INFORMATION PACKET:
Parents with Mental Retardation and their Children

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In the following pages, you will find:

*A Summary

*General facts about mentally retarded parents including:

  o Number of mentally retarded parents

  o Supporting views on mentally retarded parents and their children

  o Concerns raised about specific risks to the children of parents with mental retardation such as:

    ▪ Removal from the home by child protective services due to inadequate parenting
    ▪ The effect of the intellectual advancement of children surpassing their parents

*Policies and legislation, problems in the system, and the affect of poverty on mentally retarded parents and their children

*Practice tips and model programs

*A bibliography for further reading and information

*Web sites
This information packet will attempt to present the controversial issue of parenting by mentally retarded parents.

DEFINITIONS:

Defining mental retardation is complex and problematic, but suffice it to say that it categorizes “…mentally retarded persons are, by definition, incapable of performing certain tasks with the same efficiency or accuracy as their ‘normal’ counterparts.” (Hayman, 1990, p.8)

In addition, Hayman asserts that there is no legal or scientific consensus on the meaning of the term “parenting abilities”. (1990, p.9)

BRIEF HISTORICAL & POLITICAL CONTEXT:

“…the Mental Deficiency Act of 1913 made marriage illegal for [persons with mental retardation] everywhere in the country.

“…The 1950’s was an era of compulsory surgical sterilization and more than a quarter of the states in our union still had laws prohibiting marriage by persons with mental retardation. Research was often cited showing that children born to mentally retarded couples were at significantly increased risk for mental retardation and it was commonplace for social agencies to remove children from such couples because they were seen to be inadequate parents; it was clear that the weight of professional opinion was opposed to mentally retarded persons becoming parents.” (Edgerton, 1999, p.1)

“The days of confinement in state schools and forced sterilization ended long ago for people with mental retardation… For a growing number that means marrying and having children of their own.” (Quimby, 1998, ¶ 1, ¶ 4)

There is relatively little written on the subject of parenting by persons with mental retardation, including the issue of how such parents affect their children, but there is growing interest.

From what is written, one can gather that there are two positions:

- One position focuses on the rights of the mentally retarded, points out stereotypes, and seeks to validate and support parents with mental retardation as equal members of society including in the role of parent.

- A second position focuses on the inherent risks that cognitive limitations bring to the role of parenting children.

One of the most important reasons to explore this issue (via the research that has been done) is that, regardless of opinion, parenting by the mentally retarded does affect the welfare of children; as do the policies and legislation that create programs addressing this issue.
“Information in this area is scarce. Reasons for this include the fact that many parents who have MR are either not receiving services that would identify them…or are not identified by the service system or program in which they participate. Also, different service agencies use varying definitions of MR.” (Ingram, 1990, ¶ 1)

“Agencies that deal with people with mental retardation say the numbers are growing, partly fueled by a shift in the courts to recognize the rights of mentally retarded parents.” (Quimby, 1998, ¶ 12)

“While the number of parents with mental retardation today is unknown, it is reasonable to expect that whatever the number is it will be increasing. Reasons for this include:

- Increased recognition of the rights of people with mental retardation to have and raise their own children if they are able.
- Decrease in practices such as forced sterilization of people with mental retardation.
- Lack of consistent strategies to inform people with mental retardation about sexuality and prevention of undesired pregnancy.” (Hewitt, O'Neill, & Bestgen, 1998, p. 11)

“According to Holburn, Perkins, and Vietz (2000), the best estimate of the number of parents with mental retardation can be derived from a 1997 study (Barker and Maralani) that reported that the 1993 US Census data reported 7 million parents with disabilities.”

Of the 1175 respondents who were disabled, “1 in 5 had mental retardation. From this it can be estimated that there are approximately 1.4 million parents with mental retardation…in the US between the ages of 18 and 64 with children under 18.” (NYSARC IPTP, p. 10) It should be noted that these findings may be unreliable due to the inability to confirm diagnoses.” (NYSARC, Intensive Parent Training Program, Program Plan, p. 10)
DISCRIMINATION AGAINST PARENTS WITH MENTAL RETARDATION:

“Evidence, mainly from Australia and North America, is beginning to accumulate that parents with learning difficulties are:

* Disproportionately represented in childcare proceedings.
* Less likely to have received support in their parenting – or to have received inadequate support – before care proceedings are initiated.
* At risk of having their parental responsibility terminated on the basis of evidence that would not hold up against non-disabled parents.
* Likely to have their competence as parents judged against stricter criteria or harsher standards than other parents.
* More likely to have their children removed and their parental rights terminated.
* Disadvantaged in the child protection and court process by rules of evidence and procedure, their own limitations and inadequacies in services.
* Less likely to receive support in correcting the conditions leading to termination.”

(Booth, 2000, section: Barriers to Justice, ¶ 2-8)

ARGUMENTS AND RESEARCH UPHOLDING ABILITIES OF PARENTS WITH MR:

“…there is no reason to believe that mentally retarded parents are inherently unable to meet the physical needs of their children. Research indicates that mentally retarded individuals with a wide range of intellectual abilities function effectively in the community. [FN62] In fact, none of the skills involved in meeting the physical needs of an infant or older child—differ from the skills mentally retarded persons routinely execute.

“Similarly, there is no reason to believe that mentally retarded parents are unable to preserve the health and safety of their children. Mentally retarded parents may have a tendency to “under-protect” their children; [FN64] such treatment, however, can undoubtedly be unlearned.” (Hayman, 1990, p. 11)

“…there is substantial clinical anti empirical evidence demonstrating that when services take into account the living circumstances of parents with cognitive limitations matching parental learning needs, health and safety risk status of both children and parents can be reduced and well-being can be promoted (Feldman, 1994; Llewellyn, 1996; Tymchuk, 1992; 1994a; Tymchuk & Feldman, 1991). Parents too will feel more comfortable in their parenting roles (Tymchuk, 1991). Such efforts can be preparatory, preventive, and responsive (n3) (Tymchuk, 1994b).” (Tymchuk, 1999, ¶1)

“Tymchuk and Andron (1990) studied mothers attending a parenting program, just under half of whom did not have a history of abusing or neglecting their children. This group demonstrates that some mothers with an intellectual disability provide adequate care, at least in as much as they do not come to the attention of child protection workers. Circumstances under which mothers were judged abusive, and reasons for removing or not removing the child from the mother's care were also studied. Risk factors identified for abuse and/or neglect include living without the support of a relative, having more than
one child to care for, and shunning help from social agencies. (Glaun, & Brown, 1999, ¶7)

**Parents with Mental Retardation & Their Children**

**CONCERNS ABOUT PARENTS WITH MENTAL RETARDATION AND THE RISKS TO THEIR CHILDREN**

**INADEQUATE PARENTING SKILLS:**

“The two most often used descriptors of parents with MR have been that they are abusive and/or neglectful (Schilling et al., 1982).” (Tymchuk, 1992, p.167)

“…there is consensus that parents with MR are at risk for parenting practices that lead to referral to Child Protective Services.

“Cognitively, individuals with MR have difficulty learning, remembering, reasoning, and solving problems; and these difficulties may interfere with successful child-rearing. In a survey conducted by Budd and Greenspan...Two thirds of the concerns could be categorized as issues of child discipline and childcare. Disciplinary strategies tended to be punitive...inappropriate for the child’s age, and ineffectual...Children were not fed appropriate food, were left without supervision, and were given no stimulation...home was often an unsafe place...problems attributed to the cognitive characteristics associated with MR rather than to negative intent.” (Lynch & Bakley, 1989, p.27)

“Many adults with retardation are limited in their ability to think of alternatives and to forecast outcomes; thus the possible consequences of [for example] leaving scissors within reach of a toddler...are not viewed as abusive or neglectful by the parents.” (Lynch & Bakley, 1989, p.27)

“Reading infants cues and learning their signals...is the responsibility of the parent; for retarded adults such nuances may be difficult to perceive and to understand.” (Lynch & Bakley, 1989, p.28)

**RISKS TO CHILDREN:**

“Children of parents with intellectual disabilities are at-risk for developmental delay, psychosocial retardation, and behavior disorders (Feldman, 1998; Feldman & Walton-Allen, 1997; Garber, 1988; Gillberg & Geijer-Karlsson, 1983; Reed & Reed, 1965). “

“Often the parents’ lack of knowledge and skills result in their children suffering from: (a) untreated diaper rash; (b) malnourishment (due to improper feeding techniques, formula preparation, and/or nutrition); and, (c) gastrointestinal infections (due to poor or absent baby bottle cleaning and sterilization techniques). The children are endangered when, for example, the parents do not know how to hold or bathe the child safely, make the home environment safe, provide emergency first aid, or when to take the child for medical treatment. The parents’ failure to provide a stimulating home environment may increase risk of child developmental delay (Feldman, Case, Towns, & Betel, 1985; Feldman & Walton-Allen, 1997; Keltner, 1994).” (Feldman & Case, 1999, ¶3)
"The New York State Commission on Quality of Care for the Mentally Disabled (1993a) found that ‘(a)lmost one out of every two families…. had at one time lost the custody, at least temporarily, of one or more of their children’. On the basis of a review of agency records in St. Louis, Accardo and Whitman (1990) report that 103 of 226 children (45.6%) born to 76 parents with learning difficulties had been removed from the family home. Feldman (1998) goes so far as to suggest that, in ‘the United States and Canada, as many as 80% of these parents have their parenting rights terminated’. More recently, Cross and Marks (1995) found that a total of 13 children from 18 reported pregnancies and 16 live births were subject to child protection proceedings: ‘In 7 cases proceedings were started within 1 week of birth, 6 of those 7 starting at birth itself.’ In our own study of 20 parents (Booth & Booth, 1994b), 14 had had one or more of their children placed in short-term or permanent care.” (Booth, 2000, section: Child Removal and Parenting Failure, ¶ 2)

*An important issue, raised for a broad audience by the film “I Am Sam”, is what happens to “typically developing” children raised by mentally retarded adults. It is a fascinating topic that cannot be covered here, but see reference section for excellent articles on the subject.*

“Most of them [children of parents with mental retardation] are of normal intelligence. They are being raised by parents who in many cases cannot read to them or drive them anywhere and who often live in poverty. What is their life like and how will they be affected as adults?” (Quimby, 1998, ¶ 6)

“Research shows normal and bright school-aged children of parents with mental retardation face other problems, such as reversing roles with their parents -- bossing them around or taking on adult responsibilities their parents cannot handle, said Mrs. Apkarian.” (Quimby, 1998, ¶ 21)
PROBLEMS IN THE SYSTEM:

“…unlike most other groups with effective political lobbies, parents with intellectual disabilities do not have an effective political base.” (Tymchuk, Llewellyn, & Feldman, 1999, section: Political Self-Activism, ¶ 1)

“…in The Spokesman Review (April 10, 11, 12, 1994, Spokane, WA), William Miller reported on how child protective services in his state of Washington appeared to target young pregnant women with an IQ of 70 and below in order to remove their children at birth. Knowledge about how child protective services worked was so well known that in self-defense apparently some women left the state rather than submit to this indignity. While this situation is not unique, it is particularly troubling in the U.S. where there are federal laws such as the Americans With Disabilities Act governing nondiscrimination and the provision of suitable adaptations.” (Tymchuk, Llewellyn, & Feldman, 1999, section: Without Suitable Support, These Families Are in Danger, ¶ 1)

“…specialized parent education programs that offer intensive interventions are still rare. Most agencies asked to help the growing number of families where the parents have intellectual disabilities typically do not have necessary expertise and resources at their disposal.” (Feldman & Case, 1999, ¶ 5)

Results of a Parent Focus Group indicated that “While all parents desired specific services in order to achieve greater self- and child healthcare, safety, and well-being responsibility, many complained that not only were they seen as being unable to parent, but also that they were seen as being unable to learn about childcare. Most services which they received, including those within the disability sector, demonstrated a lack of awareness of adaptations parents felt that they needed in order to understand instructions or to apply education to their lives. All complained of a general lack of familiarity by sector staff with the complexities of their family circumstances. Child protection or legal agencies were seen as being particularly unfamiliar with issues surrounding families where a parent had a disability. Most parents recognized that they were unable to read materials, but many indicated that they could learn if things were presented to them more slowly and if they were allowed to try things out. While most desired being with other families, most also indicated a desire for education to be done within their homes.” (Tymchuk, 1999, section: Results of the Parent Focus Groups, ¶ 1)

AFFECT OF POVERTY:

“…an IWPR [Institute For Women’s Policy Research] analysis examining disabilities among children and mothers in low-income families… Nearly half of single mothers receiving TANF have a disability or a disabled child, but only a small proportion receives government supports.” (Lee, Sills, & Oh, 2002, abstract, p.1)

“For many low-income families with disabilities who are subject to work requirements and time limits, the lack of adequate income and other supports may be detrimental to
children’s well-being and to mothers’ efforts toward self-sufficiency…” (Lee, Sills, & Oh, 2002, p.6)

“…within the single-mother population receiving TANF in 1997, nearly 40 percent of mothers had a disability and 25% had a severe disability…” (Lee, Sills, & Oh, 2002, p.5)

“Only 26 states offer time limit exemptions to families if the parent or caretaker is disabled…(State Policy Documentation Project 2000).” (Lee, Sunhwa; Sills, Melissa; Oh, Gi-Taik, 2002, p.1)

“Mothers with mental retardation or intellectual disability are a subgroup of low income families, whose children are at risk for developmental delay, child abuse and neglect, and environmental deprivation (Feldman, Case, Towns, & Betel, 1985; Ramey, 1992; Tymchuk & Keltner, 1991; Whitman, Graves, & Accardo, 1987). It is critical to note that certainly not all women who are poor are intellectually limited but the majority of mothers with intellectual limitations are poor (Keltner,1992; Whitman et al., 1989). Fotheringham (1971) attributed the difficulties in parenting for parents with intellectual limitations to the effects of poverty.” (Keltner, Wise, & Taylor, 1999, section Introduction, ¶ 1)

LEGISLATION:

“In the United States recent legislative and programmatic actions that substantiate the significance of developmental disability include: (a) Public Law 99-457 which mandates early intervention and family support services from birth and permits the inclusion of early intervention for preventive purposes among children at risk, and (b) new initiatives at the Center for Disease Control that target the prevention of mental retardation in children at risk (Crocker, 1992; First & Palfrey, 1994). The mobilization of resources to provide preventive services for children at risk for developmental delay due to poverty is an enormous challenge. Poverty underlies or complicates many health problems across the lifespan and indisputably serves as a signal for new systematic, coordinated responses from human service systems. There is a serious need for increased precision in defining the parameters and dynamics of risk for developmental disability (Crocker, 1992).” (Keltner, Wise, & Taylor, 1999, section Introduction, ¶ 2)

excerpted from Administration on Developmental Disabilities
http://www.acf.dhhs.gov/programs/add/nov002.htm

“TANF-360 Initiative
In FY 2003 we anticipate finalizing our plan to tackle effective ways to help poor families, eligible for Temporary Assistance for Needy Families (TANF), who have a family member with a disability. This family member may be either a child or adult with a disability. Our goal is to take “a 360 degree look” at what these families need to be self-sufficient. We are exploring how to support “one-stop” demonstrations that would bring all appropriate agencies and supports to the planning process to help these families develop plans for self-sufficiency.”
PRACTICE TIPS:

“The Arc’s position statement on family support states that: Premature out-of-home placement is frequently the result of a failure to provide adequate supports to help a family remain intact, rather than the result of the individual’s disability itself… Supporting these families [with mentally retarded parents] with individualized services makes sense because, in the long run, it is usually best for children to remain with their natural parents.” (Ingram, 1990, ¶ 11)

“The more effective parent education programs designed specifically for parents with intellectual disabilities typically involve intensive (primarily behavioral) intervention (see reviews by Feldman, 1994; 1997). Using task analysis, instructions, modeling, feedback, and tangible reinforcement, parent educators have taught parents with intellectual disabilities a wide-range of important child-care skills to protect and promote the children's welfare. Such programs are associated with improvements in child health and development and a greatly decreased rate of child apprehension by child protection authorities.” (Feldman, Case, & Sparks, 1992; Feldman, Sparks, & Case, 1993). (Feldman & Case, 1999, ¶ 4)

Child-care training items, such as pictorial child-care manuals have been successful; there is evidence that “audiovisual self-learning is an effective, low-cost intervention to increase child-care skills” (Feldman & Case, 1999, section Discussion, ¶ 1)

“PROJECT IINTACT (Infant Interagency Network Through Accessing Computer Technology) … was to develop… a model and to provide services to a small group of families in which one or both parents was mentally retarded…” (Lynch & Bakley, 1989, p.28)

From this project, three main issues were identified:

1. “Without extensive family or agency support systems, retarded adults' success in parenting is limited... As a consequence, when intervention is not provided, the children are in jeopardy.
2. “[an] overriding need is for parents to be able to solve the ever-changing problems that must be confronted as their children grow and develop. It is in this area that parents with MR have the greatest difficulty.
3. “...communities must be prepared to invest the time and resources needed to assist families as they confront the difficulties associated with parenting.” (Lynch & Bakley, 1989, p.35)

Lynch and Bakley (1989) list recommendations for implementing programs, such as:

“...hiring a staff member trained in working with adults who are mentally retarded as the primary deliverer of services...” and “A designated staff member might… routinely review materials developed for adults with MR to determine their usefulness with clients” and “case conferences including the clients and all agencies
involved with the family should be routinely held to ensure that services are coordinated.” (p.36)

Lynch and Bakley (1989) list recommendations for planning and prevention, such as:

“Instruction in independent living should include counseling related to sexuality and family planning” and “Training in parenting should be initiated during the high school years, with emphasis on the demands and responsibilities of parenting” and “apartment complexes...for retarded parents and their children so that childcare, support groups, and intervention services could be provided to family clusters” and finally it is recommended that the “training gap” be filled by teaching “interventionists” to work with adults with MR, and teaching professionals who work with adults with MR to work with young children. (p. 36)

MODEL PROGRAMS:

Excerpted from OCFS Request for Proposal for Preventative Services: Ammended Proposal, Program Summary & Part II, Program Description:

**Intensive Parent Training for Parents with Developmental Disabilities, NYSARC**
(Program funded by TANF grant from OCFS from July 1, 2001 – May 1, 2003)

“...target population consists of parents with developmental disabilities, including mental retardation, cerebral palsy, and seizure disorders. The children of such parents are at high risk for having their children placed in foster care.” (p.2) “The proposed program has the goal of reducing the number of out-of-home placements within this population, and maintaining children of parents with cognitive limitations in their homes after returning from out-of-home placement by providing intensive in-home and center based training and support services.” (contact name can’t be given as this program will be discontinued due to lack of funds)

Excerpted from Administration on Developmental Disabilities:
http://www.acf.dhhs.gov/programs/add/nov002.htm

“The Georgia UCEDD worked with the Developmental Disabilities Council on a pilot program for TANF recipients who are parents with mental retardation. Maryland's UCEDD Growing Together project provides parenting education for parents with cognitive disabilities and has a curriculum guide, Building Foundations. At its Early Infant Transition Center intensive parent training is provided for parents with special needs whose children who have been exposed to drugs.”

“For information on University Centers for Excellence in Developmental Disabilities contact Adele Gorelick, srafiuddin@acf.hhs.gov”.

Excerpted from http://www.pearlbuckcenter.com/program.cfm

Pearl Buck Center, Inc. in Eugene, OR provides effective early intervention preschool, infant programs and case management services for families headed by developmentally disabled parents; called **Families with Special Needs Program**
For more information, contact:
Jan Aho
Program Manager
jaho@pearlbuckcenter.com
Excerpted from http://www.yai.org/services.cfm

YAI/NIPD's Parents with Special Needs is a program for mothers and fathers who are developmentally disabled and who need guidance to help foster a more positive and rewarding family life

Contact: Kostas Kouris - link@yai.org - (212)273-6314
REFERENCES:
For articles retrieved from the Internet, URLs are in bold


WEB RESOURCES:

http://thelookingglass.org

Mental Retardation Resources available at the Center for Disability Resources Library
http://uscm.med.sc.edu/CDR/index.htm

Parent w/ MR/DD training and children’s program
http://www.thearcofsomerset.org/pact.htm

Parents w/ MR/DD training
http://www.pearlbuckcenter.com/program.cfm

See Parents w/ special needs
http://www.yai.org/services.cfm