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Experiential Accounts of the Challenges of Parents with Mental Retardation

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### Abstract

Historically, there have been significant social concerns about the parenting abilities of individuals with mental retardation (MR) and for the well-being of their children. Past research has identified specific observable behaviors with which parents with MR struggle, and these findings have subsequently influenced the development of parent training programs for this population. The current study aims to expand on previous research by exploring the subjective experiences of parents with MR. Open-ended interviews were conducted which focused on the personal experiences of parents with MR in regard to the challenges and needs they faced as parents. Nine participants were recruited through Noble of Indiana, the Indianapolis branch of the Arc, which provides service and support for persons with MR and their families. These interviews were recorded, transcribed and analyzed. Using the Interpretative Phenomenological Approach, six clusters and 20 themes were identified. We focused on the clusters of Difficulties, Sources of Help, and Social Judgment as well as themes of Parent-Child Interaction, Parenting Programs, and Influence. Through comparing the subjective data obtained in this study with previous research, we are able to contribute to a more holistic understanding of the experiences of parents with MR. We are also able to make suggestions which may aid in the development of parent training programs, encourage the integration of support services, and help to decrease stigmatization and social judgment.

## Experiential Accounts of the Challenges of Parents with Mental Retardation

Imagine a seven year old child is taken away from her home and parent due to accusations of parental inadequacy. She is placed in the social services system without the consent of the parent, and there are very few resources to help regain custody of the child. This is the situation of Sam Dawson, the main character in the popular Hollywood film *I am Sam* (2001). Sam, an individual with mental retardation, loses custody of his seven year old daughter, Lucy, when a social worker becomes concerned about her welfare and his ability to parent. The story follows Sam's struggle with the legal system as he attempts to regain custody of Lucy. However, the real focus of the film is the bond between father and daughter as Sam attempts to prove himself as a responsible adult who is capable of raising a child. His circle of friends who also have mental retardation, as well as another individual without mental retardation, act as his support system. This collective effort had allowed Sam to raise Lucy without the interference of the state's legal system.

*I am Sam* (2001) brought public attention to the topic of parents with mental retardation, a situation that is more prevalent than the public may realize. Concerns for the well-being of children with parents with mental retardation (MR) and questions about the parenting abilities of these individuals with MR have been persistent and influential on public opinion and policy for many years (Kerr, 2000). The present study reconsiders these concerns by focusing on the actual experiences of the parents with MR.

The cognitive deficiencies associated with MR are the characteristics that underpin most of the social concerns about parents with mental retardation. According to the Diagnostic and Statistical Manual of the American Psychiatric Association (4<sup>th</sup> ed.),

persons with MR have significantly below-average intellectual functioning with an IQ of 70 or below (Sarason & Sarason, 2005), whereas the population mean IQ is 100 (standard deviation is 15). Furthermore, the DSM-IV-TR states that mental retardation is also defined as having impairments in some of the following areas: communication, self-care, home living, social/interpersonal skills, etc. (American Psychiatric Association, 2000). These impairments are, to some degree, related with a low IQ.

It has also been found that lower than average IQ is correlated with lower socioeconomic status of the individual (Aunos & Feldman, 2002). A possible reason for this situation could be related to difficulty in obtaining and sustaining employment that can support or aid in supporting one's household. Money management may also be a challenge for some individuals with MR. According to Ray, Rubenstein, and Russo (1994), it was found in one study that 59% of participating families, the parents with MR were assessed as not having the skills necessary to adequately manage household money such as basic arithmetic to difficulties making financial decisions. Lower socioeconomic status may thus contribute to a more unstable home environment with fewer social supports and resources at the disposal of the individual with MR (Tymchuk, 1999).

In addition to social concerns, further public apprehension about individuals with MR becoming parents relates to a biological component. Parents with mental retardation are more likely to bear children with mental retardation. The risk increases significantly when both biological parents have mental retardation (Melton & Scott, 1984).

These and other concerns not only impact the individual with MR, but potentially also impacts the children. For instance, difficulties in self-care and hygiene have been noted as a characteristic of some individuals with MR (Melton & Scott, 1984; Sarason &

Sarason, 2005). Difficulties in caring for the self may generalize into difficulties in caring for another (i.e. the child of the parent with MR). Further issues of care for the child include the potential for malnutrition, inadequate medical and dental care as well as inadequate clothing, discipline, and supervision (Ray, Rubenstein & Russo, 1994). These inadequacies attribute to frequent accusations and possible occurrences of child abuse and/or neglect by parents with mental retardation (Tymchuk, 1991). Child physical and emotional well-being is often the primary concern of the social service system. The combination of social, biological, and interpersonal factors has led to a presiding belief within the social service system that individuals with mental retardation may not be capable parents.

Public concerns about the parental inadequacy of persons with MR have, historically, influenced the rights of persons with MR and the social resources available to them. The eugenics movement of the late 19<sup>th</sup> and early 20<sup>th</sup> centuries greatly impacted sterilization policy-making (Diekema, 2003). Persons with MR were seen as a genetically unfit group that should not be procreating (Diekema, 2003). Often, women with MR were institutionalized during their reproductive years so as to avoid pregnancy and males with MR underwent castration surgery (Diekema, 2003). By 1907, some states allowed and even required sterilization of individuals with MR and by 1960, 30 states had sterilization laws allowing guardians of persons with MR to choose sterilization for their dependent without consent of the individual with mental retardation (Diekema, 2003). Sixty-thousand men and women had undergone sterilization surgeries by the end of the 1960s – a moral turning point for the eugenics movement (Diekema, 2003).

As the eugenics movement fell out of favor and birth control and other forms of contraception became more available, the issue of respecting the voice of the individual with mental retardation and his/her autonomy came under consideration. Indeed, the right of the general public to choose birth control was put into law in 1965 (Diekema, 2003). The focus became the person with MR's ability to consent to sterilization or not. In cases in which the individual with MR was deemed incompetent to make such a decision, the court was left to decide whether it was a health risk for the individual to remain fertile (Diekema, 2003). As a result of these changes in the legal system, individuals with MR were seen to have the same rights to marry, establish a home, and raise children as persons without MR (Kerr, 2000).

Studies have found that the majority of persons with MR (60-90%) do want to marry and have children (Aunos & Feldman, 2002). Despite the newly established legal rights and obvious desire to have children, an attitude of concern and disapproval continues today, especially with parents and direct-care workers of individuals with MR. Studies from the 1970s found that 80% of parents and workers favored sterilization although it was against the law, and 75% of parents of persons with MR were against their children marrying and having children of their own (Aunos & Feldman, 2002). Still, the prevalence of parents with MR continued to increase. Those individuals with mental retardation, who went through with their pregnancies, faced intense scrutiny from outsiders, constantly feared losing custody of the child, or fell under the watchful eye of social service workers who were vigilantly scrutinizing them for signs of abuse and neglect (Tymchuk & Feldman, 1991). The combination of these pressures made the opportunity to parent incredibly difficult for individuals with MR. Later, with the

introduction of the Americans with Disabilities Act of 1990, the sexual and parenting rights of individuals with MR were readdressed, further emphasizing their right to have children (Kerr, 2000). Research on parents with mental retardation and their unique situation has accumulated over the past hundred years and continues to do so.

Case studies have provided some evidence for the success of parents with mental retardation. According to Espe-Sherwindt and Crable (1993), like all other parents, some parents with mental retardation are adequate. Studies have demonstrated that a significant number of parents with MR can do quite well in caring for their children, and there is no direct correlation between higher IQs and “better” parenting (Espe-Sherwindt & Crable, 1993). Furthermore, Zetlin, Weisner, & Gallimore (1985) assert that parents with MR can display some effective parenting behaviors. In four case studies, Zetlin, Weisner, & Gallimore (1985) describe specific experiences of successful parenting by persons with mental retardation. The findings of these case studies may not be generalizable, therefore the need for more research and the social support given to many parents with MR to build these effective parenting practices still exists.

As a result of changes in the social system, research on the parenting abilities of persons with mental retardation increased and applications from the research were developed and implemented. State governments are obligated to facilitate reunification programs and services for families who have been legally separated due to an ascribed unfit status of the parent (Kerr, 2000). Such services include: assisting parents in finding housing and employment; teaching financial skills such as money management; offering further educational opportunities including higher education and parenting courses; providing mental health counseling; and drug or alcohol treatment (Kerr, 2000).

Unfortunately, many of these programs are not offered nor are they adapted to fit the specific needs of parents with MR (Kerr, 2000).

Parenting programs specifically designed for individuals with MR have been slowly developing across the United States, and show mixed results as they are still in their infancy. Many parents with MR who go through such programs *do* seem capable of providing for their children with training and social support (Aunos & Feldman, 2002). These programs address the need for improvement in childcare, health and safety skills and include, but are not limited to, such issues as: recognizing household dangers, identifying and responding to common emergencies, training older children about dangers and emergencies, comprehension of medications and household product labels (Tymchuk & Feldman, 1991). Parents with mental retardation are taught using a variety of methods including modeling, feedback, tangible reinforcement, verbal instruction, and picture books (Feldman & Case, 1999; Tymchuk & Feldman, 1990). According to Feldman and Case (1999), manuals (e.g. illustrated picture books) are effective teaching materials, which have been implemented with success rates of skill maintenance as high as 85%. With promising results as in the Feldman and Case (1999) study, it seems possible to alleviate the challenges faced by parents with MR through well-designed training programs. However, these programs struggle in several areas. Importantly, they do not necessarily consider the perceptions of the parents with MR as to which of their skills they feel need improvement. In a review of current parenting programs designed for parents with MR, specific problem areas included: lack of volunteers/trained facilitators, inadequate funding/resources, irregular attendance and high drop-out rates, and generalization of skills to other areas of the parent with MR's experiences (Ray,

Rubenstein & Russo, 1994). While the parenting programs are effective to some extent, improvement is necessary particularly in helping these parents attend regularly. They may as well be lacking the data to help instigate the much-needed changes.

Although these programs begin to address specific parenting issues and give aspects of persons with mental retardation as parents, they are designed from the outside-in—i.e., they objectively apply categories that are of concern to the researchers to the population of parents with MR. For example, child-care checklists are often used in studies to evaluate a parents' performance on a particular task. In one such study, parents with MR were assessed on their ability to sterilize a baby bottle and scored based on unprompted completion of each step of the process (Feldman & Case, 1999). The established correct process was based on healthcare professionals and behaviors of parents without MR (Feldman & Case, 1999). Accuracy scores of 80% or below for this particular task of sterilizing the bottle, as well as others, designated this task as one that required re-training (Feldman & Case, 1999). In another in-home assessment on safety, parents with MR were scored on their ability to (a) describe a potential hazard, (b) verify if the hazard existed in the home, and (c) remove the hazard if it was present (Feldman & Case, 1999). Parents had to complete all three criteria in order to be scored correctly. While objective measures such as this are useful for continuing the development of parent training programs, we also need a stronger understanding of the self-perceptions of individuals with MR in regard to their parenting experience.

It is also important to remain conscious of each parent's individual experiences, as statistics of the group may not be representative of any particular parent's challenges. Scores from formalized measures may not be indicative of areas in which the parent feels

he/she needs extra help. Therefore, qualitative research offers another perspective on this population and contributes to hypothesis-driven research. Although the objective approach can offer valuable information, it may limit the opportunity to acknowledge, "...new and unexpected insights (Willig, 2001, p.5)," during data collection. Challenges and achievements are important to recognize and understand from the point of view of the parents with MR, in order to be as efficient and effective in helping them without undermining their abilities. Irving Seidman (1998) stresses the potential consequences of not incorporating the experiences of the studied individual in analysis. Taking the stance that the individual is *the* expert in his/her life, ignoring such things as the language he/she uses in telling a story reduces the meaning that could be identified (Seidman, 1998). The addition of self-reported data of the parent with MR's experiences contributes to a more holistic understanding of concerns of individuals with MR raising a child.

Our study takes a subjective approach based on Interpretative Phenomenology (Willig, 2001). Our research questions include: what challenges of parents with mental retardation can be identified? What are some commonalities among this population? What are some differences?

## Methods

### *Participants*

Nine participants, all diagnosed with mental retardation, had IQs between 50-70, were diagnosed before the age of 18 years, and had some limitations in living. All participants were recruited through Noble of Indiana, the Indianapolis branch of the national organization The Arc. The Arc, formerly known as the Association for Retarded Citizens of the United States, is an organization of and for persons with MR and their

families. The organization's goal is to improve services and supports for these individuals and to influence public policy on their behalf. The Arc is also involved in ongoing research (The Arc, 2007).

There were seven females and two males with age ranging 26-59 years old. There were seven African Americans and two Caucasian participants. Marital status ranged among participants with three being single, one engaged, two married, two divorced, and one widowed. Custody levels varied as well. Four participants have full custody, two have visitation rights, one participant does not have visitation rights but has knowledge of the child's whereabouts, and one participant currently has no knowledge of the child's location. All participants have supported living staff; however, three participants live independently while the six other participants live in supported living communities. All nine participants are fully emancipated and acted as their own legal guardians.

#### *Materials and Procedure*

Participants were given and signed an informed consent (see Appendix A). Participants were interviewed by both researchers using a semi-structured instrument (Appendix B) designed by the researchers based on a review of the literature. Participants were debriefed (i.e. given an overview of the how their interview would be used, provided with contact information, and given the option to request a copy of the interview transcript and a copy of the final report). All interviews were audio-recorded, transcribed, and analyzed. An additional informed consent was drafted after initial interviews which included a clause allowing for the release of the participants personal file. Once the second informed consents were signed by participants, eight of the nine participants' files were obtained from Noble of Indiana. These files contained client

histories, psychological assessments including IQ and aptitude tests, current medical information, and information regarding services providing support (e.g. financial support, therapy, and transportation services). Participants' files provided supplemental information for the data obtained during the interviews.

Based on the Interpretative Phenomenological Approach, researchers analyzed the transcripts through a series of five steps. During the initial encounter stage, researchers read and re-read the transcripts, identifying any associations, questions, or reactions they had to the texts. The second stage of analysis involved identification of themes. Themes are defined as concepts that capture an essential feature in the text (Willig, 2001). In the next stage of analysis, researchers grouped the identified themes into larger clusters. Clusters develop when relationships and shared meanings are identified between themes (Willig, 2001). In the fourth stage, summary tables were produced for each of the nine participants. These summary tables included clusters and themes, as well as relevant quotes from the transcripts, page and line numbers, and additional relevant information obtained from the participant files. They allowed the researchers to note similarities and difference among the participants. In stage five, integration of cases, researchers attempted to identify new observations and insights that emerged from the study, particularly in contrast to the issues that previous literature has focused on. The researchers acknowledged that interpretation of experiences was necessary, but attempted to remain faithful to participant's narratives.

## Results

### *Individual Participant Histories*

Brief histories for each of the nine participants contribute to a better understanding of their personal experiences as parents with mental retardation.

1) Lisa, a single 38-year-old African American female, is a mother of one 14-year-old daughter, Jennifer. She is employed at Noble of Indiana. Lisa is diagnosed with mental retardation, seizure disorder, Tourette's Syndrome, and depression. She also attends behavior therapy once a week. Lisa lives in a supported living community, while her daughter lives with Lisa's mother. Lisa has unlimited visitation rights and sees Jennifer on a daily basis. Jennifer is reported as having slight hearing loss, seizure disorder, wears leg braces, and receives help from supported living staff. Lisa's most recent assessment using the Wechsler Adult Intelligence Scale – Revised reported her as having a full scale IQ of 60.

2) Bonnie, a 46-year-old African American female, is diagnosed with mental retardation and cerebral palsy for which she uses a wheelchair. She works for Noble of Indiana. She is currently married and has one 17-year-old son, Matthew. Bonnie lives with her husband and son in their own home, but receives help from staff five days a week. Bonnie met her husband through Noble of Indiana. Their son, Matthew is reportedly in the eighth grade, which is not the expected grade for his age. Bonnie's full scale IQ is 53 based on the WAIS-R.

3) Grace is a 48-year-old African American female who is legally separated from her husband. She is the mother of three daughters, aged 25, 19, and 17 years. Grace is employed with Noble of Indiana. She lives in a supported living community with her

youngest daughter, Gabby. Gabby lives with an unspecified developmental disability and is noted to have behavioral challenges. Her two eldest daughters were removed from the home in the 1980s due to accusations of neglect. The eldest daughter went to live with Grace's sister, while the middle daughter was adopted out at age eight. Grace is diagnosed with mental retardation and psychotic disorder otherwise unspecified. She experiences hallucinations and struggles with verbal aggression for which she receives regular behavioral therapy. Records show that Grace was charged with assault against her husband in an incident of domestic abuse, but charges were later dropped. According to the WAIS-R, Grace's full scale IQ is 64.

4) Reagan, a single 43-year-old African American female, is the mother of one 16-year-old daughter, Shelby. There is documentation of Reagan's attempts to place Shelby up for adoption beginning at eight months of age. Subsequently, Reagan's mother desired and obtained full custody of Shelby. Shelby currently lives with Reagan's mother and Reagan lives in a supported living community. Shelby's father denied paternity and has no involvement in either Reagan or Shelby's life. Reagan has regular visitation with her daughter. Reagan is diagnosed with mental retardation, depression, and psychotic disorder otherwise unspecified. She works at Noble of Indiana. Her full scale IQ is reported at 52 according to the WAIS-R.

5) Bridget is a 59-year-old divorced African American female. She is diagnosed with mental retardation, seizure disorder, and undifferentiated schizophrenia. She receives behavior therapy on a weekly basis. She is the mother of one living child – a daughter age 41 years. Her second child – a son – died, however documents do not show date or cause of death. Bridget's daughter, Willow, lives in a secure residential facility as

she has also been diagnosed with schizophrenia. She has frequent contact with her daughter and they have scheduled biweekly visits. Bridget has lived with two friends for 20 years in a supported living community. She is employed with Noble of Indiana. According to the WAIS-R, Bridget's full scale IQ is 68.

6) Carrie, a widowed 47-year-old Caucasian female, is diagnosed with mental retardation. She is currently unemployed and receives disability payments. She has a daughter, Molly, age 19 years and a son, Bobby, age 16 years. Her husband passed away in 2004 from complications with diabetes. She is the only participant for which a client file was not obtained. Carrie lives with her daughter, Molly in independent housing; however she does receive assistance from the social service system. Carrie's son, Bobby, lives at the Indiana Soldiers and Sailors Children's Home, which is a residential school for children of military veterans. Carrie and her husband temporarily lost custody of their children when Carrie was hospitalized for an unspecified reason. Upon her recovery, both children were placed back in the home with Carrie and her husband. Any psychological assessments including IQ are unknown.

7) Kevin is a 26-year-old biracial male who is currently engaged to the mother of his child. Kevin has one two-year-old daughter, Kelly. He and his fiancé are expecting their second child later this year. Kevin lives with his fiancé and daughter, Kelly, in independent housing; however, supported living staff visit on weekdays. Kevin is diagnosed with mental retardation and receives treatment for depression and behavior therapy on a weekly basis. He is employed at Noble of Indiana. Kevin's full scale IQ is 68 according to the WAIS-R.

8) Cecelia, a 43-year-old divorced African American female, is the mother of one 16-year-old son, Kyle. She is diagnosed with mental retardation and depression. Cecelia works at Noble of Indiana. She lives in a supported living community. Kyle reportedly lives with his father and Cecelia has legal visitation rights, however she has infrequent contact with either Kyle or her ex-husband. Cecelia had a child prior to Kyle; however, the child died shortly after birth as it was delivered at home without medical care and Cecelia's mother failed to act to alert medical services. Cecelia's mother was held responsible for this incident and charged with neglect. According to the WAIS-R, Cecelia's full scale IQ is 54.

9) Chris, a single 47-year-old Caucasian male, is the father of one 17-year-old daughter named Samantha. Samantha lives with her mother in Florida, and Chris has no legal custody rights. He is unaware of Samantha's current location and has not seen her since 2003. Chris pays child support on a monthly basis. He is diagnosed with mental retardation and lives in an apartment where he receives residential support from staff. He works at Noble of Indiana; however, he has a reported history of exploitation in the workplace. Chris has been incarcerated several times for failure to pay child support, however he is currently maintaining employment which enables him to make payments. According to the Kaufman Brief Intelligence Scale, Chris has a composite score of 52.

#### *Description of Clusters and Themes*

Researchers' findings narrowed to focus on six clusters and 20 themes. The Response Table shows the frequency and distribution of remarks relating to each of the clusters and themes (see Appendix C). The numbers in the Response Table are not indicative of significance in and of themselves, however they aid in organizing the

thematic data. Summary tables for each of the nine participants provide quotes and supplementary file information relevant to each cluster and theme (see Appendix D).

The first cluster, Difficulties, directly pertains to the challenges the participants expressed as having faced as parents with mental retardation. Within this cluster, six themes were identified as specific areas with which participants struggled. The theme of Transitions is defined as a period in which lifestyle change took place such as adjusting to schedule changes associated with raising a child and the time when a child becomes mobile. The theme of Transportation describes difficulties in mobilization resulting in dependency on others and restrictions in travel outside their living accommodations. The theme of Finances conveys problems with money management, financial decision making, and lack of funds. Health as a theme covers struggles that may involve either parent or child and includes physical and mental medical complications. The theme of Custody refers to participants who were either currently dissatisfied with their situation or had problems with custody in the past. Parent-child interaction is the final theme in Difficulties, which deals with the concerns of the parent with MR's desire to improve relations with his/her child.

The second cluster of Child Development Issues covers the themes of both Physical and Mental developmental complications for the child of a parent with mental retardation. Physical complications include such things as premature birth or seizure disorder. Mental development issues cover emotional, behavioral, and intellectual deficits.

Communication is the third cluster and is broken down into themes of Verbal and Nonverbal means of interacting with one's child. Verbal communication involves talking

with one's child whereas Nonverbal communication covers actions such as playing games, physical affection, and giving material things to the child.

The fourth cluster of Social Judgment deals with the opinions of outside persons and the subsequent perceptions and effects on the participants' beliefs and behaviors. The theme of Independence reflects participant expression of a desire to demonstrate ability to parent and be as self-sufficient as possible. The theme of Influence describes instances in which outsiders including physicians, relatives, and social service workers, conveyed concerns regarding aspects of the participants' abilities to parent.

The fifth cluster, Reaction to Pregnancy, reflects the different emotional responses of each of the participants upon the news of becoming a parent. Three themes capture the spectrum of responses including Excited, Nervous/Scared, and No Reaction.

The final cluster, Sources of Help, covers the various avenues that participants stated as resources of assistance. Themes included Family, Friends, Health Care Team, which includes physicians and nurses, Staff/Supported Living, and Parenting Programs in which participants may have attended before and/or after the child's birth.

### *Emerging Insights*

#### *Difficulties*

Participants from this study expressed having struggled with a range of issues in their role as parents. The most commonly mentioned difficulty for these nine participants was health, which either referred to their own health problems or that of their child's. Bonnie, Lisa, Grace, Reagan, Bridget, and Carrie were all affected by personal health obstacles. Bridget and Carrie also mentioned concerns regarding their children's medical status. Carrie describes her son's early health complications, "He didn't get to come

home right away. His lungs collapsed on him...He was at Riley for two weeks before he came home.” Carrie went on to share the impact of Bobby’s hospitalization as it made caring for him more challenging; however, she made sure to mention that this is no longer a concern for Bobby or her.

In contrast to health being the most mentioned difficulty, transportation was only discussed by one participant. Bonnie explained that neither she nor her husband could drive and therefore had to rely on alternative sources of transportation. This particularly caused problems when she and her husband wanted to attend meetings at school for their son, Matthew. Bonnie stated, “...they were having meetings and we couldn’t make it there.” Although Bonnie was the only participant to discuss problems with transportation, this was significant for her in her experience as a parent. Perhaps the most interesting difficulty discussed by participants was the theme of parent-child interactions.

#### *Parent-Child Interactions*

Four participants cited parent-child interactions as one area of particular struggle. Difficulties in interacting with one’s child differed in type among participants. Lisa described having difficulty physically interacting with her daughter. In response to the question of what was hardest for her when she first brought her daughter home from the hospital, she responded, “To pick her up...I was nervous...because I didn’t know if I was going to drop her...I didn’t know how to, um, how to hold her...anything. I didn’t know how to do any of that stuff.” Lisa also struggled in communicating with her daughter now that she is older. Jennifer, who has a developmental disorder, becomes frustrated with her mother when she does not understand what she is saying. Lisa explained that Jennifer becomes angry and mad when miscommunication occurs.

Yet another type of parent-child interaction mentioned by Grace was that of discipline. She expressed a desire to learn better ways to keep her daughter from “messing” with things she should not be. In other words, Grace wanted her daughter to be more obedient and she wanted more guidance in enforcing her authority. A final type of parent-child interaction mentioned was simply lack of contact. Chris explained that he felt he did not see his daughter often enough and during times when they were together this made their interactions more awkward. In the past four years, Chris has not had any contact with his daughter at all. These parents encountered a variety of challenges, some more commonly experienced than others.

#### *Sources of Help*

Another emerging insight that was noted was that participants utilized a combination of resources to assist them in activities of daily living and these were discussed specifically in the context of parenting. Family and staff/supported living were noted by all nine participants as being primary sources of help. Staff members were mainly depicted as helping with practical activities such as shopping for groceries, cooking, managing money, and cleaning the home, although some participants did these things for themselves. Family members, however, were described as fulfilling more of an emotional support system as well as being more directly involved with the process of raising the child. For example, family members offered advice and childcare, provided material items (e.g. clothing and diapers), and in some cases have taken partial if not full custody of a participant’s child. Conversely, friends were only mentioned by two participants as having been a source of help. The health care team was also not emphasized as a particularly significant source of help and the amount of involvement

and quality of assistance varied among the participants' experiences. For this study, participants' experiences with various parenting programs are especially important.

### *Parenting Programs*

Five participants attended parenting programs either before and/or after the birth of their children. Reasons for attending these parenting programs varied among the five participants. Reasons included recommendations by outside sources such as supported living communities or psychologists associated with Noble of Indiana, personal choice and interests of participant, and legal requirement by the Indiana court system. Carrie reflected on her participation in a parenting program as ordered by the courts, "...because the kids were going to be teenagers and we had to know how to take care of our teenagers."

Reactions to the effectiveness and content of the parenting programs also differed among participants. Grace remarked, "They taught me how to cook and how to help the kids out. It was a little help, but not that much." When asked what could have been improved Grace responded, "Teach how to be a better parent...like helping your kids more." She did, however, state that she found the program she participated in with her youngest daughter more effective than the programs she attended with her eldest two daughters. Furthermore, reasons for not participating in parenting programs among the four other participants ranged from feeling they were unnecessary to simply not being aware that parenting programs were an option. Examining these parents' experiences with various sources of help, particularly parenting programs, is important as this is what the majority of research on parents with mental retardation focuses on and is where changes are most likely to be made.

*Social Judgment and Influence*

A final insight into the experiences of our participants relates to their thoughts on the social judgment they have received as parents with MR. Five of the nine participants mentioned specific incidents and/or feelings of being judged and were subsequently affected. One participant discussed her experience with tubal ligation after the birth of her son. Bonnie stated, "I really didn't. I really didn't decide because my sister, she kept pressing on me like, 'Girl, you better go on and get yourself fixed'..." Bonnie went on to explain that she and her husband had wanted more children, but they were discouraged from doing so. Three participants described familial disapproval for their choices to marry and/or have children. Chris expressed his hurt when relating his ex-partner's negative opinion of him as a father. Chris explains why he believes he has not been involved in his daughter's life, "because her mom, I guess, put words in her mouth saying that I was a bad dad and stuff. You know, I really wasn't a bad father. I don't think I was."

Additionally, two participants noted skepticism of their health care team, specifically the doctors who oversaw their pregnancies, and the social service system. Lisa's physician expressed concern over her abilities to raise her child and warned her that it was not going to be easy. Bonnie talked about the potential threat of her son, Matthew, being taken away and her doctor's assertion that she could not and perhaps should not have children due to her disability. She stated, "...they didn't think I was able to keep my son because by me being disabled...They was trying to take it away and give it to another family." In all of these cases, the participants conveyed some insecurity

about their ability to parent and the particular incidents in which they felt the judgment of others.

### Discussion

The results of the current study revealed six clusters and 20 themes of which Difficulties, Sources of Help, and Social Judgment are particularly important. These clusters capture the nature of the challenges facing parents with mental retardation as well as the means frequently utilized to cope with these challenges. Participants described a range of difficulties and of these some were more frequently mentioned than others. Researchers found the theme of parent-child interaction to be the most interesting of the difficulties described by participants. Furthermore, participants talked about a variety of resources. Family and staff/supported living are reported as the most common as all nine participants used both of these sources of help. The theme of parenting programs as a source of help is perhaps most important to this study. The theme of social judgment was also prevalent among participants. The information obtained through discussing difficulties, sources of help, and social judgment highlights findings of previous research by revealing holes in the literature and by providing different perspectives on aspects of parenting that *are* consistently mentioned in previous research.

Previous research has found that common areas of concern for parents with mental retardation include finances, health of both child and parent, maintaining custody, and parent-child interaction (Aunos & Feldman, 2002; Tymchuk, 1992). Consistent with the previous research, the participants of this study also emphasized these difficulties. However, this study also reveals other challenges facing parents with MR that are not frequently mentioned in the literature: specifically, transitions and transportation.

Focusing on parent-child interaction, previous research suggests that parents with mental retardation interact differently with their children than parents without mental retardation. “The parent-child style of interaction of mothers with mental retardation has been characterized as being less varied, less supportive, and less reinforcing and more punitive and directive...(Tymchuk, 1992, p.170).” In light of assertions such as these, it is interesting to see that four participants in this study believed they struggled in this area of parenting. The participants specifically mentioned wanting more instruction and guidance to improve their parent-child interactions. Participants struggled with physical interactions with their children as well as discipline, lack of contact, and making connections with their children. There have been few observational studies resulting in lack of research on the types of parent-child interactions between parents with MR and their children other than in laboratory settings (Tymchuk, 1992). This study provides evidence that parents with MR desire to improve their interactions and gives some sense of specific interaction difficulties. More interviews with these parents to identify their concerns in the area of parent-child interaction as well as observational studies outside the laboratory may contribute to identification of types, deficits, and possible techniques to improve parent-child interactions with parents with mental retardation. Integration of various sources of help to aid parents with MR in managing difficulties in parent-child interaction as well as other challenges has been a topic of discussion in previous literature.

Previous research acknowledges that parents with mental retardation rely on multiple service sectors and supports (Tymchuk, 1999). The vast majority of research on sources of help for parents with MR has solely focused on the agencies these parents

come in contact with including, "...health care, education, housing, welfare, vocational, and other social services as well as child and adult protective services and the juvenile and adult court systems (Tymchuk, 1999, p.4)." The current study found that all nine participants also emphasized the importance and presence of their families as primary sources of help. These families as systems need to be given more credit and support as they are likely to be the most directly involved source of help according to the current study. Taking the position that the goal is to help these parents succeed, integration of all sources of help is necessary. Therefore, further research is needed to identify the specific roles family plays in supporting a parent with mental retardation. With this additional information and belief in the importance of the family system as a source of help, an attempt to integrate families into the network of services should be made. One specific way families could become more integrated is through parenting programs.

Five participants in the current study took part in at least one parenting program before and/or after the birth of the child. Previous research on parenting programs explains that the majority of programs aimed at this population gauge what areas of parenting need to be addressed based on assessments of each parent on his/her performance of specific tasks such as sterilizing a bottle, changing a diaper, and relaying situations in which the doctor should be called (Feldman, Maurice & Case, 1999). The tasks which the parent scores poorly on are then determined to be the needed areas of focus in the parenting program. The participants of this study all verified these skills and tasks were taught in their programs, and none of them reported these tasks as posing difficulties. This may indicate that the programs which these five individuals attended *were* successful in addressing and helping the participants learn the tasks. However,

some of these participants relayed dissatisfaction with the content and effectiveness of the programs and wanted to improve additional areas of their parenting such as communication and discipline. Taking their experiences into consideration, it is a reasonable suggestion that parenting programs for persons with MR attempt to cover a wide variety of parenting issues. Although basic skills in child-care are important for an individual to learn, more complex issues such as forming a connection with one's child should be addressed in these parenting programs.

Additionally, previous research found that many families were not attaining and maintaining the skills necessary to graduate from the programs and that most families would need continual help in parenting as the child developed (Ray, Rubenstein & Russo, 1994). All five participants in the current study took part in short duration parenting programs. There seems to be a disconnect between what research suggests these parents get in the way of training and the reality of the services they are receiving. These participants may have benefited from parenting programs that were longer in duration and continuously available to them as their children matured. Recalling the importance of the family system as a primary source of help, families could become more involved in the parenting programs themselves through their own attendance, encouraging the attendance of the relative with MR, helping transfer skills learned in the program to the home environment, and through providing feedback and suggestions to the parenting program's agency. Agencies providing services to parents with mental retardation should take into consideration the need for a wider range of topics to be covered and the need for more extensive periods of time in which to implement the training as they develop these programs.

The perceived need for parenting classes for parents with MR suggests that this group of people is scrutinized more than most other groups regarding judgments about parenting. According to Melton and Scott (1984), it is reasonable to assume that an individual who is incapable of caring for him/herself would also be unable to provide the proper care for a child. However, research has shown that persons with MR are typically capable of holding down jobs and living independently with the proper supports (Melton & Scott, 1984). Research has also found that parents with mental retardation are capable of functioning and providing appropriate care for their children with training and support (Tymchuk & Feldman, 1991). Yet parents with MR are being held to a higher standard than parents without mental retardation (Aunos & Feldman, 2002). Parents with MR continue to have a higher risk of losing custody of their children. Tymchuk and Feldman (1991) assert that, “the threat of child removal is an overriding feature of the lives of these parents which taints everything they do, including their interactions with their children (p.487).”

Five of our participants described incidents where this kind of social judgment was present. Although all parents may experience social pressures and are aware of others' judgments, it is neither to the same degree nor of the same quality as parents with MR. All participants expressed their interest and affection for their children as well as the desire to be good parents. While some of our participants have managed to keep custody of their children or to have regular interactions with them, others, such as Chris, have not. With better understanding of the challenges facing this population and the improvement of resources to aid them, perhaps social judgments should be diminished in

their rapidity and severity. It is our belief that public awareness of this population would benefit both the parent with mental retardation and their child.

### *Future Research*

Limitations of this study include small sample size and single interview structure. In future, research may benefit from a larger and more diverse sample as well as a multiple interview structure allowing for follow-up and deepening of the interviewer-interviewee relationship. Multiple interviews with a participant would build rapport and perhaps encourage disclosure and aid in our analysis of the interviews because of our increased familiarity with the participant. The choice to focus on difficulties, sources of help, and social judgment, specifically parent-child interactions, parenting programs and influence, was made consciously on our part due to the need for further research in these areas.

### *Conclusion*

The current study provides valuable insight into the experiences of parents with mental retardation. We acknowledge the enormous amount of information available in just one participant's account let alone all nine individuals' stories. Integration of the current studies' subjective data with previous research contributes to a more holistic understanding of the experiences of parents with mental retardation. Parents with MR do not have access to or may not be capable of utilizing the same resources available to parents without mental retardation. It should be seen as the responsibility of future researchers and agencies of assistance who work with these individuals to incorporate a comprehensive understanding in order to develop and implement the best possible resources for parents with mental retardation.

Appendix A: Informed Consent

Research is being conducted by Alexis Palfreyman and Rachel Weisenbach for their senior independent study at Hanover College. In this study, we will be addressing the difficulties and successes of parents with mental retardation. You will be interviewed and asked to answer 20 questions developed by the researchers. The interview consists of demographic questions as well as questions about your personal parenting experiences. The interview will take no more than an hour. Your responses to the interview will be audiotaped. The audiotape will not be used for purposes beyond this study. Information pertaining to demographics and any evaluations you may have had will also be obtained through your personal file. The information you provide during the interview and from your file is completely anonymous; at no time will your name be associated with the responses you give.

There are no known risks involved in being in the study, beyond those of everyday life. If you have any questions about what you will be doing in the study or about the study itself, feel free to ask now or at any time during your participation. If, at any time, you feel uncomfortable and wish to terminate the interview, you have the right to do so.

Questions about this study can be addressed to Alexis Palfreyman and Rachel Weisenbach by phone (812.866.7979) or by email at [palfreymana@hanover.edu](mailto:palfreymana@hanover.edu) and [weisenbachr@hanover.edu](mailto:weisenbachr@hanover.edu). You may also contact Skip Dine-Young, the study advisor at 812.866.7319.

I acknowledge that I am participating in this study of my own free will. I understand that I may refuse to participate or stop participating at any time. If I wish, I will be given a copy of this consent form. If I wish, I may request a copy of the interview transcript and final study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Appendix B: Questionnaire

1. First name of participant:
2. General demographics
  - a. Age:
  - b. Sex:
    - i. Male
    - ii. Female
  - c. Race:
    - i. Caucasian
    - ii. Black
    - iii. Hispanic
    - iv. Other
  - d. Marital status:
    - i. Single
    - ii. Married
    - iii. Divorced
    - iv. Other
  - e. Occupation:
3. How many children do you have?
4. How old is/are your child/children?
5. What is/are the name/names of your child/children?
6. Who do you live with?
7. What kind of home do you live in (e.g. house, apartment, etc.)?

8. How did you feel when you found out you were becoming a parent?
9. Did anybody help you during the pregnancy/getting ready for the child?
  - a. Did you take part in any prenatal programs?
  - b. Doctor input?
10. Have you ever taken a parenting class or has anyone shown you how to take care of a child? What did you learn?
11. Are you getting any outside help from others now? If so, who is helping you and what kind of help are you getting?
12. When your first-born baby arrived, what was the hardest thing for you?
  - a. Sub questions: changing clothes, putting to sleep, feeding, changing diapers, financial problems, healthcare, etc.
  - b. How did you deal with this?
13. What do you do best as a parent? What are your strengths?
14. Repeat questions 12 and 13 for each additional child.
15. Depending upon age of child/children
  - a. What became harder as he/she/they got older?
  - b. What became easier as he/she/they got older?
16. If you have more than one child, how does that affect your parenting?
  - a. Harder?
  - b. Easier?
  - c. Why?
17. Are you hoping to have more children? Are you planning to have more children?
18. How do you show your child you are pleased/happy with him/her?

19. How do you show your child you are upset/unhappy with him/her?
20. Do you have any questions/comments/concerns for us now that we have come to the end of our interview?

## Appendix C: Response Table

<b>Cluster:</b>	<b>Theme:</b>	<b>Number of Participants:</b>
Difficulties		
	Transitions	2
	Transportation	1
	Finances	4
	Health	6
	Custody	5
	Interactions	4
Child Development Issue		
	Physical	5
	Mental	4
Communication		
	Verbal	7
	Nonverbal	9
Social judgment		
	Independence	3
	Influence	5
Sources of Help		
	Family	9
	Friends	2
	Health care team	5
	Staff/supported living	9
	Parenting programs	5
Reaction to Pregnancy		
	Excited	5
	Nervous/Scared	5
	No reaction	2

Appendix D: Summary Tables

Participant 1: Lisa

Cluster:	Theme:	Quote:	Page/Line	Participant File
Difficulties	Transitions	n/a		
	Transportation	n/a		
	Finances	“...I don’t have the um, I don’t mean I don’t have the ability, but of the money to take care of her right now.”	p.5/204-205	
	Health	n/a		Seizure disorder; Tourettes; depression
	Custody	n/a		Visitation, mother has full custody
Child Development Issue	Interactions	“To pick her up...I was nervous... Because I didn’t know if I was going to drop her...I didn’t know how to, um, to hold her... anything. I didn’t know how to do any of that stuff.”	p.3/108,110-111  p.4/150, 156-157	
		“Trying to understand what she’s saying...She gets really angry and mad because I don’t understand what she’s saying.”		Hearing impairment; seizure disorder;

			wears leg braces
	Physical	<p>“Um, well she [Jessica] has staff. She has staff too. Takes her out and stuff.”</p> <p>“She’s a teenager, but in a kids’ body. And for her being handicapped, she’s not over dolls yet...”</p> <p>“She has seizures...she has another handicap but I cannot think of it.”</p> <p>“When she was born I felt so bad for her because one of her legs was longer than the other and she had to wear braces.”</p> <p>“Trying to understand what she’s saying...I can’t. It’s hard. She tries to explain stuff to me, but I just can’t figure out what’s coming out of her mouth... Because that’s part of her handicap.”</p>	<p>p.3/104</p> <p>p.3/131-132</p> <p>p.3/135-136</p> <p>p.4/138-139</p> <p>p.4/150,152-153,156</p>
Communication	Mental	n/a	
	Verbal	<p>“I would tell her. I will tell her or just do little things for her that tell her I</p>	<p>p.4/173-174</p>

	Nonverbal	care.” “Buy her whatever she wants.”	p.3/128	
		“I give her hugs. Um, every now and then I will give her maybe two dollars if I have it.”	p.4/172-173  p.4/180-181	
Social judgment		“But I don’t hit her or nothing like that. I don’t do none of that stuff. I’m not abusive.”		
	Independence Influence	n/a “...he [doctor] said it wasn’t going to be very easy to take care of a kid if you’d never had one yet.”	p.2/83-84	Tubal ligation
Sources of Help	Family	“Oh, my mom... my brother, my dad...”	p.2/68-69  p.3/97-98	
	Friends	“Well, I’m getting it [help] from my niece, um she helps out with Jessica. My nephew, he’s helped me out with her. And my dad, he puts his two cents in there.” “My brother, my dad, friends. Whew!”	p.2/68-69  p.2/72	
		“I have two of my friends. They already had kids.”		

	Health care team	So they told me - got me going.” “I had a nurse – thank God! I wouldn’t have been able to do it by myself.”	p.2/68
			p.2/80
	Staff/supported living	“I had to go see him [doctor] to get my stomach checked out and everything.” “It’s basically, um it’s like an apartment but it’s old folks and people with disabilities and...”	p.2/56-57 p.3/98-99
		“And my staff are helping me out too...”	p.3/104
	Parenting programs	“Um, well she [Jennifer] has staff. She has staff too. Takes her out and stuff.” “...they had a program going here with parents about kids and stuff and how to take care of your child and everything so. Her name was Perrilee. So she helped me out and got me going and everything, so...”	p.2/75-77
Reaction to Pregnancy	Excited Nervous/Scared	n/a “I was kind of	p.2/62

shocked.”

p.2/64-65

“I didn’t feel anything. Not at first. Bust, then after the week passed, um, she started moving. My water broke... and it scared the crap out of me (giggles).”  
n/a

No reaction

Participant 2: Bonnie

Cluster:	Theme:	Quote:	Page/Line	Participant File
Difficulties	Transitions	“...the first thing that was hard was getting up and then getting him and getting bottles prepared...cause he would wake up crying.”	p.3/97-98,104  p.4/143,145	
	Transportation	“When he started walking and he was getting into everything...I had to pick it up and put it back into the cabinets and stuff. That was kind of hard.” “...they were having meetings and we couldn’t make it there.”	p.4/157	
	Finances Health	n/a “And they didn’t think I was able to keep my son	p.2/64-65	Cerebral palsy; relies on

Child Development Issue	Custody Interactions	because by me being disabled.” n/a n/a	wheelchair use Full custody
	Physical Mental	n/a “He’s [son] not in his right grade.”	p.6/233
Communication	Verbal	“Raising him the right way and trying to keep him in school and talk to him about the right things. Things he need to know.”	p.3/129-130 p.5/195
		“Tell what a good job he did...”	p.5/201
	Nonverbal	“I’ll ask him about it like, ‘Why didn’t you do the dishes?’...”	p.5/219-220
		“Ya, I was just like, ‘Everything gonna be alright.’ I mean, I wouldn’t blow up in the store.” “...we would get something just so he could be quiet...And just let him hold them...give them to him and he’d be alright.”	p.5/214-215,223-224
Social judgment	Independence	“I pretty well handled it on my	p.2/53-54

own. Me and my husband since we were independent.” p.2/76-77

“But I said, ‘no’ cause I was the one that you know, brought it in the world. So I wanted to keep my own son. I didn’t want nobody else to take care of it.” p.2/85  
p.5/188,191-192

“We pretty much do stuff for ourselves.”

“...they said, ‘you could have it normal.’ Just like everybody else... And that was just a blessing.”

Influence

“And they didn’t think I was able to keep my son because by me being disabled.” p.2/64-65

“...they was trying to take it away and give it to another family” p.2/75-76  
p.4/178-179

“I really didn’t. I really didn’t decide because my sister, she kept pressing on me like, ‘Girl, you better go on and get yourself fixed’...”

Sources of Help

Family	“My sister. She went and bought all kind of clothes”	p.2/53
	“...I have nieces and nephews. And before I had my own, a kid of my own, I would babysit for them.”	p.2/61-62  p.2/73-74
	“...I got my sisters. I have quite a bit of sisters and they got kids. I used to watch my nieces and nephews.”	
Friends	n/a	
Health care team	n/a	
Staff/supported living	“...we have people in our home who comes to our house and helps like we have a nurse and whatever we need she helps with, like getting to the store or whatever; they are willing to help us with that...They come like five days out of a week.”	p.2/83-85,90  p.4/150-154
	“Well, I had a lady, she used to work here...She helped with some of that trying to make adjustments, so what to do as far	

		as trying to keep him from getting into cabinets and stuff...she made a lot of suggestions on what to do.”	
Reaction to Pregnancy	Parenting programs	n/a	
	Excited Nervous/Scared	n/a “Nervous...cause I was trying to hide it from my mother...”	p.1/37,39
	No reaction	n/a	

Participant 3: Grace

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	n/a		Psychotic disorder; schizophrenia Two eldest daughters removed from home in 1980s due to accusations of neglect; full custody of youngest daughter; eldest daughter with Grace's sister; middle daughter adopted out at age 8 years
	Transportation	n/a		
	Finances	n/a		
	Health	n/a		
	Custody	n/a		
	Interactions	“How to talk to	p.2/73	

<p>Child Development Issue</p>	<p>Physical Mental</p>	<p>them and how to tell them how not to mess with that. You know?"</p>	<p>p.4/160</p>	<p>Youngest daughter noted as having developmental delay and behavior challenges</p>
<p>Communication</p>	<p>Verbal</p>	<p>"And well I tell my youngest one...I tell her how when she was a little bit young how to cook."</p>	<p>p.4/155-156</p>	
		<p>"Well, I would just pick them up and put them on my lap, talk to them. Say, 'Don't do that no more.'"</p>	<p>p.4/168-169</p>	
		<p>"Well, I would just pick them up and put them on my lap, talk to them. Say, 'Don't do that no more.'"</p>	<p>p.4/171-172</p>	
		<p>"Mm hm [in response to asking if she talks things through]... Me and my kids get along well."</p>	<p>p.4/176-177</p>	
		<p>"Like if something happens at school and she's gonna fight somebody. All I do is when she comes home,</p>		

		when I come home, I go into her room and talk to her.”		
	Nonverbal	“Well, I hug them a lot.”	p.4/155	
			p.4/162	
		“We got mostly every Monday. I like to cheer her on. I’m proud of her.”		
Social judgment	Independence	n/a		
	Influence	n/a		Lost custody of 2 children
Sources of Help	Family	“I had a lot of help from my family.”	p.1/42	
			p.2/48	
		“They helped me get stuff.”		
			p.3/125	
		“...I learn from my mother and father.”		
	Friends	n/a		
	Health care team	n/a		
	Staff/supported living	“I’ve got staff... They help go to the grocery store, pay my bills, and help me with my child.”	p.2/90	
			p.3/93	
	Parenting programs	“Parenting...they taught me how to cook and how to help the kids out.”	p.2/55,57	
		“They...it was a little help, but not that much... Teach how to be		
			p.2/61,66,68	

		a better parent... Like helping your kids more.”	p.2/78,81
		“With my youngest one...I learned a little more in them.”	
Reaction to Pregnancy	Excited	“I was happy... [nodding ‘yes’ for all three pregnancies].”	p.1/27,39
	Nervous/Scared	n/a	
	No reaction	n/a	

Participant 4: Reagan

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	n/a		Depression; psychosis
	Transportation	n/a		
	Finances	n/a		
	Health	n/a		
	Custody	n/a		
	Interactions	“She’s hard to mind...she don’t mind.”	p.3/115,117	
Child Development Issue	Physical	“She was a premie.”	p.2/78	
	Mental	n/a		
Communication	Verbal	“...and talk to her.”	p.4/138 p.4/143	
	Nonverbal	“I would tell her it was wrong.” “I would hug	p.4/138	

		her...”	
Social judgment	Independence	n/a	
	Influence	n/a	
Sources of Help	Family	“My mother did...She was just there for me.”	p.2/46,48
	Friends	n/a	
	Health care team	“By the end of the first month, went in every month...mm hmm [helpful]...ya [supportive doctor].”	p.2/54,56,58
	Staff/supported living	“Yes, I in an assisted program that I’m in.”	p.1/31
	Parenting programs	n/a	
Reaction to Pregnancy	Excited	n/a	
	Nervous/Scared	n/a	
	No reaction	“No reaction... I just knew that I was pregnant.”	p.1/38,41

Participant 5: Bridget

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	“I worked in a workshop and she started going to school. So while I was going to the	p.3/113-114	

		workshop, she was going to school right across..."		
	Transportation	n/a		
	Finances	n/a		
	Health	"'bout her legs, I was worried about her legs."	p.2/87	Bridget has been diagnosed with schizophrenia and depression and is on medicated for both. She also has seizure disorder. Present when daughter was young.
	Custody Interactions	n/a n/a		
Child Development Issue	Physical	"She had seizures like I used to do a long time ago... Ya, that started when she was a little baby...she has 'em still."	p.3/122,124,126	Seizure disorder. She also lives in a secure resident facility.
	Mental			Diagnosis of schizophrenia
Communication	Verbal	"If I said, 'Willow don't do this,' she wouldn't do it."	p.3/120 p.4/144	
		"I appreciate her. I tell her..."	p.4/157	



		mother did... She taught me how to raise my child.”	p.2/65-66, 68
		“My daughter was uh, I had to use soap and water for my daughter’s legs. So my mother helped me. With the dishwasher soap, my mother helped me...and changing the diapers and feeding the baby, giving the bottle and stuff.”	p.3/101
	Friends	“My auntie did help me.” “I live with Megan and Nellie...I been with these girls for 20 years.”	p.1/31,34
	Health care team Staff/supported living	n/a “They help us clean the house, they help us cook and stuff like that.”	p.2/45
	Parenting programs	n/a	
Reaction to Pregnancy	Excited	n/a	

Nervous/Scared	“I was scared... Well I was doing something without my mother’s permission – it wasn’t right.”	p.2/50,52
No reaction	n/a	

Participant 6: Carrie

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	n/a		
	Transportation	n/a		
	Finances	“Well, Molly’s check goes to the trustee’s office and they pay our rent.”	p.1/31	
		“Well, just his mom and dad had to help us out because we didn’t even have money for diapers.”	p.3/94-95	
Health		“We didn’t have money at all.”	p.3/97	
		“Well, see Molly’s got to eat four times a day. She takes her blood test four times a day, so she has to eat.”	p.3/109-110	
		“Mmhm.” (diabetic)	p.3/112	

		<p>“He (son) didn’t get to come home right away. His lungs clasped on him.”</p> <p>“He was at Riley for two weeks before he came home.”</p> <p>“Well, I got sick twice and had to go to Wishard, so they took them to the guardian’s home.”</p> <p>“My daughter, the cat and me.”</p> <p>“He’s at Knight’s Town.”</p> <p>“She was at Options before she came home.”</p>	<p>p.3/125</p> <p>p.3/127</p> <p>p.4/139-140</p> <p>p.1/26</p> <p>p.6/228</p> <p>p.6/232</p>
Child Development Issue	Custody		
	Interactions	n/a	
	Physical	<p>“He (son) didn’t get to come home right away. His lungs clasped on him.”</p> <p>“He was at Riley for two weeks before he came home.”</p>	<p>p.3/125</p> <p>p.3/127</p>
	Mental	<p>“He’s straightened out</p>	<p>p.6/238</p>

Communication	Verbal	a lot.”	
	Nonverbal	n/a “Give them a reward.”	p.5/184
Social judgment	Independence	“Sometimes we would buy them extra stuff. Cause if we didn’t buy for one and we bought for the other, they’d have a fight.”	p.5/191-192
		“Just give them a dirty look.”	p.5/197
		“Just ignore them. They didn’t deserve what they wanted so.”	p.5/201
		“I don’t really have anything right now. I’m on disability.”	p.1/12
		“But I would like to get another job though.”	p.1/14
		“No. We quit. We quit. My husband wanted me to have more but I said, ‘Eh.’ It’s my decision, don’t mess it up.”	p.4/174-175
“Even the doctor said,	p. 4 / 177		

Sources of Help	Influence	‘Are you sure you want this (tubes tied) done?’ Yep.” n/a	
	Family	“My husband’s mom took care of her.”	p.1/34-35
		“And then my husband’s mom helped me out tremendously. So that helped. So that was real good.”	p.2/60-61
	Friends	n/a	
	Health care team	“Just the hospital.”	p.1/42
		“And the clinic.”	p.1/44
		“Yep, but he (doctor) kept running back and for, so.”	p.2/50
	Staff/supported living	“Well, um, no.” (assisted living)	p.1/31
		“The trustees office. Noble. Welfare. Well, cause Molly is on Medicaid and we got food stamps.”	p.2/86-87
	Parenting programs	“Well, let’s see we did. Yea, we took one.”	p.2/52
	“Yea, that was at St. Mary’s.”	p.2/54	
	“And how to ya	p.2/56	

		know... the usual stuff. Discipline and all that stuff.”		
		“Yep.” (after birth)	p.2/63	
		“It was court-ordered that we had to go.”	p.2/65	
		“Because the kids were going to be teenagers and we had to know how to take care of our teenagers.”	p.2/67-68	
Reaction to Pregnancy	Excited Nervous/Scared	“Excited.” “Scared, really because I thought she was going to break... I thought I was going to break her, so I didn’t even want to touch her.”	p.1/34 p.1/34, 35	
	No reaction	n/a		
Participant 7: Kevin				
<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	“Oh, getting up	p.3/94	He has





Reaction to Pregnancy		breathing technique. Stuff like that.”	p.2/72
		“Mmhm.” (bottle feeding and changing diapers)	
		“Nuh-uh.” (after birth)	
	Excited	“A little bit of both.”	p.1/44
	Nervous/Scared	“Just fainted.”	p.1/39
		“A little bit of both.”	p.1/44 p.2/46
	No reaction	“Am I going to do the right thing and stuff. That’s what I was nervous about.” n/a	

Participant 8: Cecelia

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	“Diapers, mmhmm.”	p.3/98	
			p.3/116	
		“When he was climbing the steps and movin.”		
	Transportation	n/a		
	Finances	n/a		
Health	n/a			
	Custody	“Nope!”	p.2/84	

Child Development Issue	Interactions	“I feel sad because I bought him a Christmas present and he said he don’t want me to bring it to him. Don’t want me to bring me over and give it. Sometimes he saw me, sometimes he don’t.” n/a	p.2/86-88	
	Physical	n/a		
	Mental	n/a		
Communication	Verbal	“Talking. I always told him ‘no’.”	p.4/140	
	Nonverbal	“Some things... play with him with his toys.”	p.3/134	
Social judgment	Independence	n/a		
Sources of Help	Influence	n/a		
	Family	“Mmhmm.” (family talking to her)	p.2/61	Her mother was very unsupportive of marriage and pregnancy.
		“Ya, cousins and me.”	p.2/63	
		“Mmhmm. All those things.” (diaper and	p.2/66	
			Mother-in-law was primary source of help.	
				* Note* Lost

	bottle)		child due to mother's negligence.
Friends	n/a		
Health care team	"No, not early I didn't see no doctor. When I got fat. Not that often."	p.2/49 p.2/54	Did receive care from OB
	"When I had the pain they gave me an epidural."	p.2/57	
Staff/supported living	"The nurses." "Mmhmm". (staff)	p.1/28 p.1/30	
Parenting programs	"Groceries, money and stuff." "I just taked one on the other site – at Noble." (after birth)	p.2/68 p.2/74-75	It was recommended during her pregnancy that she take a parenting class.
	"How to make safe bottles for the baby, some preventing stuff – when the baby gets sick."	p.2/79	
	"Mmhmm, ya" (affirming they talked about tasks). They did more safe stuff though."		
Reaction to Pregnancy			

Excited	“Happy.”	p.1/41
	“Mmhhh.” (excited)	p.2/45
Nervous/Scared	n/a	
No reaction	n/a	

Participant 9: Chris

<b>Cluster:</b>	<b>Theme:</b>	<b>Quote:</b>	<b>Page/Line</b>	<b>Participant File</b>
Difficulties	Transitions	n/a		
	Transportation	n/a		
	Finances	“He was taking me to see how much I was behind and how much child support and stuff.”	p.2/68 -69	*Note* job history
	Health	n/a		
	Custody	“...but right now I’m down in the dumps because I don’t even know where she’s at.”	p.1/37-38	He had been in and out of court frequently for child support.  He had been in and out of jail for a variety of periods.
	Interactions	“Just to see her more.”	p.3/115	
	“Oh ya, it was. It came to the point where I almost wanted to kill myself. And, I tried too...”	p.3/131-133		
	“It was back	p.4/145		

		in, um, 2003.” (see her last)	
Child Development Issue	Physical	n/a	
	Mental	n/a	
Communication	Verbal	“I talked to her.”	p.3/106
	Nonverbal	“I was good at that!” (referring to game playing)	p.3/96
Social judgment	Independence	n/a	
	Influence	“Because her mom I guess put words in her mouth saying that I was a bad dad and stuff. You know, I really wasn’t a bad father. I don’t think I was.”	p.3/125-127
Sources of Help	Family	“Well, my brother did there for a while. He helped me. But he’s got his family and stuff. It just went downhill from there, you know? Cuz he has two boys.”	p.2/65-66
		“He was taking me to see how much I was behind	p.2/68 -69

		and how much child support and stuff.”	
	Friends	n/a	
	Health care team	n/a	
	Staff/supported living	“I have staff because he (roommate) has to.”	p.1/27
	Parenting programs	n/a	
Reaction to Pregnancy			
	Excited	“I was kind of happy...”	p.1/37
	Nervous/Scared	n/a	
	No reaction	“Well, I didn’t really find out until about a week after she had her.”	p.1/33

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