family support service) and I thought it's better than nothing. I only have to do it for six months and then I'll be out on my own and I'm a plain mum. Like before that I'd had the troubles after she was born".

Alternatively, strong feelings were expressed by bravado as "Maybe I don't want to learn nothing or take notice of anybody cause everything I've got, I taught myself, so no one is going to tell me how to bring my kids up, what to do with my kids, it's me what I say goes."

To summarise the findings from this study, parent and professional perspectives agree on one aspect of parenting, that is, that parents have their own way of parenting and are determined to continue parenting this way. It is clear, however, that the professionals and parents differ dramatically on how adequate they regard these parenting ways. Professionals, through their concern for poor parental judgement, lack of organisational ability lack of motivation and parental unwillingness to take responsibility, believe that in general, parents with an intellectual disability have grave difficulties in being adequate parents. On the other hand, the parent perspective suggests that, in general, parents view their parenting as adequate. Continued

collection of parents views, the 'insider perspective', will provide a much needed balance to a literature currently heavily weighted in favour of the 'outsiders' perspective.

To conclude, professionals bear responsibility to raise awareness at many levels: for those currently working in health, social services, education, the legal profession and the community at large. Those involved in custody decisions must be aware that diagnostic label and IQ may not be valid predictors of competency. Further, that lack of experience and opportunity to learn parenting behaviours may be the main reason for poor childcare standards.

Consequently, the provision of training opportunities and system support needs to become the remedy of choice, for the courts as well as the social service systems.

Many agencies are recognising the lack of appropriate service provision for these families (Personal Communication [2] Centacare, NSW 1989; Family Education Unit, NSW 1990; Family Support Service, NSW, 1991; Llewellyn, 1992). Some professionals rightly feel they do not have appropriate training, time or resources to effect change in parenting, or to address the multiplicity of needs with which some parents present. Workers often rely on language dependent techniques which, although useful for other parents in need, do not suffice for parents with limited verbal expressive and receptive skills and often-unpleasant memories of schooling. Failure of the parents to learn may then be interpreted by the worker as non compliance, the parents written off as too difficult and the

children removed as the solution to ensuring protection of the child. Unhappily, this scene is still too common.

Lacks of knowledge on the part of the parents or unavailability of appropriate services clearly are not appropriate or acceptable reasons for removing children and breaking up families. Furthermore, inadequate knowledge on the part of professionals is clearly not an acceptable reason for adults with intellectual disability being denied opportunities for parenthood (Tymchuk & Feldman, 1991). The rights of people with intellectual disability to work, to live in the community, and to develop satisfying personal relationships are now well recognised if not always implemented (Human Rights and Equal Opportunity Commission, 1990). The right to parent in safe and nurturing home environments must be extended to people with an intellectual disability in an atmosphere of support and respect for the needs and rights of both parents and children.

Professional responsibility requires that we lead the way in developing a progressive and optimistic outlook about parents with intellectual disability, while realistically acknowledging their parenting challenges. I trust this article provides a kick start to implementing this professional responsibility.

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M. Feldman, PARENT EDUCATION PROJEC-E Surrey Place Centre, Toronto;

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