

Mothers with Intellectual Disabilities Who Do or Do Not Have Custody of Their Children

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Abstract

Many parents with intellectual disabilities (ID) lose custody of their children due to real or perceived parenting inadequacies. It is not clear how parents with ID who keep their children differ from parents who lose their children. In this study, 30 mothers with an intellectual disability who still had custody of all their children were compared to 17 mothers whose children were placed in care. Mothers who still had custody of their children were more involved in their community, were more satisfied with the services they received, had higher incomes, and younger children than mothers who had lost their children. No significant differences were found concerning the behaviour of their children, the mothers' health, adaptive behaviours, or the number of persons in their social network. The results suggest that services should then be offered to both mothers and children and be adapted as the children grow.

As the years pass, more and more studies present new information concerning mothers with intellectual disabilities (ID). The first studies published in the 1980s and early 1990s described parents with ID as having difficulties stimulating their children, as sometimes offering poorer environments, as not always responding adequately to the needs of their children, and as having difficulties making decisions regarding their parenting role (Budd & Greenspan, 1981; Feldman, 1994; Feldman, Sparks & Case, 1993; Heighway, Kidd-Webster & Snodgrass, 1988; Tymchuk, Andron & Rahbar, 1988). In parallel to these studies, some authors focused their research on parenting training programs and tried to implement services that would help palliate the mothers' parenting skill deficits, and increase the chances of satisfactory care and child development (Feldman,

Case, Rincover, Towns & Betel, 1989; Feldman et al., 1986; Tymchuk & Andron, 1988, 1992; Tymchuk, Hamada, Andron & Anderson, 1990a, 1990b). Subsequently, researchers began considering social networks as an important part of the equation. It was thought that members of these networks would model more effective parenting behaviours and problem-solving strategies as well as offer emotional and practical support to these parents (Feldman, Varghese, Ramsey & Rajska, 2002; Llewellyn, 1995; McConnell, Llewellyn & Bye, 1997; Walton-Allen & Feldman, 1991). Furthermore, research highlighted the importance of a supportive and non-judgmental type of support and how the presence of at least one significant person in their lives could help them parent (McConnell et al., 1997; Tucker & Johnson, 1989).

Since then, others have addressed the importance of other factors such as the parents' physical and mental health, history, socio-economic status, family functioning, child characteristics, and social factors in influencing parenting and adaptive abilities (Belsky, 1984; Feldman, 2002; Luckasson et al., 2002; Quinton, Rutter & Liddle, 1984; Tymchuk, 1992). These authors supported the view that a parent's IQ level is not indicative of her/his parenting abilities unless associated with other environmental, familial, or individual factors such as poverty, a poor social network, poor mental and physical health, and a great number of children. Unfortunately, parents with ID are still often seen as lacking parenting competence and are, in many countries, over-represented in court proceedings with regard to the care of their children (Glaun & Brown, 1999; McConnell, Llewellyn & Ferronato, 2000; Taylor et al., 1991).

To date, no studies have assessed factors related to placement of children of parents with ID. Thus, the present study compared the health, adaptive behaviours, social networks, and community involvement of 47 mothers with ID in the province of Québec who still had custody of their children to mothers whose children were in a permanent placement. According to the Québec Youth Protection Act, placement usually occurs when the security of a child is considered at risk due to physical or sexual abuse or due to serious neglect that could impair the child's mental, affective, or physical development (Régie de la santé et des services sociaux, 2002). Feldman's parenting model (2002) suggests that different factors (e.g., social network, adaptive behaviours, parents' health) could have an effect on parenting abilities, and thus an indirect effect on children's behaviours. Since parenting abilities seem to have a central role in the decision made by the Direction of Youth Protection on the placement or non placement of children, we hypothesized, based on Feldman's hypothetical parenting model (2002), that mothers with custody of their children would have higher adaptive

behaviours, better health, more persons in their social networks, more involvement in their communities, and that their children would have fewer behaviour problems, than mothers who do not have custody of their children.

Method

Participants

Forty-seven mothers living in Québec and receiving services from agencies specialized in ID participated in this study (46 mothers were Francophone and one was Anglophone). Of the 47 mothers interviewed, 30 still had custody of all their children. The other 17 mothers lost custody of all their children but had regular visits with them ranging from a few hours of supervised visits a month to unsupervised visits every weekend. All of these mothers and their families lived under the poverty line according to Canadian standards (Beaudet, 1999). Information on the mothers is presented in Table 1 and information on their children in Table 2.

Although IQ assessments were not completed, all these mothers were receiving services for persons with ID. In Québec, all agencies that offer services to persons with ID verify the eligibility of their clients by following the American Association on Mental Retardation's guidelines and applying the 1992 definition. Thus, in order to receive services from these agencies, a person needs to have, as assessed by a psychologist, an IQ of 70 +/- 5, have significant deficits in adaptive behaviours, and have had those deficits present prior to 18 years of age (Luckasson et al., 1992).

All mothers were contacted by their social workers and provided information about this study. Details about the study, the procedures, and the implications of their potential participation were explained to the mothers prior to their consent. Furthermore, their confidentiality was assured and it was made clear that their decision to participate would not affect services received now or in the future and that they could withdraw from the study at any time without penalty. Although the mothers had cognitive limitations, they all understood the consent forms when read verbally and signed at their own will. All mothers who agreed to talk to the principal researcher completed the entire assessment. After the interview, mothers received CDN\$20 for their participation.

Table 1. Mothers' Characteristics

Category	With custody (n=17)		Without custody (n=30)		t	c2
	n	%	Mean (SD)	n		
Mothers' age					1.31	
Mothers' age at birth first child			33.27 (8.39)		36.35 (6.49)	
Mothers with partner / husband	19	63%	24.13 (4.79)	12	71%	0.18
Mothers who work	8	27%		4	24%	0.25
Income levels						0.06
Less than CDN\$10,000	6	20%		9	53%	6.80 *
Between CDN\$10,000 and \$20,000	23	77%		6	35%	
Non-disclosure of income	1	3%		2	12%	

*p < .01

Table 2. Children's Characteristics

Category	With custody (n=58)		Without custody (n=35)		χ^2
	n	%	n	%	
Gender					
Male	26	46%	22	63%	2.84
Female	32	54%	13	37%	
Diagnosis	8	14%	8	23%	1.26
Children receiving special services ¹	39	76%	17	55%	4.17*
School-age children	41	71%	29	83%	1.74
In special classes	17	41%	13	45%	0.47
Children's age ²	Mean	(SD)	Mean	(SD)	t
	7.41	(4.44)	10.19	(4.67)	2.02*
Number of children with family	1.93	(1.14)	2.05	(1.39)	0.45

¹ Due to missing data, results based on 51 children living with their mothers and 31 children in placement.

² Based on oldest child aged from 2 to 13 years old.

*p < .05

Instruments

All questionnaires were completed verbally and in a semi-structured interview format. All of these English-language questionnaires were translated into French for the Francophone participants.

Family information. General information on the participants, their families (e.g., age, education, health, number of children, family income, familial environment), and the reason for placement was collected through a questionnaire based on Feldman's past research (Feldman et al., 1993, 1997; Feldman & Case, 1997, 1999; Feldman & Walton-Allen, 1997).

Community involvement. Five questions were added to the family information questionnaire and comprised the Community Involvement Scale. These questions were scored on a three point Likert-type scale (0,1,2) and the scores range from 0 to 10. The higher the score is, the more involved in the community the mother is said to be. Official norms are unavailable, but these questions have been used in previous research (Gibbins, 2000).

Supports and services. The services received and the social networks of these mothers were assessed with questionnaires adapted or designed specifically for parents with ID (Feldman, Varghese, Ramsay & Rajska, 2002; Llewellyn, 1998). These questionnaires focus on services received, satisfaction, social networks, and relationships.

Physical and mental health. The participants' physical and mental health were assessed using the SF-36 (Ware, Snow & Kosinski, 2000). This instrument (36 questions) was previously used with mothers with ID (Llewellyn, McConnell & Mayes, 2002). American norms were used because Canadian norms are unavailable.

Parents' adaptive behaviour. Agency workers who knew the participants for at least 3 months completed the long version of the Scales of Independent Behaviour Revised (Bruininks, Woodcock, Weatherman & Hill, 1996). Although this instrument does not have Canadian norms, it has the most recent norms and allows for a better discrimination between borderline and mild intellectual disability. The translation of this instrument followed the suggestions of Tassé & Craig (1999).

Child behaviour problems. The children's behaviours were measured by using the Child Behaviour Checklist (CBCL) (Achenbach, 1988, 1991). Two versions (2-3 years or 4-18 years) were used based on the age of the

child, using a French translation (Lacharité, 1993; Pettigrew & Bégin, 1986). For some of the children, the social worker or educator also completed the CBCL in order to compare their perception of the children's behaviours to that of the mothers. If the mother had more than one child, the CBCL was completed concerning the oldest child who was 13 years old or younger.

Procedures

The consenting mothers were met between one to four times each, depending on their availability. Each interview lasted between one to three hours and was conducted in the mothers' homes. During those meetings, rapport was built, confidentiality and consent were again assured, and the questionnaires were completed in a semi-structured interview, with all questions being asked out loud. Additional information concerning past experiences or anecdotal facts were recorded. In most cases, the mothers were interviewed in the presence of their social worker or educator.

Results

Inter-group comparisons

The two groups were compared on the dependent measures using 2-tailed t-tests. Means and standard deviations are presented in Table 3.

The children who remained at home were significantly younger than the children removed from the parents' care. The parents who kept their children reported more community involvement and greater satisfaction with services received. On the other hand, these two groups did not differ with regard to the number of persons in their social networks, their mental health, their physical health, their adaptive behaviours, and their children did not differ on the CBCL scores. Furthermore, no significant differences were found concerning the number of children these two groups of women had.

Other post-hoc comparisons revealed that more mothers without custody of their children had an annual income below CDN\$10,000 compared to mothers with custody of their children ($\chi^2=(1,44)=6.80, p<.05$). Children who still lived with their natural mothers received more special services than children who lived in foster placement ($\chi^2=(1,82)=4.17, p<.05$).

Table 3. Outcome Measures for Mothers with Intellectual Disability With and Without Child Custody

Category	With custody (n=30)		Without custody (n=17)		t
	Mean	(SD)	Mean	(SD)	
Community involvement score	2.90	(2.20)	1.53	(1.58)	2.25*
Physical Health score (SF-36)	26.78	(1.34)	26.63	(1.98)	0.31
Mental Health score (SF-36)	23.38	(2.15)	23.80	(2.06)	0.65
Scales of Independent Behaviour - Revised - total score	78.13	(16.43)	70.19	(8.24)	1.86
Child Behaviour Checklist - total score	51.33	(11.95)	50.33	(11.99)	0.28
Persons in social network ¹	6.38	(2.31)	5.71	(1.76)	1.03
Family members ¹	2.79	(1.88)	2.71	(2.02)	0.14
Social workers / educators ¹	2.31	(1.19)	2.35	(1.62)	0.09
Friends / neighbors ¹	1.28	(1.67)	0.59	(0.79)	1.59
Satisfaction with services ²	4.69	(0.37)	4.12	(0.69)	3.61**

¹ Data concerning one participant not computed due to an aberrant number of family members present in social network.

² Based on the opinion of 28 participants.

* $p < .05$; ** $p < .001$

Reason for placement or removal of children (mothers without custody)

Five mothers had either been asked to or voluntarily gave up custody of their children. One mother felt overwhelmed by the demand of parenting three teenagers (ages 10 to 14) and thus requested that her children be placed in foster care. Four mothers agreed to having their children placed because they either felt they could not raise them as well as someone else or help them in their schooling. Children of three of these mothers were placed with members of their families (e.g., ex-husband, sister), and the other mother's child was placed in an institution due to his own disabilities.

In eight families, removal of the children followed some allegation of abuse or neglect. In five of these cases, the allegations were targeting the boyfriend or husband of the mother at the time. Mothers were not given the custody back even after they broke up with their partners. Other reasons for placing the children in foster care included the assumed diminished parenting skills of the mothers (n=6; three mothers lived in supervised settings) or the disability of the child (n=2). In three families, the children were removed at birth, one of whom was placed at the request of the mother. For four children of various ages, placement also occurred following the separation of their parents. In those four families, the fathers, who did not have ID, were seen as more fit to raise the children, and thus gained custody of the children.

Supervised visits were offered to five families. These families had, on average, three hours a month to see each other while the other mothers, who had unsupervised visits, had between two to four days a month. Finally, in twelve families, the children were placed on a long-term basis, meaning until they reached the age of majority.

Discussion

Consistent with our hypotheses, this study found that mothers who have custody of their children were more involved in their community, had younger children, were more satisfied with the services they received, were more likely to have an annual income above CDN\$10,000, and had children who received more special services than mothers who lost custody of all their children. No group differences were found on their adaptive skills, health, number of persons in their social network, or on their perception of their children's behaviours.

Children who were still living with their natural mothers received more services than children who were placed. This might highlight greater concern for the development of children cared for by a parent with identified

special needs (Feldman & Walton-Allen, 1997). It is also possible that these results could reflect a recruitment bias, since these families were identified by service agencies. Mothers who lost custody also reported being less satisfied with the services they received, which may be explained by the fact that their children were removed. Either the perception of these mothers were correct and they did not receive sufficient support to maintain custody of their children, or these mothers perceived their services as less satisfying because they lost custody of their children. Finally, the difference in satisfaction levels, and the fact that the social networks of mothers with custody did not differ significantly in terms of the number of persons involved, highlights the importance of the perception of these mothers on the quality of support they received rather than the quantity received (Feldman et al., 2002); the number of persons involved does not seem as important as offering a type of support that empowers rather than impairs and that is well accepted and perceived in a positive light by the client (Espe-Sherwindt & Crable, 1993; Feldman et al., 2002; Llewellyn, 1995; Llewellyn, McConnell & Bye, 1998; Tucker & Johnson, 1989).

More mothers with custody had incomes between CDN\$10,000 and CDN\$20,000 than mothers without custody of their children. This difference is easily explained, as mothers with custody of their children would receive higher disability pensions since their children were under their direct care. Another significant difference was community involvement. Mothers with custody of their children reported being more involved in activities offered by their neighborhoods. It is possible that another factor, such as the quality of involvement of the social network, could explain this difference. The listing of activities did not indicate that mothers with custody were more involved in their community due to their participation in more child-related activities.

Children who were still living with their natural mothers were younger and as a group were not yet in their pre-teenage years. In our sample, children who were placed were either around the age of 2 to 6 years old or 9 to 12 years old. In follow-up research, it would be interesting to find out if older children are harder to manage for mothers with ID, and if this difficulty leads to more placements as the children grow older. Finally, even though mothers with and without custody did not differ significantly on the number of children involved in special classes and the number of children with a diagnosis, the number of children in each category was higher than the number of children found in the general population. Approximately 41% of children still living with their natural mother and 45% of children living in foster care were in special classes whereas 10% of children in Canadian elementary schools are in special classes (Statistics Canada, 2003). Also,

14% of the children living with their mother and 23% of children in foster care had some kind of a diagnosis, whereas it is estimated that approximately 3.3% of Canadian children aged 0 to 14 years of age have a disability of some sort (Cossette & Duclos, 2001). Children of mothers with ID may, then, be at risk of developmental delays, thus leading to more of them being referred to early intervention programs and special classes (Feldman et al., 1993; Feldman & Walton-Allen, 1997).

The results of this study should be considered preliminary because of the relatively small sample size. With a greater number of participants, other differences may have surfaced. Research in this field is hampered by the difficulty of finding sufficient numbers of parents with ID in the community. Although some researchers have estimated, based on their research, that approximately 1% of parents have an ID (Keltner & Tymchuk, 1992; McConnell, Llewellyn & Ferronato, 2000, 2003), identifying them is not easy. Furthermore, recruiting through service agencies may create a bias toward selecting more problematic families. We do not know much about parents with ID who live in the community and who do not receive any support from governmental agencies. Future research should seek other methods of recruitment to limit this bias and present a more accurate picture of mothers with ID.

Implication for services

These results highlight the importance of offering services to both mothers and children, and to adapt the types of support as the children grow. Not enough is known concerning the impact of the children's age upon the removal of children, but present and past research have identified that more children are placed at an older age. Services, including a parenting group allowing mothers with ID to learn about discipline and other relevant parenting skills, would probably allow them to have a less stressful relationship with their children and perhaps allow these families to stay together. Also, services should be considered lifelong and be adapted as the needs of the children and their mothers change over time. Finally, quality of support, not just the quantity of support given, should be seen as an important factor. Asking these mothers if they are satisfied with the services they receive and adapting the services offered to better meet their personal needs may make a difference in the way support is perceived and accepted. Taking a client-centred approach to providing needed services - listening to and acting on their needs, instead of just basing the services on our own values as clinicians - might have a greater effect and allow for more positive change.

Most mothers who lost custody of their children were seeing their children a few hours a week or a month. Advocacy training and services should be offered to explain to them their rights and responsibilities as parents, and to allow them to have more regular contact with their children. Even today, mothers with ID, as persons with ID, have to deal with considerable misconceptions and prejudice (Aunos & Feldman, 2002). According to legal reports (Glaun & Brown, 1999; McConnell, Llewellyn & Ferronato, 2000, 2003), the presence of a diagnosis alone influences allegations of child maltreatment and outcomes of court proceedings. In this case, an important role of any researcher or clinician who works with parents with ID should be to disseminate accurate, unbiased information about these parents to promote fair decisions and needed services that may allow the child to remain safely with his/her natural parents.

Acknowledgements

This research has been funded, in part, by the Scottish Rite of Canada, The Éléanor Côté Foundation and the Québec Chapter of the American Association on Mental Retardation.

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