

## CHRONIC SORROW REVISITED: Parent vs. Professional Depiction of the Adjustment of Parents of Mentally Retarded Children

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*In response to a questionnaire mailing, parents of mentally retarded children and social workers essentially agreed that such parents experience periodic crises during the child's development, rather than time-bound adjustment. Social workers tended to underestimate the impact on parents of later developmental periods. Clinical implications of the findings, which run counter to the prevalent professional view, are considered.*

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In the professional literature, there are two incompatible notions about the adjustment process of parents of retarded children—that parents work through their grief over time and that sorrow is chronic.

*Grief is time-bound.* The most prevalent view is that, basically, parents go through one predictable progression of adjustment to the situation of having a mentally retarded child. Most clinical studies have diagrammed the stages of grief in the order of shock, despair, guilt, withdrawal, acceptance, and finally "adjustment."<sup>10</sup> One popular medical school text described the main stages of parental acceptance as being shock, followed by denial; helping professionals, it maintained, should recognize

shock, denial, and guilt, and help the parents work through these feelings.<sup>7</sup> Another example of this attitude has been portrayed in a handbook on mental retardation for the primary physician, in which parents are said to

... usually go through three stages in adaptation: 1. emotional disorganization; 2. reintegration; and 3. mature adaptation, where parents . . . learn to live without undue stress.<sup>1</sup>

In a study that typifies much in the literature, the author<sup>5</sup> concluded:

The findings from the present study suggest that in cases where the behavior characteristic of grief persists beyond the initial two to three months, the grief process has become chronic because the internal process of decathexis of the lost child has not been carried through . . . A recommendation is then made for casework focusing on past fantasies, until the completion of decathexis.

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This recommendation is based on the assumption that the grief process can be concluded for the mother prior to her assuming the care of the baby.

*Chronic sorrow.* A minority of professionals have expressed disagreement with the view that the adjustment to having a mentally retarded child is time-bound. All would agree that, immediately after the diagnosis, parents go through a phase of grieving. This group would maintain, however, that even the best adjusted of parents may well find that, over time, there are numerous occasions on which the intense grieving feelings are re-evoked and experienced.

An astute and often reprinted article reflecting this minority view was written by Olshansky,<sup>9</sup> who presented a clinical picture of the repeated sadness experienced by parents of retarded children and argued that the wise practitioner would use this concept as a basis for intervention. More recently, Searl<sup>12</sup> argued that his own experience as the parent of a retarded child did not fit with the prevalent view of parental adjustment:

Parents of retarded people, the theorists tell us, learn to live with their children's handicaps. They go through stages of reaction, moving through shock, guilt and rejection to the promised land of acceptance and adjustment.

My own experience as the father of a retarded child did not fit this pattern. Instead, it convinced me that most people seriously misunderstand a parent's response to this situation. The standard view does not reflect the reality of parents' experience or lead to helpful conclusions.

Professionals could help parents more—and they would be more realistic—if they discarded their ideas about stages and progress. They could then begin to understand something about the deep, lasting changes that life with a retarded son or daughter brings to parents. And they could begin to see that the negative feelings—the shock, the guilt and the bitterness—never disappear but stay on as a part of the parents' emotional life.

Most parents, I believe, never fully resolve the complexity of feelings about their child's retardation. They don't "adjust to" or "accept" that fact, at least not in the way psychology books describe it . . .

In each case conventional assumptions about progressive stages toward acceptance did not seem to apply.

#### GOALS OF THE STUDY

It is critical—for both professionals and for parents of retarded children—to determine which of these two adjustment patterns best reflects the retarded children's parents' experiences. If the first view (of progressive stages toward a completed adjustment) is correct, professionals would: 1) facilitate the parents working through these stages, 2) discontinue services at the conclusion of the adjustment process, and 3) identify those parents who did not go through these stages as dysfunctional. On the other hand, if the minority view (that parents must expect to experience chronic sorrow) is correct, there are quite different clinical implications. As Olshansky<sup>9</sup> observed, professionals' perceptions of the parent will be different if they accept the idea that chronic sorrow is a natural rather than a neurotic reaction; *i.e.*, that sorrow is a natural response to a tragic fact. The recognition of the periodic crises a family of a retarded child may encounter over the life-span of their offspring would lead to the offering of a continuum of appropriate support services.

In order to determine which picture more accurately reflects parental experience, we conducted this study. We had three major concerns: 1) to determine how parents of mentally retarded children reported their adjustment process; 2) to specify the extent to which reported stress varied at designated points

over time, and 3) to examine whether practicing mental health professionals believe that parents experience time-bound grief or expect parents to experience chronic sorrow. Since social work as a profession has been very involved in providing support services to families of retarded persons, social workers seemed an appropriate group upon which to focus.

## METHOD

### *Subjects and Procedure*

The subjects included two groups—social work practitioners and parents of retarded children. Social workers (100) were randomly selected from a roster of names from Dane County Department of Social Services in Madison, Wisconsin. Thus they were included regardless of their position; *i.e.*, supervisor and social worker aides. Names of parents were obtained from client listings at the Diagnostic and Treatment Unit of the Waisman Center for Mental Retardation and Human Development. The clinic is a federally-funded center at the University of Wisconsin, which offers free evaluation services while training students who are pursuing professional degrees in the area of developmental disabilities. The first 100 parents of mentally retarded children who had received evaluation services in the years 1975–77 were selected.

Questionnaires, designed for this study, were mailed to subjects, along with self-addressed return envelopes. Only 16 of the parents responded to the first mailing; 31 questionnaires were returned with no forwarding address. Telephone contacts were then made with the remaining parents, to determine the reason for their lack of response. Many parents reported having

difficulty responding because of the evocative nature of the questions. The questionnaire asked that they graph their experiences, which was uncomfortable for some parents. Theorists have observed that the mildest empathetic probing of parents' feelings inevitably reactivates an intense but transient grief.<sup>8</sup> The subject of the questionnaire, chronic sorrow, may have restimulated the very feelings we were trying to define. Those who agreed to it by phone (38) were sent a second mailing. This effort produced 16 additional returns. Ultimately, there were completed questionnaires for 32 families.

The social workers returned 32 questionnaires after the first mailing. No effort was made to gain additional responses.

### *Questionnaire*

The authors designed the questionnaire used in this study to examine parents' experiences of time-bound grief vs. chronic sorrow. The questionnaires sent to social workers and parents differed in only one respect: We asked social workers to depict their expectation of how *parents* adjust to having a retarded child. In contrast, we asked parents to indicate how they really felt. The questionnaire had three parts: a free-form graph for depicting the adjustment process, a structured graph, and a direct question (Do you experience chronic sorrow?). The contrasting notions of time-bound adjustment and chronic sorrow were explained to social workers and parents as follows:

We are interested in the feelings that parents of retarded children experience. Professionals have written about two differing patterns parents might experience in coping with the event of having a retarded child: one is that after the initial shock

and sadness wear off, one gets gradually adjusted and the pain decreases. The other thought is that the painful feelings never disappear and, in fact reappear with other crises along the way of the child growing up . . .

The questionnaire showed sample graphs depicting these two processes, on which parents' feelings were charted over time, with "awful" as the low point and "just great" as the high point.

Based on what they (or their clients) had experienced, subjects were first asked to draw a free-form graph indicating the effect of time on their feelings. Visual inspection of these graphs enabled us to determine whether subjects' perceptions of parents' experiences seemed most similar to time-bound adjustment or chronic sorrow. In the second part of the questionnaire, subjects were asked to graph how they (or their clients) felt at ten specific developmental crisis points:

1) Diagnosis (official news of retardation from a specialist). 2) Child should have begun walking (12-15 months). 3) Child should have begun talking (24-30 months). 4) Younger brother or sister overtakes the retarded child's abilities. 5) Serious discussion of placement of retarded child outside the home (or actual placement). 6) Beginning of retarded child's attending public school, thus publicly labeled as different. 7) Management of a crisis (behavior problems, seizures, health problems, etc.) unique to the retarded child. 8) Onset of puberty (in which the body is clearly more developed than the mind). 9) Retarded child's 21st birthday, when adulthood and independence from parents are generally acknowledged. 10) Serious discussion about guardianship and care for retarded child when parents die.<sup>14</sup>

The structured graphs enabled us to construct two indices of social workers' and parents' perceptions of adjustment to a retarded child: 1) The *Total-Distress Measure*, consisting of sums of the ratings of how happy or sad parents were perceived to feel at each of the ten

crisis points. 2) *Parent Distress Early vs. Late in the Child's Development*, in which sums of ratings of parents' feelings at five early points (Points 1, 2, 3, 4, and 6) were contrasted with sums of ratings at three later points (Points 8, 9, and 10). (Point 5—serious discussion of placement—and Point 7—management of severe problems—could not be classified as specifically early or late in the child's development.) These contrasting measures were designed to tell whether social workers expected parents to experience time-bound adjustment (in which case they would see parents as being upset at the early points, far happier at the later ones) or chronic sorrow (parents rated as being upset early and late in their child's development).

*Direct question.* Finally, the questionnaire asked directly whether parents do in fact experience what Olshansky<sup>9</sup> termed "chronic sorrow." Polarized responses of "yes" or "no" were offered following a lengthy description of the concept:

In the field of mental retardation, there's a phrase that's often used to describe how parents of retarded children feel—"chronic sorrow." Things can be going along just fine, and suddenly out of the blue you might begin feeling sad again. Sometimes it may be little things that set off these feelings—those moments may be trimming the Christmas tree, hearing a special piece of music, seeing your child outside playing; or they may come at the big life changes, which bring back strong feelings of sadness—such as having your retarded child begin public school, or deciding about placement.

## RESULTS

The findings are presented paralleling the structure of the questionnaire: 1) the free-form adjustment graphs, 2) the structured developmental crises graphs, and 3) the direct question.

Table 1  
 PARENT (N=32) AND SOCIAL WORKER (N=32) RESPONSES ON FREE-FORM AND  
 STRUCTURED GRAPHS

DEVELOPMENTAL CRISIS POINTS	SOCIAL WORKERS		SD	F
		PARENTS		
Diagnosis	-4.08	-3.95	1.23	.17
Time for walking	-2.77	-1.33	2.06	7.81**
Time for talking	-2.80	-2.33	1.92	.98
Sibs surpass child	-2.53	-1.41	1.94	5.34*
Alternative placement	-2.88	-2.79	1.79	.04
Entry into school	-2.34	-.96	2.27	5.90*
Management crisis	-2.05	-2.52	1.86	1.00
Onset of puberty	-2.07	-2.02	1.38	.02
21st birthday	-2.03	-2.93	1.37	6.94*
Guardianship	-2.05	-1.64	1.62	1.03
SUMMARY MEASURES				
Type of Free-Form Graph	1.91	1.88	.32	.16
Structured Graph: Total Distress Index	-25.60	-21.89	11.30	1.73
Structured Graph: Distress Early vs. Late in Child's Development (Weighted)	-6.72	8.29	17.62	11.62**

\*  $p < .05$ ; \*\*  $p < .01$ .

### Free-Form Graphs

First, parents and social workers were asked to indicate their adjustment in a free-form style on a graph. Three judges assigned each graph to one of four categories: 1) gradual smooth line of ascent, 2) bumpy line of ascent, 3) smooth line of feelings with no ascent, 4) bumpy line of no ascent. The latter two categories were considered to be depictions of chronic sorrow. In rating the 64 graphs, there were four disagreements; these were discussed, agreed upon, and included in the analysis.

Only one-fourth of the parents indicated that they had experienced time-bound grief, by free-form graphs judged to be in one of the first two categories. The rest of the parents, by far the majority, depicted a series of ups and downs with no general upward course. Parents' and social workers' free-form graphs did not differ in form ( $F = .16, 1; 62 df, NS$ ). Evidently these profession-

als were sensitive to the fact that parents experience chronic sorrow.

### Structured Graphs

In the second part of the questionnaire, parents (and social workers) were asked to indicate how they had felt at ten clearly demarcated developmental points in the child's life. We ran two planned comparisons (see Hays,<sup>4</sup> for a description of this procedure). First, we asked: "Do parents and social workers differ in their *overall* evaluations of how upsetting it is to have a retarded child?" The answer was "no." As shown in TABLE 1, overall, the social workers were quite accurate in their perceptions of parents' feelings. Social workers' and parents' ratings of their Total Distress index were virtually identical. (Main Effect  $F = 1.73, 1; 62 df, NS$ )

Secondly, we asked: "Did parents and social workers differ in their reports of how upsetting early vs. later experi-

ences were?" We expected that they would. We thought that both groups would accurately perceive how upsetting the early experiences were (diagnosis, walking, talking, the child's being surpassed by sibs and going off to school), but thought that social workers would markedly *underestimate* how upsetting continuing life crises were (the child's entering puberty, the 21st birthday, and guardianship). In brief, we expected that therapists would be expecting parents to experience only time-bound grief, while in fact parents were enduring chronic sorrow.

The findings indicated that the two groups did differ markedly (Interaction  $F$ s for early vs. late experiences—weighted equally = 11.62, 1; 62  $df$ ,  $p < .001$ ). Social workers tended to overestimate how upsetting the parents' early experiences were. They underestimated how upsetting the later experiences were.

Parents and professionals diverged within perceptions most significantly at four of the ten points. At three of these points, the social workers assumed parents would be more upset than they really were. These were: when the retarded child would normally have been expected to walk ( $F = 7.81$ ,  $p < .01$ ); when the younger normal sibling surpassed the retarded one in functioning ( $F = 5.34$ ,  $p < .05$ ); and when the retarded child entered school in a special class for exceptional children rather than a normal class ( $F = 5.90$ ,  $p < .05$ ). In contrast, the social workers markedly underestimated how upsetting the child's 21st birthday was to parents ( $F = 6.94$ ,  $p < .01$ ).

Social workers were most accurate at estimating stress reported by the parents at three of the ten points: time of

diagnosis, time of placement (or serious discussion of placement) of the retarded dependent, and time of puberty. These periods were acknowledged by both groups as being painful.

#### *Direct Question*

Social psychologists often argue that, if you want to know something, the best way to find out is simply to ask. In this case that seems to be true. In response to the question, 63% of the parents and 65% of the social workers said yes, these parents do experience chronic sorrow.

#### DISCUSSION

The results of this study support the minority of professionals' view about the adjustment of parents of mentally retarded children. That is, chronic sorrow rather than time-bound adjustment characterizes their experience. Both in the request to draw a graph depicting their feelings and in response to a direct question, most of the parents indicated that there were various periods of stress and sadness over time.

They did not, however, indicate that the sorrow was continuous. Instead, it seems that it is a periodic phenomenon. In the free-form graphs the parents drew peaks and valleys of their adjustment. There were no graphs by parents showing a flat, total, and unchanging sorrow (although there were several such by social workers). The structured graphs assumed the periodicity of grieving. A list of potential crises was presented to the parents, based on the first author's theoretical formulation.<sup>14</sup> Each point related to a developmental stage of the affected child. The child's deviance from normal performance at these stages was considered to precipitate a period of stress for a family. The parental responses to this part of the ques-

tionnaire showed no decrease in the intensity of the emotions experienced with the passage of time. Instead, the level of intensity seems to be a function of the particular developmental stage, as well as of the individual coping strengths of the family.

Several problems may limit the use of the findings of this small study. The sample of parents upon which these findings are based is a nonrandom one with a possible bias. The names of the parent subjects were obtained from clinic records. This may skew the results toward encountering troubles over time when contrasted with all parents of mentally retarded children, because the access to this part of the population of parents is relatively easy. To check this problem we reviewed the results of a pilot study. A small group of eight parents from a parent organization, who volunteered to be involved in another project,<sup>13</sup> had been asked to also respond to this questionnaire. This group was less likely to be biased towards difficulties. Their responses were, however, similar to those of this study (*i.e.*, six of the eight drew graphs of chronic sorrow rather than time-bound adjustment.)

A second concern about the sample is the low number of respondents among parents who were contacted for the study. Although none of the pilot study subjects raised objections to the questionnaire, many of the total sample who were reached by phone indicated ways in which the questionnaire had made them uncomfortable. Our guess about the meaning of this is that our sample was a) coping better than the nonrespondents, b) able to distance themselves sufficiently from their own adjustment process to respond with perspective, and c) neither intimidated nor

alienated by the request to graph their feelings.

The request for graphing of feelings may itself have limited the number of respondents; graphing may have seemed an unnatural reporting of affective information, thereby limiting the validity of the findings. The direct question, "Do you experience chronic sorrow?" was considered to be a measure of internal consistency on individual parents' responses, which could help to dilute this concern. Indeed, those who graphed chronic sorrow, also said that they experienced chronic sorrow. Another internal measure of the validity of the responses were the many comments elaborating on topics of the questionnaire. Typical comments included the following:

Perhaps disappointing would be a better word than sorrow. I firmly believe we did have many peaks and valleys. There is sadness, but many joyous and funny moments too.

When I first realized my son was lagging I felt very guilty and wondered if I had somehow caused it. Then I began to tell myself that I'm too inept to cope with a retarded child, all the while I was coping with him.

I find each new crisis or situation has to be dealt with and I always pray our family has enough strength and courage to work through it. So far we have been able to keep the pace but it isn't easy.

### *Clinical Implications*

Our findings suggest, first of all, that chronic sorrow does not seem to be an abnormal response; rather, it is a normal reaction to an abnormal situation. To treat it as such entails allowing for periodic grieving, and perceiving that as a strength in coping. At those moments, when the child's abnormality is exaggerated in the parent's perception by the child's deviance from normal developmental milestones, it is especially

likely that the initial feelings of confusion and disappointment will be rekindled. Secondly, a continuum of services over the life span of the mentally retarded person should be provided. These should be adapted to the predictable developmental crises of families of retarded children pinpointed in this study. Finally, these periods may be primarily characterized by needs for information on management. These would differ according to each stage. Creative and energetic outreach programs offering support and information might prevent or alleviate the difficulties that ordinarily plague these families.

To some professionals who have worked extensively with families of mentally retarded children these recommendations may seem self-evident. However, they are based on data that has not been obvious to the majority of professionals who write about parents. Nor were the findings self-evident to the social workers surveyed in this study. In general, the social workers correctly estimated the overall degree to which the parents experienced distress. They agreed with the characterization of periodic upheavals and responded affirmatively to the direct question about chronic sorrow at approximately the same rate as the parents. This was more accurate than the literature would lead one to expect. However, in examining social workers' perceptions of responses over time, there was a significant underestimation of the intensity of the parents' difficulties in the later stages. Social workers and other professionals have primarily worked with parents of younger retarded children. This is partly a function of early institutionalization.

With the advent of deinstitutionaliza-

tion and the increase in school and community programs, there is a greater likelihood that the mentally retarded person will remain in the community. The findings of this study are particularly relevant to clinical practitioners as they plan programs for and work with families of older retarded persons.

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