

THE SUPPORT NETWORK OF MOTHERS OF YOUNGER AND ADULT CHILDREN WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES RECEIVING CASE MANAGEMENT

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Introduction

The burden of care for families supporting children and dependent adults with developmental disabilities has been widely recognised for many years (Olshansky, 1962; Erickson and Upshur, 1989). In addition to the well-documented stress associated with rearing a child with disabilities, Rimmerman (1994) has noted that parents often report that the lack of both family support and crisis intervention services lead them to consider out-of-home placement. Many parents face difficulties in their efforts to secure adequate services for their child or obtain information about the child's disability (Kozloff, 1979).

One service which has been reported to reduce the family's burden is case

management (Rubin, 1987). Case management is a practice modality that cuts across such human services fields as mental health, aging, child welfare, health and developmental disabilities. It is viewed as a means of providing extended, continuing care to chronically or severely impaired individuals in community settings (Rothman, 1991). Case management incorporates two functions: providing individualised counseling and advice to consumers in the community; and forging the link between consumer needs and services and supports in community agencies and informal helping networks.

In contrast to providing case management to families with children or older adults, case management in the field of developmental disabilities must

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offer services for a changing spectrum of needs throughout the life cycle. Moreover, depending upon the type and extent of the disability, case management must offer a wide range of coordinated services to meet the individual's diverse needs at any point in time.

The provision of adequate case management services to families of children with developmental disabilities requires knowledge about formal and informal processes (Bertsche and Horejsi, 1980). At present, descriptive studies regarding the families who use case management services are scarce. Are families who use case management lacking natural supports and, therefore, using formal services? In addition to case management, what are the other sources of support families rely upon?

The Medicaid Case Management service provided by Young Adult Institute, a non-profit agency serving more than 3000 people with mental retardation, learning and developmental disabilities and their families, is based upon a linkage model (Rothman, 1991). Medicaid Case Management serves individuals who need ongoing assistance in navigating the service systems e.g., living arrangements, day-time services, health services, social/recreation programmes, financial assistance, etc. (OMRDD, 1991). As in other linkage models, the main goal is to join consumers with needed services and supports (formal and informal). The case manager's function includes activities such as assessment of the individual's needs and determination of whether the family has the potential to be helpful, i.e., can it sustain the burden of caring for a highly

dependent member? After this, it is the role of the case manager to define realistic goals and facilitate in setting priorities with the family. After orienting the family to services, the case manager gives the family ongoing, concrete and emotional support.

The present study focuses on the support network of mothers receiving Medicaid Case Management. This study was based upon the accepted awareness that mothers typically bear a disproportionate share of the day-to-day care for their daughters and sons with disabilities (Botuck and Winsberg, 1991; Breslau, 1983; Carey, 1982). The purpose of the present study was to learn more about the helpfulness of different types of support for mothers receiving case management services during the period between three and twelve months after the start-up of service.

Method

Participants and Procedure:

Of the 143 families in which the mother was a biological or adoptive parent and who had a telephone, 92% (n = 132) agreed to participate. TABLE 1 presents background information about the mothers and their children.

Mothers were contacted by telephone. Six psychology students, trained by two of the investigators, conducted the interviews over a six-week period. Mothers who were Spanish/English bilingual were interviewed in the language of their choice. In addition to a number of questions regarding consumer satisfaction with case management services,

TABLE I
Characteristics of Children with Disabilities

Characteristics	f	%
Primary Diagnosis:		
Mental Retardation	109	82.6
Autism	13	9.8
Cerebral Palsy	7	5.3
Other	3	2.3
Secondary Diagnosis:		
None	88	66.7
Mental Retardation	14	10.6
Autism	7	5.3
Psychiatric/Behavioural	8	6.0
Other	15	11.4
Level of Functioning:		
Mild	34	25.8
Moderate	49	37.1
Severe	38	28.8
Profound	11	8.3
Age:		
2 - 5	16	12.1
6 - 12	16	12.1
13 - 18	10	7.6
19 - 21	15	11.4
22 - 29	51	38.6
30 - 51	24	18.2
Ambulatory:		
Yes	119	90.2
No	13	9.8
Race:		
African American	46	34.8
Latino	34	25.8
White	49	37.1
Other	3	2.3
Family Language:		
English	91	68.9
Bilingual Spanish/English	21	15.9
Monolingual Spanish	20	15.2
Number of Parents Living in House:		
Mom alone	75	56.8
Two Parents	57	43.2
Public Assistance:		
Yes	19	14.4
No	113	85.6

mothers were asked about the type and helpfulness of their supports. Using a modified version of the Family Support Scale (Dunst *et al.*, 1988), mothers were told: "I am going to list some people or groups of people who are often helpful to families raising a disabled daughter (son). Please tell me which response best describes how helpful each source has been to your family during the past three to six months. Here are the choices: *extremely helpful, very helpful, generally helpful, sometimes helpful, not helpful at all.*" If the source of support was unavailable, (e.g., co-worker, because she was unemployed) mothers were told to answer *not applicable*.

Completed interviews were returned to the research division for analysis. The data were analysed using SPSS for Windows, Release 6.0 (Norusis, 1993).

Results

The data suggest that in this sample mothers relied more heavily on professional supports than on the informal supports from family members and friends. Overall, the findings reveal that many mothers received little support from family members and frequently rated that which they did receive as not helpful. In fact it appears from this sample that the two most available and helpful sources of support to a mother from her "informal network" were her nondisabled children and her friends. As can be seen in TABLE II, which presents Factor 1 of the Family Support Scale (Informal Relations), 58% of the mothers claiming that their friends give them support rated this support as

helpful. Similarly, 80% of those mothers reporting support from their non-disabled children found this support helpful. TABLE III presents Factors 3 and 4, Kinship and Immediate Family. As can be seen in TABLE III, mothers on the whole do not receive support from their parents (55%) and relatives (31%), or from their spouse's or partner's parents (59%) or relatives (83%). As can be seen in TABLE IV, this is also true regarding social organisations. In contrast, most sources of professional support were rated by the mothers as helpful. As can be seen in TABLE V which presents Factors 5 and 6, Generic and Specialized Professional Services, more than 80% of the mothers relied upon and found professional support helpful.

These findings were similar regardless of whether the mothers were single or married, older or younger, receiving public assistance or independent thereof, and irrespective of their child's diagnosis, level of functioning, behavioural or physical challenges.

Discussion

In this study the helpfulness of mother's support was described. The most striking finding was that mothers receiving case management services in this sample relied more heavily upon professional support than support from family and friends. Moreover, reliance upon professionals and high ratings of professionals' helpfulness cut across a variety of socio-demographic variables, i.e., mother's age, race, marital status, as well as specific characteristics of her disabled child, i.e., age, gender, level of

TABLE II
Sources of Informal Support as Rated by Mothers

Type of Support	No Support	Total Support	% Not Helpful Support	% Helpful Support
Non Disabled Children	21.2% (n = 28)	78.8% (n = 104)	20.2% (n = 21)	79.8% (n = 83)
Friends	13.6% (n = 18)	86.4% (n = 114)	42.1% (n = 48)	57.9% (n = 66)
Church	40.2% (n = 53)	59.8% (n = 79)	36.7% (n = 29)	63.3% (n = 50)
Other Parents	72.7% (n = 96)	27.3% (n = 36)	22.2% (n = 8)	77.8% (n = 28)
Spouse's Friends	59.1% (n = 78)	40.1% (n = 54)	64.8% (n = 35)	35.2% (n = 19)

NOTE: The "No Support" category applies to those mothers who answered that the particular source of support was absent for them. The "No Support" and "Total Support" categories always equal 100% of the sample. The "% Not Helpful Support" category applies to those mothers who answered that the particular source of support was "not helpful at all". The "% Helpful Support" category applies to "extremely helpful, very helpful, generally helpful, or sometimes helpful". The same categories apply to TABLES III, IV and V.

TABLE III
Sources of Kinship and Immediate Family Support as Rated by Mothers

Type of Support	No Support	Total Support	% Not Helpful Support	% Helpful Support
Spouse or Partner	34.1% (n = 45)	65.9% (n = 87)	19.5% (n = 17)	80.5% (n = 70)
Mother's Relatives	31.1% (n = 41)	68.9% (n = 91)	40.7% (n = 37)	59.3% (n = 54)
Mother's Parents	54.6% (n = 72)	45.4% (n = 60)	41.7% (n = 25)	58.3% (n = 35)
Spouse or Partner's Parents	59.1% (n = 78)	40.9% (n = 54)	64.8% (n = 35)	35.2% (n = 19)
Spouse's Parents/ Relatives	82.6% (n = 109)	17.4% (n = 23)	43.5% (n = 10)	56.5% (n = 13)

TABLE IV
Sources of Support from Social Organisations as Rated by Mothers

Type of Support	No Support	Total Support	% Not Helpful Support	% Helpful Support
Parent Groups	72.7% (n = 96)	27.3% (n = 36)	22.2% (n = 8)	77.8% (n = 28)
Social Groups/Clubs	80.3% (n = 106)	19.7% (n = 26)	15.4% (n = 4)	84.6% (n = 22)
Co-workers	68.2% (n = 90)	31.8% (n = 42)	64.3% (n = 27)	35.7% (n = 15)

TABLE V
Sources of Support from Specialised and Generic Professional Services as Rated by Mothers

Type of Support	No Support	Total Support	% Not Helpful Support	% Helpful Support
School District	13.6% (n = 18)	86.4% (n = 114)	10.5% (n = 12)	89.5% (n = 102)
Professional Helpers ³	18.2% (n = 24)	81.8% (n = 108)	9.3% (n = 10)	90.7% (n = 98)
Child's Family Physician	10.6% (n = 14)	89.4% (n = 118)	17.8% (n = 21)	82.2% (n = 97)
Mental Health Social Service Agencies	46.2% (n = 61)	53.8% (n = 71)	26.8% (n = 19)	73.2% (n = 52)

³ Social workers, case managers, therapists, teachers etc.

mental retardation, etc. This finding stands in contrast to the findings from previous research which indicates that parents use informal support more than other kinds of support (Herbert and Carpenter, 1994; Raif and Rimmerman, 1993, Rimmerman and Stanger, 1992). There are three possible explanations for why mothers rated professional support as more helpful than informal support. One possibility is that mothers who access case management services have limited sources of informal support. A

second explanation has to do with how social support is defined. For example, much of the research on social support in families of children with developmental disabilities defines social support as the presence or absence of formal and informal supports (Bromely and Blacher, 1989). Our approach in this study was different and we defined social support in terms of its helpfulness. In this sample, many mothers actually have a broader informal support network than they actually reported as helpful. Similar

findings have been reported in studies of parents' perceptions of the support they receive from their parents (George, 1988; Pieper, 1976; Romeis, 1980). These studies indicate that grandparents in families with a child with disabilities are often perceived as a burden rather than as a resource. In our view it is precisely the role of the case manager to identify this type of problem within the natural support system, and to recommend interventions which will maximise utilization of informal supports whenever possible. Therefore, it may be necessary to train case managers to differentiate between different sources of support and to utilise informal and formal supports so as to maximise a family's strengths.

Finally, it is possible that reliance upon and satisfaction with professional support as opposed to informal support may be a response to (in)direct guidance of the case manager. Case managers may recommend utilisation of professional services in instances where mothers lack other support. It is possible that it is the professional support network about which case managers are most knowledgeable and most skilled in navigating. To the extent that this is so, it seems possible that reliance upon professionals may be an outcome of receiving on-going case management. Therefore, case managers involved in linking family needs to existing supports should carefully monitor the changes that occur in families who receive on-going case management to maximise empowerment rather than encourage dependency.

Footnote:

For a complete description of the consumer satisfaction survey see Ardito, Damiani, and Freeman, 1994.

Summary

The burden of care for families supporting children and dependent adults with developmental disabilities has been widely recognised for many years (Olshansky, 1962; Erickson and Upshur, 1989). The present study focuses on the support network of mothers receiving Medicaid Case Management Services. One hundred and thirty-two mothers living in New York City and receiving individualised case management services for at least three months between the period of July 1991 through December 1992 participated in the study. A modified version of the Family Support Scale - FSS (Dunst, *et al.*, 1988) was used to assess mothers' support networks. The most striking finding was that mothers relied more heavily upon professional support than support from family and friends. These findings are discussed with regard to case management.

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References

- Ardito, M., Damiani, M. and Freeman, S.E. (June, 1994). *Demographics of users of case management and their perceptions of natural supports*. Paper presented at the 118th annual meeting of the American Association on Mental Retardation.
- Bertsche, A. and Horejsi, C. (1980). Coordination of client services. *Social Work*, 25, 94-98.
- Botuck, S. and Winsberg, B.G. (1991). Effects of respite on mothers of school-age and adult children with severe disabilities. *Mental Retardation*, 29, 43-47.
- Breslau (1983). Family care of disabled children: Effects on siblings and mothers. In: Thompson, G. H., Rubin, L. and Bilinker, R.M. (Eds.). *Comprehensive management of cerebral palsy*. 299-309. New York: Grune and Stratton.
- Bromely, B. and Blacher, J. (1989). Factors delaying out-of-home placement of children with severe handicaps. *American Journal of Mental Retardation*, 94, 284-291.
- Carey, G.E. (1982). Community care - care by whom? Mentally handicapped children living at home. *London Journal of Public Health*, 96, 269-278.
- Dunst, C. J., Jenkins V. and Trivette, C.M. (1988). Family Support Scale. In: Dunst, C. J., Trivette, C.M. and Deal, A.G. (Eds.). *Enabling and Empowering Families: Principles and Guidelines for Practice*. 155-157. Cambridge, MA: Brookline Books.
- Erickson, M. and Upshur, C.C. (1989). Caretaking burden and social support: Comparison of mothers of infants with and without disabilities. *American Journal of Mental Retardation*, 94, 250-258.
- George, J. D. (1988). Therapeutic intervention for grandparents and extended family of children with developmental delays. *Mental Retardation*, 26, 369-375.
- Herbert, E. and Carpenter, B. (1994). Fathers - the secondary partners: Professional perceptions and fathers' reflections. *Children and Society*, 8, 31-41.
- Kozloff, M.A. (1979). *A program for families of children with learning and behavior problems*. New York: Wiley.
- Norusis, M. J. (1993). *SPSS for windows, Release 6.0*. Chicago: SPSS, Inc.
- Olshansk, S. (1962). Chronic sorrow: A response to having a mentally defective child, *Social Work*, 43, 190-193.
- OMRDD (1991). *Guide to provider delivered comprehensive medicaid case management*. New York: State of New York Office of Mental Retardation and Developmental Disabilities.
- Pieper, E. (1976, April). Grandparents can help. *The Exceptional Parent*, 7-9.
- Raif, R. and Rimmerman, A. (1993). Parental attitudes to out-of-home placement of young children with developmental disabilities, *International Journal of Rehabilitation Research*, 16, 97-105.
- Rimmerman, A. (1994). Out-of-home placement among families of children with developmental disability: Research perspective. *Society and Welfare*, 14, 329-342.
- Rimmerman, A. and Stanger, V. (1992). Locus of control and the utilization of social support among mothers of young children with physical disabilities. *International Journal of Rehabilitation Research*. 15, 39-47.
- Romeis, J. C. (1980). The role of grandparents in adjustment to epilepsy. *Social Work in Health Care*, 6, 37-43.
- Rothman, J. (1991). A model of case management: toward empirically based practice. *Social Work*, 35, 520-528.
- Rubin, A. (1987). Case management. In: Minahan, A. (Ed.). *Encyclopedia of Social Work*, 1, 212-222. Silver Spring, MD: NASW.