

Predictable Crises in the Lives of People With Mental Retardation

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Situations requiring novel responses or greater levels of autonomy than a person with mental retardation (MR) is comfortable with can set the stage for a developmental crisis and precipitate an Adjustment Disorder, Delayed or Post-traumatic Stress Disorder, or major psychiatric disorder, with resulting mental health consultation. Major psychiatric disorders must not only be sought for in the diagnostic process, but must also be ruled out when the phenomena displayed do not meet DSM-IV diagnostic criteria. Knowledge of the events in the lives of persons with MR that can precipitate a crisis and a mental health consultation can lead to accurate diagnosis and point to therapeutic resolution. Adjustment Disorders, Delayed or Post-traumatic Stress Disorders cannot be successfully treated unless the precipitating environmental stressor is relieved. Acute episodes of major psychiatric disorders, no matter how appropriate and well-tolerated the pharmacotherapeutic and psychotherapeutic interventions, cannot be wholly resolved without resolution of a precipitating developmental crisis. When recognized, sources of developmental crises can be defused and future episodes anticipated and prevented.

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It has become a commonplace that persons with mental retardation and developmental disabilities (MR/DD) experience the full range of psychiatric disorders. Growth of understanding of this phenomenon has concentrated on recognition of symptoms in the diagnosis of major psychiatric disorders. Less attention has been paid to stressors in the lives of persons with mental retardation and the role these play as precipitants of mental health consultation, of Adjustment Disorders, and of major psychiatric disorders.

Search of medical and psychology databases using the keywords "Adjustment Disorders," "Developmental Crises," "Life Crises," "Development," combined with "Mental Retardation/Developmental Disabilities" yielded no citations from 1995 to the present. A similar search of social work databases yielded 31 citations from 1995 to the present, of which 4 were relevant (the remainder dealt with adjustment to chronic disease). There appears to have been a loss of interest in developmental crises in the lives of persons with MR/DD, with the sole exception of the subtopic of Sexual Abuse, which continues to produce a rich literature. Podell et al¹⁰ note that persons with MD/DD are often perceived by others as less aware and less responsible, so that they are less

traumatized than others by sexual exploitation. It is possible that this observation is equally valid for all types of trauma, and that our sensitivity to the effects of developmental issues on persons with MR/DD has been blunted.

Persons with MR/DD develop along a path of atypical juxtaposition of biological, psychological and social milestones.⁴ Recent evidence suggests that most if not all persons with MR/DD share a set of executive function deficits.³ Both these phenomena result in difficulty in coping with situations that call for novel responses and increased autonomous functioning. Both, depending upon the intensity of the need, can cross the line from developmental challenge to developmental stressor.

A system of education and habilitation has been in place for a generation and more for persons with mild and moderate MR/DD, sufficiently pervasive constitute a subculture¹ in many ways analogous to the subculture that has grown up around such chronic disorders as HIV/AIDS and diabetes.¹¹ This system creates predictable adaptive challenges, which, depending upon the strengths and vulnerabilities of the individual involved, can present new adaptational opportunities or can precipitate a developmental crisis.² The individual may respond to the crisis with signs of increased anxiety, but more often

will be brought for mental health evaluation due to aggression, self-injury, noncompliance with

some externally determined need, or withdrawal or regression from previous levels of autonomous functioning.

If unrecognized, the crisis in turn can lead to an Adjustment Disorder, Delayed or Post-traumatic Stress Disorder, or major psychiatric disorder, with resulting mental health consultation. Major psychiatric disorders must be not only sought for in the diagnostic process, but must also be ruled out when the phenomena displayed do not meet DSM-IV diagnostic criteria.⁵ The prognostic significance of a diagnosis of Adjustment Disorder with Depressed Mood is quite different—considerably more favorable—than a diagnosis of Major Depressive Disorder. Knowledge of the events in the lives of persons with MR/DD that can precipitate a crisis and a mental health consultation can result in accurate diagnosis and more rapid therapeutic resolution. Adjustment Disorders and Delayed or Post-traumatic Stress Disorders cannot be treated successfully unless the precipitating environmental stressor is relieved. Acute episodes of major psychiatric disorders, no matter how appropriate and well-tolerated the pharmacotherapeutic and psychotherapeutic interventions, cannot be resolved completely without resolution of a precipitating developmental crisis.

Each of the stressors or developmental crises described below can precipitate an Adjustment Disorder or an episode of a major psychiatric disorder.

• **When the Diagnosis of Retardation is Finalized or Realized.** At this time, the family must grieve, because there has been both a symbolic and a real loss. Whatever hopes and projections family members may have had as to how this particular child would develop must be modified. This child will not be the doctor, the lawyer, the star athlete. The family will also lose freedoms that are taken for granted by the families of neurotypical children: babysitters will be harder to find, caregiving will be more extensive and will last longer. Expenses will be greater, special services will have to be obtained, and the extra effort and time involved must be accepted. The impact upon the development of the child may be experienced through temporary

depression, withdrawal, or preoccupation in the parents---all the normal concomitants of grief.

The family may have to make relationships with a host of therapists, agency representatives, and “experts” of various kinds. Many families experience a loss of autonomy, which may provoke further reaction. Concomitantly, the child also increasingly loses control over life.

Grief is never as uncomplicated as idealized schemata would have us believe, and this is particularly true for families of persons with MR/DD. Every developmental step not taken, every staffing (with its reprise of the child’s deficits and its list of goals), every new referral to a specialist, every therapy appointment, can reactivate that grief, both for the family and for the child.^{9,15}

The child for whom the diagnosis is made upon entering school must also grieve, and this at a time when peer relations are beginning to become important, and when the adjustment to school must be made. The phenomenon of school phobia, usually attributed to anxiety over separation, may have a completely different meaning in a child in this situation. Also, parents are faced with the task of informing grandparents and other extended family. If a genetic disorder is involved, this task can be doubly painful. Parents may feel blamed, or cursed.

• **Birth of Siblings.** Children who react negatively (and continue to do so over a long period) to the birth of a sibling are thought to be reacting to a loss of parental attention. Attention has never been defined precisely, but it appears to mean involvement with and approbation of the parents, and, simply, time spent with the parents. For the child with MR/DD, parents are a source of skills and teaching which help to make up for deficits; parental presence allows the child to function at optimum levels. Loss of time with parents can mean, therefore, a loss of or fluctuation in skills. Also, if children with MR/DD spend longer than normal amounts of time in earlier developmental phases, there can develop a situation where the child and a younger sibling are in the same developmental phase, and have the same needs, despite the difference in chronological age.

As in any family, the family of the child with MR/DD may be faced with having to make many choices about the allocation of resources--financial and emotional--to each child; these

choices are made more difficult by the demands on the family's time and money by therapists, clinicians, and educators. Professionals' interventions may exacerbate the situation by implying, rightly or wrongly, that they are crucial to the child's later development.

- **Starting School.** This may be the first prolonged out-of-home experience. Children in an earlier psychosocial phase of development than chronological peers are being placed in an environment that directly confronts cognitive deficits, marks them as different from chronological peers, and requires meeting these challenges without recourse to the family that has provided protection thus far. Children have few if any alternatives to forming caregiver-dependant relationships with teachers, aides, bus drivers, and other helpers. They may form omnipotent or grandiose fantasies; for example, believe they have super powers, or deny deficits or errors.

The process of stigmatization begins here. The child is either in a different class, a different school, or, if in a traditional or mainstream classroom, may, throughout the day, be removed from class to attend the resource room, speech or movement therapy, or for testing. (There may be a limit to how many times a child can be tested before beginning to doubt even those skills that he or she has mastered.) It is most likely at school that the word "retard" is first used as an insult.

For the typical child, the school experience includes recreation time and a locus for meeting peers and acquiring social skills. The quality friendships may be affected as the gap in cognitive attainments grows between the child and his or her neurotypical peers, and as he or she is tracked into special classes.¹⁴ Children with MR/DD are generally excluded from extracurricular activities, if not by disability then by the sheer amount of time involved in the concentration on acquiring academic skills. The incidence of retardation is high, but not sufficiently high that any given neighborhood will contain enough children with MR/DD to form a social group. Often in these years, children with MR/DD see friendships with neurotypical children come to an end as social skills wither and cognitive abilities reach a plateau. Children with MR/DD might be referred for mental health consultation because of fears that they are becoming "loners." Part of the therapeutic task

may be to help the family find and accept social programs with other children with MR/DD.

- **Puberty and Adolescence.** This is an anxious phase for all parents and children, but for the child with MR/DD the gap between psychosocial maturation and sexual maturation most likely will be greater than in the neurotypical child, no matter how complete the preparation for puberty has been. A child with MR/DD accustomed, and even conditioned, to taking direction from others is suddenly and unprecedentedly faced with the need to develop an unaccustomed degree of self-regulation.

For families contemplating the possibility of their child with MR/DD becoming sexually active, the fears are of an unwanted pregnancy or of the possibility of sexual exploitation. Parents are forced, therefore, to fear the community's response as much as they fear that their child may be hurt. For some families masturbation may be an issue. Parents' fears may render them unable to discuss sex with their child. Beneath all this may be an unspoken grief: here is more evidence of the child's differences. Something that should be a source of joy may be a source of pain; there may be sadness at the realization that this child will not carry on the family lineage.

- **Sex and Dating.** Persons with MR/DD experience the same range of sexuality as do neurotypical persons, but opportunities for sexual expression may be lacking.¹⁰ The adolescent with MR/DD may negotiate the difficulties of puberty but may have no arena in which to practice. Parents and other caregivers may deny the existence of sexuality in the child.⁸ Adolescents with MR/DD may be discouraged from dating, or may lack the skills to travel unchaperoned, or may simply be unthinkingly excluded from school social activities. Even for adolescents with MR/DD who have been able to acquire, and keep active, their social skills, there may be only a limited pool of available dates. Physical stigmatization, communication deficits, and physical handicaps may shrink this pool even further. Many adolescents with MR/DD have become saddened to the point of withdrawal upon being rejected for a date by a neurotypical chronological peer. Many have developed active fantasy lives: crushes, imaginary friends, imaginary telephone dialogues. It is unknown to what extent homosexual activity--actually an

extension of what is regarded as normal, shared single-sex sexual activities--may be at least partially a response to these conditions.

Sexual exploitation and sexual abuse of adolescents (and children) with MR/DD occurs at least as frequently as it does with neurotypical adolescents and children, and this possibility must not be overlooked as a precipitant of an Adjustment Disorder, Delayed or Post-traumatic Stress Disorder, or episode of a pre-existing psychiatric disorder. Such episodes may be overlooked or minimized because of a societal misperception that persons with MR/DD are less aware, and therefore both less responsible and less traumatized by sexual exploitation.¹⁰

- **Being Surpassed by Younger Siblings.** Birth order plays an important part in the lives of persons with MR/DD. If firstborn, the diagnosis might be delayed longer as new parents struggle to assess the significance of delayed milestones, and later struggle to learn the ins and outs of developmental tasks and phases in a child whose development is atypical. Moreover, there will inevitably come a time when a younger sibling's accomplishments, abilities, and scope of social interaction will surpass those of the person with MR/DD. Often this occurs, at first, in small ways. The person with MR/DD may attend a different school, may need various therapies, may not be accepted by a sports team, and may be unnoticed. But the many milestones of adolescence are public, and unmistakable: the person with MR/DD may not be able to get a driver's license, may or may not be registered to vote, most likely will not marry. A strong identification with an active culture of peers may blunt the impact of this upon persons with MR/DD, but few such peer groups exist or are encouraged. The family is faced with the task of explaining to the person with MR/DD why he or she may not do what a younger sibling can now do. They must confront the retardation directly--a sad and painful task if the person with MR/DD has been valued for his or her accomplishments only to the extent that they approach the "normalization" goals proposed by others.

For the person with MR/DD who is the youngest (a large number of persons with moderate MR/DD will be, because of the increased incidence of Down syndrome in older parents, and also because parents for whom a child with MR/DD is a second or later birth often

decide to stop having children and concentrate on this child's needs), this experience is slightly different, and shades into the experience of both the symbolic and actual emancipation of siblings.

The experience of adolescence, for persons with MR/DD, is one of a growing awareness that they are different, and that the life they see around them, the life they wish for, may not be theirs. They may experience sadness and anxiety about the future. They may engage in "acting out"; that is, in the belief that he can do anything his neurotypical siblings can do, the person with MR/DD may try to drive, or to drink, or to make a date with a chronological peer, with painful consequences. The sadness may be converted into anger, with apparently unmotivated withdrawal or aggression as the result of what the person with MR/DD experiences as a betrayal of hopes, and a denial of access to the things for which he or she has supposedly been educated.

- **Emancipation of Siblings.** As a continuation of the process just described, the person with MR/DD may react in the same way, or even more strongly, to the actual emancipation and departure of siblings. The siblings are moving out of the house, and making plans for true autonomy--the beginning of new families or new lives, which may or may not include the person with MR/DD.

The physical exit of the sibling(s) from the life of the person with MR/DD is a loss. The individual is losing a caregiver, and, depending upon how close the relationship is, perhaps a friend and advocate. Frequently, siblings are more encouraging of autonomy than anyone else in the life of a person with MR/DD. Siblings often serve as auxiliary caregivers,¹³ but there may be more mutuality in sibling relationship than in any other in the person's experience. No matter what resolutions the departing sibling makes about staying close, the exigencies of life may prevent it. The neurotypical person probably grieves, and may feel a lasting guilt for having, in a sense, left a sibling behind--to a system of care that may be less than adequate. At the same time, for the sibling, there may be a sense of relief--and a feeling of guilt attendant upon that. Siblings may be ambivalent about childbearing, due to a fantasy of increased risk of having a child with MR/DD (in the case of genetic disorders this is not always fantasy, and not all genetic disorders are known or diagnosed). Many siblings

experience anxiety during pregnancy--a sense of the fragility of embryonic development stronger than is usual.

A crisis may be heralded by an angry outburst at a wedding, a withdrawal following the departure of a favorite sibling, or "noncompliance" in the designated tasks of life. A lifetime at a sheltered workshop is not as joyful a prospect as a wedding and family of one's own.

New people will enter the life of the person with MR/DD: in-laws, nieces, and nephews, and the person with MR/DD will also become dependent upon their approbation. A new generation of children will become a focus for the person's parents; there will be new rivals, in a sense new siblings, who will inevitably surpass him or her developmentally--a repeat of the experience with sibling(s). At family gatherings, many families unwittingly treat persons with MR/DD as a peer of the grandchildren. The person with MR/DD may withdraw from family gatherings that have become assemblages of strangers, strangers who are losing touch with the person's life and activities. Such a withdrawal may occasion a referral for mental health consultation, and the appropriate intervention may be to help the person back into the family by encouraging active conversation, or by bringing up shared childhood memories.

Married siblings may feel the need to explain MR/DD to their children. When young, children may be confused by an adult who functions less well than they do. They often will ask why; this may cause the person with MR/DD some pain but this can be an opportunity for building a relationship. Children may imagine that MR/DD is contagious, but they are capable of being reassured that it is not.

For the parents of persons with MR/DD, emancipation of siblings means the loss of auxiliary caregivers, and a return of the full burden of care and nurturance. Respite care is available, but often only in a crisis. For parents contemplating some degree of freedom from the responsibilities of child rearing, the developmental deficits may suddenly loom as large as they ever did, or larger. Although understandable, parental frustration can result in the person with MR/DD withdrawing, and in anger at the emancipation of siblings. The situation can be exacerbated when no previous planning for adult residential services has been undertaken. To undertake it now, in this

atmosphere, is to increase the anxiety of the person with MR/DD and possibly introduce a sensation of being rejected, of being ejected from the family, because of the retardation. The grief a person and his family can feel at this progression of events can be profound, and there is often a core of truth in these feelings.

The range of residential and vocational alternatives available for persons with MR/DD may be severely limited, and is largely, if not exclusively, in the hands of others--social service agencies, community-centered boards, and workshop directors. Many parents find themselves feeling powerless, almost helpless, forced to placate and accommodate to the imperatives of the helping agencies, fearful of losing access to services altogether. It is not uncommon to find families who have, in effect or in fact, overtly or covertly, been obstructed or barred from obtaining services; most commonly these are the families with individuals with a behavioral or mental health problem in addition to the MR/DD. The impact of all this may be greatest upon the person with MR/DD, who senses that he or she is the agent of family unhappiness. All family members may share a fantasy that to correct the deficits, cure the MR/DD, is to solve the problem, and there is reprise of the feelings that came with the first diagnosis of retardation.

- **End of Education.** Theoretically, PL 94-142 entitles persons with MR/DD to educational services through age twenty-one. Often, however, it requires a battle on the part of parents and advocacy organizations to get the schools to deliver supposedly mandated services. For many persons with MR/DD and their families, this battle--a struggle for some time to accommodate to the new demands of adulthood and of the vocational and residential systems--is taking place simultaneously with the family's growing realization that educational interventions are coming to an end, and the person with MR/DD is now, in some sense, a "finished product." Whatever fantasies the person has, whatever fantasies the family has, must now be reconciled with the reality of current functioning. Sadly, they must also be reconciled with the frequently inadequate facilities and range of service possibilities available. This is an experience everyone has in young adulthood, but for persons with MR/DD it is more poignant, more painful. First, these events and feelings may be occurring

at the same time as the emancipation of siblings. Second, the range of life choices available to persons with MR/DD is so limited that there are few compensations. A neurotypical person may be unable to obtain a job commensurate with his or her ability or training, but may have a rich social life, a rich family life, political, artistic or religious involvement. For persons with MR/DD, job and home may be all, and the choices may be out of the family's control.

Access to services may be limited by artificial geographic and financial constraints. Vocational training may be inappropriate to the range of jobs actually available, and the focus on acquiring particular job skills may have stunted more generally applicable skills, such as travel-training, cooking, banking, and use of community leisure facilities. Often great care and preparation have gone into anticipating the person's needs, and efforts to enrich the life of the person have met with the limited capacity of systems to meet such expectations. A person with MR/DD may as a result withdraw, become angry, or regress from previously attained levels of function, and be referred for mental health consultation.

• **Out-of-Home Placement and Residential Moves.**

A first out-of-home placement for a person with MR/DD can be the result of a plan, an anticipation that the person will live adult life in an agency-run residential facility; or it can be the result of a crisis of some sort. If the latter, the chances are the placement has or had more to do with the needs of the family, the unavailability of in-home intervention or appropriate educational facilities, or some problem behavior, rather than with the wishes of the person with MR/DD. The general lack of alternative interventions for children and adolescents can lead to out-of-home placement, often to distant residential care facilities rather than to community-based facilities. Often such facilities lack expertise with MR/DD and with dual diagnosis, with resulting errors in diagnosis, treatment planning, and medication.

Movement from home to the facility, facility to facility, and facility back to home have less to do with treatment than with agency, facility, or institutional imperatives. As an example, social service agencies usually have an age cutoff past which funding for continued placement is impossible. When the money runs out, a person can be discharged or moved without regard to

clinical needs, and this may happen several times to the same person. Trust quickly erodes, even in people who may seem to lack the sophistication to understand what is happening. A person with MR/DD in a distant placement, cut off by distance and poverty from the possibility of all but the most infrequent family visits, may have the fragile bonds to residential facility staff broken again and again, most often abruptly. Such a person begins with anxiety, and perhaps withdrawal, on the initial separation from family, with accompanying ideas that he or she has been rejected, and rejected because retarded; may go on to become "unattached"; that is, unable to make relationships because unable to trust that they will last. The person may take on a veneer of bravado and provocativeness, partly out of the need to distance the threat of broken attachments, partly out of the need to establish a distant but defined identity with peers.

When placement out of the home is the result of long planning and anticipation, it is the true emancipation of the person with MR/DD. Many factors, however, combine to rob the experience of the voluntary qualities that characterize the emancipation of neurotypical adults. The neurotypical adult may practice emancipation for a long time in summer camp, on extended trips, in a college dormitory, in an extended sexual relationship, and move to independent living at his or her own pace, and to his or her own chosen location. Whatever sadness is attendant upon leaving home is compensated by these chosen gains.

When the person with MR/DD leaves home, it is usually alone. The person with MR/DD usually has little control over where he or she will be located; such decisions are made by agencies and are chosen from a limited list of alternatives. The group home or apartment may be conveniently located near accustomed haunts, or across town. The timing of the move is also most often determined by the availability of a placement, not by the person's needs. There may be new rules and demands; whereas the neurotypical adult may experience a new freedom from parental demands, the person with MR/DD, upon leaving home, may, paradoxically, experience new and greater restrictions than were experienced at home. This may be exacerbated by restrictions imposed by the environment, a new location, unfamiliar or nonexistent public transit and

public services, but are most often imposed by artificial barriers, such as restrictions on home visitation imposed by agency or Medicaid funding rules. Anxiety about emancipation will be exacerbated by all of these factors; the resulting withdrawal, regression from previous levels of functioning, or problem behavior, exacerbated by the imposed lack of family support, may occasion a referral for mental health consultation.

The person with MR/DD will most often not be moving to a single room. Relationships will have to be made with residential and vocational staff of varying sensitivity, all of whom have potential life-changing decision-making power. The person with MR/DD will often have to cope with a roommate, most often chosen by others. Unless there is continued access to a family physician (access that can be threatened by transportation difficulties or a change from private medical insurance to Medicaid, Medicare, or both), the person with MR/DD will have to cope with changing to a new physician. The new physician may wish to change longstanding medication regimens to which the person may have become accustomed, at which, because of dependency upon routine, and perhaps because of intense anxiety surrounding medication, there may be extreme anxiety. The same applies to other therapists. And it should be remembered that professionals too rarely explain such changes of regimen to persons with MR/DD. These can be sources of anxiety and withdrawal which are easily overlooked.

These same considerations apply throughout the life of the person with MR/DD, to all subsequent moves within an agency's facilities. Like the initial placement, such moves may be due not to the person's needs, but to the agency's needs (funding, government regulations, and so on), and may be far beyond the person's control.

When asked--and sometimes spontaneously--persons with MR/DD can be quite eloquent on this experience of having little or no control over their lives. When there is no compensation in autonomy for leaving home, or where autonomy is compromised or is a cause of anxiety, the grief at leaving home may be greater than anticipated, because it is not leavened by any gains. The resulting reaction may be the cause for mental health consultation.

• **Staff/Individual Relationships.** The person with MR/DD, who is now a "individual" or

"consumer" must establish a relationship with a direct-care counselor. Rarely does the individual have a choice of counselors, although counselors may have a choice of individual. That relationship is expected to be successful. If it is not, it is usually assumed to be the individual's fault. There may be the usual unwanted behaviors, and a referral for mental health consultation may result.

The nature of the counselor/individual relationship may be entirely novel for the person with MR/DD. It requires all but blind trust on his or her part. Suddenly someone who may be a chronological peer may be in charge of money, time, training and activities, and even contacts with friends and family. Counselor dedication, preparation, experience, and philosophy may vary widely. The goals of each in the relationship may be very different, and may change over time. At first, the individual most likely looks for a dependable, nurturing caregiver; later, he or she may wish for a counselor empathetic with a need for autonomy; later still, with a wish to be left alone more often. The counselor may be someone who wants for the individual what the individual wants. But the counselor may have professional goals, which are not likely to be the individual's: to move the individual to a less supervised setting, in order to comply with the agency needs, rules, and supervisors' directives; to be promoted; or simply to make a living. Counselors may find themselves implementing decisions with which they do not agree. The individual may not understand the complexity of the counselor's position, and may blame him or her for things beyond the control of either. The counselor may be in the position of having his or her skills measured by the degree to which individuals comply with agency goals. Individuals may have no mechanism by which to protest, and may have no outlet other than passive non-compliance or aggressive and destructive behavior, which often are displaced onto other individuals.

In many, if not most agencies, counselor positions are minimum-wage jobs with poor benefits and unrealistic hours. These factors, plus the ongoing frustrations of the job, result in frequent turnover of staff in residential and vocational programs. Each change of counselor is a loss for the individual. Since earlier life experiences have been poor training for peer relationships, the individual/counselor

relationship may be of enormous emotional importance to the individual, and its loss may not be cushioned by ongoing friendships or sexual relationships. Grieving may be actively discouraged, or misunderstood, when it occurs. The familiar constellation of regression, withdrawal, sadness, “noncompliance,” anger, may occur repeatedly as the result of frequent reassignment to new counselors. In time, the person with MR/DD may elect not to make new

TABLE 1. PREDICTABLE CRISES

Initial Diagnosis of MR/DD
Birth of Siblings
Starting School
Puberty and Adolescence
Sex and Dating
Being Surpassed by Younger Siblings
Emancipation of Siblings
End of Education
Out-of-Home Placement/Residential Moves
Staff/Individual Relationships
Inappropriate Expectation
Aging, Illness, Death of Parents
Death of Peers, Loss of Friends
Medical Illness/Psychiatric Illness
Deinstitutionalization
Traumatic Events

relationships, a response to repeated losses that are beyond control.

Staff supervisors are subject to some of the same phenomena. Turnover at this level can result in subtle or gross changes in a individual's life, which again are beyond control, and, possibly, understanding. Growth, change, and creativity in agency staff may or may not be encouraged, and thus growth, change, and

creativity may be discouraged in individuals. Staff may resign from a program when they are uncomfortable with the direction it is taking; individuals either cannot resign, or may have to sacrifice too much (SSI, Medicaid, placement) if they try. Individuals may know that they can move to another setting within an agency's catchment area, but they may have no idea of the possibilities available in other areas. Major administrative changes may totally reorient a program, which may have a great impact on the life of a person with MR/DD.

All of these issues and the reaction they cause may occasion referral for mental health consultation.

• **Inappropriate Expectations.** Since individuals have so little real input into decisions regarding educational, residential, vocational placement, and program goals, it is too easy for everyone making the decisions to misjudge their true capacities. By capacities is meant the person's ability to cope with life's demands and to perform necessary self-care tasks. Sometimes the individual's levels of ability may be judged by performance on objective tests, sometimes from case notes or past observation, by an impression created by the person's appearance, or by apparent verbal or social ability and too often by extrapolation from these. It must also be remembered that many persons with MR/DD are unable to generalize, for example, from simple classroom math to the task of balancing a checkbook. Furthermore, even such assessment tools as the Street Survival Skills Questionnaire¹⁶ may indicate only a person's comfort, confidence, and desire to perform a task in the real world.

It is always assumed that the person with MR/DD wishes to do as much for and by himself or herself as possible, and will advance eagerly to even greater levels of independence, to the point where contact with counselors or supervisors is minimal. Indeed, some persons with MR/DD do feel this way. For the majority, however, this goal is imposed upon them by others. This way of life requires the person with MR/DD to function at maximum performance and behavioral level at all times. And, for persons with MR/DD who lack social skills or a sphere in which to exercise them, and who have been raised to value and function primarily in relationships with caregivers, increased freedom from supervision means an increasingly isolated and lonely life. In summary,

persons with MR/DD may be uncomfortable, or unhappy, in situations and environments which tests show to be within their tested abilities. When a judgment is made that a person with MR/DD should be able to perform a task or cope with a situation, and this judgment is based upon the appearance of verbal or social facility, or a splinter skill, the mismatch between person and situation may be wildly inaccurate. For the individual with an additional mental health problem the discrepancy may be even greater.

A common reason for mental health consultation as a result of inappropriate expectations is a situation in which a individual's recently improved performance has become the rationale for "promotion" to lesser levels of supervision. Shortly thereafter, the recently noted enhanced performance level declines and the individual experiences helplessness, or displays behavior indicating helplessness or extreme anxiety. The individual may also seek more supervision by repeatedly failing, or through aggressive, impulsive, or noncompliant patterns of behavior. All of these phenomena are common signs of ambivalence and discomfort concerning the repeatedly heightened expectations for performance.

Changes in living or work arrangements may not have been spontaneously requested by the individual. They may have been suggested by staff, with compliance and staff values doing the rest. Society and professionals often equate lack of supervision with freedom, and with normal functioning. Within this societal-professional set of expectations, prestige for the person with MR/DD--and for counselors, supervisors, and advocates--may be inappropriately equated with moving him or her to situations of decreasing supervision. Since these situations may cause the person with MR/DD increasing discomfort, a painful "failure" may result, leaving all concerned disappointed and unwilling to try again, or with the familiar constellation of problems leading to mental health consultation.

Successful intervention in such a situation may require evaluation of the person's level of comfort, examination of disappointment in self (and, partly because of projection, in caregivers), and discussion with those caregivers about the values and assumptions that led to the change. The seeming paradox that must be understood is that some persons with MR/DD will function most

independently in situations that appear to caregivers as more restrictive, because these situations contain more of what the person needs to function comfortably.

A person with MR/DD may experience an analogous discomfort when capacities are underestimated. This can occur when caregivers underestimate a person's ability to cope with risk or with failure. Sadly, it may also occur when agencies, overconcerned with preserving relationships with prospective or existing employers, are unwilling to risk having a individual fail. Even more sadly, in many places opportunities for community employment or semi-independent living do not exist. Support for creative, flexible, individualized programming is often lacking at administrative levels. The result is that a person with MR/DD may climb the ladder, only to find no top rung. Here again productivity might decline, anger, disappointment, frustration, and sadness may lead to all sorts of behavior--resulting in referral for mental health consultation. The person might blame individual caregivers when it is the system that is at fault. Honest discussion of system limitations is crucial to intervention in such situations, as is helping the person with self-advocacy.

The blind application of the idea of the "least restrictive environment" often fails to take into account the needs and comforts of persons with MR/DD. The least supervised environment (most often equated with "least restrictive") can actually narrow the range of activities available to the person with MR/DD, and thus, paradoxically, become more restrictive. One of the therapist's most important tasks is to evaluate accurately the patient's biological, psychological, and social capacities and needs; to verify these with the patient, and to consult, with the decision makers in the patient's life. This can result in the patient having more input into life decisions, defusing the crisis and making future similar crises less likely.

- **Aging, Illness, and Death of Parents.** Many persons with MR/DD experience all caregivers as extensions of their parents. Moreover, parents may continue to exercise a buffering or advocate role for persons with MR/DD, responsibility for whose physical care may long have rested with themselves or a residential program. When a parent dies, therefore, there is for persons with MR/DD, as for anyone, the loss of a loved person;

also of someone who had continued to carry out *both* real and symbolic regulating functions in their lives. A period of grieving is expected, but it may take a different course, and reach a different end point than the grief of a typical person. Grief is often accompanied by a period of increased vulnerability to stress, dependency, and feelings similar to those experienced in Major Depressive Disorder. For persons with MR/DD these may be unanticipated and frightening feelings. Defenses against the pain of repeated episodes of loss, developed to deal with the loss of relatively minor figures, may modify the course of grieving. Many persons with MR/DD experience parents as omnipotent, an exaggeration and prolongation of similar feelings in neurotypical people. This may lead to anger at the dead parent, or anger at the surviving parent (for allowing the other parent to die), feelings experienced fleetingly by neurotypical people, but sometimes a prominent part of the grief of persons with MR/DD. In part this may be due to the limitations that concrete thinking places upon the resolution of these feelings into sadness, but an even more powerful constraint is the poor preparation of persons with MR/DD for experiencing sadness. Many families and caregivers, in the well-meaning but erroneous belief that persons with MR/DD cannot cope with sadness (or shouldn't ever be allowed to be sad), may block the process of grieving and thus perpetuate this anger. Also, if persons with MR/DD are not allowed to experience sadness, or fear the response others, they may become so afraid of it that they will suppress it. Grieving can then become attenuated and prolonged.

Concrete conceptualizations of grief can have other consequences. Persons with MR/DD who imagine the dead parent in heaven, watching over them, and still an active agent in their lives, may experience auditory, and even visual, hallucinations of the dead parent. These phenomena are hardly unknown among neurotypical people, but for persons with MR/DD, they may occur for prolonged periods, or even become an accustomed and comforting part of life. If unaccompanied by other manifestations of blocked grief or psychosis, appropriate intervention (if referral is made for mental health consultation) may help persons with MR/DD and their caregivers understand the place of these experiences in life.

In an attempt to come to grips with death, persons with MR/DD may blame themselves; again, a phenomenon common among neurotypical people. Here again, the limitations of concrete thinking may cause misperceptions that can be unraveled without complex abstract processes of working-through.

Sometimes the normal process of grief may be set in motion by allowing persons with MR/DD the time and opportunity to participate in the ceremonies and family discussion surrounding a death. Persons with MR/DD may, because of program or transportation constraints, have to ask to be taken to visit the grave site, a visit anyone else may make at will. Sadly, similar constraints may apply to time off from work. The desire for such a visit may occasion a crisis if the person is afraid to ask.

Persons with MR/DD may become fearful about the health of surviving caregivers. They may become preoccupied with the health of the surviving parent and/or self and others. They may become preoccupied with fears for the future--who will fill the parent's role?

Finally, the death of a parent may precipitate placement away from home, in which case the problems of placement discussed above become "crisis driven,"⁶ with the risk of inappropriate placement and expectations increased by the need to find placement quickly. The individual might lose access to other family, to familiar day program and activities, and to a long-familiar neighborhood with its wealth of associations.

The person with MR/DD may be any age at a parent's death, and in any state of health, in which case worries about his or her own health might be increased by a parent's death.

- **Death of Peers, Loss of Friends.** The experience of loss may be compounded by the sense of life beyond control. The loss of a peer may occur when someone is moved to a new facility, or a "less restrictive environment." Such moves are decided upon by others, and may take the friend into a location or sphere of activities that precludes further contact.

The loss may be the death of a friend. Another way that residential systems for persons with MR/DD differ from typical life is that usually when a resident becomes ill, he or she is moved, perhaps to a hospital, perhaps to a nursing home, in which case placement may not be continued. Both preclude easy visitation, so the death of a

friend may be experienced as a sudden notification after an unexplained removal or absence. Fears and misconceptions may arise. When the death is sudden or accidental, it may occur at home and be witnessed by residents; sadly, residential and vocational programs vary widely in their approach to grief among the survivors. With no clear idea, or with concrete ideas, about the cause of the death (or illness), persons with MR/DD may develop misunderstandings that can lead to neurotic symptom formation, maladaptive behavior, or simply to understandable fears. If a friend dies as a consequence of a seizure, one's own epilepsy becomes more frightening. A therapist called upon to deal with these issues should ask how the other residents are responding to the death, and how the program dealt with it, and consider a group approach, including the staff.

- **Medical Illness.** The appearance of new symptoms heralding the onset of illness may cause persons with MR/DD anxiety sufficient to precipitate panic, a panic likely to delay correct diagnosis. Persons with MR/DD may share with children difficulty in describing or localizing a pain, a weakness, a numbness, or a discomfort. They may overestimate or underestimate the significance of a symptom. Somatization and chronic minor complaints, encouraged by a system that repeatedly examines persons with MR/DD in order either to avoid liability, comply with administrative guidelines, or certify a continuing need for care, are in danger of creating conditions in which caregiving staff ignore the development of a significant complaint. Because of the lack of experience of consulting a physician, persons with MR/DD may signal the onset of illness by withdrawing, becoming more demanding or dependent, or becoming anxious and developing neurotic symptoms or behavior to cope with the anxiety. When these processes fail, or when the distress is overwhelming, persons with MR/DD may have a behavioral reaction, with the danger that significant medical signs and symptoms will be overlooked.

Hospitals can be extremely hostile environments for persons with MR/DD; they arrive there feeling anxious or worse. Their main defense—reliance upon caregivers and family—may be inimical to busy medical and nursing staffs and, sadly, to other patients. The unfamiliar and unstimulating environment, along

with long periods of lonely inactivity, with sudden demands for unaccustomed choices (for example, a daily menu), may be anxiety-provoking to the point of producing disorientation and confusion.

A real fear for persons with MR/DD is that hospitalization can mean the loss of a job or a residential placement. In the case of the latter, where hospitalization is prolonged, a program may not hold the person's placement, and the person may be hospitalized for as long as it takes to find a new placement. Since hospitalization for this purpose is not a Medicaid benefit, there is the real possibility of precipitous discharge. When such a problem is anticipated, admission to the hospital may be refused.

If a home or residential placement is sufficiently problematic, a patient with MR/DD may ask to remain at, act out, or refuse to leave the hospital. This may be the person's only way of communicating abuse by a caregiver or peer, a possibility that should always be considered when a patient with MR/DD seeks to prolong hospitalization.

- **Psychiatric Illness.** Everything in the foregoing section applies equally to psychiatric illness. Again, persons with MR/DD may experience the signs of mood disorder as frightening, and the resulting panic may confuse a diagnosis. The significance of withdrawal may be missed, or may be concealed by program routine (a neurotypical person with Major Depressive Disorder will stay home from work; a depressed person with MR/DD will be put on the bus to the workshop). Family history and biological markers may be helpful here, but first we must confront the fact that access to mental health services may be beyond the experience of persons with MR/DD, and, sadly, the mental health problems of persons with MR/DD may be beyond the experience of available caregivers. Lastly, as with other challenges in the medical care system, economic considerations may bar persons with MR/DD from access to services.⁷

- **Deinstitutionalization.** Persons entering community placement may do so from home or from a previous institutional placement. It is often assumed that institutions are unrelievedly awful places, and that the correct response to leaving one can only be relief. Behavioral and developmental crises that arise in the wake of leaving an institution are therefore often

misconstrued and misunderstood. No matter how awful home is, it is still home. There are reassuring routines and, no matter how few, there are important caregivers who may have been involved with an individual for decades, perhaps from childhood. These are important relationships, and however attractive the opportunities in the new place, they must be resolved. Those opportunities may require from the individual an unaccustomed and frightening degree of autonomy.

These issues may be of particular importance, with consequences of even greater severity, in persons with pre-existing personality disorders, for whom loss of caregivers is a trigger for severe and disorganizing sadness, self-mutilation, and manipulative suicide attempts. The lack of round-the-clock staffing in some community placements is experienced by some of these

of exaggerated expectation for autonomy based solely on their level of cognitive functioning without regard to the psychiatric symptomatology.

• **Traumatic Events.** Traumatic life events (divorce, parental divorce, physical abuse, sexual abuse, criminal victimization, exposure to war or other violence, societal dislocation due to fire, flood, earthquake, hurricane, or other environmental phenomena) may occur at any time in a person's life, and provoke reactions calling for mental health consultation. Delayed or Post-traumatic Stress Disorders are possible, as are simple fears and regression due to the circumstances surrounding the event.

Therapists must not only consider the nature of the trauma, but its relation to the MR/DD and the person's wishes for autonomy or dependence. This may be especially, but not exclusively, true for sexual abuse. Special interviewing techniques are recommended for therapists dealing with this issue which may have application to other forms of victimization as well.¹² It cannot be repeated too often that persons with MR/DD may be misperceived to be less disturbed by traumatic events because they are misperceived as less aware.

CONCLUSION

Successful diagnosis and treatment of persons with MR/DD and an acute mental health problem involves not only correct diagnosis and therapy, but resolution of the crisis which precipitated the episode. Mental health professionals treating

persons with MR/DD should therefore be acquainted with the predictable stressors in the lives of persons with mild and moderate MR/DD, since they may be missed entirely or mistaken for unalterable circumstances.

To successfully treat a person with MR/DD the mental health professional must be able not only to diagnose the presenting disorder but the environmental and developmental stressor that caused it to occur when it did, and be prepared to work to resolve it.

REFERENCES

1. Aman MG. **Assessing Psychopathology and Behavior Problems in Persons With Mental Retardation: A Review of Available Instruments.** Rockville, MD: US Department of Health and Human Services, 1991.
2. Evans DP. **The Lives of Mentally Retarded People.** Boulder, CO: Westview Press, 1983.
3. Garner C, Callias M, Turk J. Executive function and theory of mind performance of boys with fragile-X syndrome. **J Intellect Disabil Res** 1999;43:466-474.
4. Levitas A, Gilson SF. Psychosocial development of children and adolescents with mild and moderate mental retardation. In: Bouras N (ed), **Mental Health in Mental Retardation: Recent Advances and Practices.** Cambridge, UK: Cambridge University Press, 1994:34-45.
5. Levitas A, Hurley A, Pary R. Mental status examination of persons with mental retardation. **Ment Health Aspects Dev Disabil** 2001;4:2-16.
6. McCallion P, Janicki M, Grant-Griffin L. Exploring the impact of culture and acculturation on older families caregiving for persons with developmental disabilities. **Fam Relations** 1997;46:347-357.
7. Menolascino FJ, Gilson SF, Levitas A. Issues in the treatment of mentally retarded patients in the community mental health system. **Community Ment Health J** 1986;22:314-327.
8. Nigro G. Sexuality in the handicapped: Some observations on human needs. **Rehab Lit** 1975;36:202-205.
9. Olshansky S. Chronic sorrow: A response to having a mentally defective child. **J Soc Casework** 1962;(April):190-193.
10. Podell DM, Kastner J, Kastner S. Adolescents with mental retardation: Perceptions of sexual abuse. **Am J Orthopsychiatry** 1996;66:103-110.
11. Poindexter CC. In the aftermath: Serial crisis intervention for people with HIV. **Health Soc Work** 1997;22:125-132.

12. Razza N. A question of abuse: Talking with persons who have MR/DD about their experiences with victimization. Part 1. **Ment Health Aspects Dev Disabil** 1998;1:48-51.
13. Seltzer MM, Greenberg JS, Krauss MW, Gordon RM, Judge K. Siblings of adults with mental retardation or mental illness: Effects on lifestyle and psychological well-being. **Fam Relations** 1997;46:395-405.
14. Siperstein GN, Leffert JS, Wenz-Gross M. The quality of friendships between children with and without learning problems. **Am J Ment Retard** 1997;102:111-125.
15. Solnit AJ, Stark MH. Mourning and the birth of a defective child. **Psychoanal Study Child** 1961;16:523-527.
16. Street Survival Skills Questionnaire. Dallas, TX: McCarron-Dial Systems, 1979.

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