



LIBRARY
Michigan State
University

This is to certify that the

dissertation entitled

PARENTAL BELIEFS AND THEIR INFLUENCE ON
MARITAL SATISFACTION AND MATERNAL-INFANT INTERACTION
WHEN A DEVELOPMENTALLY DISABLED INFANT IS BORN:
AN EXPLORATORY STUDY

presented by

Judith A. VanderWal

has been accepted towards fulfillment
of the requirements for

Ph.D. degree in Family Ecology

Delores M. Berland-Hunt, Ph.D.
Major professor

Date May 8, 2001

PLACE IN RETURN BOX to remove this checkout from your record.

TO AVOID FINES return on or before date due.

MAY BE RECALLED with earlier due date if requested.

DATE DUE	DATE DUE	DATE DUE
APR 22 2004		
11 08 03		
07 30 15 099		

PARENTAL BELIEFS AND THEIR INFLUENCE ON
MARITAL SATISFACTION AND MATERNAL-INFANT INTERACTION
WHEN A DEVELOPMENTALLY DISABLED INFANT IS BORN:
AN EXPLORATORY STUDY

By

Judith A. VanderWal

AN ABSTRACT A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Department of Family and Child Ecology

2001

Professor Dolores Borland-Hunt

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

Eleven families with developmentally disabled infants were recruited to

ABSTRACT
PARENTAL BELIEFS AND THEIR INFLUENCE ON BOTH
MARITAL SATISFACTION AND MATERNAL-INFANT INTERACTION
WHEN A DEVELOPMENTALLY DISABLED INFANT IS BORN:
AN EXPLORATORY STUDY

was repeated three months later for the purpose of observing change.

By

Nonparametric correlational analysis was made. Findings were elaborated
Judith A. VanderWal
upon through qualitative data.

No relationship was found between mother's marital satisfaction and her

Marital satisfaction and maternal-infant attachment interaction after the feeding interaction at Time 1; but at Time 2, there was a moderately strong birth of a baby are both topics that have been addressed by researchers during positive correlation that was significant. Parental beliefs in a meaning or the last three decades. However, less is known about these important family purpose for this event in their lives correlated mothers with their marital concerns when an infant is born with a developmental disability. Maternal-satisfaction and were significant for mothers at both Time 1 and Time 2 and infant attachment interaction is a process that begins with the birth of an infant. Therefore, early investigation into this process may yield important information that were important to marital satisfaction. The purpose of this study was to examine relevant to early interventionists, mental health clinicians, and social scientists marital satisfaction acknowledged the importance of marital satisfaction in the regarding the genesis of a healthy vs. dysfunctional attachment process when viewed their adjustment process as unified - parents were keeping each other an infant is developmentally disabled.

appraised or their feelings and talking about their futures together. This was in

The beliefs of the parents are likely to affect the manner in which they contrast to those parents who had the lowest scores on marital satisfaction, relate to their infant, as well as to each other. The purpose of this exploratory who mentioned neither communication skills nor effective sharing with each study was to examine the beliefs and hopefulness of parents concerning the other. Mothers who believed their husband's beliefs to be more congruent with impact of their child's developmental disability on their family and the relationship of those beliefs to the marital satisfaction of the parents and the at Time 1. Mothers scored higher than fathers on Level of Functional Beliefs at maternal-infant attachment interaction. Marital satisfaction of the mother was both Time 1 and Time 2. also examined as it related to her attachment interaction with her infant.

2010

2011

2012

2013

2014

2015

2016

2017

2018

2019

2020

2021

2022

2023

2024

2025

2026

2027

2028

2029

Eleven families with developmentally disabled infants were recruited to become a part of the study when the infant was 3 to 4 months old. Both qualitative and quantitative data were collected in their homes. Data collection was repeated three months later for the purpose of observing change. Nonparametric correlational analysis was made. Findings were elaborated upon through qualitative data.

No relationship was found between mother's marital satisfaction and her feeding interaction at Time 1; but at Time 2, there was a moderately strong positive correlation that was significant. Parental beliefs in a meaning or purpose for this event in their lives correlated positively with their marital satisfaction and were significant for mothers at both Time 1 and Time 2 and significant for fathers at Time 1. Two themes emerged from qualitative data that were important to marital satisfaction. Those parents who scored high on marital satisfaction acknowledged their communication skills to be strong. They viewed their adjustment process as unified – parents were keeping each other apprised of their feelings and talking about their futures together. This was in contrast to those parents who had the lowest scores on marital satisfaction, who mentioned neither communication skills nor affective sharing with each other. Mothers who believed their husband's beliefs to be more congruent with their own scored higher on marital satisfaction, and this association was strong at Time 1. Mothers scored higher than fathers on Level of Functional Beliefs at both Time 1 and Time 2.

TO MY FAMILY

Jud, Marc, Vivian, and Barbara

Copyright by
JUDITH A. VANDER WAL
2001

ACKNOWLEDGMENTS

The successful completion of my dissertation was made possible through the encouragement and support of colleagues, family, friends and mentors. I would like to take the opportunity to acknowledge those for whom I feel the deepest gratitude:

My husband and life partner, Jud, has without fail, supported and encouraged my academic and professional aspirations. My children, Marc, Vicki, and Bethanie have cheered me on at every milestone. My daughter, Vicki, and her special needs have been the impetus for my research, my personal growth and my ongoing professional counseling to families with developmentally challenged members.

TO MY FAMILY

Jud, Marc, Vicki, and Bethanie

My mentors at Michigan State University have been outstanding. In particular, my major professor, Dr. Catherine Berland's love, has been an exceptional resource. Her dedication, guidance, and wisdom have provided me with the motivation and inspiration to continue at times of discouragement. Hers was the applause that kept me focused, while at the same time honoring me with her faith in my capabilities as a researcher. I appreciate her giving me the supervision needed but also the latitude with which I could take full authorship and ownership of this document.

I wish to thank my committee members, Dr. Ann Soderman, Dr. Marsha Carolan, and Dr. Hiram Fitzgerald for their time, their willingness to be of help, and their suggestions toward the fine tuning of this product. Their research

knowledge and expertise in **ACKNOWLEDGMENTS** and family development have been of great value in my preparation for this project.

The successful completion of my dissertation was made possible through the encouragement and support of colleagues, family, friends and mentors. I would like to take the opportunity to acknowledge those for whom I feel the deepest gratitude: who so graciously opened up their homes and lives to me.

My husband and life partner, Jud, has without fail, supported and encouraged my academic and professional aspirations. My children, Marc, Vicki, and Bethanie have cheered me on at every milestone. My daughter, Vicki, and her special needs have been the impetus for my research, my personal growth and my ongoing professional counseling to families with developmentally challenged members.

My mentors at Michigan State University have been outstanding. In particular, my major professor, Dr. Dolores Borland-Hunt, has been an exceptional resource. Her dedication, guidance, and wisdom have provided me with the motivation and inspiration to continue at times of discouragement. Hers was the applause that kept me focused, while at the same time honoring me with her faith in my capabilities as a researcher. I appreciate her giving me the supervision needed but also the latitude with which I could take full authorship and ownership of this document.

I wish to thank my committee members, Dr. Ann Soderman, Dr. Marsha Carolan, and Dr. Hiram Fitzgerald for their time, their willingness to be of help, and their suggestions toward the fine tuning of this product. Their research

100

101

102

103

104

105

106

107

knowledge and expertise in the areas of infant, child, and family development have been of great value in my preparation for this project.

LIST The family service providers from the Early On Program who recruited subjects for this study deserve special acknowledgment, for without them this study could not have come to fruition. And finally, I gratefully acknowledge the participant families who so graciously opened up their homes and lives to me. Their willingness to share with me their most personal and often painful feelings at every one of my visits was considered a deep honor. They and their special children are the heroes of this work.

CHAPTER I	
Statement of the Problem.....	2
Conceptual and Operational Definition of Variables.....	6
Family Ecosystems Framework.....	17
Children are the heroes of this work.....	19
CHAPTER II	
LITERATURE REVIEW.....	23
Background.....	23
Maternal-Infant Attachment.....	25
Maternal Affect.....	32
Parental Beliefs.....	36
Stress.....	38
Maternal Perceptions of Support by Partner.....	40
Marital Satisfaction.....	43
Summary.....	44
CHAPTER III	
METHODOLOGY.....	46
Research Objectives.....	46
Research Design.....	49
Sampling Procedures.....	51
Sample Description.....	53
Data Collection Procedures.....	57
Instrumentation.....	60
Study Contributions and Limitations.....	65
CHAPTER IV	
FINDINGS.....	68
CHAPTER V	
SUMMARY AND CONCLUSIONS.....	101
Study Limitations.....	109
Suggestions for Future Research.....	101

LIST

LIST

FIG.

CH-

IN

S

R

O

R

F

S

CH-

ITE

B

M

M

P

S

M

M

S

CH-

VE

R

R

O

S

S

D

H

S

CH-

CH

CH-

S

S

S

S

TABLE OF CONTENTS

APPENDICES.....	164
REFERENCES.....	186
LIST OF TABLES.....	x
LIST OF FIGURES.....	xii
CHAPTER I	
INTRODUCTION.....	1
Statement of the Problem.....	3
Research Questions.....	5
Conceptual and Operational Definition of Variables.....	6
Research Assumptions.....	16
Family Ecosystems Framework.....	17
Significance of the Research.....	19
CHAPTER II	
LITERATURE REVIEW.....	23
Background.....	23
Maternal-Infant Attachment.....	25
Maternal Affect.....	32
Parental Beliefs.....	35
Stress.....	38
Maternal Perceptions of Support by Partner.....	40
Marital Satisfaction.....	43
Summary.....	44
CHAPTER III	
METHODOLOGY.....	46
Research Objectives.....	46
Research Design.....	49
Sampling Procedures.....	51
Sample Description.....	53
Data Collection Procedures.....	57
Instrumentation.....	60
Study Contributions and Limitations.....	65
CHAPTER IV	
FINDINGS.....	68
CHAPTER V	
SUMMARY AND CONCLUSIONS.....	154
Study Limitations.....	159
Suggestions for Future Research.....	161

APP

REF

LIST OF TABLES

APPENDICES.....	164
-----------------	-----

REFERENCES.....	186
-----------------	-----

Table	Page
1 Family Size.....	54
2 Age Distribution of Parents.....	55
3 Annual Family Income.....	56
4 Parents' Highest Education Attainment Levels.....	57
5 NCAST Feeding Scores for Time 1 and Time 2.....	70
6 Parents' Previous Beliefs about Disabilities.....	73
7 Parents' Belief in a Purpose.....	74
8 Parents' Early Birth Experiences.....	77
9 Parents' Hopefulness.....	78
10 Mean Functional Belief Scores of Parents.....	80
11 Mother's Satisfaction with Partner Support.....	81
12 Mother's Belief in Congruency Between her Beliefs and Those of her Partner.....	82
13 Family Inventory of Life Events (Family Stress).....	83
14 Marital Satisfaction of Both Parents.....	84
15 Predictors of Mother-Infant Attachment Interaction.....	103
16 Predictors of Maternal Marital Satisfaction (Dyadic Adjustment Scale).....	124
17 Beliefs as Predictors of Paternal Marital Satisfaction (Dyadic Adjustment Scale).....	133
18 Differences Between Means on Functionality of Beliefs Between Mother and Father, Marital Satisfaction, and Mother's Satisfaction with Partner Support for Time 1 and Time 2.....	151

35

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

LIST OF TABLES

Table	Page
1 Family Size.....	54
2 Age Distribution of Parents.....	55
3 Annual Family Income.....	56
4 Parents' Highest Education Attainment Levels.....	57
5 NCAST Feeding Scores for Time 1 and Time 2.....	70
6 Parents' Previous Beliefs about Disabilities.....	73
7 Parents' Belief in a Purpose.....	74
8 Parents' Early Birth Experiences.....	77
9 Parents' Hopefulness.....	78
10 Mean Functional Belief Scores of Parents.....	80
11 Mother's Satisfaction with Partner Support.....	81
12 Mother's Belief in Congruency Between her Beliefs and Those of her Partner.....	82
13 Family Inventory of Life Events (Family Stress).....	83
14 Marital Satisfaction of Both Parents.....	84
15 Predictors of Mother-Infant Attachment Interaction.....	103
16 Predictors of Maternal Marital Satisfaction (Dyadic Adjustment Scale).....	124
17 Beliefs as Predictors of Paternal Marital Satisfaction (Dyadic Adjustment Scale).....	133
18 Differences Between Means on Functionality of Beliefs Between Mother and Father, Marital Satisfaction, and Mother's Satisfaction with Partner Support for Time 1 and Time 2.....	151

19	Differences Between Means on Mother-Infant Attachment Interaction for Time 1 and Time 2.....	153
----	---	-----

Figure

1 Conceptual Map.....

LIST OF FIGURES

CHAPTER I

Figure	INTRODUCTION	Page
1	Conceptual Map.....	48

During the last thirty years the family has undergone a number of changes, both structurally and functionally. In response to societal changes, family research has proliferated in response to these rapid and diverse changes. Despite the large number of infants born with abnormalities, much less research has been generated with regard to exceptional families, particularly families where one or more members are developmentally disabled. According to the March of Dimes, each year an estimated 1,000,000 babies are born with birth defects, and a significant number of these infants will be severely developmentally disabled.

In 1992, Congress passed the Individuals with Disabilities Education Act (IDEA), which provided early intervention services for disabled children birth through five years of age. With the signing of this Act, family therapy, an area previously overlooked in its importance to individual children with disabilities and the family system, was added to the list of more traditional disciplines serving these families (Malone, et al, 1997). However, most of the research generated about families and disabilities occurred during the 1970's and 1980's. Marriage and family therapy training programs have typically not included working with issues unique to these families. In addition, such training, if included in a training program, is most likely based upon these older

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100
101
102
103
104
105
106
107
108
109
110
111
112
113
114
115
116
117
118
119
120
121
122
123
124
125
126
127
128
129
130
131
132
133
134
135
136
137
138
139
140
141
142
143
144
145
146
147
148
149
150
151
152
153
154
155
156
157
158
159
160
161
162
163
164
165
166
167
168
169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221
222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274
275
276
277
278
279
280
281
282
283
284
285
286
287
288
289
290
291
292
293
294
295
296
297
298
299
300
301
302
303
304
305
306
307
308
309
310
311
312
313
314
315
316
317
318
319
320
321
322
323
324
325
326
327
328
329
330
331
332
333
334
335
336
337
338
339
340
341
342
343
344
345
346
347
348
349
350
351
352
353
354
355
356
357
358
359
360
361
362
363
364
365
366
367
368
369
370
371
372
373
374
375
376
377
378
379
380
381
382
383
384
385
386
387
388
389
390
391
392
393
394
395
396
397
398
399
400
401
402
403
404
405
406
407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
452
453
454
455
456
457
458
459
460
461
462
463
464
465
466
467
468
469
470
471
472
473
474
475
476
477
478
479
480
481
482
483
484
485
486
487
488
489
490
491
492
493
494
495
496
497
498
499
500
501
502
503
504
505
506
507
508
509
510
511
512
513
514
515
516
517
518
519
520
521
522
523
524
525
526
527
528
529
530
531
532
533
534
535
536
537
538
539
540
541
542
543
544
545
546
547
548
549
550
551
552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605
606
607
608
609
610
611
612
613
614
615
616
617
618
619
620
621
622
623
624
625
626
627
628
629
630
631
632
633
634
635
636
637
638
639
640
641
642
643
644
645
646
647
648
649
650
651
652
653
654
655
656
657
658
659
660
661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770
771
772
773
774
775
776
777
778
779
780
781
782
783
784
785
786
787
788
789
790
791
792
793
794
795
796
797
798
799
800
801
802
803
804
805
806
807
808
809
810
811
812
813
814
815
816
817
818
819
820
821
822
823
824
825
826
827
828
829
830
831
832
833
834
835
836
837
838
839
840
841
842
843
844
845
846
847
848
849
850
851
852
853
854
855
856
857
858
859
860
861
862
863
864
865
866
867
868
869
870
871
872
873
874
875
876
877
878
879
880
881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935
936
937
938
939
940
941
942
943
944
945
946
947
948
949
950
951
952
953
954
955
956
957
958
959
960
961
962
963
964
965
966
967
968
969
970
971
972
973
974
975
976
977
978
979
980
981
982
983
984
985
986
987
988
989
990
991
992
993
994
995
996
997
998
999
1000

CHAPTER I

INTRODUCTION

During the last thirty years the family has undergone a number of changes, both structurally and functionally, in response to societal change. Family research has proliferated in response to these rapid and dramatic changes. Despite the large number of infants born with anomalies, much less research has been generated with regard to exceptional families, particularly families where one or more members are developmentally disabled. According to the March of Dimes, each year an estimated 150,000 babies are born with birth defects, and a significant number of these infants will be severely developmentally disabled. In 1992, Congress passed the Individuals with Disabilities Education Act (IDEA), which provided early intervention services for disabled children birth through five years of age. With the signing of this Act, family therapy, an area previously overlooked in its importance to individual children with disabilities and the family system, was added to the list of more traditional disciplines serving these families (Malone, et al, 1997). However, most of the research generated about families and disabilities occurred during the 1970's and 1980's. Marriage and family therapy training programs have typically not included working with issues unique to these families. In addition, such training, if included in a training program, is most likely based upon these older

sub

to

the

of

the

the

the

the

the

the

the

the

the

the

the

the

the

the

the

the

the

studies. It is, therefore, vitally important for professionals who work with these families to become equipped with more and updated knowledge regarding how they can best be served, particularly in regard to prevention of family dysfunction and early intervention for optimal development of the child. There is a strong consensus that the quality of maternal-infant interaction is vital to the mental health of the developing child. A secure mother-infant attachment is widely endorsed by child development and mental health professions as vital to the healthy development of the child. Mother-infant attachment is dependent on the quality of mother-infant interaction and has been shown to be predictive of later childhood behaviors. Traditionally, it has been the normal, healthy infant-mother relationship that has been the focus of interaction studies. Fewer studies have examined this relationship with severely developmentally disabled infants and, in particular, that relationship during the critical period of early infancy, when maternal adjustment to a disability is a primary process.

It has been shown across many studies that maternal depression negatively influences the dyadic interaction between mothers and normal infants, and infants of depressed mothers are considered at risk for becoming insecurely attached to their infants. Depression is often studied as an outcome influenced by the belief systems of individuals. While the process of attachment formation has been studied and identified, less is known about the beliefs of the parents and how they might influence the quality of interaction between mothers and their infants.

1382

1383

1384

1385

1386

1387

1388

1389

1390

1391

1392

1393

1394

1395

1396

1397

It is theorized that the beliefs of mothers regarding their developmentally disabled infants are different from those of mothers of normal infants. It is not clear how these beliefs come to influence the attachment interaction process. It would be very important to mental health professionals working with families with developmentally disabled children to understand the unique parental beliefs that may influence mother-infant interaction when an infant is atypical. In addition, while several studies have concluded that there is more marital distress in families with developmentally disabled children, there have been many studies that have shown otherwise. Very few studies have examined factors that may contribute to the process of marital breakdown when a developmentally disabled child comes into the family. Studies of very early relational processes (soon after the birth of the developmentally disabled child) between these marital and parental partners are missing from the literature.

Statement of the Problem

The present study had the following purposes:

It examined beliefs of parents around the birth of a developmentally disabled infant and the level of functionality of those beliefs to the parents' marital satisfaction. In this study, marital satisfaction was examined for legally married parents living in the same household. It also examined the relationship of the level of functionality of the mother's beliefs to the quality of maternal-infant attachment interaction.

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

10/20

It examined the mother's level of marital satisfaction, her perception of her spouse's emotional and instrumental support, and her perception of the congruency of her partner's beliefs with her own, in relation to the quality of her attachment interaction with her developmentally disabled infant.

And, finally, since maternal-infant attachment and marital satisfaction are dynamic processes that occur over time, it examined the impact of time (a 3-month period) on quality of maternal-infant attachment interaction and marital satisfaction in families with a developmentally disabled infant.

The following variables were used as control variables for the study: age of parents, level of maternal depression, the number of additional stressors present prior to and at the time of the birth, family income level, size of family, and education of parents.

It can be argued that in some cases, the father is the primary caregiver of the infant, and can, thus, also be considered an attachment figure. While this investigator acknowledged this to be true, it was decided that primary caregiving father subjects would be difficult to locate and recruit into this study sample, since fathers represent a very small percentage of the primary caregivers of infants today. So as not to confound the study by including one or two possible primary caregiving fathers, the sample for studying infant attachment interaction included only mothers. While fathers are acknowledged to be direct contributors to maternal-infant interaction, paternal variables were studied as they mediated upon the mother's level of marital satisfaction. Since both maternal-infant attachment and marital satisfaction are dynamic processes

1810

1820

1830

1840

1850

1860

1870

1880

1890

1900

1910

1920

1930

1940

1950

1960

1970

1980

1990

that occur over time in response to the birth of a child, this study focused on temporal changes in these two outcome processes as influenced by the above control variables. This investigation focused on changes occurring over a duration of three months, with the initial assessment made when the infant was three or four months old and the second and final assessment took place three months later – i.e., six or seven months of age. The study used both quantitative and qualitative methods of analysis. Qualitative-like questions were asked for two purposes: (1) for facilitating depth of thought by subjects before responding to scaling questions; and (2) for adding depth to discussion of the results of the analysis.

Research Questions

When an exploratory study is designed in an area where very little research has been done, then it is usually appropriate to write questions to guide the research rather than hypotheses. The following research questions comprised the focus of this study:

1. Is there a relationship between the level of functionality of maternal beliefs about the infant's developmental disability and the quality of the mother-infant attachment interaction?
2. Is there a relationship between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the quality of her attachment interaction with her infant?
3. Is there a relationship between the mother's level of marital satisfaction and the quality of the mother-infant attachment interaction?

4 Is
ac
sa

5 Is
of
me

6 Is
en
le

7 Is
ac

8 Is
ce

9 Is
w

10 Is
of

11 Is
m

12 Is
m

inter

inter

13 Is

14 Is

15 Is

4. Is there a relationship between the level of functionality of maternal beliefs about the infant's developmental disability and her level of marital satisfaction?
5. Is there a relationship between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the level of her marital satisfaction?
6. Is there a relationship between the mother's level of satisfaction with the emotional and instrumental support she receives from her partner and her level of marital satisfaction?
7. Is there a relationship between the level of functionality of paternal beliefs about the infant's disability and the father's level of marital satisfaction?
8. Is there a significant difference in the level of functionality of parental beliefs between Time 1 and Time 2 (three months later)?
9. Is there a significant difference between the mother's level of satisfaction with the support she receives from her partner between Time 1 and Time 2?
10. Is there a significant difference between mothers and fathers on their levels of marital satisfaction at Time 1 and at Time 2?
11. Is there a significant difference between Time 1 and Time 2 on levels of marital satisfaction for mothers and fathers?
12. Is there a significant difference on the quality of maternal-infant attachment interaction between Time 1 and Time 2?

Dependent Variables

Conceptual and Operational Definitions of Variables

(1) *Quality of Mother-Infant Attachment Interaction* is a synchronous process of infant-mother responsiveness which, in later infancy, leads to a bonding process between the mother's responsiveness to the infant's physical needs. In this study, the researcher examined families whose infants had two different types of chromosomal abnormalities that fall within this category: Down Syndrome and Prader Willi Syndrome. These conditions accompany a

1909

1910

1911

1912

1913

1914

1915

1916

1917

1918

1919

1920

1921

1922

1923

1924

1925

1926

1927

1928

1929

prognosis that the child will have a developmental delay that could range from mild to severe, with most falling within the moderate range. Special education classifies developmental delays according to I.Q., and those I.Q. categories are specified as mild, moderate, severe, and profound. A person with mild mental retardation has an I.Q. of between 50-75, while a person with moderate mental retardation has an I.Q. of 30-50. An individual with severe mental retardation has an I.Q. of 20-30, and a person with profound mental retardation (who often has other accompanying disabilities such as physical or sensory disabilities) has an I.Q. of 20 or below (Falvey, et al., 1993). While the prognosis for the degree of severity of impairment for these two chromosomal abnormalities is uncertain, any condition suspected to produce mental retardation in the mild range and below would likely meet with similar stress and grief responses by parents who had hoped for a healthy, normal newborn.

Dependent Variables

This study focused on two major outcome variables: (1) quality of mother-infant attachment interaction; and (2) level of marital satisfaction. Their conceptual and operational definitions follow:

(1) **Quality of Mother-infant Attachment Interaction** is a synchronous process of infant-mother responsivity which, in later infancy, leads to a bonding of each member of the dyad with the other (Bowlby, 1969). This attachment process begins with the mother's responsiveness to the infant's physical needs, and the maternal attachment phase begins before the infant forms the bond. This process is also described in the Review of Literature. While the infant

attach

and o

perso

afgar

Page

sele

WATER

Conte

defin

comm

ATTC

and n

the s

the

ESS

the n

the

to

the

to

the

the

attachment process begins when the infant is approximately four months old and can begin to discriminate between an attachment figure and another person when they are in close contact, it is not considered complete until the infant is eight to twelve months old. It is at this stage, which coincides with Piaget's fourth stage of sensorimotor development, that the normally developing infant has achieved object permanence. This is also the stage when psychoanalytic theorists judge "true object relations" to emerge. Conceptually, quality of mother-infant attachment interaction behavior could be defined as the way in which the mother responds to the infant's needs communicated by crying or other signals of distress. It would also be perceived in the way the infant seems to prefer the attachment figure to other individuals and responds to her in ways that are unique from responses to others. During the stage of development when the infant achieves object permanence, attachment may become even more obvious, as the now attached infant may resist the attempts of unfamiliar individuals to care for him/her, particularly in the mother's presence. While this process is expected to be delayed for the developmentally disabled child, the process is assumed to be attainable and can be observed.

For the purpose of this study, quality of mother-infant attachment interaction was identified as the degree to which the parent is sensitive to the child's cues; responds to the child's distress and fosters social, emotional, and cognitive growth. It was also defined as the degree to which the infant provides the mother with clarity of cues, as well as the infant's responsiveness to the

categ

ntara

Feed

obse

prese

none

are a

ntara

6 a s

ste

only

devel

Ad, s

meas

Atti

Gene

Seis

bu c

Q, a

2-3

Set

caregiver (Barnard, et al., 1983). For the purpose of this study, attachment interaction was observationally coded and measured by use of the NCAST Feeding Scale (Sumner & Spietz, 1994). This rating scale requires a 50-minute observation of a mother-infant feeding. The scale consists of 76 items as either present or not present during the feeding. The investigator observed an in-home mother-infant feeding and scored the feeding interaction. When scores are added, a total score of 76 are possible, with higher levels of quality interaction receiving higher points.

(2) **Level of Maternal and Paternal Marital Satisfaction**, conceptually, is a subjective feeling reported by a respondent regarding the degree to which s/he is satisfied with the marital relationship. Operationally, this study included only legally married couples who are identified as the biological parents of a developmentally disabled infant. This concept was measured by the Dyadic Adjustment Scale (Spanier, 1976), a standardized measure. This instrument measures the degree to which respondents report subjectively their satisfaction with their committed partner relationship, as well as their objective responses to behaviors, which are indicative of factors that are strongly associated with satisfactory or unsatisfactory marital relationships. This instrument measures four dimensions of the relationship: dyadic satisfaction, dyadic cohesion, dyadic consensus and affectional expression, but the total scores are computed by the author for this study. Three different types of rating scales are used with the DAS. Total scores are the sum of all items, ranging from 0 to

refec

Inter

tion

ssat

W. M.

cto

ad. S.

figer

the /r

about

the

them

their

about

the

the

the

the

151. Higher scores reflect a better relationship, with a score of 100 or less reflecting a distressed relationship.

Independent Variables

The five major independent variables included in the study were as follows: (1) the level of functionality of maternal beliefs about the infant's disability, (2) maternal level of belief in a congruency of her partner's beliefs with her own; (3) maternal level of satisfaction with the emotional and instrumental support she receives from her partner, (4) maternal level of marital satisfaction, and (5) the level of functionality of paternal beliefs about the infant's developmental disability.

Level of Functionality of the Parents' Beliefs Surrounding the Infant's Birth.

Conceptually, **Functional Beliefs** are defined as (a) positive beliefs about the infant's disability acquired from pre-birth experiences with others who have this disability, (b) the belief that their infant's diagnosis was presented to them in a sensitive and helpful manner, (c) the absence of a severe negative reaction to the infant's diagnosis, (d) positive perceptions of the quality and amount of information given them about the disability and their child's condition, (e) positive and hopeful feelings about the present and future for the infant and the family, (f) a belief in a purpose or meaning for the birth, and (g) no responsibility or blame placed on anyone for the infant's disability.

Operationally, these beliefs were elicited through an unstructured interview format conducted by the investigator and subsequently scaled by the

case

rest

small

from

about

• The

at

The

• The

at

re

The

to

the

for

are

the

are

the

are

the

the

parents at Time 1. At Time 2, parents were not asked a second time about their beliefs prior to their infant's birth, nor feelings or experiences regarding similar developmental disabilities. Nor were parents asked about the information they received at the infant's birth, and they were not again asked about their emotional reaction to their infant's birth for the following reasons:

- This information was elicited within the first 3 months after the infant's birth and the elapsed period of time for retrospection at Time 1 was less than at Time 2. Therefore, recall was expected to be most accurate at Time 1.
- These beliefs were not expected to change between Time 1 and Time 2; and if minor change occurred, this likely could be attributed to diminished recall due to lapsed time.

These beliefs were audiotaped and transcribed for discussion purposes.

The beliefs were scaled using a Likert-type scale according to their level of functionality. Sections B and C of the Interview Guide for Time 1, and Section F of the Interview Guide for Time 2 give the scaling questions for this variable and can be found in Appendix D. Answers to scaling questions were given by both parents on a scale of 1 to 5. There are 9 scaling questions, following open-ended interview questions, and at Time 1 each parent could receive a possible score ranging from 9 to 45, with a higher score reflecting a higher level of functionality of parental beliefs around the infant's birth. At Time 2, the score parents received for the 4 scaling questions for Time 1 (Questions B-3, B-7, B-8, and B-10) were added to the 5 scaling questions asked at Time 2 (Questions F-5, F-8, F-11, F-11b, and F-15). These questions (Time 2) were identical to

those

for the

with

the m

the m

st m a

total

11 Ap

the e

the e

the s

the s

the s

the s

the s

the s

the s

instr

the a

the s

those asked at Time 1, Section C. Again, a score consistent with that possible for Time 1 – ranging from 9 to 45 – was obtained for Time 2.

(2) **Maternal Level of Belief in a Congruency of her Partner's Beliefs with her Own.** Conceptually, this variable is defined as the subjective belief of the mother that her partner's views of the infant's disabilities (his current feelings, hopefulness about the future of the family, assignment of blame) are similar to her own.

Operationally, the score for this variable was the difference between the mother's own scores on questions in Section C of the Interview Guide for Time 1 (Appendix D) about her hopefulness, the meaning and purpose she gave to this event, her belief that either she or her partner was to blame, the current impact this event had on her family, and the scores she gave for her partner on the same questions (Section E of Interview Guide, Time 1 – Appendix D). These interview questions were administered during the individual interview portion at Time 1 only. The range of scores is 0 to 25. The higher the difference between scores received by the mother in Sections C and Section E, the greater the amount of incongruity between her beliefs and her perception of her partner's beliefs. The score was inverted in the analysis to satisfy the direction of this research question.

(3) **The Maternal Level of Satisfaction with the Emotional and Instrumental Support Received from her Partner.** Conceptually, support is the aid or assistance given by one person to another. Usually, this is a measure of the number of physical and verbal behaviors performed to assist

arab

now

with

spen

suco

out

he

se

he

me

Se

me

me

Se

Se

Se

Se

Se

Se

Se

another. This construct was subjective, based upon the mother's perception of how supportive her partner was to her both emotionally and physically.

Operationally, the mother was asked to scale her level of satisfaction with the support she received in terms of (a) the amount and quality of time he spends in interaction with the disabled infant, (b) the amount of physical support he gave her, both in performance of household tasks and in infant care, (c) the amount of emotional support he gave her in terms of discussion of feelings and related concerns around the infant's birth; and (d) his ability to listen and empathize when she was in emotional need. Mothers reported this level of satisfaction on an ordinal Likert scale from one to five points at both Time 1 and Time 2. The interview scale for this variable can be found in Sections D and G of the Interview Guide in Appendix D. Four questions comprised this Likert scale, with a possible score ranging from 4 to 20. The higher the score, the higher the level of maternal satisfaction with her partner's support.

(4) The Mother's Level of Marital Satisfaction. This variable, in addition to being treated as a dependent variable, is an independent variable in the sense that it is being examined in relationship to the dependent variable of quality of maternal-infant attachment interaction. Marital satisfaction, conceptually, is a subjective feeling reported by the mother regarding the happiness and no desire to continue living in transitory melancholia and degree to which she is satisfied with her marital relationship.

Operationally, this concept was measured by the Dyadic Adjustment Scale (Spanier, 1976), a standardized measure, at both Time 1 and Time 2.

The n

the sa

18300

28300

measu

88.52

Tree

De su

1979

0879

1788

1114

Tree

1872

1874

1874

1874

1874

1874

1874

1874

This instrument measures the degree to which the mother reports subjectively her satisfaction with her committed partner relationship, as well as her objective responses to behaviors that are indicative of factors that are strongly associated with satisfactory or unsatisfactory marital relationships. This measurement focuses on four dimensions of the relationship: dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression. Three different types of rating scales are used with the DAS. The total score is the sum of all items, with scores ranging from 0 to 151. Higher scores reflect higher satisfaction with the relationship, with a score of 100 or less reflecting a distressed relationship. The total score is recommended by Spanier to be used in research. The total score was used in this study to measure Maternal Level of Marital Satisfaction.

Other Definitions

Conceptually, number of stressors is the sum of the number of additional stressors outside of the birth event, both pre- and post-birth, existing over the previous 12 months (including the birth of the disabled infant), that are pile-up factors reported by the mother, and (3) educational level of parents.

(1) **Level of Maternal Depression.** Depression can be conceptualized as a negative emotion or mood of individuals, which can be temporary or enduring. Depression can be placed on a continuum from extreme hopelessness and no desire to continue living to transitory melancholia and sadness. Depression is the extent to which one experiences pessimism and sadness -- a general feeling that one is unable to experience pleasure. It is defined as a mood state characterized by a sense of inadequacy, a feeling of

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

25500

despondency, a decrease in activity or reactivity, pessimism, sadness, and related symptoms (Reber, 1985).

Operationally, this variable was measured through the use of the Beck Depression Inventory - Short Form (Beck, Ward, Mendelson, Mock & Erbaugh, 1961), a standardized, widely used measure of depressive states. Scores may reflect a temporary, normal psychological grief state that is in response to the disappointment of the birth of a developmentally disabled child. The Beck Depression Inventory was administered at both Time 1 and Time 2.

(2) **Number of Stress Pile-up Factors Reported by the Mother.** Conceptually, stress pile-up consists of the conditions, in addition to the birth event, that are seen to create pressure and strain on the family system. Stress refers to a response of the organism to conditions that consciously are experienced as noxious (Hill, 1949; McCubbin & Patterson, 1982).

Operationally, number of stress pile-up factors refers to the number of additional stressors outside of the birth event, both pre- and post-birth, existing over the previous 12 months (including the birth of the disabled infant), that are identified by the mother as noxious and contributing to the strain on the family system. This variable was measured at Time 1 only by the use of a standardized self-report instrument, Family Inventory of Life Events and Changes (FILE) (McCubbin, Patterson, & Wilson, 1983), which assesses the "pile-up" or sum of normative and non-normative stressors and intrafamilial strains experienced by members of the family. The constructs measured are (1) Intrafamily Strains; (2) Marital Strains; (3) Pregnancy and Childbearing

Stran

Stran

lega

of 71

Soci

educ

2017

18/12

date

2017

18/12

18/12

18/12

18/12

18/12

18/12

18/12

18/12

18/12

Strains; (4) Finance and Business Strains; (5) Work-Family Transitions and Strains; (6) Illness and Family Care Strains; (7) Losses; (8) Transitions; and (9) Legal Strains. The range of scores is 0-71, and represents one point for each of 71 items. A higher score implies higher stress.

(3) **Educational Level of Parents.** This is a common control variable in social science research. The parents were asked to indicate the highest educational level they completed on the Demographic Data Questionnaire administered at Time 1. (See Appendix C.) When maternal independent variables were being tested, the mother's level of education was used. When paternal independent variables were being tested, the father's level of education was used.

Research Assumptions

It was assumed that families who give birth to a developmentally disabled child are in crisis for a few months after the child's birth – exactly at the time when the attachment process begins between mothers and normal infants. Therefore, the study of impediments to the attachment process between a mother and a developmentally disabled infant is best studied at an early time in infancy. Since attachment is an ongoing interactive process that is not completed until a normal infant is approximately 12 months old (Rosenblith, 1992), it was assumed that a period of grieving is likely to interfere with the attachment process after a developmentally disabled infant is born. In some families, this grieving period may be prolonged, particularly when other factors,

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

5000

such as maternal perceptions of lack of support, feelings of isolation in her grieving process, low marital satisfaction, additional stressors, and maternal negative beliefs around the birth, are also present. For other families, a three-month period of time following initial assessment (when the infant is around 6 months of age) may evidence change occurring in the grieving process, and the maternal-infant attachment process may already be in effect. Research has shown that this process is somewhat delayed when an infant is born developmentally disabled. It is also assumed that committed partners who are satisfied with their relationship prior to the birth of the disabled infant are likely to still be satisfied with their relationship three months post-birth. However, if the mother begins to feel isolated and unsupported by her partner, a likely result of different grieving patterns by the partners, as well as a result of deep depression, and/or additional outside stressors, then the effects are more likely to be evidenced on the relational satisfaction of both partners at a point in time six months after the birth of the infant.

A Family Ecosystems Framework

This study incorporated, as its foundation, Bronfenbrenner's Family Ecosystems Theory, which is a systems framework for conceptualizing family and child development (Bronfenbrenner, 1979). Ecological theory views the activity of the family as a complex interplay and interaction of family members both within the family and across its contextual borders. Properties of the

to

between

assess

where

some

other

for

that

de

more

more

was

have

person

and

that

and

to

the

the

the

the

families and their multiple environments, as well as processes taking place between them, are interdependent and analyzed as a system. The theory assumes all families are semi-open, goal directed, dynamic, adaptive systems. When change takes place within any level of the system, be it the cultural, societal, community, extended family, or family level, it will have an effect on other parts of the system. Decision making is the central control process in families that direct action to attain individual and family goals.

Brief: Bronfenbrenner (1979) builds an organizational and research framework that describes the structure of the ecological environment within which human development occurs. The four systems within this framework are titled the *microsystem*, the *mesosystem*, the *exosystem*, and the *macrosystem*. A child's microsystem is a complex network that consists of a pattern of activities and roles experienced in a daily face-to-face setting with particular individuals who have distinctive characteristics of temperament, personality and systems of personal beliefs. This primarily refers to the child's immediate family. The

An understanding of the development of maternal attachment to an atypical infant remains incomplete. In addition, the existing research, the bulk of which was conducted primarily in the 1970's and early 1980's, is not consensual with regard to mother-infant attachment in this population. The question arises as to why some mothers are able to adjust and cope with the child's birth of an atypical infant, while other mothers are less able to adjust effectively.

Most of the attachment research with disabled infant populations has focused on infant subjects older than nine months of age. Many studies have

to be

some

about

is to

about

where

be it

that

other

that

that

that

that

that

that

that

that

that

framework is not just the idea that human's develop in a familial and societal context, but rather its emphasis on studying the interrelationships among these identified subsystems, especially during periods of transition (Bretherton, 1993).

In this study, primarily factors within the family – such as microsystem variables as maternal perceptions, the marital relationship, and infant-mother attachment interaction – were the focus. In addition, exosystem variables that were experienced as stressors on the mother were included in the study. Beliefs about disabilities expressed by both parents, which reflected macrosystem interchanges were an important component of this study. While other societal factors may have been important, the actual assessment of additional factors in relation to the outcome variables were deemed to be beyond the scope of this single study.

Significance of the Research

An understanding of the development of maternal attachment to an atypical infant remains incomplete. In addition, the existing research, the bulk of which was conducted primarily in the 1970's and early 1980's, is not consensual with regard to mother-infant attachment in this population. The

The focus of this study was on an important variable that has been somewhat ignored in the literature – that of the mother's perceptions and crisis of the birth of an atypical infant, while other mothers are less able to adjust effectively.

Most of the attachment research with disabled infant populations has focused on infant subjects older than nine months of age. Many studies have

define

research

national

power

usac

there

ear,

-a de

men

control

ear,

bas,

Sto,

Enga

ongo

W" on

Enga

Sto

del

W" on

Enga

defined the term "infancy" as all those children from birth to age two. General research on infant needs and developmental tasks would suggest that a more narrow age range for infant study samples would enhance the explanatory power of the design. This study included only those families of developmentally disabled infants ages three and four months at the time of the first interview. Therefore, this study was expected to yield information about those very critical early attachment processes, when family adjustment processes are also critical – a period in the life cycle that has not received attention in the literature.

Another area of concern shared by Hodapp (1995) resides within the methodologies used in many studies. The subject groups have traditionally not controlled for disability types – a result of sampling at-risk families receiving early intervention services. Hearing impairments, speech delays, cerebral palsy and autism are often included among the groups selected for a particular study. Therefore, it has been suggested that study groups be narrowed with regard to disability. This study focused on those families of infants with the chromosomal abnormalities of Down Syndrome and Prader Willi Syndrome, which are known to produce mental retardation, though the prognoses can range from mild to severe delays.

The focus of this study was on an important variable that has been somewhat ignored in the literature -- that of the mother's perceptions and beliefs about disabilities in general, both currently and historically, about her own developmentally disabled infant and how these beliefs influence her interaction with her infant. In addition, since there is little to be found regarding

te cu

de m

gier

moine

sucoo

where

more

lely

tecln

ocul

tecl

riar

stet

frag

rie

tot

tecl

tecl

tecl

tecl

the quality of partner support as defined by the mother, this study investigated the mother's perceptions and attitudes regarding the types of spousal support given and desired. Nothing was found in the literature that would investigate the impact of mother's and father's shared perceptions to the mother's feeling emotionally supported by her partner. This was seen by the researcher as another area where this study is likely to fill in some knowledge gaps. In particular, the mother's perception of the congruency of her beliefs with those of her partner is likely to shed some light on her satisfaction with the couple relationship. Her feelings of isolation or, conversely, shared empathy (emotional support) in the couple relationship are likely to influence her interactions with her developmentally disabled infant.

Ancillary to this study of maternal beliefs and their influence on maternal-infant interaction, was the intent to investigate the birth of a developmentally disabled child in direct relation to marital satisfaction for both partners. These findings were expected to illuminate how the couple relationship indirectly influenced maternal-infant interaction, how partner support related to the mother's interaction behaviors with her infant, as well as how the couple relationship was influenced by the birth of a developmentally disabled child. All these factors are important to a more complete understanding of families with developmentally disabled infants, and this more complete understanding will assist therapists in their clinical work with these families.

disad

has b

tsad

shad

had

had

had

had

had

had

had

Abuse and other maltreatment are more common with developmentally disabled children than with nondisabled siblings or peers (Blacher, 1984). It has been proposed that parental abuse and neglect of young developmentally disabled children may be related to an interference during the normal

The literature important to this study was reviewed under the headings: attachment process between mother and infant (Capuzzi, 1989; Shaw and Vondra, 1993). Conversely, Fine (1986) reported that abuse of the handicapped child can be viewed as symptomatic of how family members are coping with their beliefs and the resulting stress of diagnosis. Thus, research on the very early interaction between mother and her developmentally disabled infant is vital to the understanding of professionals working with these families

toward prevention of abusive interactions between parents and their developmentally disabled children.

Societal change relative to the developmentally disabled members of the population has created new demands on these exceptional families. Formerly, most individuals with severe developmental disabilities were incarcerated within large residential institutions, where conditions were often inhumane and services limited. People with severe disabilities have long been regarded by society as the least capable, the most dependent, and beyond habilitation, education and treatment. The predominant approach to the problems of the severely disabled was custodial maintenance. Historically, only limited assistance, support and understanding have been available to persons with severe disabilities, their parents, and families.

Table

Table

Table

Table

Table

Table

Table

Table

Table

Table

Table

Table

Table

Table

CHAPTER II

LITERATURE REVIEW

The literature important to this study was reviewed under the headings:

maternal-infant attachment, maternal (and paternal) affect, maternal (and paternal) beliefs, stress, maternal perceptions of support by partner, and marital satisfaction. In addition, a background section has been included to bring the reader up to date with the dramatic changes that have taken place within this population during the last four decades.

Background

Societal change relative to the developmentally disabled members of the population has created new demands on these exceptional families. Formerly, most individuals with severe developmental disabilities were incarcerated within large residential institutions, where conditions were often inhumane and services limited. People with severe disabilities have long been regarded by society as the least capable, the most dependent, and beyond habilitation, education and treatment. The predominant approach to the problems of the severely disabled was custodial maintenance. Historically, only limited assistance, support and understanding have been available to persons with severe disabilities, their parents, and families.

It wasn't until the 1970's that social, educational, and legal events began to change trends in service delivery. Parents and professionals joined voices to advocate for basic rights and services for persons with severe disabilities. After centuries of passivity and fatalism concerning their disabled children, parents began reversing that position; as a consequence, there has been a fundamental shift in the role of parents and the functions of these families. Institutional reform, deinstitutionalization, right to treatment, nondiscrimination, and mandated educational services have taken place. The Education for All Handicapped Children Act (P.L. 94-142) of 1975 is a legacy of this advocacy movement. This law requires that all children who are handicapped, and who because of their handicap, require special education and related services, are entitled to a free and appropriate education in the least restrictive environment. The law stipulates, moreover, that educational services be made available for all handicapped children between the ages of 3 and 21. In addition, in 1992, Congress passed the Individuals With Disabilities Education Act (IDEA), which provided early intervention services for children birth through five years of age. This witnessed a philosophical shift from individually oriented care to family-centered care for this population (Malone, et al., 1997).

Clearly, on the whole, families with developmentally disabled children today are experiencing roles and stresses not experienced prior to the 1970's -- a marker of societal change. Research has merely shadowed these changes in an attempt to determine necessary services for these children. It has only been since 1992 that families have been the focus of early intervention services.

betwe

halo

dash

prom

rele

re mo

and no

month

more

cost

signa

sepa

rela

five

more

more

more

more

five

more

five

Maternal-Infant Attachment

Attachment is usually described as an emotional tie or bond of affection between infant and parent (mother). Attachment is defined as an affectional tie that one person forms between him/herself and another. The manifestations of attachment are the attempts to gain and to maintain a certain degree of proximity to the attachment object (Stone & Chesney, 1978). Two conditions have been found to be related to the development of attachment by the infant: the mother's sensitivity in responding to her infant's signals, and the amount and nature of the interaction between them (Bowlby, 1969). From about two months, infants take an increasingly active role in initiating interaction with their mothers. However, the success or failure of the infant's adaptive efforts is contingent on the mother's ability to recognize and to respond to the infant's signals – referred to as maternal "sensitivity." Attachment includes many behaviors such as the infant calling out for contact, clinging, crying, making eye contact and smiling (Widerstrom et al., 1991). For effective interaction to develop, the infant and the mother must give clear cues to each other, the mother must respond to the infant's cues, the infant must respond to the mother's caregiving, and the environment must facilitate the mother-infant interaction (Capuzzi, 1989). The relationship that evolves between infant and mother depends not only on what occurs, but how the interaction pattern develops. It is this patterning that is closely related to the quality of the interaction, according to Sroufe (1989). In Bowlby's theory of attachment, the developing human derives core expectations about the environment, especially

once

exper

over th

the in

found

has a

over tu

also a

studie

assign

made

22 reg

norma

other

once

At 0

to e

other

to re

secur

to as

stud

concerning the availability and responsiveness of others. From early interactive experience, an individual either derives or does not derive a sense of mastery over the environment and worthiness of the self. This becomes the basis for the individual's "internal working models," according to Bowlby, and the foundation from which the individual perceives the world. Thus, an infant who has experienced reliable, sensitive care (responsiveness to its signals, overtures, moods, and states) will come to expect not only that the caregiver is available but that the infant is effective in eliciting care (Bowlby, 1973). Among studies measuring infant behavior, *quality* of attachment has been found to be a significant predictor of later competence, reflecting the nature of the internal models with which the infant learns to function in the world.

Maternal Attachment Behaviors

Attachment research has shown secure attachment between infant and caregiver to be highly predictive of later social and emotional adjustment of the child. A *secure* attachment in infancy has been associated with longer attention span, greater compliance, greater persistence, enthusiasm, and cooperation at age two (Londerville & Main, 1981) and better social relations with peers in preschool (LaFreniere & Sroufe, 1985). In studies of low-income families, *insecure* patterns of attachment have been strongly related to externalizing behavior problems at ages 5 and 7-8 (Lyons-Ruth, et al., 1991; Renken, et al., 1989). Other longitudinal studies have found that infants securely attached at 12 months had higher Bayley scores at 21 months than did insecurely attached children; insecurely attached infants were likely to be socially withdrawn and to hesitate about participating in activities in nursery

scroo

strong

Man

stodie

notab

intera

beha.

Fral

beha.

Water

toon

relat

toon

Ans.

fractu

toad

deser

riant

tanq

stere

grave

school; and insecurely attached infants became frustrated easily, reacted strongly to the frustration and quickly gave up trying to solve the problems (Main, 1973; Waters et al., 1979). Bornstein (1995) has reviewed a number of studies that focus on early maternal attachment behavior as predictors of later vocabulary and verbal intelligence in young children.

Since attachment is considered a dyadic process, it involves reciprocal interaction from both mother and infant. Each individual's interactional behaviors will be discussed separately in relation to the literature reviewed. Finally, literature regarding the developmentally disabled infant's attachment behaviors will be reviewed.

Maternal Attachment Behaviors

Maternal behavior in the dyadic relationship was stressed as most important to the attachment process by Shaw & Vondra (1993). They found that variables more closely related to maternal adjustment are of greater importance in determining attachment security and thus concluded, as has Ainsworth, et al. (1978) and Bowlby (1969) that attachment security is largely a function of maternal sensitivity to the infant's needs. Shaw & Vondra did not include handicapped infants in their sample, however. Belsky, et al. (1984) describe sensitive responsiveness as an exchange between the mother and infant in which the mother adjusts the rhythm and tempo of the interaction to maintain behavioral synchrony. It is not so much the presence or absence of discrete behaviors but their appropriateness and timing that is important.

Clarke-Stewart (1973), in rating mothers on responsiveness to their infants,

found

stimul

metre

ajac

with

node

restr

Syndr

proce

endov

period

hier

area

strin

One p

Syndr

area

data p

page

Phase

Social

found that mothers scoring high on expression of positive emotion and social stimulation had more securely attached normal infants than low-scoring mothers. Though far less is known regarding attachment processes with atypical children, Werner (1999) found maternal competence and a close bond with the primary caregiver to be among protective factors for children with high incidence disabilities.

Emde and Brown (1978) describe the maternal attachment process relative to the developmentally disabled infant, in particular the Down Syndrome infant. They describe maternal attachment as a three-phase process. In phase one, during pregnancy, the anticipated child becomes endowed with narcissistic and object love. In phase two, during the neonatal period, there is an increase of interest, caring, and love toward the now real infant. During phase three, after the neonatal period, there is a further increased interest and positive feeling, as the infant becomes capable of social smiling, eye-to-eye contact, and there is a qualitative change in wakefulness. One phase builds upon the other. In the attachment process with a Down Syndrome infant, this attachment process is more complex. Phase one is the same, but phases two and three are not. In phase two, attachment does not build postnatally on the image of the expected child. Instead that expected image must be mourned before an attachment based on reality can begin. Phase three is complicated by being somewhat delayed by the dampened social responsiveness of the infant with regard to later social smiling and eye-

to-2)

before

Inter

the c

seven

attach

proce

of the

des

Watin

Spr

Rose

Spr

to 20

sys

Dele

stages

from

Dele

con

Dele

to-eye contact. During both phases two and three, grief work may be required before energy can be "freed up" for the facilitation of the attachment process.

Infant Attachment Behaviors.

By far, the majority of the studies capture the importance of the role of the parent (almost always the mother) in the attachment process. However, several studies of handicapped infants focused on the role of the infant in the attachment process (Emde & Brown, 1978). Since attachment is, indeed, a process that involves reciprocity between caregiver and infant, the importance of the child's responsivity cannot be understated. Normal newborns provide cues that guide mothers in initiating, modulating, and terminating interactions. Mothers who allow their infants to initiate interaction may be promoting synchrony in their relationship. The attachment research, according to Rosenblith (1992), argues that mothers should focus on establishing a synchronous relationship by permitting babies to express their own needs and to control themselves as much as possible.

Papousek and Papousek (1975) argue that mothers are not systematically providing stimulation and reward to their infants -- mother's behaviors are also social responses to their infants. Rosenblith (1992) also states that it is likely that some newborn behaviors elicit differential caretaking from the mother. Since this researcher is investigating interactions between developmentally disabled infants, in comparison with normal infants and their mothers, it is expected that there will be delayed responses by the developmentally disabled infants to their mothers' interactions. This is likely to

factor

doing

Date

read

re n

reco

the

Colin

the

the

hand

reco

tag

reco

the

the

the

read

the

the

the

the

factor into the combined mother-infant attachment interaction scores obtained during a feeding observation.

Developmentally Disabled Infants and Attachment Interaction.

Children with developmental disabilities are more likely to be deficient in the behavior that promotes and sustains interaction and reciprocity. Faced with the infant's lack of responsivity and extensive caregiving needs, a mother may become engaged in a cycle of diminished quality interactions with her infant (Able-Boone & Stevens, 1994). Bailey and Wolery (1984), Blacher (1984), Collins-Moore (1984) have suggested that the following characteristics of some childhood disabilities may impede the formation of parent-child attachment: the child's appearance, especially facial disfigurement, negative response to being handled; unpleasant crying; atypical activity level; high threshold for arousal; no response to communication; delayed smiling; feeding difficulties; medical fragility; presence of medical equipment; life-threatening conditions; prolonged hospitalization and separation; impaired ability to vocalize; inability to maintain eye contact; and unpleasant behaviors, such as seizures.

Emde and Brown (1978) provide case histories of attachment processes with Down Syndrome infants: The baby's placid nature, inability to express needs normally, infrequent crying, and poor quality eye-contact all interfere with the reciprocity of early interactions. Cicchetti and Sroufe (1976) found that infants with Down Syndrome were significantly delayed in the onset of laughter, while Greenwald and Leonard (1979) found that Down Syndrome infants failed to use vocalizations in conjunction with coordinated object/person-oriented

gesti-

mary

ch'ol

and o

that

relat

199

proo

resou

fig

fig

ma

sec

able

range

con

stat

stat

stat

gestures. Several studies cited by Stahlecker & Cohen (1985) suggest that many disabled children display fewer attachment behaviors than nondisabled children, especially those behaviors requiring perceptual-motor coordination and/or gross motor skill. Stahlecker & Cohen (1985) conclude from their study that the extent of infant responsiveness may influence the quality of the relationship formed through interaction with the mother. Blacher & Bromley (1987) found that the child's mental age, rather than chronological age, was important in determining degree of maternal responsiveness. Mothers were more responsive to those handicapped infants with higher developmental levels.

In contrast, other studies on the development and quality of mother-infant attachment with deaf infants, with blind infants and with Down Syndrome infants, have consistently shown that attachment relationships between impaired infants and their mothers, though delayed, are demonstrable by the second year of life. Some studies have shown that even autistic children are able to develop secure attachments to their mothers (Shapiro, et al., 1987; Rogers, et al., 1991).

Clearly, the research indicates wide discrepancies regarding attachment in children with disabilities. Blacher (1984) sums up these discrepancies by stating that "for every study of very bizarre or impaired children in which attachment has been shown, there are others showing delayed, dulled, or complete lack of attachment in handicapped children" (p.14).

made

to the

rescue

term

1990

made

from

column

based

before

adjust

before

column

page

to the

July

the

the

the

Maternal Affect

It is generally accepted that maternal depression negatively influences maternal-infant interaction. Depressed mothers fail to experience and convey to their infants much happiness with life. Such feelings diminish responsiveness, and so depressed parenting may have short, as well as long-term consequences for infants (Lyons-Ruth, et al., 1986; Tronick & Gianino, 1986). It is also generally agreed that in the period following the birth of an impaired child, the mother's emotional response repertoire may be significantly diminished, and that the diminished repertoire may hamper development of optimal attachment relations (Stahlecker & Cohen, 1985). Encountering a disability generally precipitates a crisis and affects the entire family.

Immediate reactions may be those of shock, disappointment, and depression, with the family often following a fairly predictable series of stages of adjustment (Seligman & Darling, 1989). In their review of research on parental reactions to a diagnosis of child disability, Parker and Zuckerman (1990) found common themes: shock, denial and bewilderment. During the initial awareness stage, parents may be unable to comprehend the nature of their child's disability, no matter how sensitively or repeatedly it is explained. This may be part of an essential coping mechanism that allows parents to assimilate bad news gradually and continue to fulfill their day-to-day responsibilities. Many writers have suggested a similarity to the sequence of stages in the acceptance of death or dying -- namely, shock, denial, sadness and anger,

adap

Kran

mou

Notr

that

emot

years

198

sed

may

con

de no

norm

negat

dsas

1991

dag

same

the at

only

that

adaptation and reorganization (Seligman & Darling, 1989; Wright, et al., 1984; Krahn, 1983). Solnit and Stark (1961) developed a model of maternal mourning following the birth of a disabled infant that influenced later research. No time restraints were placed on the mourning process, but it was observed that mothers (and presumably fathers) proceed in order from dissociation to emotional disorganization to emotional re-organization over the early childhood years (See Hodapp, 1995, for a review.)

In contrast, a number of studies reviewed by Wikler, Waslow & Hatfield (1981) have suggested that the reactions and stages experienced by parents of disabled children are not necessarily experienced sequentially. Their reactions may, in fact, occur repeatedly, precipitated by various life crises and turning points. Olshansky (1962) has argued that parents of mentally retarded children do not ever completely abandon the grief process. Rather, he suggests the *normal* reaction to the birth of a child with a disability is *chronic sorrow*. More negative affect is reported among parents of school-aged children with disabilities than parents of children without disabilities (Margalit & Ankonina, 1991).

Pearl (1993) identified stages specific to parental reactions to the diagnosis of a developmental delay or disability in an infant: projection of blame, fear, guilt, mourning, withdrawal, rejection and acceptance. Pearl sees the ability to withdraw and collect oneself as a healthy, necessary quality. It is only when one begins to shun others, avoid situations, and maintain isolation that it becomes potentially damaging. She sees rejection as negatively

mea

recoo

and s

chic

to wa

one "

the a

reac

proce

the s

the s

an o

atta

osac

date

Cur

of de

of st

/st

refr

the

impacting attachment interaction, with some forms of rejection as failing to recognize positive attributes, setting unrealistic goals, escaping by desertion, and presenting a favorable impression to others while inwardly rejecting the child. Anger, therefore, a normal component of grieving, can be directed toward the disabled child (Shapiro, 1988).

While depression is a normal reaction to the birth of a disabled infant, one might conclude that there is a variety of emotional responses inherent in the acceptance process; and individuals vary in the amount of time it takes to reach acceptance. Some never reach acceptance while others revisit the grief process throughout the child's lifetime. The mother's own emotional history and the specific meanings that she projects onto the child may further complicate the specification of maternal emotional state (Hodapp, 1988). If depression is an ongoing maternal emotion, it is likely that the quality of mother-infant attachment will be affected.

There is far less research on the reactions of fathers to the birth of a disabled child. Though paternal affect will be not measured in this study, paternal beliefs are related to affect. A brief review, therefore, is important. Cummings (1976) found that fathers of retarded children exhibited higher levels of depression and impaired self-esteem. Lamb & Meyer (1991), in their review of studies of fathers' reactions, found that fathers are more affected by the visibility of the disability, presumably because of their great sensitivity to socially defined norms and evaluations. Furthermore, because fathers often have higher expectations for sons than for daughters, they are especially

usage

and

emot.

and

emot.

react

proce

the

can

be e

Emo

ries

devel

proce

then

the

pro

be a

are

the

disappointed when a son is diagnosed as having mental retardation. Damrosch and Perry (1989) asked mothers and fathers retrospectively to describe their emotional reactions since the birth of their child with Down Syndrome. Mothers and fathers differed in their reactions. Mothers more frequently described their emotions as up and down repeatedly, whereas fathers reported early emotional reactions followed by later acceptance.

Parental Beliefs

Beliefs regarding disabilities in general are likely to affect relational processes between mothers and their developmentally disabled infants. Very little consideration has been given in the literature to maternal beliefs, particularly concerning the mother's historical view of disability and her current beliefs about handicaps in relation to her own developmentally disabled child. Employing an ecological perspective on the family, Gallimore, et al. (1989) investigated the different "social constructions" held by families with developmentally disabled children. They noted that some families believe their priority to be that of the impaired child, doing all they can in terms of intervention, while others felt their nondisabled children should receive more time and attention. To Gallimore, et al., the meaning of this event and circumstance in the family is the most important influence on the family's behaviors and how these behaviors are interpreted by each family member. In a review of literature by Able-Boone and Stevens (1994), it was found that the mothers who sought meaning for their situations experienced less distress.

Thas

not a

child

Shas

rega

her n

offer

found

beac

to no

ge

same

expe

Sub

ge

con

know

asac

to be

to be

These mothers tried to understand their child's condition and how it may or may not affect the family. It has been shown that perceptions of implications of the child's disability by family members, greatly influence their ability to cope (Shapiro, 1988; McCubbin & Patterson, 1983).

In addition, beliefs held by the father, as perceived by the mother, regarding the infant's disability may be relevant to the mother's interaction with her infant. Though we have almost no information regarding the impact of differing parental beliefs on the maternal-infant relationship, Frey, et al. (1989) found that mothers whose spouses had a more positive view of the child became more positive themselves. Fathers' acceptance of the disabled child is found to be instrumental in family acceptance (Pearl, 1993; Lamb & Meyer, 1991).

Before their children are born, most parents of disabled children hold the same stigmatizing views of the disabled that others in society hold. The experience of giving birth to and parenting a child who is "different," however, usually has a profound effect on parents' beliefs, values, and attitudes (Darling, 1991). Parents enter the birth situation, then, with a particular base of knowledge, attitudes, expectations, and hopes. They possess varying degrees of knowledge about disabilities and various attitudes toward people with disabilities.

A family's culture often shapes the beliefs they hold about disabilities and parenting. Richardson (1970) and others have shown that almost all groups in the population have negative attitudes toward the physically disabled,

and C

nega

pare

with C

the r

Barso

Para

onior

they

seem

order

perce

hard

hard

the or

feeling

now

frag

this

sign

and Gottlieb (1975) and others have shown that the mentally disabled are also negatively labeled in our society. During the prenatal period, then, most parents dread the possibility of giving birth to a disabled child. When a child with disabilities is born, the parents must both respond to the birth and confront their beliefs about disabled persons (Seligman, M., 1991).

Not all parents share the same perception of severity of the handicap. Barsch (1964) asked parents to rank order a number of handicaps for severity. Parents of cerebral palsied, organically brain damaged, and Down Syndrome children tended to rate other problems as more serious than their own, although they still ranked their own problem relatively high in seriousness. This finding seems to indicate that while parents as a whole have a general sense of a rank order of seriousness of disabilities, they tend to soften in seriousness that perception in relation to their own child. Perhaps, over time, living with a handicapped child normalizes the experience for these parents. On the other hand, parents may be defending against acknowledgment of the seriousness of the problem by changing their perception, and thus, experiencing less stress.

Leskinen (1994) found in his study of disabled children, aged 2-8, that feelings of guilt and other-blame were not significant predictors of maternal involvement with the child. Rather, the expectancy of the child's developmental progress predicted directly the higher degree of involvement with the child. This was not true for fathers, however; and guilt on the part of the father was a significant positive predictor of level of paternal involvement. The parents'

hope

the c

amon

enna

would

1986

hand

stron

Dow

asso

with

care

more

of the

deve

and

nowe

stres

of the

hopefulness was the most significant predictor of their level of involvement with the child as well as their emotional adjustment.

Positive beliefs can be conceptualized as “internal supports.” Included among “internal” supports are those family and personal characteristics that enhance coping in stress and recovery following crisis. Such internal resources would include concepts such as self-esteem, hope, and spiritual beliefs. Cook (1963) found that differences in diagnostic category and severity of the child’s handicap correlated with differences in child-rearing attitudes. He found a strong authoritarian and more punitive trend among mothers of children with Down Syndrome and cerebral palsy. Parental rejection was more likely to be associated with a mild handicap, while parental overprotection was associated with more severe conditions. Bailey & Simeonsson (1988) state that the parents’ perceptions of the child’s behavior and characteristics are probably more powerful determinants of parent-child interactions than any assessment of the infant.

Stress

The earliest parenting research (in the 1960’s and 1970’s) of families of developmentally disabled children were “pathology focused,” with the disabled child the cause of divorce, role tensions and stuck family cycles. Gradually, however, researchers have shifted their focus to the presence of the child as a “stressor” on the family system (Crnic, et al., 1983). Throughout the literature of the 1980’s, authors refer to the diagnosis of childhood or infant disability as

synon

defin

since

with t

sever

disab

cons

stres

stud

relat

to w

facto

trare

sourc

exper

eve

stadi

com

perso

care

res

synonymous to a family crisis. According to McCubbin and Patterson's (1983) definition of a crisis, the birth of a disabled child can be described as a "crisis," since the stressor is extreme, very few families have existing resources to deal with this unexpected event, and most families would identify the stressor as severe.

Bailey & Simeonsson (1988) believe that, at the least, the birth of a disabled child creates a stressor that has both physical and psychological consequences for individuals and families. They conclude that ultimately, stressors must be evaluated in terms of their effects on families. They found studies documenting that seriously stressful events may bear a direct relationship to subsequent illness and health status after the event. The extent to which stress is experienced varies according to a number of factors. Child factors such as temperament, caregiving demands, rhythmicity, behavioral characteristics, severity of handicap, and type of handicap constitute one source of variation in stress. A second source of variation in how stress is experienced is individual and family factors, such as personal belief systems; level of psychological functioning; age of parents; economic resources; and support from extended family, friends, neighbors, and professionals. Active coping, rather than avoidance, positive family relations, and opportunities for personal growth are all important for positive affect in the face of stress for parents of disabled children (Margalit & Ankonina, 1991).

While research generally supports stress as an ongoing factor in the lives of family members when a child is disabled, McCubbin and Patterson

136

adap

stra

crs s

dema

a'ian

phys

one

tera

isab

level

W...

of ce

fare

Ter...

na

scu

Scu

Str

(1983) identify a factor which appears to influence the course of family adaptation to a stress or crisis over time: the pile-up of additional stressors and strains. If a family experiences strains prior to or following the occurrence of a crisis, these strains are exacerbated and families become aware of them as demands in and of themselves. The number of additional strains and stressors a family with a developmentally disabled child experiences is likely to affect physically and psychologically the various dimensions of their relationships with one another.

Maternal Perceptions of Support by Partner

It has previously been demonstrated that there is evidence in the literature for the fact that additional stress is placed upon the caregivers of disabled infants. Mothers of preschool handicapped children revealed higher levels of reported stress compared to families with nonhandicapped children (Wilton & Renaut, 1986). In a study by Bailey & Simeonsson (1988), mothers of developmentally disabled children reported twice as many support needs as fathers.

There also is evidence in the literature that maternal satisfaction with the marital relationship is important to the mother's interaction with her *normal* infant. It is also generally accepted that *marital satisfaction* is directly related to spousal perceptions of support given by the partner. In studies relating social support to pregnant mothers, it was found that mothers who had access to stronger social networks during their pregnancy reported lower levels of stress,

anxiety

attitude

more

(On the

Wings

material

there's

however

offers

appears

Fredrick

her spouse

of the

structure

Western

space

service

process

philosophy

Teaching

Association

offer

anxiety, and depression, a better marital adjustment, and a more positive attitude toward their pregnancy. Support from the husband was found to be more effective than that from friends, neighbors, or relatives outside the home (Crnic, et al., 1983). Conversely, in a study of maternal stress by Honig and Winger (1997), it was discovered that having a mate in the home did not reduce maternal stress. Only 60% of married mothers of disabled preschoolers listed their spouse as a member of their personal support network. Little is known, however, about how this process of spousal support acting as a buffer to stress differs with respect to the developmentally disabled infant-mother dyad. It appears that maternal marital satisfaction is also important (Beckman, 1983; Friedrich, 1979) to the mother's assessment of the support she receives from her spouse.

Lamb & Meyer (1991) reviewed a few of the studies addressing the roles of fathers: Fathers tend to perceive diagnosis of the disability as an instrumental crisis and are concerned about the cost of providing for the child, whether the child will be successful, and whether the child will be able to support himself or herself in the future. Mothers, on the other hand, tend to perceive the diagnosis as an expressive crisis and are thus especially concerned about the emotional strain of caring for the child and about the child's ability to be happy. Fathers are more concerned than are mothers about the adoption of socially approved behavior by their children, regardless of disability, as well as the social status and occupational success of their offspring. Therefore, fathers are more concerned about long-term implications

of the

found

Bonnie

that th

intera

nded

their p

are ch

booka

W. J. C.

-by v

Alarm.

secu

Percep

involv

the av

Parent

and fa

Success

Side

Since

of the disability than are mothers. When compared to mothers, fathers were found to have more difficulty accepting a son with a mental handicap (Price-Bonham & Addison, 1978) or physical disabilities (Tavormina, et al., 1981.)

In the attachment literature with normal children it has been concluded that there are characteristic differences between maternal and paternal interaction styles, which ensure that mothers and fathers have distinct and independent influences on their infants' development. Fathers are noted for their playfulness -- particularly physically stimulating play -- whereas mothers are characteristically associated with caretaking and more conventional, "containing" modes of play (Lamb & Meyer, 1991). The most common way in which fathers influence attachment behaviors of their normal infants is indirectly -- by way of influence on their wives. When the relationship between parents is warm, fathers provide the emotional support that facilitates the formation of secure and stimulating infant-mother relationships. The importance of maternal perceptions of spousal support would depend not only on the father's involvement in child rearing but also the way in which he attributes meaning to the event.

Parental Congruency of Beliefs Surrounding the Birth:

There seems to be nothing in the literature that would tie the mother's and father's shared perceptions of the birth to mother feeling emotionally supported. Nor is there anything in the developmental disability literature that studies the effects on maternal-infant attachment when parental beliefs concerning the infant are incongruent.

devel

var at

addi

s rfi

the di

attach

same

stat

Barra

relat

resco

found

estat

stat

stat

stat

stat

stat

stat

stat

Marital Satisfaction

This study will investigate the direct relational outcome of the birth of a developmentally disabled infant on the marital relationship. This outcome variable has a natural correspondence with all other aspects of the study. In addition, there still is no consensus in the literature whether marital satisfaction is influenced by the birth of a developmentally disabled child.

Belsky, et al. (1984) note that all marriages tend to deteriorate following the birth of a baby. They found that mothers of both securely and insecurely attached infants rated marital quality at 3 months following birth about the same; but by 9 months, ratings of mothers of securely attached infants stabilized, whereas those of insecurely attached infants continued to decline. Barnard and Eyres (1979) found in their study of 200 families that a good relationship between parents correlated with the mother's involvement and responsiveness with the infant.

Wright, et al. (1984) state that the crisis of a disabled infant's birth was found to have the potential for either bringing the parents closer together and establishing mutual support or estranging the parents from one another. Parents who were able to communicate their feelings and provide support for each other during the crisis were able to adapt more successfully to the child's birth than those who could not communicate and who eventually separated. Blacher (1984) states that the literature abounds with studies of the negative impact of a disabled, primarily retarded, child on family functioning. She noted that these studies show the birth of a handicapped child affecting in a negative

way S

financ

rate c

gener

disab

much

are re

man

care

perce

family

been

Synd

over a

great

are d

in a

on n

the

the

way some or all of the following: the marital relationship, sibling relationships, finances, relationships with friends and relatives. Kazak (1986) estimated the rate of divorce of parents of diagnosed children to be twice the rate in the general population. However, Kazak defines "diagnosed" to include all disabilities experienced by children, some of which may be severe, requiring much more care than others. Dyson (1991) found that more severe handicaps are related to greater parental stress. Featherstone (1980) suggests that marriages are influenced by stress of a disabled child in the following ways: (1) parents can experience intense emotional responses; (2) the child may be perceived as a symbol of shared failure; (3) the organized structure of the family system can be restructured; (4) a potential area for marital discord has been generated. Gath (1978) found that parents deciding to keep a Down Syndrome infant at home led to marital problems in the first two years, but not over a longer time span. While it is not conclusive that marital discord is greater in these families, it is likely that the factors creating tension and discord are different.

Summary

While, by law, early intervention services are now being provided to families with children born with developmental disabilities, and these services now include counseling as a focus of parenting, most of the research has been in the area of maximizing the cognitive and physical functioning of the infant. This review of literature reveals that very little is known about what might

influe

devel

the be

family

stor

natur

metno

disab

also b

secu

exper

attach

is sim

knowl

chanc

influence the process of mother-infant attachment interaction when an infant is developmentally disabled. This information is notably missing with regard to the beliefs of the parents about the disability and what the future holds for their family. The very early stage of family adjustment when a less-than-perfect child is born has seldom been studied, except retrospectively, due to the sensitive nature of this process. In addition, the few studies found in the literature had methodological flaws – namely, not controlling for infant age and type of disability.

It is known that some families seem to adjust better than others. It has also been determined that most of these infants have been shown to be securely attached in toddlerhood. However, other families continue to experience severe stress that seems to affect the development of the mother's attachment to the infant, and contributes to a lessening of marital satisfaction. It is important for counselors and therapists to be able to draw from a strong knowledge base in their ability to partner with these families toward continuing infant and family growth.

object

demo

infant

follow

1. The
the
at

2. The
so
qu

3. The
qu

4. The
re

5. The
so
le

6. The
em
le

CHAPTER III

METHODOLOGY

This chapter presents the research design including the research objectives and the method of data collection. The sample is described on demographic variables, which include size of family, characteristics of the infant, and the age, income and education of the parents

Research Objectives

The objectives of this exploratory study were met by examining the following:

1. The relationship between the level of functionality of maternal beliefs about the infant's developmental disability and the quality of the mother-infant attachment interaction.
2. The relationship between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the quality of her attachment interaction with her infant.
3. The relationship between the mother's level of marital satisfaction and the quality of the mother-infant attachment interaction.
4. The relationship between the level of functionality of maternal beliefs about the infant's developmental disability and her level of marital satisfaction.
5. The relationship between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the level of her marital satisfaction.
6. The relationship between the mother's level of satisfaction with the emotional and instrumental support she receives from her partner and her level of marital satisfaction.

7. The relationship between the level of functionality of paternal beliefs about the infant's disability and the father's level of marital satisfaction.
8. The difference in the level of functionality of parental beliefs between Time 1 and Time 2 (three months later).
9. The difference between the mother's level of satisfaction with the support she receives from her partner between Time 1 and Time 2.
10. The difference between mothers and fathers on their levels of marital satisfaction at Time 1 and Time 2.
11. The difference between Time 1 and Time 2 on levels of marital satisfaction for mothers and fathers.
12. The differences on the quality of maternal-infant attachment interaction between Time 1 and Time 2.

(A diagrammatic conceptual model for these objectives can be found in Figure

1.)



Time 2



Time 1



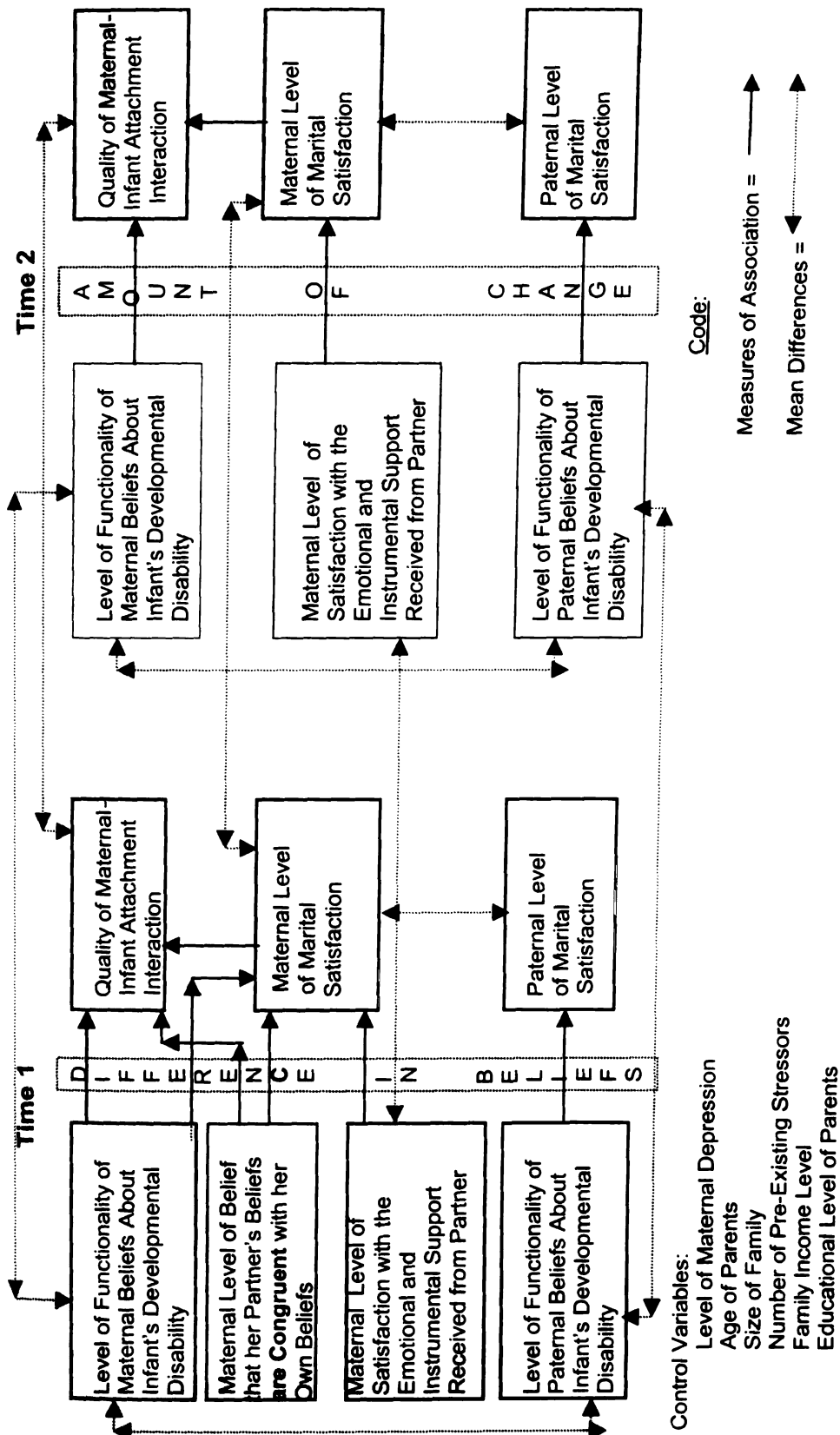


Figure 1. Conceptual Map
Parental Beliefs: Their Influence on Marital Satisfaction
And Maternal-Infant Interaction When a Developmentally Disabled Infant is Born

exotic

research

care

and to

long

mont

purpose

most

the p

samp

midw

comm

advoc

some

state

under

know

the c

and

at m

Research Design

In order to carry out the objectives most effectively, a descriptive exploratory study was designed, incorporating both qualitative and quantitative research methodologies. It was descriptive of those factors that influence parents of developmentally disabled infants in their levels of marital satisfaction, and the quality of maternal-infant attachment interaction. The study design, a longitudinal three-month study, began when the infants were three or four months old, with assessment at that time and again three months later. A purposive sample of 12 families with a developmentally disabled infant four months old or younger and cared for in the parents' home was recruited where the parents were married and living together in the home environment. The sample was obtained through early intervention service providers in a midwestern state and included residents of urban, suburban and rural communities. In addition, a chapter of The Down Syndrome Society, a parent advocacy group, promoted this study through newsletters and meetings, and some of the subjects were recruited through this organization.

Both quantitative and qualitative data were collected in the homes of the subjects. This research was developed for the purpose of enhancing the understanding of early interventionists and marriage and family therapists who work with families experiencing social and emotional transitions as a result of the birth of a developmentally disabled child. What is primary to this work is not simply the objective facts regarding behaviors relevant to marital satisfaction and mother-infant attachment interaction for this population. Equally important

is ga

migh

and w

The c

unde

elabo

Fres

dep o

lass:

ethn

is hop

obser

cont

Seve

The q

that

There

above

prev

Me

the

is gaining an understanding of parental beliefs about disabilities and what this might mean in terms of the process of adjustment for these families. Numbers and words are both needed if we are to understand the world of these families. The qualitative interview data was seen as vitally important to a deeper understanding. The intent of the qualitative analysis, therefore, was to elaborate upon the quantitative analysis, thereby providing richer detail. Firestone (1987) suggests that qualitative research persuades through rich depiction and strategic comparison across cases, thereby overcoming the "abstraction inherent in quantitative studies."

There are various methods for obtaining qualitative data. True ethnographic research often begins with a "general" idea of what the researcher is hoping to find. As observations are made and themes noted, further observations are made for confirmation and/or revision purposes, and this continues until saturation has been reached and no new information emerges. Several designs have evolved from this basic ethnographic model that fit within the qualitative paradigm.

Most recently, many researchers have developed designs that link both qualitative and quantitative data. This study represents an attempt to do this. The researcher began by developing an interview guide (See Appendix D) that allowed for an open discussion of parental beliefs. Clearly, the researcher had previously developed a set of variables and knew the associations that she wanted to examine. However, she was open to additional information that might be elicited with regard to those variables in order to gain a deeper

under

num

each

anal

give

reco

quan

both

data

Qu

Varac

Page

poss

form

form

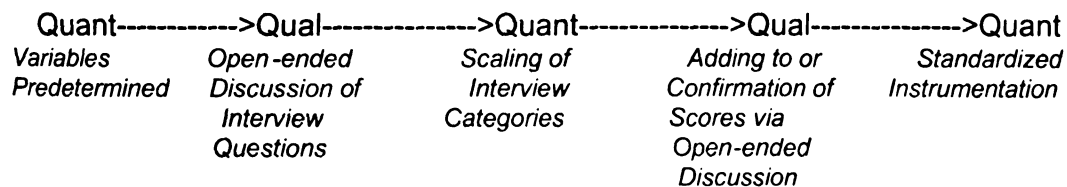
Page

Page

Page

understanding of those relationships. Then an attempt was made to elicit a numerical score from interview data based upon a scaling question following each category of beliefs. This numerical score was included in the statistical analysis. Further elaboration by participants was encouraged after they had given numerical responses to their discussions. All of the interviews were recorded through audiotape and later transcribed verbatim.

Finally, standardized instruments were administered to gather additional quantitative data. The same method of data collection was implemented for both Time 1 and Time 2. This linkage between the quantitative and qualitative data analysis for this study can be conceptualized as follows:



Sampling Procedures

Due to the nature of the study sample and the expected scarcity of possible subjects, a nonprobability purposive sampling design was conducted. For this reason, as well as the sample being limited to two-parent intact families, this study cannot be generalized beyond the sample nor to single-parent families. The study is also not generalizable to primary caregiving fathers.

Recruitment of subjects took place over an 8-month period of time, which was necessary to obtain twelve subject families. Early intervention

servi

telep

to m

stee

ask

instr

conf

from

nves

explor

ation

Dow

care

a Do

nves

at me

mar

the

the n

stac

nves

corst

service providers were contacted by newsletter, training sessions, and telephone calls to inform him/her of the nature of the study and to ask him/her to make initial contact with eligible families. These providers were given specific verbal instructions on how to approach the family for the purpose of asking if they might be interested in participating in the study. They were instructed to mention the merit and nature of the study, the assurance of confidentiality, and to ask if the parents would be willing to receive a phone call from the primary investigator who would further explain the study. The primary investigator was in weekly phone contact with each service provider who expressed willingness to recruit subjects until all needed subjects gave approval for participation in the study.

In addition, the primary investigator was in contact with a chapter of the Down Syndrome Association for their assistance in similar recruitment. This parental support organization is usually informed by the hospitals of the birth of a Down Syndrome infant for the purpose of early parent contact. The investigator submitted newsletter recruitment articles and made presentations at monthly meetings of this organization. Families of developmentally disabled infants aged 4 months or younger were eligible for participation in the study, if the infant did not have a terminal prognosis, if the infant was being cared for in the home environment, and if the parents were married and living together. An attempt to recruit both parents into the interview process was made by the investigator. However, three fathers declined to be interviewed due to time constraints. Two fathers did not complete the Dyadic Adjustment Scale at Time

1. ho

Time

infan

prog

from

quan

matr

men

Time

subs

comp

add

Ther

Time

and

and

insol
Pepe
the
the

1, however; and one of these two fathers did not complete this instrument at Time 2. At the time of interviewing one family, it was discovered that their infant had a genetic disorder that involved severe multiple impairments and prognosis was terminal at childhood. This family was subsequently dropped from the study. Therefore, a total of eleven subject families were part of the quantitative analysis, with interview data collected from eleven study participant mothers and eight fathers. Even though only eight fathers were present at both interviews, one of the three absent fathers joined us for part of the interview at Time 1¹. Thus, his scores are included in data on two of the interview subscales (Hope and Meaning/Purpose). In addition, this father was willing to complete the Dyadic Adjustment scale at Time 1 and Time 2, and one additional father completed this measure of marital satisfaction at Time 2. Therefore, The Dyadic Adjustment Scale was completed by eleven mothers at Time 1 and Time 2, and nine fathers at Time 1 and ten fathers at Time 2.

Sample Description

Descriptive univariate statistics were computed to describe the sample and the distribution on each of the demographic variables. In the computer analysis, the sampling mean was computed to give the average of the scores

¹In spite of the fact that the researcher had difficulty getting fathers to participate in the study, the percentage of fathers recruited was considerably higher than the 30% expected response rate. Most researchers expect a much higher response from mothers than fathers in parenting couples studies.

on ea

comp

mem

nd ce

chidr

from

Here

riant

Die n

Has C

Four

Here

on each of these variables. Both the standard deviation and range was computed to determine the variability of the sample characteristics.

Family Size: Subject families, all Caucasian, ranged in size from 3 members to 6 members, with an average family size of 4.27 members. This indicates that the average subject family consisted of 2 adult parents and 2.27 children, which includes the developmentally disabled infant. (See Table 1.)

Table 1
Family Size

Family Size	<u>N</u>
3	3
4	3
5	4
6	1

Mean = 4.27
S.D. = 1.01

Infant Characteristics: All infants were full term and ranged in age from 3 months to 4 ½ months at the time of the first observation. Five infants were 3 months old at Time 1, three infants were 3 ½ months old, and three infants were 4 ½ months old. Six infants were boys and five were girls. Ten of the infants were diagnosed with Down Syndrome soon after birth and one infant was diagnosed with Prader Willi Syndrome within one week following birth. Four of the Down Syndrome infants were found to have heart defects, which were surgically reparable.

and

35. 1

with

born

upper

age

1. 35

age

born

with

age

age

age

Age of Parents: The oldest mother was 42 at the time of the first visit and the youngest mother was 27. The average age of all subject mothers was 35. However, four of the mothers were 39 or older; and this, being consistent with the findings for the occurrence of chromosomal abnormalities of infants born to mothers in the general population, skews the average age toward the upper end of the range. Fathers' ages ranged from 28 to 40, with an average age among all subject fathers being 34. (See Table 2.)

Table 2
Age Distribution of Parents

<u>Mothers</u>		<u>Fathers</u>	
Age	N	Age	N
27-30	2	27-30	3
31-34	4	31-34	3
35-38	1	35-38	2
39-42	4	39-42	3

Mean = 35	Mean = 34
S.D. = 5.23	S.D. = 4.45

Family Income: Family income is an ordinal variable with eight evenly divided categories. The range of income categories for the subject families extended from the \$30,000 - \$44,999 annual income category to the highest income category, which was \$120,000 and above. The mean income was 4.64 which is within income Category 4 (\$60,000 - \$74,999). Mean income is, therefore, \$69,149. However, since three families indicated that they were in the "\$120,000 and above" income Category 8, we cannot know the exact mean, since we are unable to determine how far "above" the \$120,000 base for

Gate

fam

Table

variab

range

gradu

failing

school

Gate

75 for

colleg

study

Category 8 these families received in annual income. In addition, since three families fell within Category 8, income is skewed toward the higher end. (See Table 3.)

Table 3
Annual Family Income

Income Category	<u>N</u>
1. less than \$15,000	0
2. \$30,000 - \$44,999	2
3. \$45,000 - \$59,999	3
4. \$60,000 - \$74,999	1
5. \$75,000 - \$89,999	2
6. \$90,000 - \$104,999	0
7. \$105,000 - \$119,999	0
8. \$120,000 and above	3

Mean = 4.61 (\$69,149)

S.D. = 2.38 (category)

Median = Category 4 (\$60,000 - \$74,999)

Parent Level of Education: Parent level of education is an ordinal variable, and subject mothers had minimum educational levels falling within a range of high school completion (Category 4) to completion of a University graduate degree (Category 9). Subject fathers had minimum educational levels falling within a range of high school completion and some technical or trade school education (Category 5) to completion of a University graduate degree (Category 9.) The mean category of education level for mothers was 7.18 and 7.3 for fathers. These means fall within Category 7 – indicating that 2 years of college have been completed. Seven mothers and four fathers had at least four-year-college degrees. The median for mothers was Category 8 (four years

of col

This g

secul

ratio,

reserv

assess

retrie

the re

of college) and the median for fathers was Category 7 (2 years of college).

This group, with its high levels of education, is not representative of the larger population. (See Table 4.)

Table 4

Parents' Highest Education Attainment Levels

Mother's Education		Father's Education	
Category	<u>N</u>	Category	<u>N</u>
4. High School	1	4. High School	0
5. High School plus trade or technical school	1	5. High School plus trade or technical school	1
6. Some college	2	6. Some college	2
7. Two-year college degree	0	7. Two-year college degree	3
8. Four-year college degree	5	8. Four-year college degree	2
9. University graduate degree	2	9. University graduate degree	3

Mean = 7.18 (2 years college)
Median=8 (4 yrs. College)

Mean = 7.3 (2 years college)
Median=7 (2 years college)

Data Collection Procedures

The setting was natural, with all data collected in the homes of the participants. The primary investigator made all home visits and direct observations of mother and infant interactions, and also administered all assessment measures and conducted interviews. When conducting focused interviews, the interviewer used an interview guide, but within this framework, the interviewer had considerable flexibility. Each interview was, therefore,

tailor

cover

quest

respo

this w

flex b

and n

provid

and s

Wing

the fa

gal w

patio

phone

festivi

Age

Each

respo

was

inter

percep

tailored to the particular family situation. However, after each subtopic was covered through open-ended questions and responses, the related subscaling question followed. The interviewer found, true to open-ended questioning, that respondents summarized entire topics in one long sequence of statements, and this was allowed. These are the characteristics that contribute to the great flexibility of the focused interview, making it possible to obtain breadth, depth, and richness of information. At the same time, the use of an interview guide provides a degree of structure to the interview. This combination of flexibility and structure supports the focused interview.

Within a few days of receiving notification from a service provider that a willing participant family was available, the investigator made a telephone call to the family and mailed a letter of explanation about the study. A followup phone call was made a week later to determine if the family was committed to participate and an appointment scheduled for the first visit. At the second phone call, only one family declined to become a participant. At the time of the first visit, participants were asked to sign the letter of explanation and consent (Appendix B) and complete the Demographic Data Questionnaire (Appendix C). Each of the interviews for all study group participants was conducted with respect to the format previously described, as indicated by the interview guide. It was also recognized that topics introduced by the respondents could be further explored if the interviewer felt this important to elucidating and clarifying perceptions relevant to this study. All interviews were audiotaped and

trans

sepa

tree

emp

faire

for e

ques

diag

sign

fam

Scal

farc

Depn

men

telet

See

areg

ment

teat

tein

Dyad

transcribed verbatim for use in discussion of the study results. The two separate visits are discussed as follows:

Time 1: At the time of the first interview, when the infant was between three and five months of age, both parents were interviewed together, empathically, in a focused, open-ended interview format. However, since fathers declined to be interviewed in three cases, joint interviewing took place for eight families and mother-only interviews occurred with three. Interview questions were focused on the birth experience, their reactions to the diagnosis, previous experience with developmental disability and reactions of significant others. It was deemed important to establish rapport with the families at this time. Both parents were administered the Dyadic Adjustment Scale in nine of the cases. (Eleven mothers completed this instrument at Time 1 and nine of the fathers.) In addition, the mother was given the Beck Depression Inventory, and the FILE. Each parent who participated in the interview was then interviewed separately regarding his/her feelings and beliefs, as outlined in Sections C, D, and E of the Interview Guide for Time 1. (See Appendix D.) An infant feeding observation took place during this visit at a regularly scheduled feeding time.

Time 2: This conjoint and individual interview session took place three months after the first interview, when the infant was between six and eight months old. The technique for interviewing was similar to that of Time 1, with the Interview Guide for Time 2 (Sections F and G) being used. In addition, the Dyadic Adjustment Scale was completed by eleven mothers and ten fathers.

Time

inter

Appe

Diad

Auth

satisf

quali

DAS

score

resear

respo

less s

1993

answ

DAS

thre

respo

State

pro is

Time 2 was expected to elicit any changes in responses from the previous interviews, as well as change in attachment interaction during feeding.

The table depicting this data collection schedule can be found in Appendix A. It was possible to stay very close to the schedule as outlined.

Instrumentation

Dyadic Adjustment Scale (DAS)

Author: G.B. Spanier, 1976. This instrument was used to measure relational satisfaction of both parents. This 32-item instrument is designed to assess the quality of the relationship as perceived by married or cohabiting couples. The DAS was developed on a sample of married and divorced persons. The mean score on the total DAS for the married sample was 114.8 (*SD* 17.8). The research literature provides no evidence of differences in men's and women's responses to the Dyadic Adjustment Scale (Spanier, 2001). A score of 100 or less suggests that the couple's relationship is distressed (Spanier & Filsinger, 1983). The higher the score, the better the perceived adjustment by the person answering the question.

The DAS has excellent internal consistency with an alpha of .96. The DAS has shown known-groups validity by discriminating between married and divorced couples on each item. The instrument also has evidence of concurrent validity, correlating with the Locke-Wallace Marital Adjustment Scale. This instrument was selected based upon its acceptability in the field and its familiarity to the investigator.

Beck

Autho

extens

cognit

statist

osyon

al. 19

Culof

depre

mode

nstru

sa o

ts ge

Nurs

Autho

ctse

a dep

of pa

sets

the p

cogn

part

conta

Beck Depression Inventory - Short Form

Authors: Beck, Ward, Mendelson, Mock & Erbaugh, 1961. This is an extensively used 21-item self-report measure that assesses current affective, cognitive, motivational, and physiological symptoms of depression. Test-retest stabilities of the BDI have been reported to range from .48 to .86 among psychiatric patients and from .60 to .83 among nonpsychiatric subjects (Beck et al., 1988) Split-half reliability of the scale has been found to be high (.86-.93). Cutoff scores have been established, with 0-9 reflecting no or minimal depression, 10-18 reflecting mild to moderate depression, 19-29 reflecting moderate to severe depression, and 30-63 reflecting severe depression. This instrument was used to measure depression levels for mothers, and depression is a control variable for the study. It was chosen by the investigator based upon its general acceptability in the field and the ease of its administration.

Nursing Child Assessment Feeding Scale (NCAST - Feeding)

Author: Barnard (1979), revised for greater clarity of reading in 1994. This observational scale was used to assess maternal-infant attachment interaction, a dependent variable for the study. This rating scale assesses four categories of parent behavior in a feeding situation. These categories are the parent's sensitivity to the child's cues, the parent's ability to alleviate the child's distress, the parent's social and emotional growth fostering activity, and the parent's cognitive growth fostering activity. The categories of the infant are the infant's clarity of cues, and the infant's responsiveness to the caregiver. The scale contains multiple items for a total of 76 items (Barnard, et al., 1983). For data

analy

analy

total

attac

contr

The r

relac

deme

base

Feed

valid

Mun

meth

score

mea

norm

eng

posi

with

Acce

owe

analysis, the four ordinal subscale scores were totaled and the sum used to analyze the mother's interaction with her infant. In addition, the mother/infant total (6 subscales) was used to determine the quality of the mother/infant attachment. The two infant subscales were also summed to determine the contribution of the infant to the mother/infant total at both Time 1 and Time 2. The reliability estimates of the subscales are 0.86 and there is a higher reliability for the total score than for the subscales. Validity has been demonstrated by a significant correlation of .54 with the HOME. The scale is based on the theory of Child Health Assessment Interaction. The NCAST - Feeding reportedly has the most complete information concerning reliability and validity and is an excellent choice in terms of these two important features (Munson & Odom, 1996).

The NCAST Feeding Scales were divided into (a) the total score of the mother, (b) the total score of the infant, and (c) the combined total feeding score for mother and infant. The creators of the NCAST Feeding Scales give means for various ethnic groups, as well as for level of education. Infants in the normed population ranged in age from 1 to 12 months, with an average age range between 5 – 6 months. They found the mother's level of education to be positively correlated with feeding interaction scores, but found no differences with regard to ethnicity. Age was strongly correlated with level of education. Adolescents were found to have the lowest scores on the scale and also the lowest levels of education.

Time

during

was O

to see

reliab

this n

shoul

upon

edit

Fam

Autu

repor

every

to me

were

the de

acros

Opera

Fam

to + 2

In order to obtain a valid score from just one feeding observation for both Time 1 and Time 2, the researcher called the study participant's home early during the day of observation to determine what feeding schedule the infant was on for that day. This enabled the observer to plan her arrival at the home to score what was determined to be a regular feeding time.

Training on this instrument is 16 hours or more until an interrater reliability of .85 is reached. This investigator has been trained to reliability on this instrument. This scale is widely used to identify children and families who should be referred for intervention. It has appeal to the investigator based upon its practicality of use. It does not require videotaping for the scoring of additional raters, which is often felt to be intrusive to many mothers.

Family Inventory of Life Events and Changes (FILE)

Authors: McCubbin, Patterson, and Wilson (1982). The FILE is a 71-item self-report instrument designed to measure the "pile-up" or sum of nonnormative life events and changes experienced by a family unit in the past year. It was used to measure the control variable, "Number of Stress Pileup Factors." Mothers were asked to respond by checking whether or not each event occurred within the past year. National norms were based on approximately 980 couples across the family life cycle, from young married couples to retired couples. The overall scale reliability was .85. Correlations between the FILE and the Moos Family Environment Scale ranged from $-.42$ to $+.42$ for subscales and from $-.24$ to $+.23$ on the total scale score. This scale was selected based upon the

cons

def'n

Inter

rega

inter

infra

with

instr

autn

infra

tele

inter

in ad

ques

has

inter

tec

form

even

even

even

constructs that it measures, which closely correspond to the operational definitions of this variable.

Interviews

Although the interviews are not standardized instruments, information regarding the interviews may be helpful for the reviewer at this point:

The interviewer/investigator used a combined open-ended and focused interviewing technique inquiring about (1) parental beliefs surrounding the infant's birth, (2) maternal perceptions of the congruity of her partner's beliefs with her own, and (3) maternal perceptions of her partner's emotional and instrumental support. The focused interview has been described by many authors (Bailey & Simeonsson, 1988) to be particularly well suited when information is sought about complex, emotionally laden topics or about values, beliefs, or attitudes underlying an expressed opinion or behavior. These interviews were audiotaped and transcribed primarily for discussion purposes. In addition, parents were asked to summarize their answers to the open-ended questions by scoring their beliefs and feelings on a 5-point Likert-type scale that was created by the investigator. The procedure for conducting the focused interviews and the interview guides are discussed in the section entitled "Techniques of Data Collection." Also refer to the Interview Guide and Scaling Format in Appendix D. The interview guide was given to a panel of two child development professionals and three parents of children with disabilities for review and approval. Approval was obtained from all three parents. One professional gave approval and also gave suggestions for future use of this

meas

exam

It was

contr

attach

devel

respe

lead

devel

of this

these

thera

devel

stress

ass s

early

social

devel

age

measure. The second professional gave approval contingent upon closer examination of this study. She did not have an opportunity to do this, however. It was then decided that a requisite number of critiques had been obtained to contribute to the face validity of this measure.

Study Contributions and Limitations

This study will contribute to existing knowledge of parent-infant attachment formations, and, more specifically, to the attachment interaction of developmentally disabled infant-mother dyads, which may differ in many respects from the normal mother-infant dyad. Since attachment interaction leading to quality of later attachment influences later child and family development psychologically, socially, and cognitively, a better understanding of this interactive process is important to the enhancement of functioning in these families. This study may have strong implications for the work of family therapists. It may enable them to design clinical interventions to enhance developmentally disabled infant-mother interactions when that interaction is stressed. In addition, the knowledge gained through this study can help them assist families where the marital relationship is in distress, and is likely to assist early intervention specialists in designing early intervention programs for these special needs families.

This study is limited in its focus on two-parent intact families of developmentally disabled infants. This family structure, of course, excludes a large population. It is hoped that some of those “meaning” variables that were

de:
po:
sig:
ma:
the
ach
de
fat
st:
oc:
ca:
an
s:
to
the
m:
m:
st:
n:
e:

determined to be significant, can be applied to future studies with a broader population. It may be possible to develop instruments for which those significant meaning variables can be operationalized.

It is also acknowledged that this study is limited to the study of maternal-infant attachment interaction. Society is changing from its traditional views of the mother as exclusive primary caretaker of the children, and more men are acknowledging this to be their role in the family. However, while societal ideology changes more rapidly than actual practice, it is still the case that fathers represent a very small percentage of primary infant caregivers. A future study with male representation in the primary caregiver sample may be possible, given the increasing numbers of fathers who are becoming primary caregivers.

This study is also limited by examining *very early* attachment interactions and the processes that influence the infant-mother attachment formation over a six-month period. While this is an important phase of the attachment process, it does not explain possible additional factors to this process occurring when the child enters other developmental stages. It is the desire of the primary investigator to continue her investigation with these families over the course of time. Therefore, this is anticipated to be the beginning of several additional studies examining the attachment process with special needs families.

The study is also limited in its population generalization by the small numbers of participants included. It is beyond the scope of the study to include large numbers of participants, but justification can be made for this factor based

up

of

in

with

me

ge

the

far

upon the nature of the population. It would be difficult to recruit large numbers of two-parent families with infants diagnosed with developmental disabilities at birth due to the incidence of these occurrences in the midwestern area from which the sample was recruited. A future study might include more metropolitan populations for a larger sample selection.

In addition, the characteristics of children in the sample limit generalization only to families with infants disabled from developmental delays that are diagnosed at birth. The study results may not have application to families of infants with other types of disabilities.

var

pre

sla

de

De

of t

sa

Tal

sa

no

no

Ad

35

Tr

SC

CHAPTER IV

FINDINGS

This chapter will include, first, descriptive statistics on each of the study variables, excluding demographic variables on the sample, which were presented in the Sample Description, Chapter III. Following the descriptive statistics, this chapter will present quantitative findings followed by qualitative data findings for each of the research questions.

Descriptive Statistics of Study Variables

Descriptive univariate statistics were generated for the sample on each of the independent, dependent and control variables for the study. The sampling means and standard deviations are given, discussed and followed by Tables.

NCAST Feeding Scale: In this study, the families that comprised the sample were all Caucasian, all had completed high school, and the youngest mother was 27 years of age. This sample of mothers is similar to the sample norms described by the authors of the NCAST Feeding Scales as HighEd Adults, and those norms are shown in Table 5.

In the present study the mother's score for Time 1 (when the infant was 3-5 months old) ranged from 29 to 46, with a mean score of 39.27 (*SD* 4.73). The infant's score at Time 1 ranged from 5 to 21 with a mean score of 12.45 (*SD* 3.96). The combined mother-infant total score ranged from 40 to 67, with

a mean score of 51.45 (*SD* 7.17). These scores are lower than the scores for the normative sample. (See Table 5.) This could be explained by the fact that the feeding score in this study was between mothers who had infants younger than the mean for the normative sample. It might also be noted that, based on the researcher's observations, the infants' developmental interaction levels appeared to be lagging already at the Time 1 observation.

The mother's score at Time 2 (when the infant was 6-8 months old) ranged from 34 to 47, with a mean score of 39.36 (*SD* 4.46). The infant's score at Time 2 ranged from 12 to 21, with a mean score of 16.45 (*SD* 2.73). The combined mother-infant total score ranged from 47 to 65 with a mean score of 55.55 (*SD* 6.44). Again, these scores were lower than for the normative sample, but the increase in scores from Time 1 to Time 2 are likely to be reflecting the increased capacity of the infant to respond to the mother. Also, at Time 2 the infants were observed to have gained in their developmental ability to initiate interaction. See Table 5 for comparisons between the study sample means and the means for the normative sample.

M
In
To

S
S
S

T

ca

T

Se

S

a

m

as

te

7

Table 5
NCAST Feeding Scores for Time 1 and Time 2

	NCAST Mean for HighEd Group	Study Sample Mean Time 1	Study Sample Mean Time 2
Mother's Score	41.18	39.27	39.36
Infant's Score	20.20	12.45	16.45
Total Score	61.38	51.45	55.55
S.D. Mother	5.95	4.73	4.46
S.D. Infant	3.86	3.96	2.73
S.D. Total	8.74	7.17	6.44

Depression: Mother's depression was measured at both Time 1 and Time 2 by the Beck Depression Inventory. The following cutoff score guidelines have been determined for this instrument:

- (a) none or minimal depression = less than 10
- (b) mild to moderate depression = 11 - 17
- (c) moderate depression = 18 - 29
- (d) severe depression = 30 - 63

The mean Beck Depression Inventory scores for minimal, mild, moderate, and severe classifications, respectively, according to Beck (1967, pp. 196) are 10.9 (*SD* 8.1), 18.7 (*SD* 10.2), 25.4 (*SD* 9.6), and 30.0 (*SD* 10.4).

For this study, the range of scores for Time 1 was between 0 and 16 with a mean of 5.45 (*SD* 5.05). The range of scores for Time 2 was 0 to 9 with a mean of 4.45 (*SD* 3.5). Only two subjects scored high enough to be classified as minimally depressed at Time 1, and at Time 2 these scores were further reduced. Thus, at Time 2 depressive symptoms fell below the score for minimal depression.

Interviews with Mothers and Fathers Regarding Beliefs.²: The interviews included open-ended questions. After each group of related questions, a summary-scaling question was asked that yielded the level of functionality of the mother's and father's beliefs for that particular group of questions. All eleven subject mothers participated in the interview. However, at Time 1, two fathers declined to be interviewed (were not present at the interview), and one additional father was present for only a portion of the interview. All three of these fathers were unavailable for the interview at Time 2. The interview subscales that followed each group of related questions give more information than the total score. These subscales will be discussed below, followed by discussion of the total score for all the subscales. Since the interview scale was developed by this researcher, no norms have been established.

Subscale scores include: (a) mother's beliefs about disabilities prior to the birth of the disabled infant; (b) father's beliefs about disabilities prior to the birth of the disabled infant; (c) mother's belief in a purpose or special meaning for this birth; (d) father's belief in a purpose or special meaning for this birth; (e) mother's early birth experiences, including her early emotional reactions and information resources provided her; (f) father's early birth experiences including

²Two families learned of their infant's diagnosis three to four months prior to the birth. However, scores do not reflect this prior knowledge.

his earl

mother

father's

his early emotional reactions and information resources provided him; (g) mother's hope for a positive future for the infant and for the family; and (h) father's hope for a positive future for the infant and for the family.

Descriptive statistics for each of these subscales follow:

(a) *Mother's prior beliefs about disabilities.* This subscale had 5 points possible, with a score of 5 indicating that the mother's exposure to developmentally disabled persons was completely positive, and she thus had formed only positive beliefs about developmental disabilities prior to the birth of her infant. A low score would indicate the opposite – that her previous experiences with individuals who had developmental disabilities were negative. The range of scores, computed at Time 1 only, was from 2 to 5, with a mean of 3.64 (*SD* 1.21). (See Table 6.)

(b) *Father's prior beliefs about disabilities.* Eight participant fathers were asked the same subscale questions as mothers and subsequently gave a summary scale score in the same manner as did mothers. The range of scores for fathers, computed at Time 1 only, was from 2 to 5, with a mean of 3.0 (*SD* .93). Fathers had a slightly lower mean on this subscale than mothers, indicating a tendency for some fathers to have formed less positive beliefs about developmental disabilities prior to the birth of their child than did mothers. (See Table 6.)

Table 6
Parents' Previous Beliefs about Disabilities

Mothers		Fathers	
Score	<u>N</u>	Score	<u>N</u>
5	3	5	1
4	4	4	0
3	1	3	5
2	3	2	2
Mean = 3.64 S.D. = 1.21		Mean = 3.0 S.D. = .93	

(c) *Mother's belief in a purpose.* This subscale consisted of questions that were intended to contribute to the overall score on the "hopefulness" subscale. However, this "belief in a purpose" by mothers was discovered to stand alone in its salience and is, therefore, being treated as a separate variable (Meaning/Purpose) in the analysis of "Functional Beliefs." It was also scored as a part of the "hopefulness" subscales (g and h) and will be discussed later.

Following an open-ended discussion regarding the kinds of meanings held by the mother regarding the infant's disability, as well as her belief that there was a purpose or a meaning for this event in her life, she was asked a scaling question. Five points were possible. If her score was a 5, this indicated that she believed in a purpose for this event and that meaning was either to be discovered or was already discovered by her. Some mothers talked about this event as enhancing their personal and family growth. Some mothers stated a spiritual purpose for their infant's disability. The range of scores at

Time 1 was from 3 to 5, with a mean of 4.37 (*SD* .81), indicating that, for the most part, mothers attributed a special purpose or meaning for this event their lives. At Time 2, the range was from 3 to 5, with a slightly lower mean of 4.18 (*SD* .87). (See Table 7.)

(d) *Father's belief in a purpose.* The scores for fathers were computed in the same manner as for mothers. At Time 1, the range of scores for nine fathers was from 1 to 5, with a mean of 3.78 (*SD* 1.48). At Time 2, scores were obtained from eight fathers, and the range was again 1 to 5, but the mean dropped to 3.0 (*SD* 1.77). This would indicate that at Time 2 some fathers had changed their belief in a purpose or special meaning or were questioning this in their lives. Mothers scored higher than fathers at both Times 1 and 2 on this subscale, indicating that mothers were better able than fathers to find meaning or a purpose for their infant's disability. (See Table 7.)

Table 7
Parents' Belief in a Purpose

<u>Mothers</u>				<u>Fathers</u>			
<u>Time 1</u>		<u>Time 2</u>		<u>Time 1</u>		<u>Time 2</u>	
Score	<u>N</u>	Score	<u>N</u>	Score	<u>N</u>	Score	<u>N</u>
5	6	5	5	5	4	5	3
4	3	4	3	4	2	4	0
3	2	3	3	3	1	3	1
2	0	2	0	2	1	2	2
1	0	1	0	1	1	1	2
Mean = 4.37		Mean = 4.18		Mean = 3.78		Mean = 3.0	
S.D. = .81		S.D. = .87		S.D. = 1.48		S.D. = 1.77	

(e) *Mother's early birth experiences.* Mothers were asked to recall their emotional reactions to the diagnosis of their infant, the manner in which they were informed and the helpfulness of the information given them at the time of diagnosis. After discussion, they were asked three scaling questions, yielding 15 possible points. The higher the score, the more positive their emotional reaction, the greater empathy they perceived conveyed by medical staff who informed them, and the greater degree of helpfulness they assigned to the information given them. The range of scores at Time 1 was from 7 to 14, with a mean of 9.59 (*SD* 2.34). This subscale was not administered at Time 2, since recall was considered to be most accurate at Time 1. (See Table 8.)

The means for each of three subscales (1 to 5 points possible for each) for Mother's Early Birth Experiences were: emotional reaction, 2.14; sensitivity of manner in which they were informed of the diagnosis, 3.64; and their satisfaction with informational resources given them, 3.82. It appears that mothers were satisfied with the information they received and moderately satisfied with the manner in which they were informed of the diagnosis. However, their emotional reaction to the diagnosis was moderately low, indicating the emotions experienced were negative, which was expected.

(f) *Father's early birth experiences.* Fathers contributed to the discussion regarding emotional reactions to the diagnosis, the

sensitivity of the manner in which they were informed, and the helpfulness of information given them. The range of scores for eight fathers at Time 1 on this subscale was from 7 to 13, with a mean of 9.0 (*SD* 2.07), which is slightly lower than the mean for mothers. Fathers, therefore, believed their early birth experiences to be less favorable than mothers. (Parents were scaled on these questions while in the company of each other and after conjoint open discussion.) (See Table 8.)

The means for each of the three subscales (1 to 5 points possible for each) for Father's Early Birth Experiences were: emotional reaction, 2.0; sensitivity of manner in which they were informed of the diagnosis, 3.13; and their satisfaction with the informational resources given them, 3.88. As with mothers, their emotional reaction reduced the mean for this Early Birth Experiences scale for the fathers. In fact, their score on the emotional reaction subscale was less than that of mothers. This was also true for their judgment on the sensitivity of the manner in which they were informed. They rated the informational resources given them slightly higher than the mothers did.

Table 8
Parents' Early Birth Experiences

<u>Mothers</u>		<u>Fathers</u>	
Score	<u>N</u>	Score	<u>N</u>
14.0	1	13.0	1
13.0	1	11.0	1
11.5	1	9.0	2
10.0	1	8.0	2
9.5	1	7.0	2
9.0	1		
8.5	1		
8.0	2		
7.0	2		
Mean = 9.59 S.D. = 2.34		Mean = 9.0 S.D. = 2.07	

(g) *Mother's hopefulness.* Mothers were asked a series of open-ended questions regarding their current adjustment, their view of the infant's prognosis and its effects on the family currently and into the future, and the assignment of blame on either the self or the partner. In addition, this subscale included the meaning and purpose score mentioned above. Four scaling questions comprised this subscale with 20 possible points. Again, a score near 20 indicated the mother carried no guilt for her child's condition, she believed the prognosis to be positive rather than negative, and she had a great deal of hope for the future. The range of scores at Time 1 was from 15 to 20, with a mean of 17.86 (*SD* 1.7). At Time 2, the range of scores was 16 to 20, with a mean of 18.0 (*SD* 1.67). (See Table 9.)

(h) *Father's hopefulness.* This same subscale was administered to fathers. Nine fathers were available and agreed to scale their beliefs at Time 1, and eight fathers scaled their beliefs at Time 2. At Time 1, the range of scores for fathers was from 8 to 20, with a mean of 16.0 (*SD* 4.24). At Time 2, the range was 9 to 20, with a mean of 16.13 (*SD* 3.91). It is noted that, while the mean on this subscale was lower for fathers than mothers at both Times 1 and 2, the range was greater. Two fathers scored considerably lower on this subscale, somewhat skewing the mean. The mean for both mothers and fathers was slightly higher at Time 2 than at Time 1. (See Table 9.)

Table 9
Parents' Hopefulness

<u>Mothers</u>				<u>Fathers</u>			
<u>Time 1</u>		<u>Time 2</u>		<u>Time 1</u>		<u>Time 2</u>	
Score	<u>N</u>	Score	<u>N</u>	Score	<u>N</u>	Score	<u>N</u>
20	2	20	3	20	1	20	2
19.5	1	19	2	19	2	18	2
19	2	18	1	18	2	17	1
17	4	17	2	17	1	15	1
16	1	16	3	15	1	12	1
15	1			10	1	9	1
				8	1		
Mean = 17.86		Mean = 18.0		Mean = 16.0		Mean = 16.13	
S.D. = 1.7		S.D. = 1.67		S.D. = 4.24		S.D. = 3.91	

Total Interview Scores of Beliefs for Mothers and Fathers. When these subscales were totaled for both mothers and fathers, it was necessary to add those two subscales that were administered at Time 1 only (“prior beliefs about disabilities” and “early birth experiences”) to the subscale scores obtained at Time 2. This computation process yielded the same possible 45 point total for both Times 1 and 2.

Mother’s total. Total interview scores for all 11 mothers at Time 1 ranged from 30 to 44. The mean at Time 1 for the total interview was 35.55 (*SD* 4.5). At Time 2, the total range of scores was from 29 to 44 with a mean of 35.41 (*SD* 4.36). Clearly, although over all 5 subscales, mothers’ scores dropped slightly from Time 1 to Time 2, their beliefs remained fairly consistent and quite positive from Time 1 to Time 2. (See Table 10.)

Father’s total. Total interview scores for fathers at Time 1 ranged from 20 to 41. The mean for the eight fathers at Time 1 was 31.38 (*SD* 6.99). At Time 2, the range for fathers was from 21 to 37, with a mean of 31.13 (*SD* 5.59). Fathers scored lower than mothers at both Times 1 and 2, with scores dropping slightly at Time 2. Over all five subscales their scores remained fairly consistent from Time 1 to Time 2. Although fathers had a greater range of scores in comparison to mothers, the small sample size precludes drawing any specific conclusions about this. (See Table 10.)

Table 10
Mean Functional Belief Scores of Parents

<u>Mother</u>		<u>Father</u>	
Time 1 Total	Time 2 Total	Time 1 Total	Time 2 Total
35.55 (SD 4.5)	35.41 (SD 4.36)	31.38 (SD 6.99)	31.13 (SD 5.59)

Mother's Satisfaction with Partner Support: Following interview questions with regard to the kinds of support the mother receives from her partner, both instrumental and emotional, mothers were asked to scale their satisfaction with that support at both Time 1 and Time 2. Twenty points were possible. The range at Time 1 was 13 to 19, with a mean of 17.18 (SD 1.62). The range at Time 2 was 12 to 20, with a mean of 17.05 (SD 2.91). Although the mean remained fairly consistent between Time 1 and Time 2, the range was greater at Time 2. Three mothers raised their scores to the highest possible score (20) and two mothers dropped their scores below the Time 1 lowest level (13). This indicates that some mothers felt they were receiving more support, and some felt they were receiving less support at Time 2. (See Table 11.)

Case
1
2
3
4
5
6
7
8
9
10
11

Mother's

own: After the m
infant and her fan
some questions.
score of 0 would
were at all congr
husband believe
The range was .5

The level of congru
self-scaling scores d
The level of congruen
(=5).

Table 11
Mother's Satisfaction with Partner Support

Case	Time 1 Score	Time 2 Score
1	17.0	17.5
2	17.0	17.0
3	19.0	20.0
4	13.0	16.0
5	19.0	20.0
6	18.0	12.0
7	17.5	19.5
8	16.5	15.0
9	18.0	20.0
10	17.0	12.5
11	17.0	18.0
Mean = 17.18		Mean = 17.05
S.D. = 1.62		S.D. = 2.91

Mother's Belief that her Partner's Beliefs are Congruent with her own: After the mother scaled her own beliefs and hopes for the future of her infant and her family, she was asked to scale her husband's beliefs on the same questions. These data were collected at the interview for Time 1 only³. A score of 0 would indicate the mother did not believe that her husband's beliefs were at all congruent with her own. A score of 5 would indicate that she felt her husband believed the same way that she did on the scaling questions asked. The range was .5 to 5, with a mean of 3.55 (*SD* 1.35). (See Table 12.)

³The level of congruency was obtained by first determining the difference between the mother's self-scaling scores on "hopefulness" and the scores she gave her husband. In order to analyze the level of congruency more directly, scores were then reversed (5=0, 4=1, 3=2, 2=3, 1=4, 0=5).

Famil

intra-family s

administered

the listed eve

The a

across the lif

study, the ra

5.72), indica

stressors tha

^aOne mother re
concerned abo
omitting that m
ter also increa
score was com

Table 12
Mother's Perception of a Congruency Between
Her Beliefs and The Beliefs of her Partner

Score (from high congruency to low congruency)	<u>N</u>
5.0	2
4.5	1
4.0	4
3.0	2
2.0	1
.5	1

Mean = 3.55

S.D. = 1.36

Family Inventory of Life Events (FILE): The FILE is a measure of intra-family strain (more specifically, number of stressors) that was administered to mothers at Time 1. Mothers were asked to indicate which of the listed events occurred during the past 12 months.⁴

The authors of this instrument determined norms for a large population across the life cycle. They provide a mean of 9.21 stressors (*SD* 5.6). In this study, the range of number of stressors was 0 to 19, with a mean of 10.09 (*SD* 5.72), indicating that mothers were reporting a slightly higher number of stressors than for the normative sample. (See Table 13.).

⁴One mother reported *no* stress in her life including the birth of the infant. The researcher was concerned about the validity of this respondent's score. Therefore, a second analysis was done, omitting that mother's score. The mean then increased to 11.1 (*SD* 4.89). The sample median then also increased to 12 stressors, which is considerably higher than the normative mean. This score was computed in subsequent analyses, however.

Table 13
Family Inventory of Life Events (Family Stress)

Score (No. of Stressors)	N
0	1
4	1
6	1
8	1
9	2
10	1
14	1
16	2
19	1

Normative Mean = 9.21 (*SD* 5.6)
Sample Mean = 10.09 (*SD* 5.72)
Median = 9

Marital Satisfaction of Both Parents: The Dyadic Adjustment Scale (DAS) was used to measure the relational satisfaction for both parents. In this study, the range at Time 1 for mothers (N 11) was 93 to 136, with a mean of 113.68 (*SD* 14.1). The range at Time 1 for fathers (N 9) was 99 to 139, with a mean of 119.22 (*SD* 15.21). The range at Time 2 for mothers (N 11) was 96 to 138, with a mean of 115.82 (*SD* 14.34). The range at Time 2 for fathers (N 10) was 94 to 140 with a mean of 116.5 (*SD* 17.12). The mean for the mothers went up from Time 1 to Time 2, while the mean for the fathers went down. (See Table 14). It appears that mothers' marital satisfaction increased from Time 1 to Time 2, whereas fathers indicated a decrease in marital satisfaction from Time 1 to Time 2. One couple was in the "distress" range (below 100) at Time 1, and remained there at Time 2, with the husband indicating even lower marital satisfaction at Time 2. Another couple scored only a couple of points

over the

into the

at Time

still score

and 130

14.)

Time 1

Time 2

Quantity

limited

the que

data.

presen

tables

Questi

over the “distress” range at Time 1, and by Time 2, both of their scores dropped into the “distress” range. One other wife reported scores in the “distress” range at Time 1 (her husband scored 108), and increased her score at Time 2, but still scored within the “distress range.” Those couples who scored in the 120's and 130's at Time 1, remained in those same ranges at Time 2. (See Table 14.)

Table 14
Marital Satisfaction of Both Parents

	DAS Normative Mean	Mothers' Mean	Fathers' Mean
Time 1	114.8 (married) SD 17.8	113.68 (n 11) SD 14.1	119.22 (n 9) SD 15.21
Time 2		115.82 (n 11) SD 14.34	116.5 (n 10) SD 17.12

Quantitative and Qualitative Findings by Research Questions

In view of the fact that this study is exploratory and sample numbers are limited to eleven mothers and eight fathers for most of the statistical measures, the quantitative findings will be supported and elaborated upon with qualitative data. The quantitative analysis and qualitative supportive data analysis will be presented in the order of the research questions and objectives. Summary tables will follow the quantitative findings for groups of related research questions as follows:

Questions 1, 2, and 3: Predictors of Maternal-Infant Interaction – Table 15
(page 103)

Questions 4, 5, and 6: Predictors of Maternal Marital Satisfaction – Table 16
(page 124)

Question 7: Predictors of Paternal Marital Satisfaction – Table 17 (page 133)

Questions 8, 9, 10, and 11: Differences Between Means on Functionality
of Beliefs between Mother and Father, Marital Satisfaction and
Mother's Satisfaction with Partner Support Between Time 1
and Time 2 – Table 18 (page 151)

Question 12: Difference Between Means of Maternal-Infant Attachment
Interaction Between Time 1 and Time 2 – Table 19 (page 153)

Correlations were run to provide data for answering the first seven research questions. Partial correlations were also run on subgroups formed on the control variables. Results are considered significant at $p < .05$. Correlations were computed using Spearman's rho. This is a nonparametric rank-order correlation coefficient, which measures association at the ordinal level. Unlike the Pearson correlation, which makes the assumption that the data come from a bivariate normal population, no assumptions are made about the nature of the population samples for the Spearman correlation.

To examine whether differences between group means were statistically significant, the researcher decided to use the Wilcoxon Matched-Pairs Signed Ranks Test. This is a nonparametric test for use when samples are small and groups are not independent of each other – i.e. related. Since this study is exploratory and hypotheses were not generated, this statistical measure was used solely for the purpose of examining differences as they might add clarity to the research questions and objectives. Therefore, as differences approach a

level of significance according to this statistical measure, they are to be interpreted cautiously for the purpose of analyzing this particular sample and not as they might apply to another population.

Qualitative data was analyzed in the following manner:

- Audiotape recorded data was transcribed verbatim.
- Predetermined variables were manually coded onto the transcribed data.
- Data from each case were then divided and grouped according to each variable code.
- Within each variable code, further analysis was made for common themes that emerged, and themes were indexed for comparison across cases.

(1) Is there a relationship between the level of functionality of maternal beliefs about the infant's developmental disability and the quality of the mother-infant attachment interaction?

Quantitative Findings: Level of Functionality of Beliefs was determined by summing the total interview scores of mothers. This total score included subscale scores regarding mothers' beliefs about developmental disabilities prior to the birth of her infant, the manner in which she felt she was informed of the diagnosis, the quality of information given her, her emotional reactions, and her current beliefs and hopes for the future.

The scores representing the Level of Functionality of Maternal Beliefs were correlated with the mother's score, as well as with the combined mother-infant interaction scores on the NCAST Feeding Scale. These correlations were computed for both Time 1 and Time 2. The results of these correlations are depicted in Table 15. Very weak, if any, (Time 1: $r = -.03$, $r = -.14$; Time 2: $r = .15$, $r = .01$) associations were found between the mother's beliefs and her interactions with her infant at Time 1 or Time 2. None of these associations reached the threshold of significance at the .05 level or better.

As the researcher proceeded with the interviews, one of the interview subscales began to signal some singular relevance – the mother's belief in a purpose or meaning for this event in her life. Based upon this evolving data, the researcher decided to look at this "Meaning/Purpose" subscale within the "Functionality of Beliefs" scale in greater depth. Therefore, the score given by the mother regarding her belief in a purpose or meaning for this event was correlated separately with the NCAST feeding interaction scores for both Time 1 and Time 2. Spearman rho correlations were run on both the mother-infant feeding score, as well as the mother-only feeding interaction score. The mother-only feeding interaction score was deemed by the researcher to be more important than the infant's scores for this particular study, due to the emphasis placed on "mother" variables. In addition, developmental delays observed in the infant's interaction were likely to be influencing the combined mother-infant interaction score.

The correlation results for Meaning/Purpose Subscale and Mother-Infant Feeding Interaction (mother-only NCAST score) analysis are summarized in Table 15. A moderate positive correlation⁵ was found at Time 1 for this subscale and the mother-only interaction score, and it approached a significance level ($r = .54, p < .10$). While this subscale did not associate as strongly with the infant-only interaction score ($r = .10$), the combined mother-infant interaction score at Time 1 did show a moderate positive correlation for this particular sample ($r = .46$) but was not significant at the .05 level. At Time 2, the mother's interaction score was again found to have a moderate, positive correlation with Meaning/Purpose for this sample ($r = .41$), but there was a low association ($r = .27$) between this Meaning/Purpose subscale and the combined Mother-Infant Feeding Interaction score.

The original association for Time 1 was run again, controlling for mother's age ($r = .62$), income ($r = .68^*$), family size ($r = .72^*$), education ($r = .54$) and stress ($r = .77^*$), sequentially. For most of these partial correlations, the association between Meaning/Purpose and Mother's NCAST Feeding Scale increased in strength.

When the relationship was partially correlated with Level of Depression, the strength of the original relationship diminished somewhat from $r = .54$ to $r = .46$. The correlation did not reach the .05 significance level. As mentioned

⁵It is acknowledged that the descriptive modifiers for correlations in this study – i.e. “mild,” “moderate” – are conservative and are based upon scientific studies in general. In social science research, however, it is rare to find correlations higher than $r = .60$, and correlations above $r = .50$ are often described as “high” with correlations above $r = .60$ as “strong.”

previously (p. 70), actual scores on Depression were low, and only two mothers scored in the “mild” clinical depression range on the Beck Depression Inventory. However, it appears that Level of “Depression” (or what might more appropriately be labeled “affect”) may account for some of the relationship between mother’s belief in a purpose or meaning and her interaction with her infant – particularly at Time 1.

When the total score for all subscale categories of beliefs of the mother was correlated with her feeding interaction, no significant associations were found. This was true for additional subscales, with the exception of one – Meaning/Purpose. The *Mother’s Belief in a Meaning or Purpose for this Event*, which was determined to be a functional belief, did associate moderately with her *Feeding Interaction* at Time 1. There was a mild association between these two variables at Time 2. Therefore, it appears, that for this small sample of mothers, one might conclude that mothers who had a conviction that there is either (a) a spiritual purpose for the infant being placed in her care or (b) that she will derive a meaning for the birth of her developmentally-disabled child – perhaps adding to her own individual growth or the growth of others – contributed to the quality of her interaction with her infant.

Qualitative Findings: Qualitative data seem to support the importance of mothers deriving a meaning for this event in their lives. Meaning/Purpose related to her interaction with her infant, as well as her satisfaction with her marital relationship, will be discussed later.

Those mothers of *strong* religious faith (3 total) indicated that the birth of their child was part of God's plan for them. It might be noted here that several mothers were recruited from a regional area where religious conservatism contributes to the makeup of the population. One of these mothers said:

We believe that God has placed (child) in our family for a specific reason. We may not know what that reason is now, and we may never know, but I truly believe that he was placed with us for a specific reason. I believe it has made my faith stronger.

Another mother believed that her faith has held her up through this experience.

I don't know how people who don't have that trust in God – how they'd get through this. Once I came to the realization that the important thing is, you know, God has a plan for her life and has a very special plan for her and for our family now – once I came to that realization, then it didn't seem so bad any more.

One additional mother, who did not speak as zealously about her religious faith, but said she attended church worship services, said **I think we both felt that God knew what he was doing when he gave (child) to us.**

The aforementioned mothers attributed a spiritual purpose and meaning for their infant's disability. For others, meaning was interpreted as a growth opportunity for those who come in contact with the child. Two additional mothers fell in this category. **I feel he's going to do a lot of things for many people in their lives. He already has.** Another mother expressed it in this in way: **They're here to help not just their parents but other people around them learn how to be more compassionate people – even their parents, hopefully.** At the time of the second interview, these same mothers spoke about the contributions their child was already making to their own growth. **I think sometimes that this is a way of making me remember what's really**

important in life. It's so easy to get caught up in a job or trying to get ahead, or the nicer things in life. By the time of the second interview, one mother who had a graduate degree (as well as did her husband) had reframed her beliefs about success, no longer in terms of education, but in terms of a very new measure:

I think I realize that it matters more like (sic) the measure of success of a person is in terms of how they touch people's lives and being a good person rather than a high-paying job or things like that. They aren't the measure of how successful a person was, and part of that is you redefine things so that, by definition, he can be a success.

Some mothers had difficulty responding to this question. At Time 1, four of the mothers were struggling with their own thoughts on this issue. For some, who were not overtly spiritual, their answers reflected their inability to easily find a meaning for this event in their lives. A special education teacher said:

Well, a lot of people tell me that God gives kids with special needs to special parents. Quite honestly, I don't believe that at all. In my line of work, I worked with lots of parents who are very neglectful to kids with special needs, are very uncaring – and as I see it – and if those were God's intentions, then He wouldn't have given that child to those parents. In my opinion, God wouldn't have given any children to those parents, because they're not good parents. I don't relate this as his having Down Syndrome as 'this is a special gift from God,' or a special meaning in my life; but, at the same time, he, being here, is purposeful, by all means.

None of the mothers gave a low score when scaling this five-point interview measure. At Time 1, two mothers chose a neutral score for this measure (3); at Time 2, one mother raised her score and three mothers lowered their scores – but only one level.

In an effort to explain this finding, one might consider the possibility that those mothers who do derive a positive meaning, whether spiritual or otherwise, for an uncontrollable and disappointing event in their lives, develop a determination to treat that child in accordance with those beliefs. Their child is seen as a positive contribution to their family and to society. Therefore, their interaction with their disabled infant would reflect that positive thinking. Another way one might choose to look at this association would be that mothers who look for and derive positive meanings for unexplained circumstances in life are naturally going to be positive in their interactions with others – regardless of who they might be. Either way, it behooves those professionals who work with these families to help them derive positive meanings for such events in their lives. It also seems to signal some importance for future research. An investigation of “meaning and purpose” among parents of children with disabilities in general and its relationship to adjustment and acceptance of those parents could add to information that may have a significant impact on special education service providers, mental health clinicians, and policy makers.

(2) Is there an association between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the quality of her attachment interaction with her infant?

Quantitative Findings: Level of Congruency in Beliefs is represented by the difference between scores of mother and *her* scores of the father regarding their hope for the future for the infant and family, as well as a sense of meaning and purpose for this event in their lives. To address this question, the Level of Congruency in Parental Beliefs as Perceived by the Mother were correlated with the NCAST Feeding Scale scores for mother and infant, as well as for the mother only.

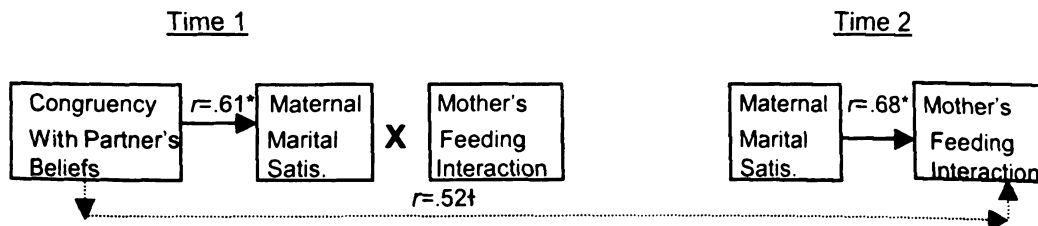
Using the Spearman rho correlation, the mother-only scores on the NCAST Feeding Scale and the combined scores of infant and mother on this measure were correlated with the Level of Congruency scores of the mother for Time 1 only. (Level of Congruency was measured at Time 1 only.) The results of this analysis are summarized in Table 15. There appears to be no relationship between the Level of Congruency of Beliefs between mother and father, as perceived by the mother and the Mother-only Feeding Interaction ($r = .05$), and the combined Mother-Infant Feeding Interaction ($r = .01$). Neither correlation reached the .05 level of significance.

This finding of no relationship was not surprising to the researcher, since it was expected that any relationship found between these two variables would be indirect. It was anticipated that "Congruency" would affect "Marital Satisfaction" which would then have an effect on "Maternal-Infant Interaction." More discussion on this follows:

Mother's Perceived Level of Congruency did correlate strongly with her Marital Satisfaction at Time 1 ($r = .61, p < .05$); and Mother's Marital Satisfaction correlated strongly with the Mother's Feeding Interaction at Time 2 ($r = .68, p < .05$). (See Tables 15 and 16.) It may be helpful to conceptualize these findings by considering the following:

1. The *Level of Congruency of Beliefs as Perceived by the Mother* was measured at Time 1 only.
2. The *Level of Congruency of Beliefs as Perceived by the Mother* had a strong positive correlation with *Marital Satisfaction* at Time 1.
3. There was no relationship between the *Mother's Marital Satisfaction* and her *Feeding Interaction with her Infant* at Time 1. (Discussion regarding possible reasons for this can be found in the analysis of research question No. 3.)
4. There was a strong positive correlation between *Mother's Marital Satisfaction* and her *Feeding Interaction with her Infant* at Time 2.

Visually, this relationship may be conceptualized as follows:



As can be seen from this diagram, the researcher computed an additional correlation between *Congruency with Partner's Beliefs* and *Mother's Feeding*

Interaction at Time 2 (broken arrow). This resulted in a positive correlation that was moderate in strength, but only approached statistical significance. This supported the explanation that *Mother's Perceptions of Congruency* did influence her interaction with her infant, but through her *Marital Satisfaction*, even though three months time had elapsed since the "Congruency" measure was scored.

Further information was desired with regard to this "Congruency" measure for the purpose of obtaining a better understanding of the process by which mothers assigned scores to their husbands on the subscales within *Level of Functionality of Beliefs*. It was discovered that mothers overestimated the combined scores on level of father's Hope and his Belief in a Meaning or Purpose by over two points (mother's mean for her partner was 21.86, while fathers scored 19.78). These differences were tested statistically, and a level of significance was not reached. However, the researcher, not completely satisfied with the statistical results, chose to examine those three cases that had the highest actual discrepancies scores (where mothers had overestimated their husband's scores), and the three cases that had the lowest discrepancies scores (where mothers estimated their husband's scores to be the closest to his actual scores). The mean score that the three overestimating mothers gave their husbands was 21, and the actual mean score of their husbands on this measure was 13. Therefore, these highly overestimating three mothers had a discrepancy mean of 9 points over their husbands' actual scores. (These mothers also had the lowest scores on Level of Marital Satisfaction, as will be

discussed later.) By comparison, those three mothers who gave scores for their husbands closest to their husbands' actual scores had only a 1-point mean discrepancy, and these three mothers underestimated their husbands scores on this measure. (These mothers had the highest scores on Level of Marital Satisfaction.)

This could be interpreted in the following ways: (1) that mothers who scored their spouse most accurately on Hope/Meaning had a better intuitive sense of their spouses' beliefs on this measure; (2) for those mothers whose spouses' true scores were low and mothers scored them much higher, it could be explained that mothers were protecting themselves from their spouse's pessimism through denial; or (3) the reverse could be the case – i.e, where husbands scores were low in Hope/Meaning and mothers scored them higher, the husbands may have made a deliberate attempt to hide their pessimism from their wives in an effort to protect them from their true feelings – an attempt “to be supportive.”

Qualitative Findings: Qualitative data contributes to these hypotheses.

One mother's statements provided support for Explanation 3 above:

I think he – this is my impression – I may be wrong, but I feel that he feels that he has to be strong for me, so I don't think he allows himself, or maybe I don't allow him to communicate his fear and so forth ...

Three mothers attributed the coping mechanism of denial to their husbands. One mother had this to say about her husband (and he actually scored higher than she scored him):

Good (regarding his adjustment). I know I mentioned earlier that we have a little bit of discrepancy in our outlook where (husband) is – I don't know – if he's accepted that fact that (child) does have some degree of a mental impairment, or if I'm being negative, or if he's not being realistic about (child) being able to be a rocket scientist or be a president or those kind of things. We tend to differ on that a little bit, I would definitely say.

Another mother, who scored her low-scoring husband 13 points higher than what he scored himself on Hope and a belief in a Meaning or a Purpose for this event also wondered if he might be in denial.

I think he's adjusted pretty good. Whenever he talks to one of his friends about it or something, he always says, "We think it's a mild case." In a way, I think he's somewhat in denial too. But he always says that ...

In yet another case, where there was no discrepancy between the actual scores for the parents, there was a concern expressed by the mother just the same.

I think (he has adjusted) remarkably well, sometimes almost to the point where I worry that he is almost too hopeful – that she'll overcome it or that there's a drug that's going to come out – or whatever.

Where these mothers may have had some concerns about their husbands' denial contributing to unrealistic hope, the researcher found, upon close examination, two other possible explanations. It was discovered that the three cases with the greatest discrepancies (between those scores of the father that were given by the mother and the actual scores of the fathers) were also those three cases that received the lowest scores by the mother, as well as her husband, on her Level of Marital Satisfaction at both Time 1 and Time 2. In all three of these cases, mothers scored their husbands higher on Hope/Meaning than what husbands scored themselves. Therefore, it would seem that either

(1) these mothers were not well-attuned to their husbands' feelings regarding this event in their lives, perhaps due to a lack of relationship closeness felt by her; or (2) that husbands were not very self-disclosing in the relationship, contributing to the mothers' lower levels of Marital Satisfaction. It was also discovered that the three cases in which the mothers scored their husbands closest to their actual scores were the three cases where partners had the highest scores on Level of Marital Satisfaction.

In summary, for this sample, the variable Level of Congruency of Beliefs as Perceived by the Mother does give insight into relational dynamics of a marital couple when a developmentally disabled infant is born. The Mother's Marital Satisfaction was influenced by her perceptions, which, in turn, influenced her Feeding Interaction with her infant. Microsystem dynamics can be visualized through this analysis of these second order effects of the parental relationship on the infant. Marriage and Family Therapists may be able to benefit from this finding. An effort can be made, when working with these couples, to clarify such misperceptions.

Very little research, if any, has examined mother's perceptions of her partner's beliefs as congruent with her own when adjusting to the crisis of giving birth to a developmentally disabled infant. These findings indicate that further investigation of parental perceptions of partner beliefs may be important to an understanding of "the making or breaking of a marital relationship" – a phenomenon often described by quantitative researchers studying divorce patterns among couples raising handicapped children.

(3) *Is there a relationship between the mother's level of marital satisfaction and the quality of the mother-infant attachment interaction?*

Quantitative Findings: Mother's level of Marital Satisfaction is measured by the total score she received on the Dyadic Adjustment Scale, administered at both Time 1 and Time 2. To address this question, a Spearman rho correlation was run between the mothers' scores on the Dyadic Adjustment Scales and her scores on the NCAST Feeding Scales for both Time 1 and Time 2. The mother-infant score and the mother-only score on the NCAST were used in the correlations. This analysis is summarized in Table 15.

The Spearman rho correlational analysis of the mother-only NCAST score and her Level of Marital Satisfaction indicated a mild *negative* correlation at Time 1 ($r = -.31$); and the mother-infant combined score resulted in a moderate *negative* correlation ($r = -.47$), indicating that as marital satisfaction decreased, the quality of the mother's infant attachment interaction was somewhat higher. The opposite was true for Time 2, since there is a moderately-strong *positive* correlation between Mother's Marital Satisfaction and the Quality of her Interaction with her Infant ($r = .68$), which reached a significance level of $p < .05$. As her Marital Satisfaction decreased, so did the Quality of her Interaction at Time 2. At Time 2, the combined Mother-Infant Interaction correlation was moderate and did not reach statistical significance ($r = .45$). This correlation was also in a positive direction.

As mentioned earlier, however, the mother-only feeding interaction score is deemed to hold greater importance for this study than the infant's score (and, therefore, also the combined mother-infant score). While at Time 1, Marital Satisfaction had a weak, negative relationship with the Mother-Infant Interaction, by Time 2 this negative relationship was not only reversed, but was moderately strong.

Partial correlations were run on this original association at Time 2, controlling for age ($r = .72^*$), education ($r = .75^*$), income ($r = .74^*$), family size ($r = .72^*$), stress ($r = .72^*$), and depression ($r = .76^{**}$). These partial correlations revealed an even stronger correlation between the Mother's Marital Satisfaction and her Feeding Interaction when these variables were controlled or held constant. All the correlations reached a statistical significance of at least .05. (See Table 15).

Qualitative Findings: At Time 1, there was a low, not significant, *negative* correlation between the Mother's Level of Marital Satisfaction and the Quality of Her Infant Attachment Interaction. At Time 2, this was reversed. The Time 2 correlation was significant, *positive*, and moderately-strong. No qualitative data was gathered that might help explain this phenomenon. Both of these variables were measured by standardized research instruments, and the interview guide did not address either variable.

The researcher hypothesizes, however, that at Time 1, when the infant was only three months old, the mother was likely receiving enough support from sources other than her husband (friends, relatives and early intervention

specialists coming into the home) for her marital satisfaction to have little influence on her relationship with her developmentally disabled infant. It is also likely that, though she was still grieving her loss from having a “less than perfect child,” her attention was distracted from the marital relationship to the adjustment of caring for a new infant, regardless of the condition of the infant. Most new mothers do find the change in their lives of caring for an infant to be a distraction from whatever else is happening in their lives at that time and attend to their new roles of “mothering” with diligence. By Time 2 (when the infant was six months old), it is posited that a routine of infant care had been established, family and friendship supports had waned, and the mother was most likely able to turn her attention to other kinds of environmental concerns. If the marital relationship was a concern, it was more likely to be reprioritized at that time – or at least a greater awareness surfaced for her – thereby possibly having an effect on her interaction with her infant (as well as with others in the family).

Future researchers and early interventionists might consider the possibility that a more accurate measure of mother-infant interaction might be obtained when the infant is older than three months. Early interventionists might also take note that since the presence of a service provider is likely to have a positive effect on the mother, there might be a greater need for more frequent visits as the infant gets older rather than during the very early months following birth. (Most mothers were still getting Early On support on a weekly basis, however, at the time of the second interview.)

As discussed in the Literature Review, mother's level of depression has been found across the large majority of infant attachment studies to influence attachment interaction between a mother and her normally developing infant. It was determined that none of the mothers in this study were depressed at Time 2. The results of this study analysis suggest that infant-interaction may be affected by mother's emotional affect, regardless of its intensity as measured by a depression scale. This, of course, assumes that the mother's satisfaction with her marriage may be affecting her emotional affect in ways that are not measured by the depression scale chosen for this study. This finding seems important to the work of future researchers.

TABLE 15
Predictors of Mother-Infant Attachment Interaction

NCAST FEEDING SCORES				
	Time 1		Time 2	
	Mother	Mother/Infant	Mother	Mother/Infant
Functional Beliefs	.03	-.14	.15	.01
Meaning/Purpose	.54†	.46	.41	.27
Control Variables For Meaning/Purpose:				
age	.62†	na	na	na
educ.	.54			
income	.68*			
fam.sz	.72*			
stress	.77**			
depress	.46			
Congruency with Partner's Beliefs	.05	.01	na	na
Mother's Marital Satisfaction	-.31	-.47	.68*	.45
Control Variables For Mother's M.S.				
	na	na	age... .72*	na
			educ. .75*	
			inc. .74*	
			fam.sz.72*	
			stress .72*	
			depres.76.**	

N = 11 mother-infant dyads

**p < .01

*p < .05

†p < .10

(4) Is there a relationship between the level of functionality of maternal beliefs about the infant's developmental disability and her level of marital satisfaction?

Quantitative Findings: Level of Functionality of Maternal Beliefs has been operationalized as the total interview scores of the mothers regarding their beliefs about disabilities prior to the birth of their infant, the manner in which they were informed of the diagnosis, the quality of information given them, their emotional reactions, and their current beliefs and hopes for the future. Level of Functionality of Beliefs was correlated with the mother's Level of Marital Satisfaction (Dyadic Adjustment Scale) at both Time 1 and Time 2. Using the Spearman rho, a moderate positive correlation was found at Time 1, ($r = .46$), for this sample only. A low positive correlation was found at Time 2 ($r = .25$). (See Table 16.) Neither correlation reached the .05 probability level set for statistical significance.

In the process of examining subscales for this interview measure at Time 1, two subscales were found to have moderate positive relationships with marital satisfaction, which, when correlated separately, approached levels of significance. These subscales are Mother's Beliefs about Developmental Disabilities prior to the birth of her infant ($r=.57$, $p=.07$) and Mother's Current Beliefs and Hope for the Future ($r=.51$, $p=.11$). Mother's Beliefs about Developmental Disabilities was again correlated with her Marital Satisfaction, controlling for education only, since it was deemed that premarital beliefs were

unlikely to be related to any of the other control variables, which are “current” variables. The strength of this relationship increased to $r=.77$, $p=.01$.

At Time 2, Mother's Previous Beliefs about Developmental Disabilities (which was scaled at Time 1 only) again correlated positively with Mother's Marital Satisfaction at Time 2, but the correlation was reduced to a $r=.41$ and did not approach the .05 probability level set for statistical significance. However, at Time 2, another subscale was found to have a moderately-strong positive relationship with marital satisfaction. This subscale, Mother's Belief in a Meaning or a Purpose for this event in her life and in the life of her family, also reached a level of significance ($r=.69$, $p=.03$). When the correlation between Mother's Belief in a Meaning or a Purpose and her Marital Satisfaction at Time 2 was repeated, controlling for age, education, income, family size, stress, and depression, all control variables reduced the strength of the correlation slightly, with the exception of income. Income may be reflecting the possibility of hopefulness for the future and could be serving as a coping mechanism. Many more choices are available to parents with higher levels of income (See Table 16.)

Qualitative Findings: As was discussed, the *overall* scores on Level of Functionality of Maternal Beliefs, which included subscales, did not correlate at a level of significance with Marital Satisfaction. However, two subscales were found to correlate moderately with Marital Satisfaction at Time 1 – Previous Beliefs about Developmental Disabilities and Current Beliefs /Hope for the

Future – and one subscale correlated at a moderately strong level at Time 2 – Belief in a Meaning/Purpose.

It would be difficult to derive an explanation for this based upon interview data. Qualitative data was obtained during the Time 1 interview only for mother's beliefs about developmental disabilities prior to the birth of their child. The number of mothers who had previous exposure to developmental disabilities (contacts with disabled relatives, friends) was about equal to those who had no exposure. Two subject mothers were special education teachers and had a great deal of experience working with individuals with developmental disabilities. One mother with high exposure describes her experience in this manner:

I actually volunteered to be a counselor for a handicapped week (at a camp), and there were many Down's children there. You know, some adults in diapers (sic). We were changing diapers for them. So it was an eye-opening experience... Because it's been very positive in certain respects and because it's very challenging – I

wouldn't say negative, but very, very challenging. It's not all fun and games, that's for sure.

That mother gave a neutral score (3) on this five-point scale. It seems that those with the most experience, such as the above mother and the two teachers, gave neutral scores, since they were better able to assess both the advantages and disadvantages connected with having a developmentally disabled child. One of the teachers said this:

Well, that's my line of work, so I have a lot of insights – not as much insight as when you have a child of your own with a disability ... I'd seen both sides of the token, unfortunately.

Those with some exposure, but not the daily contact as the previous three mothers, tended to score their experiences as positive (4 and 5). A mother who volunteered on an annual basis to help with a Christmas Party for developmentally-disabled individuals had this to say:

I would say, in general, I have a very soft spot for the underdog kind of guy, and right or wrong, I felt somewhat of that same feeling – just a real feeling of compassion. I also felt more grateful for my capacity.

She described her feelings in terms of compassion. Another strongly religious mother with minimal experience described her feelings about people with developmental disabilities in line with her religious faith, not necessarily from an experiential point of view:

My husband does have a cousin who has Down Syndrome, and she's kind of our buddy. We taught our children already before (infant) was born that God makes all different kinds of people... There are different ways in which God challenges people. So that was the attitude we took with people with special needs.

Among the mothers who had no exposure or experience with individuals with developmental disabilities, scores tended to range from neutral to low.

Comments such as these were prevalent. **I think I was scared of them. I just think, 'Oh, those poor souls,' sometimes, you know. They can't help the way they are, and you just feel bad for them.** Another stated: **Not negative – maybe a little pity.** Yet another stated: **You felt sorry for them. It was kind of the feeling that I had vs. a negativeness. It was really a feeling.**

While the interview data does not explain the correlation of this variable with Marital Satisfaction for these mothers, it does reveal general tendencies among this sample to evaluate individuals with developmental disabilities

according to the actual amount of exposure the mothers had. Nine of these mothers fit into these exposure categories based upon interview information. For two mothers, there was insufficient interview data to assign them into a category. Those categories can be depicted as follows:

	For mothers who have had daily experiences caring for individuals with developmental disabilities (N=3) (mean = 3.7)	For mothers who have had some exposure to individuals with developmental disabilities (N=3) (mean = 5)	For mothers who have had no exposure to individuals with developmental disabilities (N=3) (mean = 2.7)
General themes conveyed with regard to their feelings and beliefs	The experiences are based upon reality and are neither positive nor negative.	There is an idealistic belief connected to their minimal exposure and is based upon feelings of compassion or religious convictions	Feelings of pity, fear

These observations, which are, of course, limited to this study seem to support what social science researchers see as inherent in patterns of discrimination. "Integration" and "mainstreaming" have been implemented for the prevention of uninformed stereotyping regarding disabilities. This information, obtained through qualitative data collection, is not surprising and is not directly linked to the research questions. However, it may be of value to those who provide services to families adjusting to the birth of a developmentally disabled child. It highlights the need for an understanding that many of these parents must work through the same feelings of discrimination

and patterns of generalizing resulting from lack of exposure that plague the rest of society. This also illustrates the importance of conceptualizing an individual's macrosystem exchanges when working with families.

Mothers' Previous Beliefs may not directly influence the Mothers' Marital Satisfaction. However, the adjustment process may have a direct influence on Marital Satisfaction (and the reverse could be true). The question, then, might be, how do these beliefs affect the mother's adjustment process when she gives birth to developmentally disabled infant and this infant becomes a part of her family? This researcher made an attempt to examine the relationships between Previous Beliefs of the Mother about Disabilities and her Emotional Reaction at the time of diagnosis, as well as Previous Beliefs About Disabilities and the Mother's Hope for the Future at Time 1. These correlations were positive, but very low: Emotional Reaction ($r = .23$) and Hope for the Future ($r = .32$).

What is, perhaps, more relevant is the finding through examination of the actual scores. Four of the mothers who scored very high on Previous Beliefs (and had very positive feelings about individuals who are developmentally disabled) were the most devastated when they were informed of the diagnosis of their infant. These were also the mothers who had a small amount of exposure to developmental disabilities but not enough to have a realistic view. When these mothers were then told their infants had such a disability, those positive (but unrealistic) feelings did not insulate them from the impact of the diagnosis. (One very strongly religious mother was an exception to this.)

From the way in which mothers were asked to scale this information, as presented above, it is unlikely that an attempt to make a statistical association between the mother's previous beliefs and her adjustment to the diagnosis would yield much information. High scores on Previous Beliefs, for this sample, seem to relate to low scores on Emotional Reaction – a negative relationship. Upon visual examination, those mothers who scored neutral and fell within Category 2 reported a better early emotional experience. Further analysis based upon this data is beyond the scope of this study. Future research, with greater subject numbers, taking into account the effects of these categories and using a different method of scaling and/or analysis might reveal more information with regard to mothers' previous beliefs about disabilities and her adjustment process.

The subscale, *Mothers' Current Beliefs/Hope for the Future*, correlated moderately with *Marital Satisfaction* at Time 1. The qualitative data support the scores that mothers gave on this variable, with one exception. It was clear, from this exception, that this mother was in an emotional grieving stage. Yet, she scored 19 on this twenty-point total scale. Another strongly religious mother gave interview data that was very positive at Time 1, and her score of 20, which represents the highest score possible, reflects this. If she grieved this infant's birth at all – and she claims she did not – she adjusted within the first week following the birth. At Time 1, she said, **I've adjusted fine. I think the adjustment from two to having three kids is a bigger adjustment than having a child who's born with Down Syndrome.**

Two mothers, both in their 40's, were almost at a stage of acceptance and adjustment by Time 1, with only sporadic moments of grief. One within this category reported that she is doing **reasonably well**, adding that gathering and reading information has helped her.

I've had the time with being on maternity leave ... to digest a lot of material and do a lot of research and gain some understanding about it so that it's not such a – oh, I don't know what the right words are even – not insurmountable. But, you know, there's a lot of hope out there and a lot that you can do, so I tend to now just get focused on let's get going, get working with her, and let's help her reach the fullest potential she can. And so once you get to that mode, then it's kind of – it turns into more positive.

All eight remaining mothers claimed that they were moving along in the process of adjustment by Time 1, but had frequent bouts of sadness. Those within this category had comments such as these:

I'm doing better than I was. I was pretty shaky for awhile, and now it's on and off. Sometimes I feel like everything's going to be O.K., or whatever, but those are the times when he's doing real well. At other times I'll see other children his age, and I'll see how well they're doing and then it gets really hard.

Another mother said this:

I think it just depends on the day. Some days I find myself crying for no reason.

And yet another mother had this to say regarding her day-by-day struggle to reach acceptance:

For the most part, we've adjusted and accepted it. We still have some doubts, or sometimes we just go off on a tangent and go 'Why does this have to happen to us?' (Sigh)... I have my days. I kind of go back and forth. Sometimes I go, 'We can do this – this isn't so bad.' In some ways we feel blessed. Some days I think we'll take good care of this special child. Sometimes I think we're special because we've

been selected for this. And in other ways, I feel like 'Why were we selected?'

Based upon these interviews and the scores given by the mothers, there seems to be no magical method for predicting how long it will take for parents to reach acceptance. The researcher believed that at the time of the first interview three mothers had already come to almost full acceptance of their child's condition, as their adjustment seemed very close to that of mothers of infants without disabilities. By Time 2 an additional five mothers had reached this same level. Three cases had not yet stabilized, as their infants were awaiting heart surgery. This assessment was made by comparison across cases. It is important to note that at Time 1, four of the infants had diagnosed heart problems and parents were told that surgery would be needed at some point in the infant's first year to correct these. One of these medically fragile infants was also having problems with the sucking reflex and had to be tube fed periodically. All of the parents of these infants were monitoring their infants' oxygen levels. At Time 1, no mothers attributed their grieving to the fact that their infant had medical problems. This changed at Time 2, as will be discussed later.

Early interventionists may be able to benefit by understanding the diversity of the adjustment process for these families. One is not just to assume that all mothers react to the birth of a developmentally disabled infant in the same manner. The most obvious exception was the strongly religious mother who dismissed any further discussion about her current feelings and her

adjustment: **No. We don't think about her that way. We think about her as one of our other kids, and that's just basically the way it's always been."**

Subscales Hope for the Future and Current Adjustment were added together, and there were very minor differences in their discussions relative to these two similar groups of questions. At Time 1, all mothers were considering what the future might hold for them, some to a greater degree than others.

Even mothers who appeared to have achieved an early adjustment had some thoughts about what the future might hold for their child and their family. The mother who said she had no period of grieving and whose religious faith influenced her attitude about all that pertained to this life event was wondering about her child's ability to become independent:

We have talked about (it), and we're not fixated on it or anything, is just the long-term care that (child) might not live independently or independent of us. Maybe she'll go to a group home or something. So I think that in terms of looking at when you're being "empty nesters," we're realizing that might not ever happen.

Three additional mothers talked about the concern that their child may never become independent. One of the special education teachers, who was already planning for her daughter's future, had this to say:

And then, when she's an adult, I would like her to be set up in a home. She'll have the option of – if she wants to stay with us, she can stay, but if she doesn't want to stay with us – we don't know what her capabilities are going to be, so she may not even be in assisted living. But then, as I've learned from doing my job, it's going to be a very sensitive, very tough issue.

In addition to the concern for their child's achievement of independence, three mothers talked about their child's future in terms of his/her education.

This was the main focus of a mother, who had a graduate degree, and whose husband also had a graduate degree:

Yeah, we already had his college fund started. We were confronted with, 'Oh my goodness! He's not going to college.' But I was reading that some Downs children are able to take classes from Community Colleges. And so, maybe he'll be able to do a little Community College work or something, but maybe not. It's hard, because that is a big part of our lives.... And so to have him not be able to participate in that aspect of our lives, you know, science and school and stuff ...

One of the teachers appeared to be regaining some control in her life through proactive measures connected with planning for the education of her infant:

I already have her PPI teacher. She already knows she can't leave the district for six years. I have the hope that (child) will go to regular kindergarten. I want her to be in a regular classroom as long as she can be in there, and as far as she can go in the regular classroom.

A common area of concern for the future was whether the child would have friends and how other children might treat him/her. Six mothers discussed this category. Examples of this concern by two mothers follow:

It makes me sad to think that friends-wise, will he have a lot of friends. I don't know. I think that kids are more accepting now than they used to be.

The things I think about are his being teased. And will he have friends.

Two mothers wondered whether their child would have a job as an adult. Only one mother worried about finances. She gave up her business to stay at home fulltime to care for her infant who had a heart condition. Prior to his birth, she had planned to continue working.

In summary, at Time 1, concerns about the future were prevalent, and themes included the ability to live independently, the child's education, friendships, and job. Only two mothers indicated that they were not spending a lot of time anticipating the future. **We don't know if it's going to be severe or mild. We can't plan. So at this point we'll just go one day at a time.**

By Time 2, when the infant was six months old and interacting at a higher level, mothers commented that they were beginning to see what the infant was achieving in terms of developmental milestones. This gave them renewed hope. Two infants had had their heart surgery just prior to this second interview. Two infants were going to have their surgery within the next few months. Another family, who had been told before the child was one month old that her mild heart condition would not require surgery, had just been told the week prior to the second interview, that the infant did need heart surgery – immediately – and it was scheduled for the following week. Mothers of the two infants who were recovering from heart surgery, as well as four additional mothers whose infants experienced no major medical problems at birth, saw the future as positive. Several said that they were no longer thinking about the future. They were enjoying their children and taking things day by day, indicating that they were entering an acceptance stage and were adjusting to their child's disability. One mother said at Time 2:

We just try to take it day by day and not look too far into the future. You know, let's just take the here and now, and as things come along, be with them as they do. So we don't even talk that way a lot (about the future). We really deal with the here and now with him.

Another mother attributed her positive beliefs about the future to learning that had taken place since Time 1.

I think the reason why is because we know a lot, we've learned a lot – probably more than the last time we saw you, and the more you know, the less in the dark you are, and the less afraid you are, and the more hope you have.

One mother compared her beliefs at Time 2, after her infant's heart surgery, with those at Time 1 in this manner when asked if she still had any concerns about the future:

Not any more. At first, all of a sudden it would dawn on me ... oh, my gosh, my kid has special needs! He's going to be different, and life is going to be so hard for him, and it's going to be so hard for us. I never, never feel that any more. He's just a kid.

Yet another mother was afraid she might get caught up in the cycle of thinking too positively about the future. This was likely her way of preparing herself for future disappointments.

You know, you look at the progress he's making, and you hear everyone say, 'guy, he's doing so good,' and you think does that mean that ...? It's a good thing and a bad thing. I try to catch myself of (sic) not getting sucked into that cycle.

For those five remaining mothers, the researcher did not have enough interview data to categorize one. Of those four who still expressed worrisome concerns about the future at Time 2, three were mothers of infants who had ongoing medical (heart) problems. In two of these cases, marital problems were exacerbated by the ongoing concerns about their infant (as will be discussed in the section on differences in marital satisfaction between Time 1 and Time 2 –

Research Question 11.) One mother had difficulty even looking toward the future.

I just don't want to get my hopes up on that heart surgery. We kind of get our hopes up that it's going to be a cure-all, and that she's going to have endurance and be peppy. I don't want to get my hopes up and have it not work.

Again, these beliefs illustrate the diversity with which mothers come to accept their child's disability, the length of the acute grieving period, and adjustment. When medical conditions are present, it makes it far more difficult for those parents to reach acceptance, since their futures are still seen as uncertain. More on this topic will be discussed later in this chapter – particularly as father's beliefs will also be considered and contrasted with those of mothers.

The Time 1 correlation ($r = .51$) between Maternal Marital Satisfaction and the Mother's Current Beliefs and Hope decreased at Time 2 ($r = .36$). This researcher saw the infant's developing responsiveness as contributing to the mothers' Hope, although mothers' scores on the measure did not increase significantly. The beliefs of the mother about the future of her disabled infant at Time 2 did not have as strong an influence on her satisfaction with her marriage. The mothers' level of Marital Satisfaction also increased at Time 2.

However, the subscale, *Mother's Belief in a Meaning or Purpose*, for this event in her life did correlate with *Maternal Marital Satisfaction* at Time 2, and this correlation reached a moderately strong level ($r = .65$). Mother's Belief in a Meaning or Purpose has been discussed previously. It appears that the mother's ability to find a meaning for her infant's disability could possibly indicate that she makes positive attributions to life events in general. It is also

important to consider the fact that four mothers attributed meaning to their infant's birth as preordained by God. Religiosity is likely to influence the mother's attitude toward other relationships as well, including her marital relationship. Therefore, a plausible explanation for this moderately strong association at Time 2 is likely to point to the mother's general attitude and world view, which would also influence her satisfaction with life, as well as her marital relationship.

(5) Is there a relationship between the mother's perceived level of congruence of her spouse's beliefs with her own beliefs about their infant's disability and the level of her marital satisfaction?

Quantitative Findings: Level of Congruency of Beliefs is represented by the differences between scores of the mother and *her* scores of the father regarding their hopes for the future for the infant and family, as well as a sense of meaning and purpose for this event in their lives. This Level of Congruency score was correlated with the mother's score on the Dyadic Adjustment Scale. This correlation was computed for Time 1 only. The results of this analysis are summarized in Table 16. A strong positive correlation ($r = .61$) for this sample only was found for Time 1. It was statistically significant at $p < .05$.

This strong positive correlation was expected, since the researcher believed that a commonality of beliefs in the eyes of the mother would allow her to become more open in her communication with her spouse. If she felt her husband did not share her beliefs, it is likely that the mother would choose not to self-disclose her thoughts and feelings, creating distance in their

communication. Or if she did share her feelings with her partner, and he countered them with very different feelings, she might perceive this as a lack of support for her beliefs. The strong correlation between these variables supports the researcher's assumption.

Qualitative Findings: There is no additional qualitative data that has not already been presented in the discussion under research question No. 2. There it is noted that the mothers' perceptions were discrepant to the fathers' actual scores. These discrepancies between spouses and possible explanations for the discrepancies have been discussed. *Accuracy of perceptions* is not deemed important to this correlation. Even though mothers overestimated the functionality of their spouse's beliefs, their perceptions contributed to their marital satisfaction. As previously stated, further research regarding parental perceptions seems important to the work of mental health clinicians.

(6) Is there a relationship between the mother's level of satisfaction with the emotional and instrumental support she receives from her partner and her level of marital satisfaction?

Quantitative Findings: Level of Satisfaction with Emotional and Instrumental Support is represented by the combined scores of each of these categories of support as scaled by the mother regarding the support she receives from her husband. These scores were obtained during the interviews at both Time 1 and Time 2. This Level of Satisfaction with Support score was

correlated with the mother's scores on the Dyadic Adjustment Scale for both Time 1 and Time 2 using the Spearman rho. This analysis is summarized in Table 16. At Time 1, a moderate correlation approached a level of significance ($r = .54, p < .10$). There was a low association ($r = .27$) at Time 2.

It was decided to repeat the Time 1 correlation between Maternal Marital Satisfaction and Maternal Level of Satisfaction with Partner Support, controlling for age, education, income, family size, stress, and depression. Each of these control variables reduced the strength of the original correlation – in most cases, dropping it into the “mild” range ($r = .37$ to $r = .52$), with the greatest change coming from age, education, income, and family size.

The researcher was interested in learning how the mothers weighted the two categories of support. Spearman rho correlations were run between each of the “support” categories (Instrumental Support and Emotional Support) and her Marital Satisfaction. From the data that emerged from discussion within this section of the interview, the researcher suspected that Instrumental Support was secondary in value to Emotional Support when scaled by the mother. Even though it was determined that at Time 2 there was no association between the mother's overall Level of Satisfaction with the Support she receives from her husband and her Marital Satisfaction, these correlations were run for both Time 1 and Time 2. These correlations are included in Table 16.

Low associations were found for Instrumental support with Marital Satisfaction at both Time 1 and Time 2. However, mild to moderate

correlations between Emotional Support and Marital Satisfaction appeared at both Time 1 ($r = .44$) and Time 2 ($r = .42$). It appears that level of Emotional Support had a greater influence on mothers' Marital Satisfaction than did Instrumental Support.

Qualitative Findings: The moderate positive correlation between these two variables was expected at Time 1. However, the drop in this correlation at Time 2 was unexpected and not consistent with research on marital satisfaction for the general population.

This cannot be entirely accounted for by examining qualitative data. Examining individual scores provided a better picture. Mothers gave their spouses fairly high scores on Emotional Support. Only one mother's score was lower, but in the neutral range at Time 1, and that same mother and one additional mother scored in the neutral range at Time 2. Both of these mothers scored below the normed mean on Marital Satisfaction.

The researcher perceived mothers' scores on Instrumental Support as conforming to their interview discussions. However, several mothers acknowledged the lack of Instrumental (physical) Support they received and still scored high on Marital Satisfaction. Some of these mothers rationalized their scores with the following kinds of comments:

Hm-m-m. It could be better, but, again, part of that is he's working some pretty long hours where he's employed. I guess I could say it could be better, but we've kind of worked it where I'm only working two days a week. But I would like to see a little bit more.

It's not very good. That's (the score) pretty low, but that I don't think has anything to do with her (infant) either. It has to do with because I'm a stay-at-home mom, and he doesn't get home until 7:00.

One mother blamed herself for her husband's lack of instrumental support:

Sometimes I think he could do a little bit more. It's my fault, too, because I want it done when I want it done and the way I think it should be done. It's kind of something that's hard for me to let go and just say, 'O.K., do this whenever you feel like you can get it done.' And if he doesn't do it by the time I think it should be done, then I'll just do it.

The researcher believes that, since these mothers were on maternity leave at Time 1 or, in four cases, not planning to work full time, they considered themselves the primary homemakers. Therefore, they modified their expectations of their husbands with regard to instrumental assistance. Thus, their marital satisfaction was not compromised by a felt lack of support from their spouses.

These expectations and scores might have been different if these mothers were working as many hours outside the home as their husbands. By Time 2, four mothers were back to work fulltime. Two of these mothers had scored their husband's support as "high" while they were on maternity leave at Time 1. By Time 2, when they were back to their jobs, their scores had dropped. These two mothers also scored below the norm on Marital Satisfaction. As it often happens when a newborn arrives in a family, husbands are more willing to be physically supportive to their wives. Three months later, old patterns tend to creep back in, and fathers are not as likely to be as helpful to their wives. There was an exception: One mother who returned to full-time

work raised her score on Instrumental Support at Time 2. She had the following to say about her husband's improvement:

It's been since that first interview that (husband) has spent time with (infant) all day, by himself, and I think it was an eye-opening of ... oh my gosh, this is what it's like! ... And so I think having an opportunity to be alone with (infant)

and truly understanding how much work he is along with everything else has had a positive impact on him.

This mother's marital satisfaction also increased six points from Time 1 to Time 2.

Table 16
Predictors of Maternal Marital Satisfaction (Dyadic Adjustment Scale)

	Time 1	Time 2
Functionality of Beliefs	.46	.25
Previous Beliefs	.57†	.41
Control Variable For Prev. Beliefs		
<i>educ.</i>	.64*	
Curr. Beliefs/Hope	.51	.36
Meaning/Purpose	.19	.65*
Control Variables For Meaning/Purpose		
	<i>age</i>	.56†
	<i>educ.</i>	.65*
	<i>income</i>	.77**
	<i>fam.size</i>	.60†
	<i>stress</i>	.57†
	<i>depression</i>	.58†
Congruency with Partner's Beliefs	.61*	na
Partner Support (Combined Categories)	.54†	.27
Control Variables For Partner Support:		
	<i>age</i>	.37
	<i>educ.</i>	.39
	<i>income</i>	.40
	<i>fam.size</i>	.40
	<i>stress</i>	.52
	<i>depression</i>	.44
Instrumental Support	.17	.23
Emotional Support	.44	.42

N =11

** $p < .01$

* $p < .05$

† $p < .10$

(7) Is there a relationship between the level of functionality of paternal beliefs about the infant's disability and the father's level of marital satisfaction?

Quantitative Findings: Level of Functionality of Paternal Beliefs consists of the total interview scores of the fathers. These scores included their beliefs about disabilities prior to the birth of their infant, the manner in which they were informed of the diagnosis, the quality of information given them, their emotional reactions, and their current beliefs and hopes for the future. Functionality of Father's Beliefs was correlated with the fathers' scores on the Dyadic Adjustment Scale. This correlation was computed at both Time 1 and Time 2. The results of this analysis are summarized in Table 17.

At Time 1, a moderately-strong, positive correlation approached significance ($r = .65, p = .08$). At Time 2, a weak, positive correlation was found, ($r = .32$). It was not found to be statistically significant. The Time 1 original association was then partially correlated, controlling for age, education, income, family size, and stress. (Stress is an objective measure scored by the *mother*, based on whether particular events occurred in the life of the family.) With the exception of age, these partial correlations reduced the size of the original correlation into the moderate range. Income, which reduced the original correlation of $r = .65$ to $r = .49$, seemed to have the strongest influence on this original association. (See Table 17.)

The researcher wondered if any of the interview subscales might be influencing the strength of these associations. These subscales were

examined and two subscales emerged as having strong correlations that reached significance when correlated with Marital Satisfaction. These two subscales are: (a) Hope – the positive belief about what the future holds for the infant and the family; and (b) Meaning/Purpose – the belief in a meaning or purpose that the father has attributed or believes will become attributed to himself, his family, or others as a result of his infant's disability.

At Time 1, Hope was found to have a strong, positive correlation with Marital Satisfaction ($r = .71, p < .05$). Purpose also had a strong, positive correlation with Marital Satisfaction ($r = .77, p = .015$). When these original correlations were run again, controlling for age, income, education, family size, and stress, the original correlations changed only slightly.

The same correlations were run for Time 2. This time, Hope had a mild/moderate positive correlation with Marital Satisfaction ($r = .45$). Meaning/Purpose had a moderate positive correlation with Marital Satisfaction ($r = .60$). Again, these correlations were rerun, controlling for age, education, income, family size and stress. These partial correlations increased the original associations. Several of these increased quite a bit, and the correlation with Meaning/Purpose reached statistical significance at Time 2. Stress was the only control variable that reduced the correlation of Hope and Paternal Marital Satisfaction at Time 2 ($r = .31$). (See Table 17.)

Qualitative Findings: These statistical results imply that “early” Hopefulness (when the infant was only three months old) was a better predictor for the Father’s Marital Satisfaction than later. Perhaps during the immediate

period of time following the birth of the infant a determination was activated within the father to look at life's unexpected events from a positive point of view. This may also have been in line with what some mothers suspected – that their husbands were either in “denial” or attempting to handle their situations with “strength” in an effort to be supportive. There is evidence for this in the qualitative data collected from both mothers and fathers (mothers' data discussed earlier). It would seem reasonable, then, that if fathers decided consciously or otherwise to see this event in their lives as hopeful, this proclivity toward optimism (and denial in some cases) would carry over into other aspects of their lives, including their marital relationship.

At Time 2, six months following the birth, whether or not fathers continued to hold on to their hope and optimism with regard to their infant's future, they were unlikely to be able to deny the tone or quality of their marital relationship. (Their scores on the Dyadic Adjustment Scale dropped almost three points at Time 2.) The infant's ability to interact with the parents was enhanced by Time 2, and mothers reported more Hope at Time 2. However, the distraction caused by demands to be met by caring for a new infant that occurred at Time 1 was no longer operative at Time 2. Therefore, both mothers and fathers could again focus attention on the marital relationship. The interaction between marital partners that occurred between Time 1 and Time 2 also was likely to be consistent with prebirth or “normal” marital dynamics, leading to a more realistic evaluation of marital satisfaction, though hope for the infant still may have been running high.

Qualitative data to support this follows. Nine fathers were interviewed at Time 1 and eight fathers at Time 2. One father said at Time 1:

I always look on the bright side – sometimes too much and be optimistic and then in the back of my mind, you know the down side, but you don't go for that guess ... you know.

Another father chose to alter his worldview at Time 1 that included his other children as well.

You think about the big picture with this, you know. All of us are going to be gone some day. I mean, your life doesn't go on forever, so you make the best of it while you're (sic) here with us, and that's all you can do. If you want to reflect on what's going to happen thirty years from now, you'd just have a nervous breakdown. You just wouldn't be able to function. There'll be times that we're just sitting around thinking about what could happen, and his future, and that; but I think that with my other two kids. You know, my other two kids are normal. You don't know from one day to the next if they're going to get cancer or heart problems or get hit by a drunk driver. So you just can't think that far into the future, because you never know when you're going to lose them anyway.

Yet another father had a great deal of optimism at Time 1 regarding the future of his daughter:

I just have a lot more hope that – maybe it's still a kind of denial or something – because she doesn't ... If they tell you now she can't learn, I'm not going to believe she can't learn or at a comparable rate or something. Maybe I'm hopeful that maybe we'll get to that point that (sic) they'll find – they know a lot about how they learn – they don't learn like you and I do. Once they find out whether their problem is dyslexia or ...

Four fathers expressed optimism. Two fathers were very pessimistic in their views of the future at Time 1. One father was trying to take a positive approach

but was unable to talk about it without revealing his internal conflict and grieving:

You know, I'm not afraid of the future, by no means. I'm nervous, I guess. When I look in the future, I'm nervous . And I'm sad, I guess. Yeah, I'm kind of sad for (infant), just because I know he has things that are going to be difficult for him (voice cracks). I'm a little nervous about that too. But, in general, I look at it and try to plan for it, but I'm not worried or scared of it. I'm not wanting it to happen. But I just keep going through the things in my head going, 'How are you going to deal with that? How are you going to deal with that?'

Another father was very pessimistic and this was exhibited in the form of anger. His marital satisfaction scores also reflected this pessimism and anger.

I'm just too much of a realist. I live in the real world, and I know no matter what the book says, I've got a pretty good idea of what it's going to be like down the road. The bottom line is a lot of people don't like the way I look at it, but the bottom line is I have a child that I'm going to have to work ten times harder to raise than I would a normal child, and she's still going to be the one that most the other kids pick on. And that's real life.

Three other fathers were considered by the researcher to be "neutral" regarding their beliefs and hope for the future. At Time 2, the fathers who were optimistic at Time 1 remained optimistic at Time 2 (interview data was not available for one of these fathers at Time 2). The three fathers who were neutral at Time 1 were also categorized by the researcher as neutral at Time 2. One of the fathers who had expressed pessimism at Time 1 was very optimistic at Time 2, while the second father continued to express extreme pessimism at Time 2. The father who moved from pessimism to optimism commented:

I don't paint a picture in ten years. I don't know. I know he's going to be (child's name), my son, but I have absolutely no expectations other than he's going to be (child's name), my son, and he's going to do great things in my mind. I know he will. ...I'm looking with exuberance. I can't wait, you know.

Fathers, as did mothers, talked about the kinds of concerns they had for the future. Three fathers highlighted concerns about their child's education, wondering if mainstreaming would be the appropriate path for them. Five fathers expressed concerns about the eventual independence of their child, or whether **when we go on our retirement trip or something, we'll have a third person along.** One father articulated it this way: **You know, you expect your kids to be gone when they're 25. You never know, though, from divorce or whatever, they sometimes come back, but it's very likely she'll be with us a long time.** One father expressed concern that he might not be around to provide for his son. Another father worried that he would have a son only for a short period of time, since he was of the belief that Down Syndrome children do not live as long as normal children. The one difference noted between mothers and fathers regarding the kinds of concerns they had was that mothers worried whether their children would have friends or a significant other. This was not a concern expressed by the fathers, which conforms to findings across other studies.

By Time 2, the researcher found two fathers taking active measures to assure a better future for their children. As a result of his internet research, one father became very active in an international support group, and he and his wife had volunteered to become Treasurers at the State level for that support group.

Another father had turned the college savings account he had started pre-birth for his son into a savings account that he called a life insurance plan for his child if something happened to him.

With regard to the *Meaning/Purpose* subscale, qualitative data supports the father's scoring but does not directly provide an explanation about the high correlation of this subscale with *Marital Satisfaction*. Fathers were less likely than mothers to ascribe a meaning or a purpose for this birth event in their lives. Where fathers believed that there was a purpose or meaning, the association with marital satisfaction was stronger than that of the same association for the mothers. The same explanation that was given for this finding with the mothers is likely to apply to the fathers as well. Because some fathers connected this event to the plan of a higher power or for personal growth purposes, it is possible that they make positive attributions to life events in general, including their marriage. Religiosity factors into this as well. Where fathers talked about their religious faith in connection with this birth event, they gave testimony to it being part of God's plan for them. At Time 1, three fathers discussed this event as having meaning in terms of their religious faith (as did three mothers). One described his belief as being a part of God's plan:

We decided we wanted another child, and we felt God blessed us with one, and this was planned, and we had talked about it before if we had a child that was a special needs child, it's intended for us. Maybe it's not ours to always ask questions why or how God will use us through him or her. ... If you

believe it's all providential, then you don't look for alternative meanings, but I can find them as I look for them.

One father described their child's birth as having a purpose in their lives rather than a spiritual meaning.

I'm not spiritual, so there's no spiritual side ... But I think, from externally, his birth and having Down Syndrome is a test for us. It's to help us grow and understand; and if you can 'beat this' – if that's how we would say it, then you're going to improve yourself. You've got a test. You've got a challenge in front of you, and it is an opportunity to better yourself and the people around you.

One father gave himself a neutral score, since he wasn't sure. He was approaching it from a scientific point of view. Three fathers did not believe there was a meaning or purpose for this event. One of these fathers disagreed with friends and family members telling him that he was privileged by God:

I haven't spent a lot of time thinking about that (a meaning). I know we've had a lot of people say that God gave you this baby because He knew you could take care of it so well. My feeling is if He has that kind of power, why didn't He give us a normal ... so I guess I don't think about that a whole lot.

Another father approached it from a strictly scientific point of view: **No, it was a chance happening. It wasn't heredity or anything like that. It was just a chance thing and these things happen.**

At Time 2, no fathers had moved from other categories toward a belief in a Meaning or Purpose. Instead, the father who was neutral at Time 1 decided that there was no purpose for this event. One father who had given a tentative response at Time 1 indicating a "growth" purpose for this event, answered negatively at Time 2. There may be some implications here for Marriage and Family Therapists working with this population. Helping parents to search for

positive meanings or personal growth outcomes could be helpful in working with troubled relationships. Certainly, this has implications for future research.

TABLE 17
Beliefs as Predictors of Paternal Marital Satisfaction
(Dyadic Adjustment Scale)

Time 1			Time 2		
Functional Beliefs	Hope	Meaning/ Purpose	Functional Beliefs	Hope	Meaning/ Purpose
.65†	.71*	.77*	.32	.45	.60
Control Variables:					
age .67	.78*	.77*	na	.73†	.76
educ. .58	.75*	.73*		.53	.80*
income .49	.72*	.73*		.47	.82*
fam.sz. .56	.69†	.71*		.55	.82*
stress .54	.72*	.73*		.31	.77*

N = 8

* $p < .05$

† $p < .10$

(8) Is there a significant difference in parental beliefs (Level of Functionality of Beliefs) between Time 1 and Time 2?

Quantitative Findings: Mothers interview scores regarding her current beliefs and hopes for the future, her belief in a meaning or a purpose for this event in her life, and her unwillingness to assign blame to herself or her husband for the infant's disability did not change substantially over the 3-month period between Time 1 and Time 2. This also held true for the father.

However, the scores (45 points possible) between mother and father on this variable differed. At Time 1, mothers had a mean score of 35.45 and fathers a mean of 31.38, and this difference approached significance at $p = .09$. At Time 2, the mean for mothers was 35.41 and the mean for fathers was 31.13. This time, the difference was significant at $p = .03$. It is not known why the level of significance was different between Time 1 and Time 2, but it could be due to the small numbers in the sample. It appears that mothers scored higher than fathers did on this measure at both Time 1 and Time 2. (See Table 18.)

Two subscales emerged as contributing toward the Functionality of Beliefs total score emerged during correlational analysis as important predictors for the father's Level of Marital Satisfaction. The researcher chose to additionally examine the differences on those subscales between Time 1 and Time 2 for both mothers and fathers. Those subscales are *Hope* (the parents' belief in a positive future for the infant and family) and *Meaning/Purpose* (the parents' belief that there is a meaning or purpose for this event in their lives, though it may not yet be discovered).

At both Time 1 and Time 2, while mothers scored higher on Hope (20 points possible) than fathers, their differences between means did not approach significance. At Time 1, mothers also scored higher than fathers did on Meaning/Purpose (5 points possible), and this difference did not approach a level of significance. At Time 2, the difference between the means of mothers (4.36) and fathers (3.0) on Meaning/Purpose approached a level of significance at $p = .08$. This Meaning/Purpose subscale seems to partially account for the

difference between means between mothers and fathers on their “Functionality of Beliefs” scores. (See Table 18.)

Qualitative Findings: Mothers' higher scores on the subscale *Meaning/Purpose* has already been discussed in detail in the analysis of Research Questions 1 - 3. There was no additional qualitative data that could supplement these findings.

(9) Is there a significant difference between the mother's level of satisfaction with the support she receives from her partner between Time 1 and Time 2?

Quantitative Findings: There was very little difference between mothers' scores on her level of satisfaction with the support she receives between Time 1 and Time 2. Out of a possible 20 points each time, mothers had high mean scores of 17.18 and 17.05, respectively. (See Table 18.)

Qualitative Findings: Mothers appeared to be satisfied, for the most part, with the amount of support they were receiving from their partners. While most acknowledged that the amount of instrumental support received could be greater, they rationalized legitimate reasons for this when scaling their level of satisfaction. Their scores were not completely in sync with their interview discussions, but many mothers were quick to rationalize their satisfaction, even when they admitted a lack of support. This has been discussed in detail in the analysis of Question No. 6.

(10): Is there a significant difference between mothers and fathers on their levels of marital satisfaction for Time 1 and Time 2?

(11): Is there a significant difference between Time 1 and Time 2 on levels of marital satisfaction for mothers and fathers?

Quantitative Findings: Fathers scored higher (119.22) on Marital Satisfaction than mothers (113.68) at Time 1, and this difference was significant at $p = .05$. There was no difference at Time 2.

The researcher visually examined the highest three scores and lowest three scores on Marital Satisfaction for the purpose of ascertaining differences between those who were very satisfied with their marital relationships and those who were not. Fathers' scores were higher than mothers' scores for both extreme groups primarily at Time 1, which was addressed above. Marital partners matched their positions within the highest-scoring and lowest-scoring groups so there were no large differences in marital satisfaction between husbands and wives within the matched pairs. (Where the mother scored in the upper three cases, it happened that her husband did also and this was true for the three lowest-scoring pairs on Marital Satisfaction.)

Significant findings (not quantified, however) follow:

1. The mean age for mothers in the highest-scoring group was 38.3, and the mean age for fathers was 36.6. The mean age for mothers in the lowest-scoring group was 34, and the mean age for fathers was 34. While the age difference is not as significant for fathers, a maturity factor may be operating with regard to marital expectations

among the mothers. The older mothers appear to be more satisfied in their marriages.

2. Even more significant, is the fact that the lowest-scoring mothers were employed full time outside of the home. Two of the highest-scoring mothers were stay-at-home moms, and one mother worked two days a week. There is likely to be a stress factor operating upon these differences.
3. All couples in the lowest-scoring group had medically fragile infants who were facing impending heart surgeries. There is likely a “chronic stress” factor operating for parents in this lowest-scoring group.
4. The two groups of parents differed on their scaling of “Emotional Support.” Mothers could receive as many as 20 points on Maternal Level of Satisfaction with the Emotional and Instrumental Support Received from Her Partner. However, these two subscales were not divided equally. Instrumental Support was comprised of three questions, totaling 15 points, whereas Emotional Support consisted of one question that allowed for 5 possible points. Mothers in the lowest-scoring group scored 3.8 on Emotional Support, while mothers in the highest-scoring group scored 4.3. High-scoring mothers, therefore, indicated greater satisfaction with the amount of emotional support they received from their husbands. This reflected the mothers’ weighting on this scale, generally. The researcher now believes that if this scale were to be revised for a future study, it

should produce a score equal on these two support dimensions.

Thus, the quantitative data alone for this study does not yield enough information on Partner's Support. Qualitative data helped elucidate the relevance of Emotional Support.

5. Differences for dads included their beliefs. Fathers in the highest-scoring group scored their Hope for the Future at a mean of 19, which was eight points higher than fathers in the lowest-scoring group, who scored a mean of 11. The same was true for a Belief in a Purpose or Meaning for this event in their lives. (All three of these fathers claimed religious beliefs, and the researcher categorized two of these fathers as "strong believers." Therefore, religiosity is likely influencing these beliefs.) The highest-scoring fathers scored 4.7 (out of a possible 5), whereas the lowest-scoring fathers had a mean score of 2 on Meaning/Purpose. This implies that fathers who scored the highest on Marital Satisfaction had a more positive belief system than did the fathers who scored lowest. The question might be asked, "Did fathers' belief systems change as a result of their infants' birth?" It is the researcher's belief, from having conversed with them, that there was a prebirth tendency toward pessimism with these low-scoring fathers that was exacerbated by the birth of their developmentally disabled infant. Where Marital Satisfaction was most likely borderline before the infant's diagnosis, the added stress of having a disabled child may have pulled levels of Marital

Satisfaction downward. This will be addressed in the discussion of qualitative data obtained through interviews with fathers.

6. Number of stressors reported by the mothers during the 12 months prior to the first interview were higher among the lowest-scoring group on Marital Satisfaction (mean 13). The mothers in the highest-scoring group reported fewer stressors (mean 9.7), which may have influenced levels of marital satisfaction – not surprisingly.

It bears mentioning that no differences were found between these two high and low groups on income, education, mother's level of depression, and mother's level of satisfaction with the instrumental support she received from her partner.

Qualitative Findings: There seems to be no plausible explanation for these Time 1 differences. Qualitative interview data does not add to an understanding of these differences. Normative data for the Dyadic Adjustment Scale, the instrument selected to measure Marital Satisfaction for this study, indicate that there are no differences between men and women on this scale. One possible, but perhaps remote, explanation for these differences might lie in the finding that some mothers suspected that fathers were using the coping mechanism of “denial” early in their adjustment to the circumstances of their infant's birth. If, as suggested by mothers and corroborated by fathers in a couple of instances, denial was operating for any of the fathers at Time 1, then the fathers' higher marital satisfaction scores might reflect this. By Time 2, this

coping mechanism likely was replaced with a more realistic awareness, which would explain the reduction in scores for the fathers.

Interview data gathered at both Time 1 and Time 2 give a clearer picture of the marital dynamics that occur when parents are confronted with the addition of a developmentally disabled infant to their family. The remaining portion of this section is devoted to an elaboration of the quantitative findings on marital satisfaction for this sample. The findings relevant to the three highest-scoring and three lowest-scoring cases will be developed through discussion of the interview data.

Other than questions pertaining to the amount of Support the Mother Received from her Spouse and the Mother's Perception of a Level of Congruency between her Beliefs and those of her Partner, no direct questioning of Marital Satisfaction occurred in the interview. Such discussion evolved through open-ended questions in other areas – i.e., Partner Support. As the researcher began interviewing mothers about their Emotional Support, it became apparent that Communication was emerging as a common theme. By Time 2, it was decided to explore this theme at a deeper level with these mothers.

From interview data, two major themes emerged. One became apparent through the conversational content of those that expressed high levels of marital satisfaction. This content included similar beliefs and feelings expressed by each partner. These beliefs and feelings revealed each partner was experiencing similar process of adjustment – a unified adjustment process.

There was evidence from the interviews that these couples looked at this event as though they were in this together, and they were walking the road to the future together. This was in contrast to an obvious absence of this content among those couples who were less satisfied with their relationship. The researcher coded this theme as “we-ness.”

The second theme that emerged, was, as mentioned earlier, “communication.” Parents who had greater satisfaction with their marital relationship talked more with each other, and at greater depth, which was in contrast to those couples who were less satisfied.

It is generally accepted that when the loss of a child occurs in a family, those couples that grieve together usually stay together. One could also claim that this is probably true for couples who experience the birth of a child with a major disability. The data collected from this study sample supports that claim.

“We-ness”

Comments abounded that gave evidence for a spirit of “we-ness” among happily married couples, and they were too numerous to include in this discussion. Examples were chosen as follows:

When interviewing one highly satisfied couple at Time 2 about their current adjustment, the wife said:

Yeah, I am really, really truly surprised that the two of us – it was devastating. We mourned. We cried. But we got on with it.

But we’re going to get into it – let’s put it that way (planning their future together). We’re just three happy campers!

The husband, from this same couple (this was his second marriage), had this to say, when he was interviewed separately from his wife:

I was previously married – I have two other kids that are with us – and that didn't go well. So maybe along with ... (sic) this was meant for us to be together and meant to have a special child to raise.

He was seeing this event in his life as a way to maintain closeness in his current marriage. Another father who scored fairly high on his marital satisfaction said, in his statements about his current feelings at Time 1:

We've waited for a kid for a long time, and to me, it doesn't matter that he has Down Syndrome. He's mine, and I've waited a long time for a child and I'm thrilled to death. It's the best thing that ever happened to me – what's good for me, what's good for (wife), what's good for everybody. ... He has added another whole dimension to my life, to (wife's).

Three of these couples were making a concerted effort to put the “we-ness” into their futures (as alluded to in the previous quote by the wife). One mother explained how her husband had to take off from work on Fridays in order to attend their infant's therapy sessions.

He takes off from work and comes. No, it's not very many that the dads come (sic). Most of them – it's just the moms that are there. But I think it's better for her and it's been a real learning for us together because we think it's important for both of us to be involved. We really are involved with our kids, but especially with her and her special needs; and I think we've seen that through being involved with (name of early intervention program).

These parents talked enthusiastically of their involvement with the preprimary impaired program that was providing therapy for their daughter. The husband was actually helping single mothers work with their infants in the program. This

parent team added additional comments regarding their joint experiences as they were becoming involved with the work of therapy for their child.

(Mother): **I think the other thing for me, in terms of personal growth or learning or that kind of stuff is again through (name of program). You see that, I don't know, you see the breadth of the possibilities of some of the disabilities that are there. It's such an eye-opening experience. It gives you such a totally different feeling. I have such a heart for those kids that I never would have had if we hadn't had (infant) and hadn't gotten involved with (name of program).**

(Father in response to researcher's comment that their lives are very different now): **Yeah, they're enriched because of it, and our perspectives are broadened. Our sensitivities are – you know – it could be something that's totally unrelated, but any time you see someone that's disadvantaged, it's like it tugs at your heart.**

This happily married couple was making an effort to turn their experience into a conjoint growing experience. Another father was also involved in his son's development, and joined his wife for all of the infant's medical appointments – another indication that “we-ness” was going to continue well into the future with regard to their infant's disability.

My schedule allows me to make his doctor's appointments, and that's something I wouldn't have done. Without the Down Syndrome, I would have said, 'It's just your four month – no big deal – but here with Dr. (name), it's on my schedule. I will not schedule anything workwise on that day, so that I can work from here (home). ... I make a very conscious effort to try to make his appointments.

It isn't always possible for fathers to take time off from work for these daytime kinds of activities, and these efforts to strengthen the marriage as a result of adversity seem commendable. There may be many creative ways in which

Marriage and Family Therapists can help couples find joint endeavors around their experience with a developmentally disabled child to strengthen the marriage. One couple was working on this through becoming involved in a support group:

(Father): **And we're more involved now, too. We had our first State Chapter meeting in (name of city), so we're part of one big group now. As a matter of fact, they elected us Treasurers, so we're really going to be involved now.**

By contrast, three marriages appeared to be stressed by the birth of their infant. The "we-ness" discussed above was noticeably missing from the conversations of these couples. In fact, comments were made that led the researcher to believe that these parents were experiencing very individual feelings that they were not disclosing to one another. The researcher asked one mother what her perceptions were of how her husband had adjusted:

Kind of middle of the line. I don't think he has adjusted as well as I have. I think he still has some issues with it. He talks about it when he feels ready to talk about it.

Another mother responded to the researcher's question about whether her husband was still experiencing the sadness or anger that she expressed for herself: **I think he does, but he doesn't – he wants to be strong for me, so he doesn't show it.**

There appeared to be a myth believed by two couples that the husband needed to be "strong" for his wife, and, therefore, he did not disclose his true feelings to her. An awareness of such myths by Marriage and Family Therapists seems critical to their work with these couples.

Communication

It seems logical that couples who achieved a “We-ness” around their adjustment to the birth of their developmentally disabled infant, achieved this through their communication with one another. How did communication differ for happily married couples vs. those who were experiencing lower levels of marital satisfaction? It appears that happily married couples find the time and make an effort to communicate on a frequent basis. One mother stated:

I'd say we daily try to talk about where he's (infant) been and what he's done today, what we see differently.

She also added that the focus of their communication has changed. They spend more time talking about their infant and suddenly realized she had some conflicting thoughts about this:

(Infant's) birth has made him the center of attention, so maybe you tend to talk more about (infant), his disabilities than maybe husband and wife type of thing (sic). So that takes priority somewhat. I would say that has happened with him to an extent – not fully – yeah, it does.

Another mother addressed a similar issue. She discovered that her attention was entirely too focused on her infant by talking with her husband about it, and was able to make some corrections:

For awhile (husband) was jealous, because I was spending so much time – everything was geared toward (infant). I think that's pretty normal. We were able to talk about it. ...I said something's bothering you, and I think we should talk about it. Actually, I had to tell him what I thought it was before he would agree with me. You know, I apologized for spending so much time with (infant) and not enough on him, and he was, it also seemed to me, was (sic) distancing himself from the baby. That really bothered me, so I had to really nail it down to what was really wrong. Since we've had that talk, it's been much better.

Another happily married couple was trying achieve a balance between talking about the routine day-to-day events and at a deeper level with each other:

(Mother): **It (communication) might actually be a little bit better now.**
(Father): **We talk a lot now. I mean, just to be sure that we're both O.K., you know. Are you upset? Is something going on? – type of thing where maybe things are getting ...**(Mother): **I would definitely say it has increased communication – two fold – on an emotional level, as well as on a time level of, 'O.K., what are we going to plan?**

Clearly, happily married couples were finding themselves communicating more to each other. The goal, then, for Marriage and Family Therapists working with this population would be to help these couples develop better communication and to broaden the focus of their communication to things other than the infant.

By contrast, comments made by couples less satisfied with their relationship included the following: When the researcher inquired of one low scoring mother on marital satisfaction about the emotional support she receives from her husband, she said this:

I'm not a real emotional person anyway. I don't require a whole lot of emotional support. If I did, I don't think he'd be able to give it.

The researcher then inquired about their communication. The mother then went on further to say:

It was probably better at first – when (infant) was first born. We really had only each other to talk to about the situation. But I think that as time has gone on, we've gotten used to it, I'd say. The communication is not where I'd like it to be, but it's all right.

In this instance, the birth of their infant had the potential of drawing the couple closer together, since they had each other to lean on during the crisis. But “as time went on,” they returned to their pre-birth infrequent communication pattern.

One father, facing yet another crisis – the crisis of an unexpected impending heart surgery for his 6-month-old infant – had this to say about communication patterns in his relationship with his wife:

I think it (the birth of their developmentally disabled daughter and her subsequent medical problems) affects the problems that you have in the relationship, because you just don't have the time and energy. We've never done real well at communicating. But now we have a special needs child, and she (wife) just goes and cuts me out of making decisions, there's a good price on our relationship. That's something that we've always done. It's just that the stakes are different now. So the hurt feelings are stronger.

In this case, the husband explained that, due to a lack of communication between them, the wife had recently made an important decision around which he felt there should have been more communication. The researcher then commented, ‘So, if anything, this has strained the relationship between you two.’ The mother then added, **I think to a point. I think we're trying to go out more.**

The relevance of good communication has been highlighted by this discussion. Research has found, as mentioned in the literature review, that the birth of a developmentally disabled child has the potential to either make or break a marriage. The research is lacking, however, on the process by which this phenomenon occurs. Information was obtained through this study by analyzing interview data for such couples undergoing early adjustment

processes – processes by which the future of their relationship can almost be predicted. For those couples who had good communication before the birth, there was evidence that the birth of their child brought them closer. For those couples who were experiencing communication difficulties and marital problems before the birth, this may be a crisis that has the potential to drive them even further apart. One mother summed up her thoughts on the subject of communication and how important it is in the lives of couples experiencing adjustment to the birth of a developmentally disabled child:

I can see where communication could be real bad, and then I guess I could see if – I don't know if anybody in your study has said that communication has gone down the drain, but I guess I could see where that could happen, because stress levels are high. You know, lots of visits and financially – I could see where that could really go down the drain. But for us, it's been the opposite. It's been a positive experience. We've had an opportunity to really support each other.

There were no significant differences among the variables between Time 1 and Time 2. One would tend to conclude from this that three months is not enough time to see significant change, and, thus, discount the importance of these two observations and interviews. It is significant in theory, however, that mothers in this sample had established an early pattern of interaction with their infants that remained fairly stable over the three-month period of the study. This was an unexpected finding, since it was believed that mothers would still be in early stages of grieving the loss of their anticipated normal, healthy child at Time 1. Therefore, lower affect levels were expected to reflect on the quality of their feeding interaction with their infants. By Time 2, it was expected that

mothers' higher levels of adjustment would be seen in their feeding interaction. Since this assumption was not borne out, this has implications for early interventionists who make assessments of attachment interaction when the infant is very young. While it may appear that early observations are likely to be fairly accurate and may be predictive of later interaction, there is a need for additional research to test continuity for these observations.

More important to Marriage and Family Therapists is to gain an understanding of the processes by which mothers vs. fathers approach their adjustment to the birth of a developmentally disabled infant. There were two major differences.

At both Times 1 and 2, mothers scored higher than fathers on the Level of Functionality of their Beliefs. It appears that mothers may begin their process of adjustment with more hopefulness and more easily find a meaning for this event in their lives. Fathers, however, approached this change in their lives with less optimism, and have a more difficult time attributing a meaning or purpose for this event in their lives. That is not to say they were without hope for a positive future. They tended to see the future realistically. If their worldview leans toward realism, then it may be that a belief in a spiritual purpose or a meaning for this event would be too elusive for their modus operandi. "Religiosity" is likely associated with the women's ability to ascribe purpose and meaning to this event, and it is generally accepted by social scientists that "religiosity" is more predominant among women than men.

The second interesting finding was that the men initially scored significantly higher than did their wives on Level of Marital Satisfaction at Time 1. At first glance, this does not seem to fit with the previous finding of no significant differences between Time 1 and Time 2 for either fathers or mothers. The researcher believes, from interviewing these fathers and mothers, that while the men claimed to approach this event realistically, some may have been using the defense mechanism of denial in their efforts to cope. There was some evidence in the interview data to support this. It is possible that that there was a need for some fathers to inflate their levels of marital happiness in an effort to cope with the "reality" of their infant's birth – a generalizing process of their use of the coping mechanism of "denial." This supposition is supported by the drop in their scores on Level of Marital Satisfaction at Time 2 when the difference between the mothers and fathers was no longer significant. It is supposed that fathers would be unlikely to maintain this coping mechanism over the 3-month duration of time of this study. It is interesting to note the additional support for this supposition within the differences of the fathers on "Meaning/Purpose" between Time 1 and Time 2 (which did not reach a statistical level of significance). Fathers had a mean score on this measure of 3.78 (out of a possible 5) at Time 1 and dropped to a mean of 3.0 at Time 2. Whereas some fathers may have stepped out of their "realistic worldview" at Time 1 in an effort to cope with their loss, they no longer had a need to find meaning for their infant's birth at Time 2.

It is important to remember that the researcher has attempted to provide plausible explanations for the findings of this study. Since this study is exploratory, and the sample small, nothing can be concluded with respect to these explanations. Future research with a larger sample is needed to determine the accuracy of these suppositions. The purpose of this study is to provide social science and special education researchers with a basis for future inquiry.

TABLE 18
Differences Between Means on Functionality of Beliefs between
Mother and Father, Marital Satisfaction, and Mother's Satisfaction
with Partner Support for Time 1 and Time 2

	Time 1		Time 2	
	Mothers	Fathers	Mothers	Fathers
Functionality of Beliefs	35.45†	31.38†	35.41*	31.13*
Hope	17.86	16.0	18.0	16.12
Meaning/ Purpose	4.36	3.78	4.36†	3.0†
Partner Support (mother only)	17.18	na	17.05	na
Marital Satisfaction	113.68*	119.22*	115.8	116.5

* $p < .05$

† $p < .10$

(12) Is there a significant difference on Quality of Maternal-Infant Attachment Interaction between Time 1 and Time 2?

Quantitative Findings: Tests of significant differences were run on the mothers' scores, the infants' scores and the combined mother-infant scores. The mothers' scores remained virtually the same between Time 1 and Time 2. The infants' scores increased from Time 1 (12.45) to Time 2 (16.45) and reached a level of significance at $p = .02$. One would expect that a 3-month period of time would dramatically influence the infant's ability to interact with the mother, highlighting the need to use the mother's score only in determining predictors of her interaction with her infant. This was previously discussed.

The increase in the infant interaction score from Time 1 to Time 2 is also reflected in the difference in means on the combined mother-infant interaction scores between Time 1 and Time 2. This combined score increased from Time 1 to Time 2, but did not approach a level of significance.

Qualitative Findings: Since this was an observational measure, no interview data was gathered that would support or refute this quantitative finding.

TABLE 19
Differences Between Means on Mother-Infant Attachment Interaction
For Time 1 and Time 2

	Time 1			Time 2		
	Mother	Infant	Combined	Mother	Infant	Combined
NCAST Feeding Scores	39.28	12.45*	51.45	39.36	16.45*	55.55

* $p < .05$

CHAPTER V

SUMMARY AND CONCLUSIONS

This research has produced some important findings with regard to parental beliefs and how they influence marital satisfaction and attachment interaction when a developmentally disabled infant is born. Although this sample is small, these findings point to a strong need for future research. The support of additional research is likely to be helpful to service providers who work with this population either in a clinical setting or through early intervention.

The findings of this study indicate that the adjustment process to the birth of a developmentally disabled infant is unique and personal for each married couple. This is not inconsistent with what is experienced by couples adjusting to the birth of a new baby in general. The following study data, supported by additional research, surfaces as most likely to be relevant to mental health clinicians, early interventionists, educators, policy makers and social science researchers:

- ♦ The mother's satisfaction with her marital relationship and its influence on her interaction with her infant is a very important finding. Research has previously shown that depression correlates strongly with maternal-infant interaction. Mothers in this study did not qualify as "depressed;" however, small differences in levels of affect – i.e., dissatisfaction with certain aspects of their marital relationship can have an influence on their attachment interaction with their infant. Therefore, this study, with its major dual

purpose – to examine predictors of Marital Satisfaction as well as Attachment Interaction when a developmentally disabled infant is born – produced information that could not have been obtained if one or the other was studied separately. Marital Satisfaction emerged as having a strong relationship with Mother-Infant Attachment Interaction.

- ◆ Within the finding that Mother's Level of Marital Satisfaction can influence her Attachment Interaction, one needs to be aware of how mothers come to view their marital relationship. Important to this view of the mother is the support she receives from her husband. This is a general finding across studies of marital relationships – particularly when children are born. However, it may have special significance for those mothers who are adjusting not only to having a new infant but an infant with special needs. Early support groups dealing with emotional and relational issues for parents of special needs infants, highlighting the ongoing need for sharing of instrumental kinds of tasks, may be beneficial. Currently, early intervention programming is designed for optimizing the potential growth of the infant. Nothing seems to be available to these parents that may help build and strengthen their marital relationship when faced with this kind of crisis.
- ◆ Still another consideration relates to the adjustment process for these couples. We now have a depth of knowledge that has been gained through the "grief and loss" research. It is widely accepted that a period of grieving following major loss is necessary for healthy adjustment. It also follows that

couples who are able to communicate with one another during this grieving period can experience a closeness that might not be experienced if each were grieving along his/her own separate path. Many people do not see the birth of a special needs child in association with "loss." Until the 1980's, very little was known about the adjustment process for these parents, and many parents were not validated for the emotional reactions that they experienced following the birth of a disabled child. "Grief" was not a process commonly embraced by society for loss other than death. Many individuals still do not know how to approach parents grieving the loss of an anticipated healthy and "normal" infant. (The interview data collected during this study provides a wealth of information about this dilemma. However, it is not within the scope of the current study to address this in depth.)

Providing early support groups that honor these parents' rights to grieve and that help couples through a grieving process in which they can support one another is seen by the researcher as beneficial and therapeutic.

- ◆ Yet another finding emerges from this study with regard to the "appropriate" vs. "actual" emotional reactions experienced by these parents. Myths abound that are easily swallowed by parents in crisis. Many of the fathers in this study attempted to deny their loss and felt the need to remain strong for their wives. However, while this may have been helpful during overwhelming periods of grief the mothers were experiencing, it also created distance. Something was lacking in the honesty of their communication that was clearly being felt at another level in their relationships. Dispelling these

myths would be important to the work of mental health clinicians and those leading previously discussed support groups.

- ◆ Based upon the finding that parents who find a meaning or purpose for their child's disability score higher on marital satisfaction, Marriage and Family Therapists working with these couples can help them to discover possible opportunities for growth in their lives and in their marriages. Based upon the finding that couples with relationship difficulties are not likely to be attuned to each other's beliefs or feelings about the future with regard to their developmentally disabled infant, Marriage and Family Therapists can help them find new avenues for communication.
- ◆ Policy makers and employers can begin to understand the special needs of these families. When families with special needs children find themselves inundated with extra medical appointments and therapy sessions, they are often faced with time constraints. Not many parents are able to take time off from their jobs for these kinds of activities. If it helps for both parents to be involved in this aspect of their infant's life (which has been deemed important to parents in this study), then employers and policy makers can pay heed to these needs.
- ◆ The study design, which included an examination of both quantitative and qualitative data, allowed for an in-depth of understanding that could not have been provided by quantitative analysis alone. It also enabled the researcher to visually examine those marriages at the extreme ends of the quantitative spectrum on Marital Satisfaction – the upper three cases and

the lower three cases – and to compare interview data between those two groups of cases to examine actual similarities and differences. This comparison process yielded an important finding with regard to the couples within the upper and lower quartiles on Marital Satisfaction. Communication and a sense of unification along the path toward adjustment were two themes that emerged as very different between those two groups of cases. Therefore, researchers who are willing to step outside their quantitative or qualitative domains to incorporate both within their inquiry may be able to contribute more to an understanding of these kinds of processes.

- ◆ A qualitative examination of mothers' pre-birth beliefs about developmental disabilities yielded information that will remind service providers, educators and clinicians that parents must work through the same discriminatory beliefs held by society in general when making an adjustment to the birth of a developmentally disabled child. While this highlights not only the ecological model of Family Systems that takes into account the interaction between society and the family, it supports the need for mainstreaming individuals with developmental disabilities throughout every level of society. It has particular application for education, not only for the classrooms in which these "special needs" children are members, but in the colleges and universities that train educators. All students in the educational and health fields could benefit by extensive exposure to "exceptional" and "special needs" children and adults throughout their training in order to gain a realistic view of their lives.

It would be difficult to examine Parental Beliefs without utilizing a qualitative approach. The interview data revealed *processes* by which families adjust to the birth of a developmentally disabled infant. Parental beliefs have not been examined in the past with regard to adjustment processes, but those processes are very important to an understanding of how service providers can best help these families adjust to their special circumstances. This study underscores the importance, therefore, of combining two very important research paradigms in an effort to obtain a better understanding of “process” variables as they influence outcomes.

Study Limitations

This was an exploratory study. It was not designed for the purpose of generalizing to a population. It is limited to this small sample of families. It is also limited by the sample to developmentally-disabled infants and their families as well as to dually-parented families. In addition, the following limitations must be considered:

- ◆ The researcher developed the interview questionnaire and its numerical scales. It, therefore, is lacking in the psychometric properties needed for use in a large study. If it were to be used in further research, revisions should be made based upon weighting factors, as mentioned in the previous chapter.
- ◆ The researcher chose to measure the Mother's Perceived Level of Congruence of her Spouse's Beliefs with her Own Beliefs at Time 1 only. It

was anticipated that this would yield enough information relative to her Marital Satisfaction and Attachment Interaction. Since this variable became a central variable to this study in terms of the statistical results, it was decided in retrospect that data obtained for this variable at Time 2 might have yielded additional information. It is recommended that this be done in future research.

- ◆ Likewise, the Beck Depression Inventory was administered to mothers only. In retrospect, the administration of this measure to fathers could possibly have added important information. It is recommended that this be done in future research.
- ◆ The three-month interval between Time 1 and Time 2 may have not been a time span long enough to observe significant change. This time span was chosen by the researcher in an effort to study very early adjustment processes. It is the researcher's intention to follow up with additional visits to these families in the future, and this may yield important data regarding the stability of these early findings.
- ◆ While the researcher found parents to be open and truthful in their discussions with her, it is important to remember that painful issues were addressed, and parents may have withheld certain kinds of information in an effort to protect themselves from re-experiencing emotional pain. It was gratifying to the researcher to find that most parents wanted to talk at a very deep level about their initial emotional reactions. The researcher saw this as enabling a therapeutic release for many parents.

- ◆ The researcher had great difficulty recruiting families for this study. Initially, four mothers volunteered, but fathers declined and expressed this as due to the fact that they could not find time to fit the interviews into their busy work schedules. As a result of this early recruiting dilemma, the researcher modified her study to include families where mothers, but not fathers, participated in the interview. Therefore, the actual number of *couples* from whom qualitative data was obtained was reduced to nine. In a similar future study, it would be recommended that the study sample be more homogenous.
- ◆ Along the same line, it is recognized that those parents who volunteered to be participants in the study, may be inherently more adaptive than other parents experiencing the same kinds of crises. It is recognized that there were several families who were approached by early intervention providers to be a part of this study and, for one reason or another, declined to participate. The nature of these two groups – willing participants, and those who declined – could have biased the results of this study.

Suggestions for Future Research

It has been mentioned previously that researchers consider future designs linking the qualitative with the quantitative paradigms for a deeper understanding of processes that occur throughout the life cycle for exceptional families. Quantitative designs alone are unlikely to obtain information relevant to the beliefs of these families, and beliefs are very important to the work of

clinicians who desire an understanding of how best to help these families change and grow from their experiences. It is also recognized that qualitative data obtained from a larger population would yield more information than what could feasibly be analyzed. Questionnaires that allow for open-ended responses might be a solution.

Researchers need to find and use consistent instruments to measure attitudes and beliefs that may be influencing Marital Satisfaction and Maternal-Infant Attachment Interaction for this exceptional population. In this study, for example, it was noted that the Beck Depression Inventory did not yield scores indicating depression, but the Dyadic Adjustment Scale revealed lower levels of Marital Satisfaction for mothers who had lower scores on Attachment Interaction with their Infants. Scores obtained on the Beck Depression Inventory, when correlated with scores on the Dyadic Adjustment Scale, had very low correlations, suggesting that the Beck Depression Inventory was not sensitive to relationship nuances that may have affected the Mother's Attachment Interaction.

As mentioned in the Study Limitations section of this chapter, Mother's Perceived Level of Congruence of her Spouse's Beliefs with her Own Beliefs emerged as an important variable in relation to her Marital Satisfaction at Time 1 and it was determined that it was indirectly related to her Attachment Interaction at Time 2. It was not measured at Time 2, however. It would be recommended that this be examined in future studies at various times to determine consistency of this relationship.

Likewise, as also mentioned in the Study Limitation Section of this chapter, the Beck Depression Inventory was not administered to fathers, since it was seen as a variable likely to affect the Mother's Attachment Interaction with her infant. Future studies might include this measure with fathers, particularly as it relates to his adjustment process and his Marital Satisfaction.

This research needs to be replicated with larger samples. The value and need for research among these exceptional families is without question. The stresses encountered by these families render them vulnerable in many areas of their lives, including their marriages and their ability to remain intact. This, in turn, has many implications for society, which would include the education, welfare, and health systems. The challenge for researchers is to discover how marriages can be strengthened and how attachment to these special infants can best be assured and, after learning more, to share this with parents and professionals.

APPENDICES

APPENDIX A
Home Visit Data Collection Schedule

APPENDIX A

HOME VISIT DATA COLLECTION SCHEDULE

Pre-Study Home Visit: Within two weeks from date of verbal agreement to participate:

Letter of Informed Consent
Consent Form
Brief Questionnaire (Demographic Data)

For Developmentally Disabled Infant Study Group: (n 11 mothers, 8-9 fathers)

Time 1 Infant: 3-4 mos.	Time 2 Infant: 6-7 mos.
BDI - Mother	BDI - Mother
DAS - Conjoint	DAS - Conjoint
FILE - Mother	Individual Interviews
Conjoint Interview	Mother-Infant Feeding Observation
Individual Interviews	
Mother-Infant Feeding Observation (in a few cases, the researcher returned two to three days later to observe and score this)	

APPENDIX B

Letter of Consent for Participants and Consent Form

(Michigan State University Dept. of Family Ecology Letterhead)

Date:

Dear Mr. and Mrs. _____:

It is with appreciation that I was informed by _____ of your interest and willingness to participate in a study on families with special needs infants. Please take a moment to read about the purpose of this study. When complete, it is likely to enhance community and clinical services to families with special needs in the future.

This study, which is being partially funded by Michigan State University and is a research project of a doctoral student in Marriage and Family Therapy at Michigan State University, will investigate family adaptation to the birth of a special needs child. It will examine primarily mother-infant experiences and the special needs child's influence on the marital relationship. I am the primary investigator, a doctoral student at Michigan State University, and will be working directly with you through home visits. In addition to being a doctoral student, I am also a Marriage and Family Therapist, and have had experience working with exceptional families in my clinical work. I am the parent of a daughter with Down Syndrome, as well as the parent of two additional children. I have focused on the strengths of and stresses experienced by families with and without special needs children throughout my student and professional careers. Currently, I am counseling families of developmentally disabled children and adults through Thresholds in Grand Rapids.

What you might want to know in regard to your participation

- I plan to make a total of 4 home visits, over a 3-month period, each visit being approximately 1 – 1 ½ hours in duration. *(I have found my visits can be cut to two in most cases.)*
- I will interview Mrs. _____ (and Mr. _____, should he choose to participate) during the first and third visits. During these visits, I will also ask that you complete various instruments measuring the nature of your family relationships. I will be audiotaping the interviews to insure accurate transcription.
- During the second and fourth visits, I will simply observe an infant feeding. *(I have found that the feeding observation visit can be combined, in most cases, with the interview, eliminating these two additional visits.)*
- All of the data collected will be kept confidential, and names will be omitted from all measuring instruments and records, as well as from any resulting presentations and publications. Audiotapes will be used for assessment only in connection with the study and kept in confidential files.
- So as not to break confidentiality, participants will not be given specific information regarding the study's progress or data collection. They will, however, be given information regarding the findings of the study when the study is completed.
- Participation is totally voluntary. Prospective participant mothers (and fathers) will be encouraged to consider their participation based upon their ability to remain in the study for the full 3 months. However, they can decide to drop their participation from the study at any point in time without penalty. Participants can also choose not to answer any particular question within the questionnaire or interview.

Subjects selected will be contacted by the primary investigator soon after receipt of the completed attached questionnaire and consent form. All participants who complete the study will be awarded \$75.00 in appreciation for their contribution to this study. Thank you for giving

consideration and thought to becoming a participant in this worthwhile project. If you have any further questions, please feel free to c ontact the primary investigator, Judith A. VanderWal, M.A., L.L.P., at (616) 676-2586.

Sincerely,

MICHIGAN STATE UNIVERSITY

Judith A. VanderWal, M.A., L.L.P.
Licensed Marriage and Family Therapist

Doctoral Candidate of the De partment of Family and Child Ecology
Initial)
Michigan State University

(Participants to

CONSENT TO PARTICIPATE IN STUDY

Having read the letter explaining the study on special needs families, I have voluntarily agreed to participate as a subject in the study, which includes completion of various assessment forms, interviews, and mother-infant observations to be conducted in my home as set forth in the above letter. I understand that in order to participate, I must give voluntary consent.

Date _____

Date _____

Home Phone _____

APPENDIX C
Demographic Data Form Completed by Participants

DEMOGRAPHIC DATA

Subject I.D. # _____

1. Are you in a committed relationship? _____
2. How many individuals (including yourself) currently live in your household for at least 50% of the year? _____
3. Please list the gender and ages of all children included in No. 2 above.

<u>Gender</u>	<u>Age</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

4. Are there any other persons living in your home (besides you, your committed partner and the children listed above?) _____

If yes, please list their gender, age, and relationship to you.

<u>Gender</u>	<u>Age</u>	<u>Relationship to You</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

5. Please indicate your approximate gross annual income (combined incomes of both partners) by checking the appropriate box.

- ☐ Less than \$15,000
- ☐ \$15,000 - \$29,999
- ☐ \$30,000 - \$44,999
- ☐ \$45,000 - \$59,999
- ☐ \$60,000 - \$74,999
- ☐ \$75,000 - \$89,999
- ☐ \$90,000 - \$104,999
- ☐ \$105,000 - \$119,999
- ☐ \$120,000 and above

6. What is the last grade of education that the mother has completed? (Check the appropriate box.)

- ☐ Sixth grade or less
- ☐ Seventh or Eighth Grade
- ☐ Ninth, Tenth, or Eleventh Grade
- ☐ High School
- ☐ High School + Technical or Trade School
- ☐ Some College but no Degree
- ☐ A 2-year College Degree
- ☐ A 4-year College Degree
- ☐ A University Graduate Degree

What is the last grade of education that the father has completed? (Check the appropriate box.)

- ☐ Sixth grade or less
- ☐ Seventh or Eighth Grade
- ☐ Ninth, Tenth, or Eleventh Grade
- ☐ High School
- ☐ High School + Technical or Trade School
- ☐ Some College but no Degree
- ☐ A 2-year College Degree
- ☐ A 4-year College Degree
- ☐ A University Graduate Degree

7. Mother's Age on last birthday _____ Father's Age on last birthday _____

8. Do any of the adults or children in the home (other than your infant) suffer from a serious illness or limiting condition? _____

If yes, please explain: _____

9. Have any of the adults in the home been treated for mental or emotional reasons? _____

If yes, please explain: _____

APPENDIX D
Interview Guide and Scaling Format

Interview Guide and Scaling Format
(All interviewing to be audiotaped)

Section B

Interview 1

Conjoint Interview Portion

(Italics denote open-ended questions that will not be scored, but will be used for discussion.)

B-1. *What beliefs and feelings did you have regarding this condition prior to the birth of your child?*

B-2. *What kinds of exposure to and experiences did you have with others with this condition prior to the birth of your child?*

B-3. (Give subjects index card representing scale, prior to each scaling question.)

Male Female

As you think of your responses to the two previous questions, on a scale from 1 to 5, with 1 representing previous experiences and beliefs as very negative and 5 as very positive, what would you score your beliefs, experiences and feelings regarding this condition? scores to be obtained, one for each parent)

_____ B-3

B-4. *How were you informed of your infant's condition?*

B-5. *What were you told?*

B-6. *What feelings did you experience or emotional reactions did you have following the diagnosis?*

B-7. **As you think of your answers on these previous 3**

Male

Female

questions, on a scale from 1 to 5, with 1 representing the least effective, the least sensitive or least tactful manner of informing you of the diagnosis, and 5 representing the most sensitive, tactful or helpful manner of informing, what score would you assign to the manner in which you were informed? (2 scores obtained)

_____ B-7

B-8. **On a scale from 1 to 5, with 1 representing a severe negative emotional reaction, and 5 representing no negative reaction, how would you score your emotional reaction?** (2 scores obtained)

_____ B-8

B-9. *What kinds of information were you given by physicians, social workers, other professionals regarding your infant's condition and prognosis?*

B-10. **Again, thinking about your answer to that question, on a scale from 1-5, with 1 representing being very poorly informed, and 5 representing your belief that you were fully informed, how would you score how well you were informed? (2 scores)**

Male Female

_____ B-10

Section C

Individual Interview Portion

Audiotape and score this section as done previously for Section B. All questions in this section will be asked of each individual, separately, out of hearing distance of the other partner. After asking all questions of one partner, repeat the format with the other partner.

C-1. *How have you adjusted since the birth?*

C-2. *What feelings do you now experience when interacting with your infant?*

C-3. *What thoughts and feelings do you experience when you are alone, regarding your relationship with your infant?*

C-4. *What does the future look like for you, the child, your family?*

C-5. **As you think about your answers to these questions, on a scale from 1 to 5, with 1 representing the most negative and hopeless feelings you might presently be experiencing and 5 the most positive and hopeful feelings, how would you score the hopefulness of your feelings? (2 scores)**

<u>Male</u>	<u>Female</u>
_____	_____

C-5

C-6. *Are there any positive spiritual meanings that you have connected with this birth?*

C-7. *Have you been able to connect any other positive relevant meanings or purpose for this event in your life?*

C-8. **On a scale from 1 - 5, with 1 representing no meaning or purpose for this event, and 5 a definite purpose, how would you score meaning and purpose? (2 scores)**

<u>Male</u>	<u>Female</u>
_____	_____

C-8

C-9. *Many parents of infants born with disabilities believe that they have contributed in some way to their child's condition and try to search for answers that will prove or disprove their responsibility. Do you feel you are responsible in any way for your child's disability? (If so, please tell me more about that.)*

C-10. *Do you feel your partner may be responsible in any way for your child's disability? (If so, please tell me more about that.)*

C-11. **On a scale from 1 to 5, with 1 representing complete responsibility for your infant's disability assigned by you to yourself and 5, no responsibility, how would you score your belief that you are responsible for your child's disability. (2 scores)**

<u>Male</u>	<u>Female</u>
_____	_____

C-11

- C-12. On a scale from 1 to 5, with 1 representing complete responsibility for your infant's disability belonging to your partner and 5 no responsibility belonging to your partner, how would you score your belief in the responsibility of your infant's disability being assigned to your partner? Male Female _____ C-12
- C-13. *What kinds of changes have taken place in your life and your family's lives as a result of your infant's birth?*
- C-14. *If there have been significant changes, how do you view them in terms of the impact on your lives?*
- C-15. *What kinds of unusual caregiving demands have you experienced?*
- C-16. On a scale from 1 to 5, with 1 representing your child's birth as having only a negative impact up to this time and 5 representing only positive change or impact, how would you score the impact of this birth upon your immediate family? (2 scores) Male Female _____ C-16

Section D

Interview Questions for Mother Only (re partner support)

(Use the same format as in Sections B, and C)

D-1. *How does your partner interact with (infant's name?)*

D-2. *How much time does your partner spend with your infant?*

D-3. **As you think of your answers to these questions, on a scale _____ D-3**
from 1 to 5, with 1 representing low satisfaction with the amount
of time that your partner spends interacting with your
infant, and 5 representing complete satisfaction with the time
he has with your infant, how would you score your partner on
the amount of time he spends with your infant? (1 score)

D-4: **Again, thinking about the time your partner spends with your _____ D-4**
infant, on a scale from 1 to 5, with 1 representing low satisfaction
with the quality of your partner's interaction with your infant, and
5 representing complete satisfaction with the quality of your
partner's interaction with your infant, how would you score your
partner on the quality of his interaction with your infant? (1 score)

D-5. *How would you describe your partner's help in caregiving for your infant? For other children in the family (if relevant)? How does this compare with the birth of previous children?*

D-6. *How would you describe your partner's help in performing household tasks since the birth of your child?*

D-7. *How has the amount of physical support your partner gives you changed since the birth of your infant?*

D-8. **In relation to the previous 3 questions, on a scale from 1 to 5, _____ D-8**
with 1 representing low satisfaction with the amount of
physical assistance you receive from your partner, and 5
representing complete satisfaction, how would you score the
physical assistance you receive from your partner?
(1 score)

D-9. *How much do you rely upon your partner for emotional support?*

D-10. *How often do you discuss your feelings and related concerns with each other about your infant's and family's well-being?*

D-11. *Tell me about the ways in which you feel you can lean on him when you are feeling emotionally in need?*

D-12. *In what ways is he unable to provide you with the emotional support you need?*

D-13. *In what ways has your ability to communicate with your partner regarding your feelings and emotional needs changed since the birth of your infant?*

**D-14. Thinking about these questions, on a scale from 1 to 5, with
1 representing a complete lack of emotional support felt by you _____D-14
from your partner, and 5 an exceptional amount of emotional
support felt by you from your spouse, how would you score the
emotional support you receive from him? (1 score)**

Section E

Questions for mother only regarding spouse's beliefs :

"I would like to ask you some questions now about your perceptions of your spouse's beliefs and feelings currently. These may be difficult for you to answer. However, I would like you to try to answer them as best you can without having direct knowledge. For some of these questions, you may have only the ability to speculate."

- E-1. *How has your partner adjusted since the birth?*
- E-2. *What feelings do you think he experiences when interacting with your infant?*
- E-3. *What feelings do you think he experiences in solitude regarding his relationship with his infant?*
- E-4. *What do you believe his perception of the future is for himself, your child, your family?*
- E-5. **When you think about these questions regarding your partner, on a scale from 1 to 5, with 1 representing your perception of your partner's most negative and hopeless current feelings and 5 representing the most positive and hopeful feelings, how would you score the hopefulness of your partner's feelings? (1 score)** ____E-5
- E-6. *Has he connected any positive spiritual meanings to this birth? (If so, please tell me more about this.)*
- E-7. *Has he been able to find any other positive relevant meanings or purpose for this event? (If so, please tell me more about this.)*
- E-8. **Again, as you think about your partner's beliefs, on a scale from 1 to 5, with 1 representing there being no purpose for this event, and 5, a definite purpose for this event, how would you score your partner's belief in a purpose for this? (1 score)** ____E-8
- E-9. *Does your partner assign any responsibility for the child's condition to himself? (If so, please tell me in what ways.)*
- E-10. *Do you believe your partner assigns any responsibility to you for your child's condition? (If so, please tell me in what ways?)*
- E-11. **As you think about your partner's beliefs, on a scale from 1 to 5, with 1 representing your partner assigning complete responsibility for your infant's condition to himself and 5, no responsibility, how would you score his belief that he is responsible for your child's disability?** ____E-11
- E-12. **On a scale from 1-5, with 1 representing your partner assigning complete responsibility for your infant's condition to you and 5, no responsibility, how would you score your partner in his assignment of responsibility for your infant's disability to you?** ____E-12

E-13. *What kinds of changes would he see as having taken place in his life and your family's lives as a result of your infant's birth?*

E-14. *How would your spouse view these changes in terms of the impact on your lives?*

E-15. **Again, thinking about your partner's beliefs, on a scale from 1 to 5, with 1 representing your child's birth as having only a negative impact up to this time and 5 representing only positive changes or impact, how would you score your spouse's perception of the impact your infant's birth has had on your immediate family?** _____E-15

Section F

Interview 2

Interview 2 will follow precisely the same format, using only individual interview questions and all interview questions for mother only. Scaling questions will remain the same. Before asking interview questions, explain to the individuals that many of the questions being asked of them will seem familiar, since they have been previously asked.

- F-1. *How have you adjusted since the birth?*
- F-2. *What feelings do you now experience when interacting with your infant?*
- F-3. *What thoughts and feelings do you experience in solitude regarding your relationship with your infant?*
- F-4. *What does the future look like for you, the child, your family?*
- F-5. **As you think about your answers to these questions, on a scale from 1 to 5, with 1 representing the most negative and hopeless feelings you might be presently experiencing and 5 representing the most positive and hopeful feelings, how would you score the hopefulness of your feelings?** (2 scores)
- | | <u>Male</u> | <u>Female</u> |
|--|-------------|---------------|
| | _____ | _____ F-5 |
- F-6. *Are there any positive spiritual meanings that you have connected with this birth?*
- F-7. *Have you been able to connect any other positive relevant meanings or purpose for this event in your life?*
- F-8. **On a scale from 1 to 5, with 1 representing no meaning or purpose and 5 a definite purpose for this event, how would you score your belief that there may be a meaning or purpose for this birth event.** (2 scores)
- | | <u>Male</u> | <u>Female</u> |
|--|-------------|---------------|
| | _____ | _____ F-8 |
- F-9. *Many parents of infants born with disabilities believe that they have contributed in some way to their child's condition and try to search for answers that will prove or disprove their responsibility. Do you feel you are responsible in any way for your child's disability? (If so, please tell me more about that.)*
- F-10. *Do you feel your partner may be responsible in any way for your child's disability? (If so, please tell me more about that.)*
- F-11. **On a scale from 1 to 5, with 1 representing complete responsibility for your infant's disability assigned by you to yourself, and 5, no responsibility, how would you score your belief that you may be responsible?**
- | | <u>Male</u> | <u>Female</u> |
|--|-------------|---------------|
| | _____ | _____ F-11 |
- F-12. *What kinds of changes have taken place in your life and your family's lives as a result of your child's birth?*

F-13. *If there have been significant changes, how do you view them in terms of the impact on your lives?*

F-14. *What kinds of unusual caregiving demands have you experienced?*

F-15. **On a scale from 1 to 5, with 1 representing your child's birth as having only a negative impact up to this time, and 5 representing only positive change or impact, how would you score the impact of this child's birth on your immediate family? (2 scores)**

Male Female

____ ____ F-15

Section G

Interview 2 Questions for Mother Only (re partner support)

- G-1. *How does your partner interact with (infant's name?)*
- G-2. *How much time does your partner spend with your infant?*
- G-3. **As you think of your answers to these questions, on a scale from 1 to 5, with 1 representing a low satisfaction with the amount of time that your partner spends interacting with your infant, and 5 representing complete satisfaction with the amount of time he spends with your infant, how would you score the amount of time your partner spends with your infant? (1 score)** _____ G-3
- G-4. **Similarly, with regard to quality of time, on a scale from 1 to 5, with 1 representing low satisfaction with the quality of time your partner has with your infant and 5 representing complete satisfaction with the quality of time he has with your infant, how would you score your partner on the quality of time he has with your infant?** _____ G-4
- G-5. *How would you describe your partner's help in caregiving for your infant? For other children in the family (if relevant)? How does this compare with the birth of previous children?*
- G-6. *How would you describe your partner's help in performing household tasks since the birth of your child?*
- G-7. *How has the amount of physical support your partner gives you changed since the birth of your infant?*
- G-8. **In relation to the previous 3 questions, on a scale from 1 to 5, with 1 representing low satisfaction with the amount of physical assistance you receive from your partner, and 5 representing complete satisfaction, how would you score your satisfaction with the amount of physical assistance you receive from your partner? (1 score)** _____ G-8
- G-9. *How much do you rely upon your partner for emotional support?*
- G-10. *How often do you discuss your feelings and related concerns about your infant's and family's well-being with each other.*
- G-11. *Tell me about the ways in which you feel your child can lean on him when you are feeling emotionally in need?*
- G-12. *In what ways is he unable to provide you with the emotional support you need?*
- G-13. *In what ways has your ability to communicate with your partner regarding your feelings and emotional needs changed since the birth of your infant?*

G-14. Thinking about these questions, on a scale from 1 to 5, with 1 representing a complete lack of emotional support felt by you from your partner, and 5 an exceptional amount of emotional support felt by you from your partner, how would you score the emotional support you feel coming from your spouse? (1 score) ____ G-14

REFERENCES

REFERENCES

- Able-Boone, H. & Stevens, E. (1994). After the intensive care nursery experience: Families' perceptions of their well being. Children's Health Care, 23(2), 99-114.
- Ainsworth, M.D.S., Blehar, M.C., Waters, E., & Wall, S. (1978). Patterns of attachment. Hillside, NJ: Lawrence Erlbaum.
- Bailey, D.B. & Simeonsson, R. (1988). Family assessment in early intervention. Columbus, OH: Merrill.
- Bailey, D.B. & Wolery, M. (1984). Teaching infants and preschoolers with handicaps. Columbus, OH: Merrill.
- Barnard, K.E., & Eyres, S.J. (Eds.) (1979). Child health assessment, part 2: The first year of life (DHEW Publication No. HRA 79-25). Washington, DC: U.S. Government Printing Office.
- Barnard, K.E., Eyres, S., Lobo, M., & Snyder, C. (1983). An ecological paradigm for assessment and intervention. In Brazelton, T.B. & Lester, B.M. (Eds.), New approaches to developmental screening of infants (pp. 199-218). New York: Elsevier.
- Barsch, R. (1964). The handicapped ranking scale among parents of handicapped children. American Journal of Public Health, 54, 1560-1567.
- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J.E., & Erbaugh, J. (1961). An inventory for measuring depression. Archives of General Psychiatry, 4, 561-571.
- Beckman, P. (1983). Influence of selected child characteristics on stress in families of handicapped children. American Journal of Mental Deficiency, 88, 150-156.
- Belsky, J., Rovine, M., & Taylor, D.G. (1984). The Pennsylvania infant and family development project, II: The development of reciprocal interaction in the mother-infant dyad. Child Development, 55, 706-717.
- Blacher, J. (1984). A dynamic perspective on the impact of a severely handicapped child on the family. In Blacher, J. (Ed.), Severely handicapped young children and their families: Research in review (pp. 3-50). Orlando: Academic Press.

- Blacher, J. & Bromley, B. (1987). Attachment and responsivity in children with severe handicaps: Mother and teacher comparison. Child Study Journal, 17(2), 121-132.
- Bornstein, M.H. (1995). Parenting infants. In M.H. Bornstein (Ed.), Handbook Of Parenting: Children and parenting (Vol. 1, pp. 3-39). Mahwah, NJ: Lawrence Erlbaum.
- Bowlby, J. (1969). Attachment and loss, Vol. 1: Attachment. New York: Basic Books (2nd rev. ed., 1982).
- Bowlby, J. (1973). Attachment and loss: Vol. 2. Separation: Anxiety and anger. London: Hogarth Press.
- Bretherton, I. (1993). Theoretical contributions from Developmental Psychology. In Boss, P.G., Doherty, W.J., LaRossa, R., Schumm, W.R., & Steinmetz, S.K. (Eds.), Sourcebook of Family Theories and Methods (pp. 275-297). New York: Plenum Press.
- Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (1989). Ecological systems theory. In R. Vasta (Ed.) Annals of Child Development, Vol. 6, (pp. 187-249). Greenwich, CT: JAI Press.
- Bubolz, M.M. & Sontag., M.S. (1993). Human ecology theory. In Boss, P.G., Doherty, W.J., LaRossa, R., Schumm, W.R., & Steinmetz, S.K. (Eds.), Sourcebook of family theories and methods: A contextual approach (pp. 419-450). New York: Plenum Press.
- Capuzzi, C. (1989). Maternal attachment to handicapped infants and the relationship to social support. Research in Nursing & Health, 12, 161-167.
- Cicchetti, D. & Sroufe, L.A. (1976). The relationship between affective and cognitive development in Down Syndrome infants. Child Development, 47, 920-929.
- Clarke-Stewart, K.A. (1973). Interactions between mothers and their young children: Characteristics and consequences. Monographs of The Society for Research in Child Development, 38, 6-7 (Serial No. 153), 101-108.

- Collins-Moore, M.S. (1984). Birth and diagnosis: A family crisis. In M.G. Eisenberg, L.C. Sutkin, and M.A. Jansen (Eds.), Chronic illness and disability through the life span: Effects on self and family (pp. 39-46). New York: Springer.
- Cook, J.J. (1963). Dimensional analysis of child-rearing attitudes of parents of handicapped children. American Journal of Mental Deficiency, 68, 354-361.
- Crnic, K.A., Greenberg, M.C., Ragozin, A.S., Robinson, N.M., & Basham, R. (1983). Effects of stress and social supports on mothers in premature and full term infants. Child Development, 54, 209-217.
- Cummings, S.T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. American Journal of Orthopsychiatry, 46, 246-255.
- Damrosch, S. & Perry, L. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down Syndrome. Nursing Research, 38, 25-30.
- Darling, R.B. (1991). Initial and continuing adaptation to the birth of a disabled child. In Seligman, M. (Ed.), The family with a handicapped child, 2nd ed. (pp.55-89). Boston: Allyn and Bacon.
- Dyson, L.L. (1991). Families of young children with handicaps: Parental stress and family functioning. American Journal on Mental Retardation, 95, 6, 623-629.
- Emde, R.N. & Brown, C. (1978). Adaptation to the birth of a Down's Syndrome infant: Grieving and maternal attachment. Journal of the American Academy of Child Psychiatry, 299-323.
- Falvey, M.A., Bishop, K.D., & Gage, S.T. (1993). Mental retardation. In Brodwin, M.G., Tellez, F. & Brodwin, S.K. (Eds.), Medical, psychosocial and vocational aspects of disability (pp. 165-177). Athens, GA: Elliott & Fitzpatrick, Inc.
- Featherstone, H. (1980). A difference in the family: Living with a disabled child. New York: Penguin Books.
- Firestone, W.A. (1987). Meaning in method: The rhetoric of quantitative and qualitative research. Educational Researcher, 16, 7, 16-21.
- Fine, M.J. (1986). Intervening with abusing parents of handicapped children. Techniques, 2, 4, 353-363.

- Fischer, M.A., (1988). The relationship between child initiations and maternal responses in preschool-aged children with Down Syndrome. In Marfo, K. (Ed.), Parent-child interaction and developmental disabilities: Theory, research and intervention (pp. 126-144). New York: Praeger.
- Frey, K.S., Fewell, R.R. & Vadasy, P.E. (1989). Parental adjustment and changes in child outcome among families of young handicapped children. Topics in Early Childhood Special Education, 8, 38-57.
- Friedrich, W.N. (1979). Predictors of coping behavior of mothers of Handicapped children. Journal of Consulting and Clinical Psychology, 47, 1140-1141.
- Gallimore, R., Weisner, T., Kaufman, S. & Bernheimer, L. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. American Journal on Mental Retardation, 94, 216-230.
- Gath, A. (1978). Down's Syndrome and the family: The early years. New York: Academic Press.
- Gath, A. (1985). Parental reactions to loss and disappointment: The diagnosis of Down's Syndrome. Developmental Medicine and Child Neurology, 27, 392-400.
- Gottlieb, J. (1975). Public, peer and professional attitudes toward mentally retarded persons. In J.J. Begab & S.A. Richardson (Eds.), The mentally retarded and society: A social science perspective (pp. 99-125). Baltimore: University Park Press.
- Greenwald, C. & Leonard, L. (1979). Communicative and sensorimotor development of Down's Syndrome children. American Journal of Mental Deficiency, 84, 296-303.
- Harris, S.L., Handelman, J.P., & Palmer, C. (1985). Parents and grandparents view the autistic child. Journal of Autism and Developmental Disorders, 15(2), 127-137.
- Hartman, A. (1978). Diagrammatic assessment of family relationships. Social Casework, 465-476.
- Hill, R. (1949). Families under stress. New York: Harper & Row.

- Hodapp, R. (1988). The role of maternal emotions and perceptions in interactions with young handicapped children. In Marfo, K. (Ed.), Parent-child interaction and developmental disabilities: Theory, research and intervention (pp. 32-46). New York: Praeger.
- Hodapp, R. (1995). Parenting children with Down syndrome and other types of mental retardation. In M.H. Bornstein (Ed.), Handbook of parenting: Children and parenting (Vol. 1, pp. 233-253). Mahwah, NJ: Lawrence Erlbaum.
- Honig, A.S. & Winger, C.J. (1977). A professional support program for families Of handicapped preschoolers: Decrease in maternal stress. The Journal of Primary Prevention, 17(3), 285-296.
- Kazak, A.E. (1986). Families with physically handicapped children: Social ecology and family systems. Family Process, 25, 2, 265-281.
- Kwai-sang Yau, M. & Li-Tsang, C.W.P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. The British Journal of Developmental Disabilities, 45(1), 38-51.
- Krahn, G.L. (1993). Conceptualizing social support in families of children with special health needs. Family Process, 32(2), 235-248.
- LaFreniere, P.J. & Sroufe, L.A. (1985). Profiles of peer competence in the preschool: interrelations among measures, influence of social ecology, and relation to attachment history. Developmental Psychology, 21, 56-69.
- Lamb, M.E. & Meyer, D.J. (1991). Fathers of children with special needs. In Seligman, M. (Ed.). The family with a handicapped child, 2nd ed., (pp. 151-179). Boston: Allyn and Bacon.
- Leskinen, J. (1994). Parents' causal attributions and adjustment to their child's disability. Jyvaskyla, Norway: University of Jyvaskyla.
- Londerville, S. & Main, M. (1981). Security of attachment, compliance, and marital training methods in the second year of life. Developmental Psychology, 17, 289-299.
- Lyons-Ruth, K., Repacholi, B., Alpern, L., & Connell, D.B. (1991). Disorganized attachment behavior in infancy: Stability, maternal correlates and the prediction of aggression in kindergarten. Biennial Meeting of the Society for Research in Child Development, Seattle, WA.

- Lyons-Ruth, K., Zoll, D., Connell D., & Grunebaum, H.U. (1986). The depressed mother and her one-year-old infant: Environment, interaction, attachment and infant development. In E. Tronick & T. Field (Eds.) Maternal depression and infant disturbance (pp. 61-83). New York: Wiley.
- Main, M. (1973). Exploration, play, and cognitive functioning as related to mother-child attachment. Unpublished doctoral dissertation, Johns Hopkins University. Baltimore.
- Malone, D.M., Manders, J., & Stewart, S. (1997). A rationale for family therapy specialization in early intervention. Journal of Marital & Family Therapy, 23(1), 65-79.
- Margalit, M. & Ankonina, D.B. (1991). Positive and negative affect in parenting disabled children. Counselling Psychology Quarterly, 4(4), 289-299.
- McCubbin, H.I., & Patterson, J.M. (1983). The family stress process: The Double ABCX Model of adjustment and adaptation. In H.I. McCubbin, M.B. Sussman, & J.M. Patterson (Eds.), Social stress and the family: Advances and developments in family stress theory and research (pp. 7-38). New York: Haworth Press.
- McCubbin, H.I., Thompson, A.I., & McCubbin, M.A. (1996). Family assessment: Resiliency, coping and adaptation. Madison, WI: University of Wisconsin Publishers.
- Munson, L.J. & Odom, S.L. (1996). Review of rating scales that measure parent-infant interaction. Topics in Early Childhood Special Education, 16(1), 1-25.
- Olshansky, S. (1962). Chronic sorrow: A response to have a mentally defective child. Social Casework, 43, 190-93.
- Papousek, H. & Papousek, M. (1975) Cognitive aspects of preverbal social interaction between human infants and adults. In R. Porter, & M. O'Connor (Eds.), Parent-infant interaction (pp. 241-260). Amsterdam: Elsevier.
- Parker, S.J. & Zuckerman, B.S. (1990). Therapeutic aspects of the assessment process. In S.J. Meisels, & J.P. Shonkoff (Eds.), Handbook of early Childhood intervention, (pp. 350-370). New York: Cambridge University Press.

- Pearl, L.F. (1993). Providing family-center early intervention. In W. Brown, S.K.Thurman, & L.F. Pearl (Eds.), Family-centered early intervention with infants & toddlers: Innovative cross-disciplinary approaches, (pp. 81-102). Baltimore: Paul H. Brookes.
- Price-Bonham, S. & Addison, S. (1978). Families and mentally retarded children: Emphasis on the father. Family Co-ordinator, 27, 221-230.
- Reber, A.S. (1985). The dictionary of psychology. London: Penguin Books.
- Renken, B., Egeland, B., Marvinney, D., Mangelsdorf, S. and Sroufe, L.A. (1989). Early childhood antecedents of aggression and passive-withdrawal in early elementary school. Journal of Personality, 57(2), 257-281.
- Richardson, S.A. (1970). Age and sex differences in values toward physical handicaps. Journal of Health and Social Behavior, 11, 207-214.
- Rogers, S.J., Ozonoff, S., & Maslin-Cole, C. (1991). A comparative study of attachment behavior in young children with autism or other psychiatric disorders. Journal of the American Academy of Child and Adolescent Psychiatry 30(3), 483-488.
- Rosenblith, J.F. (1992). In the beginning: Development from conception to age two, Second Ed. Newbury Park, CA: Sage.
- Seligman, M. (1991). Family systems and beyond. In Seligman, M. (Ed.), The family with a handicapped child, 2nd ed., (pp.27-53). Boston: Allyn and Bacon.
- Seligman, M. & Darling, R.B. (1989). Ordinary families, special children: A systems approach to childhood disability. New York: Guilford.
- Shapiro, J. (1988). Stresses in the lives of parents of children with disabilities: Providing effective caregiving. Stress Medicine, 4, 77-93.
- Shapiro, T., Sherman, M., Calamari, G., & Koch, D. (1987). Attachment in autism and other developmental disorders. Journal of the American Academy of Child and Adolescent Psychiatry, 26(4), 480-484.
- Shaw, D.S. & Vondra, J.I. (1993). Chronic family adversity and infant Attachment security. Journal of Child Psychology and Psychiatry and Allied Disciplines, 34(7), 1205-1215.
- Solnit, A. & Stark, M. (1961). Mourning and the birth of a defective child. The Psychoanalytic Study of the Child, 16, 523-537.

- Spanier, G.B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. Journal of Marriage and the Family, 38, 15-28.
- Spanier, G.B. & Filsinger, E.E. (1983). The Dyadic Adjustment Scale. In E.E. Filsinger (Ed.), Marriage and Family Assessment. Beverly Hills, CA: Sage.
- Spanier, G.B. (2001). Dyadic Adjustment Scale: User's Manual. North Tonawanda, NY: Multi-Health Systems.
- Sroufe, L.A. (1989). Relationships and relationship disturbances. In A.J. Sameroff & R.N. Emde (Eds.), Relationship disturbances in early childhood: A developmental approach (pp. 97-124). New York: Basic Books.
- Stahlecker, J.E. & Cohen, M.C. (1985). Application of the strange situation attachment paradigm to a neurologically impaired population. Child Development, 56(2), 502-507.
- Stone, N.W. & Chesney, B.H. Attachment behaviors in handicapped infants. Mental Retardation, 16(1), 8-12.
- Tavormina, J.B., Boll, T.J., Dunn, N.J., Luscomb, R.L. & Taylor, J.R. (1981). Psychosocial effects on parents of raising a physically handicapped child. Journal of Abnormal Child Psychology, 9, 121-131.
- Tronick, E.Z. & Gianino, A.F. (1986). The transmission of maternal disturbance to the infant. In E.Z. Tronick & T. Field (Eds.), Maternal depression and infant disturbance (pp. 5-11). New York: Wiley.
- Waters, E., Wippman, J., & Sroufe, L.A. (1979). Attachment, positive affect, and competence in the peer group: Two studies in construct validation. Child Development, 50, 821-829.
- Werner, E.E. (1999). Risk and protective factors in the lives of children with high-incidence disabilities. In R. Gallimore, L.P. Bernheimer, D.L. MacMillan, D.L. Speece & S. Vaughn, (Eds.), Developmental perspectives on children with high-incidence disabilities (pp.15-31). Mahwah, N.J. Lawrence Erlbaum.
- Widerstrom, A.H., Mowder, B.A., & Sandall, S.R. (1991). At-risk and handicapped newborns and infants: Development, assessment and intervention. Englewood Cliffs, NJ: Prentice Hall.

- Wikler, L., Waslow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 51, 63-70.
- Wilton, K. & Renaut, J. (1986). Stress levels in families with intellectually handicapped preschool children and families with nonhandicapped preschool children. Journal of Mental Deficiency Research, 30(2), 163-169.
- Winton, C.A. (1995). Frameworks for studying families. Guilford, CN: Dushkin Publishing Group, Inc.
- Wright, J.S., Granger, R.D., & Sameroff, A.J. (1984). Parental acceptance and developmental handicap. In Blacher, J. (Ed.), Severely handicapped young children and their families: Research in review (pp. 51-90). Orlando: Academic Press.

MICHIGAN STATE LIBRARIES



3 1293 02177 4231

