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Deinstitutionalization as a Function of Interagency Planning: A Case Study

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Habilitation

Note from the Habilitation Department Editors

The papers submitted to the Habilitation department during its first year reflect a growing interest in the development of needed services for adults labeled retarded. This interest is quite understandable. The emerging national commitment to appropriate education for all children presupposes that community opportunities will be available after graduation. Existing adult programs are being asked to provide an increasing array of services, and new programs are developing in such areas as vocational training of the severely handicapped, community living arrangements, recreational programs, and a variety of other personal support services.

As these programs continue to develop, the intent of the Habilitation department is to provide useful information to persons directly involved. Two kinds of papers seem particularly well suited to this effort. The first includes descriptions of treatment procedures or program methods which have been used successfully in habilitation pro-

grams. Since it is expected that many readers will use ideas gained from these papers, they are expected to include enough detail to facilitate use of the procedure and to provide evidence which clearly supports the effectiveness of the procedure in producing habilitative gains for individuals served. The second kind of paper which appears most useful at this time relates to the *direction* of habilitation programs. These papers examine professional and public values as they relate to the objectives or directions of adult services. By making specific recommendations for program development, these papers should assist in both the development and evaluation of needed habilitation programs. For publication, these directions papers should be relatively brief (6 to 8 manuscript pages).

Included in this issue is a procedural paper by Fox and Karan which illustrates an important role for a program consultant in adult services. G.T.B. and G.J.W.

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Deinstitutionalization As a Function of Interagency Planning: A Case Study

The literature on training the mentally retarded includes ample documentation of the effectiveness of behavior modification procedures for developing a wide range of appropriate behavior patterns. One significant limitation in most studies, however, has been that relating to behavior maintenance

and generalization. Although generally acknowledged that response maintenance and generalization must be programmed directly (Kazdin, 1975) there is at present a paucity of research with the mentally retarded which provides an empirical basis for such programming. In one of the few available

studies, Keith and Lang (1974) investigated the posttraining behavior retention of 162 institutional residents and found that over 40 percent of the behaviors acquired during a 2½ year contingency management training program were lost within 3 to 26 months after training ended.

In the absence of evidence to the contrary, findings such as these have direct implications for deinstitutionalization programs which have objectives of either averting the need for extended custodial care or of returning to the community those individuals who have been trained for placement in appropriate community settings (Scheerenberger, 1974). The ultimate success of deinstitutionalization programming depends on matching habilitated individuals with the least restrictive environment which is capable of maintaining the highest degree of behavioral competence and independence.

Available community resources such as foster homes, group homes, sheltered workshops, and activity centers will be expected to support the highest competence for each individual. To complicate matters somewhat, it is unlikely that any one community resource will be able to, or even should, provide the primary supportive environment. Instead, as deinstitutionalization efforts progress it can be expected that a number of local resources may become involved with any one individual: some providing work opportunities, others providing living arrangements, still others providing recreational opportunities and so forth. The capacity to which the personnel in these settings are able to communicate on both an intra- and inter-agency level in developing effective and complementary programs will determine the degree to which each setting maintains the highest level of competence and independence for the individual.

The development of effective and complementary programming both within and among various community agencies may require the involvement of specialized liaison agents who may function as consultants (Gardner, 1967; Tharp & Wetzel, 1969) for the purpose of training and providing feedback to local community staffs (Keith & Lang, 1974); and as "middle-road researchers" (Gold, 1973) who combine the basic integrity of sound research practices

with sufficient flexibility (Reppucci & Saunders, 1974) to meet the requirements imposed by applied settings.

The Case Study

An illustration of the role and function of a liaison agent is provided in the following case study. The liaison agent worked together with the staffs of two community resources and the combined and coordinated efforts prevented the almost certain institutionalization of a young retarded woman. Prior to the implementation of the present study, the woman had experienced such extreme and pervasive behavioral regression that custodial institutionalization was viewed as the only viable living arrangement for her.

The client, Ms. K., is a 26 year old woman with Down's syndrome. From the age of 6 until the age of 18 she attended a residential training school for the mentally retarded where she acquired an impressive range of self-help, academic, and social skills. Shortly after reaching the age of 18 Ms. K. was returned to her home since school policies set an upper age limit on the students eligible for their program.

Ms. K's adjustment to home life was apparently quite successful. Her parents reported that she maintained the self-care skills she had learned, she helped with household tasks, she frequently accompanied her parents to the family business where she assisted with basic clerical duties including filing and stuffing envelopes, and she regularly participated in several of the social activities offered by the area center for the mentally retarded.

Then over a 2 year period Ms. K's behavioral repertoire slowly began deteriorating. The level of this deterioration was described by her parents in the following way:

She lacks the motivation to do anything unless forced. She spends hours at the table eating almost nothing. It takes her 3 hours to go upstairs, 2 hours a day to clean her dentures, and 4 hours to fold five towels.

In addition, the parents noted that she rarely spoke more than a few words a day and began wetting herself regularly. Medical examinations revealed no physical basis for the regressive trend.

Subsequently, Ms. K. was evaluated by a university affiliated facility (UAF) multidisciplinary team of clinical specialists at the University of Wisconsin's Harry A. Waisman Center on Mental Retardation and Human Development. Although consideration was given to implementing behavior modification programming to alter some of the contingencies which were hypothesized as maintaining her present behaviors, the priority concern at the time, over and above her extreme behavioral deterioration, was focused on Ms. K's very serious weight loss from a previously reported 115 pounds to 75 pounds. As a result Ms. K. was hospitalized and placed on a ward which specialized in treating anorexia nervosa. It was agreed that during her hospital stay alternative living arrangements would be explored since the parents felt they could no longer handle the restrictions imposed on them and other family members by Ms. K.'s helplessness.

After 10 weeks of hospitalization Ms. K.'s body weight was still near 75 pounds and no other behavioral improvements were noted. Although custodial care placement was recommended and accepted by the parents, a placement into a semi-independent group home was arranged on a strictly trial basis. Further, since one requirement of the group home was that all individuals residing there had to be working or in a rehabilitation training program, Ms. K. was simultaneously enrolled in a habilitation center for retarded citizens.

The Group Home Experience

During the first several weeks of trial placement Ms. K. required total assistance in dressing and walking in order to be ready in time for the daily bus going to the habilitation center. She wet her clothing almost daily and if left alone to eat a meal would rarely eat more than a small portion of her food even after extended periods of time. Her involvement at the habilitation center consisted of little more than walking to and from the bus, eating lunch, and toileting. These three activities alone required practically the entire day (9 a.m. to 3 p.m.) to complete. Staff members in both settings unanimously concluded that: (a) she was not

benefiting from her trial placement; (b) they could not continue to give her the time and attention she required to complete even the most minimal self-help tasks; and (c) unless some significant improvements in her behavior occurred soon, continued efforts would be questionable.

It was at this point that the specialized liaison agent became actively involved. Having been a member of the original multidisciplinary team, this individual had followed Ms. K.'s lack of progress throughout her hospitalization and into the present. On the basis of his observations it appeared as if a common feature across settings was the inconsistent manner in which people attempted to encourage Ms. K. to improve her eating, walking, toileting, and so forth.

The Liaison Agent

The liaison agent met with representatives from each community resource and as a group they attempted to obtain consensus on the nature of the client's problems while also discussing reasonable remedial approaches which could be implemented within two settings. The outcome of this meeting resulted in establishing two broad treatment objectives: (a) efforts should be directed at reversing the regressive trend of Ms. K.'s behavior patterns, and (b) Ms. K. should learn acceptable levels of performance once new behavior patterns were established.

To meet these objectives the liaison agent identified the various staff members within the two community agencies who had the most direct contact with Ms. K. Using both didactic as well as direct modeling forms of instruction (Gardner, 1972) he taught these staff members the basic techniques of behavior shaping while demonstrating the necessity for using a consistent and systematically applied treatment program. During the first few weeks after the program was implemented he provided supervision and feedback to the staffs in both settings. As they demonstrated their skill in carrying out the program the liaison agent began fading out his involvement so that an occasional visit by him was all that was required to insure that appropriate procedures were continuing.

Program Rationale and Primary Focus

The predominant feature of most of Ms. K.'s behavior was the inordinate amount of time required to complete almost any behavioral chain. Although programming efforts could have been directed at improving any of her deficit-type behaviors, the initial thrust of the program was directed at improving her eating behaviors (i.e., increasing her food intake while simultaneously decreasing the amount of time she normally required.) This focus was pinpointed for three reasons: (a) her body weight, now at 72 pounds, was dangerously close to a critical point*[†]; (b) since she usually ate her meals in three different settings, it was hypothesized that the effects of the programs would not be restricted to a specific place thus enhancing the possibilities for both behavior maintenance and generalization, and (c) since excessive time was the critical common variable across behaviors, the methodology developed to reduce her eating time would probably be directly applicable to her other behaviors as well.

Setting and Apparatus

Except for weekends, each daily meal occurred in a separate setting. The breakfast meal was served in the residential cottage which housed 9 residents and 2 house-parents. Lunch was served in a classroom at the habilitation center where Ms. K. usually ate with 5 other clients. The dinner meal was served in a community dining hall which included the residents from the entire group home setting (approximately 100 people).

The equipment used in each setting remained constant and consisted of a modified alarm clock and a 60 minute timer with an attached bell. The modification of the alarm clock included two parts: (a) the minute hand was painted a bright yellow to increase visibility, and (b) the last $\frac{1}{4}$ of the white face of the alarm clock was painted red. Since there was some question as to whether

Ms. K. could tell time, the color contrast was viewed as one way to maximize the stimulus cues which would signal that the meal time should soon be completed.

Treatment and Results

On the basis of the environmentally imposed time requirements of each agency, it was initially decided that reducing the eating time to 50 minutes was a goal compatible with Ms. K.'s participation in other activities and events. Therefore, when treatment began, as the meal was placed before Ms. K. the staff person responsible for that meal was instructed to tell her she had 50 minutes to complete it. The alarm clock was then set with the minute hand placed at the 2 position and then moved conspicuously in front of Ms. K.'s place. The timer was also set for 50 minutes and positioned behind the alarm clock so that it was not visible to Ms. K.

After the 50 minutes elapsed the timer bell rang and the staff member simply walked over to Ms. K.'s table and removed all remaining food, liquids, and utensils. If food and drink were still left, Ms. K. simply lost the opportunity to finish and had to wait until the next meal. If however, she completed the entire meal, she was verbally praised and awarded a gold adhesive star which she placed in a folder. Accumulated gold stars could subsequently be exchanged for special privileges, toys, games, jewelry, etc. The entire procedure was demonstrated within each setting and practiced by the various staff members until they were able to replicate the steps exactly.

This program strategy was utilized for all three meals, 7 days a week. A daily bodily weigh-in of Ms. K. occurred each night immediately after the dinner meal. The scale was sensitive enough to detect $\frac{1}{4}$ pound increments so that weight gains relative to the previous evening's measure were apparent and socially praised. The weight data was graphed on a weight chart located in Ms. K.'s bedroom. Each time the graph revealed a $\frac{1}{4}$ pound weight increase, Ms. K. was given a treat to be distributed among the other residents of her cottage. The daily progress on the weight chart soon became an important concern for all the residents of the cottage who became actively interested in Ms. K.'s

* Throughout the study a nutritionist and a physician were consulted and were instructed to terminate the program at any time that Ms. K.'s weight and/or general health became of serious concern.

progress and provided constant encouragement and praise for her efforts.

After reaching a pre-established criterion of eight consecutively completed meals, the 50 minute requirement was reduced to 40 minutes with all other procedures remaining the same. Ms. K. reached this new criterion consisting of six consecutively completed meals after approximately 2 weeks of continued program implementation. At the end of this period, Ms. K.'s bodily weight had reached a high of 89 pounds. It was at this time that the liaison agent reduced his involvement to an occasional contact, sometimes in person, sometimes by phone.

A 15 month follow-up revealed that Ms. K.'s weight was 100 pounds and that she was consistently completing most meals within the required 40 minutes. Additionally, at the time of this writing the clock and timer were being gradually eliminated and their function replaced by Ms. K.'s own wrist watch. This was the first step in a program to develop self-control procedures in the form of stimulus cues which Ms. K. could present to herself as she began to take more responsibility for managing her own behavior.

During the treatment phase, accumulated anecdotal information revealed concomitant improvements in many of her other behaviors as well. Staff members from both community agencies all noted substantial gains in her academic, social, self-care, and mobility skills. In fact, spontaneous conversation which was at an absolute minimum when programming was initiated increased to such an extent that her houseparents wondered whether they should implement a program to "shut her up." Perhaps of most importance is that since Ms. K.'s trial placement was successfully completed, the various staff members feel prepared to deal with new problems if they should arise, and no longer is any consideration being given to total care residential placement.

Discussion

The role of the liaison agent in the present study bears some resemblance to the role of the benefactor in Edgerton's (1967) follow-up study of 51 adults discharged from a large California state institution for the mentally retarded. The importance of the benefac-

tor's relationship to the patients in Edgerton's study was that they promoted an environment essential to encouraging and maintaining competent behaviors.

It would not be an exaggeration to conclude that, in general, the ex-patient succeeds in his efforts to sustain a life in the community only as well as he succeeds in locating and holding a benefactor. (p. 204)

There are, however, two critical distinctions between the role of specialized liaison person advocated in the present study and the benefactor. The primary distinction is that the involvement of such an individual should become an essential part of planned deinstitutionalization programming and not left to chance or circumstances. Secondly, the individuals filling this role must have specialized skills in behavior technology, applied research and intra- and interagency or trans-environmental programming (Crossen, Youngberg, & White, 1970).

As stated previously, as deinstitutionalization efforts continue, it is expected that a variety of local resources will become involved with each individual. The ability of these resources to provide programs which complement and augment rather than supplant each other's efforts may be critical to deinstitutionalization success. Communication linkages within and between agencies thus must be formally developed and encouraged to support the finest programming efforts available. At this time the specialized liaison individual may be the primary catalyst necessary for these linkages. The involvement of such individuals could provide a programming consistency across settings not often found among community resources. Once programs are under way, and staffs have been appropriately trained, it would be expected that the liaison agent's involvement would be reduced thus freeing him/her to foster the development of optimal programming for other individuals.

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