

CHAPTER 5

Accountability Systems for Protection of the Rights of Autistic Children and Youth

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NOT LONG AGO, we invited fifteen children to participate in brief interviews about their rights. The respondents ranged in age from three to fifteen years, and all attended school at the Princeton Child Development Institute, an education and treatment program for autistic children and youth.¹

The children were first asked, "Do you like to come to school?" In response to this question, fourteen children answered yes, and one child did not make a verbal response. When asked, "What else do you like?" one child did not answer; the responses of the other fourteen children were: "I like to do work," "Lunch," "I will like to play toys," "School," "To go to Room Number 14," "Do exercise," "I like my chicken, chicken is my favorite kind. I eat chicken off the bone. They were just delicious," "I like to play with the Letter Train," "For God so loved the world," "Jumping," "PCDI," "Ed," "Bathroom," and "Like school."

The third question was "Are your teachers fair to you?" Twelve children said yes, one child said, "Fair to you," one said, "Fair to," and one did not answer. This item was followed by the inquiry, "What does it mean to be fair?" When this question was posed, two children repeated the word "fair" and two gave no answers. The other children's responses were: "It means to be fair—I don't know," "Nothing," "What's this?" "It means going to Room Number 7," "Because Beth is fair—so did

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Sharon," "Because she tries to tell you," "My pair—my socks are white," "I don't know," "PCDI," "Stan," or "Teacher."

These mini-interviews were concluded by making a direct inquiry about the children's rights. When asked, "Do you have your rights?" ten children said yes, three repeated the word "rights", one said "hand", and one did not offer an answer. The final question, "What are rights?" evoked no verbal response from two children; three children repeated the word "rights," and two said "right hand." The others' replies were: "I don't know," "Nothing," "What's this?" "You can write on math or spelling or SRA Reading," "R—rights—rabbis," "I love school, and I take the chocolate milk and the regular milk and the skim milk," "Louie," and "All right."

These brief interviews serve to illustrate how the language characteristics of autistic children and youth pose special problems that must not be neglected in designing systems to protect their rights. While many—adult mental patients, persons in correctional facilities, individuals in alcohol or drug treatment programs, and educable mentally retarded children and youth—may benefit from direct instruction about their rights and be taught to make use of review and appeal processes, many autistic children and youth display a lesser ability to profit from such direct instruction, particularly at the outset of intervention. Thus, one child who participated in our interviews was unable to make any verbal response, although consistently responding with vocalizations. For him the newly acquired ability to vocalize in response to a question from another person represented substantial progress, but it will be some time before he achieves readiness for instruction about his rights.

It may also be noted that, when confronted with closed-ended questions requiring yes or no answers, most of the children made agreeing responses. These agreeing answers were offered even though children's responses to the open-ended items (e.g., "What does it mean to be fair?" and "What are rights?") revealed that they did not understand the questions. While learning to say yes, to agree, and to cooperate with others has been an important component of these children's treatment programs and has greatly improved their relationships with peers, siblings, parents, and teachers, this pattern of agreeableness does not place them in a favorable position *vis-à-vis* questions whether their rights have been violated.

Examination of children's answers to open-ended questions indicates a broad array of language delays, deficits, and excesses. Several children interviewed were echolalic, repeating portions of the questions that were asked. Some of the children displayed perseverative speech—as in going "to Room Number 14" or "to Room Number 7." Many of the children offered one-word answers or brief phrases, having not yet developed the skills requisite for complex, descriptive, or "paraphrastic" speech.

While an important program goal must be to assist children in acquiring the linguistic and conceptual skills that will enable them to receive direct instruction about their rights, participate in the selection of educational and treatment goals, and give informed consent, their current language development problems must be taken into account in developing more immediate procedures for the protection of their rights.

In addition to the language characteristics discussed above, a variety of other behavioral characteristics of autistic children and youth tend to limit their access to traditional protective mechanisms. Many children entering treatment display severe behavior problems such as physical aggression, self-injurious behaviors or destruction of home furnishings, and highly repetitive self-stimulatory responses such as twirling, rocking, or spinning objects; these behaviors tend to evoke disengagement, disapproval, or even active hostility from others.

This difficult situation is often compounded by many youngsters' affective deficits—that is, they do not enjoy the company of others and have not learned to value adult attention. They must be taught, first to tolerate, and later to enjoy physical contact; to express affection or liking for others; to give compliments; and to value social attention and praise.

The absence of appropriate affective behavior from children's repertoires is especially salient because it portends that they are unable to employ those social interaction skills that could serve to attenuate others' disapproval and hostility. Unfortunately, these "others"—parents, guardians, teachers, and treatment personnel—who display disappointment and disengagement are often precisely those individuals who have the greatest responsibility for safeguarding the children's rights and for giving consent and making decisions regarding treatment goals and strategies.

The serious implications of this interaction between children's behavior problems and adults' responses to them must not be underestimated; even the most competent parents, teachers, and therapists occasionally report feeling that children's extreme inappropriate behaviors are maliciously directed at them. Although almost all parents and human-services providers probably experience such feelings occasionally, it does not seem unreasonable to hypothesize that this experience may be encountered somewhat more frequently by persons working with autistic children and youth, due to the severe and extraordinary problems characteristic of this population. An adequate system for the preservation of children's rights must undertake to protect them from decisions that may be made during adults' periods of disappointment or disengagement.

Finally, autistic children's dependency tends to limit their access to traditional protective systems. In this respect, their problems resemble those of chronic institutionalized mental patients, nursing home resi-

dents, or severely or profoundly retarded persons. Deficits in self-care, home maintenance, or community-living skills contribute to placement in institutions, special education programs, or treatment agencies where, unless special precautions are taken, individuals may have low visibility to other members of society and low access to reviewers and advocates. Some very special systems are needed to protect the rights of persons who cannot yet count the number of meals served per day, have not yet learned to discriminate between clean and dirty bed linen, and do not yet understand the uses of banks, post offices, and stores.

From Ethical Concerns to Functional Protective Systems

Although the literature pertaining specifically to the rights of autistic persons is still quite small (Lovaas, 1978, p. 377; National Society for Autistic Children, 1975; Ritvo, 1976; Sullivan, 1976), there is growing consensus in the human services field as a whole about those ethical issues that require attention. Questions that must be continuously raised and answered include these: Is intervention justified? Has informed and non-coerced consent been obtained? (Martin, 1975) Are treatment goals and methods appropriately selected and sufficiently specified? Are client rights of confidentiality and anonymity protected? Is the adequacy of treatment evaluated? (Association for the Advancement of Behavior Therapy, 1977.) Are there individualized habilitation plans for each client? Are there adequate provisions for ongoing program monitoring, program review, and program evaluation? (National Association for Retarded Citizens, 1976.)

It is not always easy to translate ethical concerns and program guidelines into effective systems for the protection of client rights. How can the consumers or potential consumers of program services know whether a treatment agency really offers individualized instruction and treatment programs? How can consumers and other members of the community make informed judgments about whether treatment goals have been appropriately selected? Assuming that individualized programming is available, how can large numbers of individualized programs be effectively reviewed and their results summarized? (The problem of how to evaluate the data obtained from many single-subject interventions has been a troublesome issue for some time.) How can someone external to the treatment agency know whether there is a need for the services being provided, and whether the program is responsive to consumers' input and feedback?

Just as there has been growing consensus about ethical issues pertaining to the rights of autistic persons, so has there been increasing agreement on the importance of developing accountability systems that

can protect those rights. Programs that currently offer individualized habilitation plans may already be producing data on treatment effects and client progress. Indeed, the day-to-day operation of a good human-services agency usually produces a broad array of data about program processes and products. To the extent that such data can be efficiently collected, accurately summarized, and effectively disseminated, they can serve as an assurance of program accountability and protection of client rights, by facilitating ongoing public review by consumers and various other community representatives.

The Annual Report: Framework for a Protective System

The use of an annual report to convey information about a program's personnel, accomplishments, new or expanded services, and funding problems or prospects is not a new idea. Many agencies already have annual reports that serve as newsletters, financial reports, funding requests, or informational brochures. However, insofar as the annual report is also used as a vehicle for presenting specific, objective data to outside parties—parents, representatives of referral or funding agencies, members of advisory or review boards, peer reviewers, potential consumers, and other members of the community—it may also serve as a system for preserving client rights.² (Martin, 1975, p. 100).

The types of data to be included in an annual report that can function as a protection system should be determined primarily by (1) the professional literature on program development and operation, treatment strategies, and the ethics of intervention; (2) current legal standards; (3) federal and state program guidelines and guidelines developed by such consumer groups as the National Society for Autistic Children and the National Association for Retarded Citizens; and (4) local community norms and expectations about behavior problems and appropriate treatment services.

Some types of program data, such as staff turnover rates, staff-client ratios, absenteeism, lost-time accidents and work-related injuries, are probably already being collected on a regular basis and are easily summarized and presented. Other data (e.g., data on internship programs) may be regularly collected, but are perhaps less readily summarized. Still other measures, such as measures of follow-up services or information dissemination activities, may require the development of new data collection procedures. And finally, certain aspects of the proposed protection system—such as measures of the acquisition of new skills that would help autistic children and youth participate in the protection of their

² A model for an annual report and training sequences relevant to the implementation of the protective system can be obtained from the authors.

rights—may require the development of new services, new data collection activities, and new procedures for summarizing and reporting data.

Perhaps most difficult, the program administrator, advocate, or human-services professional will be faced with the need to balance the desired comprehensiveness of the protective system against current parameters of cost and personnel resources. Although these tasks are not always easy, the outcome, effective preservation of the rights of autistic children and youth, is laden with social significance.

Components of the Protective System:

Measures of Program Processes and Products

While some students of program evaluation contend that variables pertaining to program processes are unimportant, and that only client behavior change should be studied in assessing program accountability, we do not share that assumption. Services to autistic children and youth have a relatively recent, brief history, and the absence of comparative data from different treatment agencies means that there are few guidelines for determining what levels of behavior change constitute "good" or "poor" outcomes for this difficult-to-treat population. Under these circumstances, it appears important to include data on the independent variables (e.g., amount and types of service, utilization of personnel and financial resources) as well as the dependent variables (e.g., skills acquired, inappropriate behaviors controlled, and post-treatment outcomes) in an overall evaluation of program effectiveness and monitoring of client rights.

The sections that follow outline several broad areas of program operation and outcome that provide raw material for the construction of data-based accountability systems critical to the protection of client rights. Within each of these areas, specific measures are enumerated and described, and rationales for selecting such measures are discussed.

MEASURES RELATED TO THE PROVISION OF EDUCATION AND TREATMENT SERVICES

Numbers and Types of Individualized Instruction and Treatment Programs.

An individualized instruction or treatment program may be said to exist if the client's file contains (1) a written response definition that provides an objective description of the skill deficit or behavior problem, (2) a specified data collection procedure, (3) a specified teaching or treatment procedure, and (4) data sheets and a graph or other form of data summary. It often proves useful to maintain each of these sets of

documents as a separate section in the client's folder, so that data on numbers and types of individualized programs can be readily retrieved. Data summarization is straightforward and merely involves listing each individualized program of each client. It will be useful for program reviewers and community representatives to know the total number of individualized programs implemented during the reporting period, as well as the mean number of individualized programs per client. These measures offer documentation that the agency does in fact provide individualized habilitation plans.

In addition, a complete list of individualized programs could be reported. This can be done in tabular form showing the number of clients for whom each type of program has been implemented. In the case of autistic children, it is especially important that lists of instructional and treatment programs should include both new skills acquired and behavior problems overcome. Ideally, these two types of program will receive at least equal attention. An agency that places a great deal of emphasis on treatment of inappropriate behavior but little emphasis on skill acquisition programs may run the risk of creating an unpleasant environment for clients, and may be perceived by community members as unnecessarily punitive.

The availability of this list of individualized programs enables consumers and program evaluators to make their own decisions about whether children's instruction and treatment goals have been appropriately selected, thus helping assure that this area of client rights is monitored. Experience suggests that community representatives can be excellent judges of the social validity of behavior change goals.

External Evaluators' Ratings of Individualized Programs. The reader will have noted that we have not thus far discussed the success or failure of individualized programs, but merely how many and what types of program are provided. Unfortunately, current technology in the field does not offer solutions to all of the problems presented by autistic children, and even the best of human-service professionals occasionally discover that they do not know how to teach a particular child to use functional speech, or how to teach another child to read, or how to help a particular youth control facial grimacing or noncontextual giggling. Since most practitioners working with autistic populations will from time to time experience failure with respect to certain treatment goals for particular children, and since little is known of what constitutes a "high," "average," or "low" failure rate, it seems appropriate to employ some measures that are related not to treatment outcome but only to the availability of services that autistic children have a right to receive. On the other hand, neither can issues concerning the effectiveness of treatment be ignored; there is no rationale for the existence of a treat-

ment agency that does not change behavior, and it is therefore necessary to examine the effects of individualized programs.

The problems of how to evaluate large numbers of individualized educational and treatment programs were mentioned previously. Single-subject designs do not at first glance appear to lend themselves to the development of generalizations about the effects of treatment, but since they usually constitute the real substance of autistic children's treatment it is important to develop methods that permit summary of these data. One solution to this problem is to select an evaluator external to the treatment agency and request that this individual examine the individualized programs for each client and rate each of these programs along certain dimensions. Dimensions to be evaluated and rated might include (1) Does the client's record contain a written-response definition that provides a specific and objective description of the skill to be acquired or the behavior to be changed? (2) Is there a written description of the data collection procedure? (3) Has the data collection procedure been appropriately selected for this client and this behavior? (4) Is there a written description of the instruction or treatment procedure? (5) Has the intervention procedure been appropriately selected for this client and this behavior? (6) Does the client's record contain a graph or other form of data summary that displays previous and current levels of the target behavior? (7) Has the client's behavior changed since the intervention procedure was implemented? If so, was this behavior change in a desired or an undesired direction? and (8) Are changes needed in data analysis or summarizing procedures? The results of such an evaluation are readily summarized, and are easily understood by most lay and professional audiences.

Several words of caution may be in order as regards undertaking this evaluation procedure. First, the selection of an evaluator external to the treatment agency is a rather sensitive task. The evaluator should have widely recognized professional credentials, should be known and accepted in the field, and should be personally acquainted with the literature on autism and with the characteristics of autistic populations. It is also important that there be mutual respect between the evaluator and members of the governing and review boards, program administrators and staff members, and consumers and their parents or other representatives. Unless there is broad agreement on the selection of the evaluator, the results of the evaluation may receive little credence.

Second, definitions of the evaluator role and the functions of evaluation may be significant determinants of how well the evaluation will be received by staff members. Evaluation of large numbers of individualized programs almost inevitably brings the evaluator into contact with teachers, therapists, and other direct-service personnel who have primary responsibility for designing and implementing client programs and

gathering and analyzing performance data. With adequate preparation, the evaluation can become an important part of the agency's staff-development program, since it sets the occasion for practitioners to receive acknowledgment of their work as well as specific feedback about instructional strategies and treatment technology. Thus, it is important to select an evaluator who can achieve warm and reassuring interactions with program personnel and deliver corrective feedback without becoming excessively demanding or punitive. Finally, to further guarantee that the evaluation can serve a staff-development function, program administrators should provide strong assurances that omissions or errors in programming that come to light during the evaluation will not set the occasion for informal punishment or formal disciplinary action but will be used to design additional learning opportunities for program personnel.

Third, the administrator must attempt to reconcile the completeness of the evaluation with the costs incurred. Experience suggests that an appropriately qualified evaluator may be able to examine and rate as many as twenty-five or thirty different individualized programs for autistic children in one work day. In a small group home, school, or treatment program, it may be necessary to purchase only from one to three days of a consultant's time in order to obtain a complete review of all individualized programs. This level of completeness is highly desirable because it verifies that each individual receiving program services has a set of individualized programs, and that the appropriateness of each of these programs has been examined. In a larger treatment agency, however, funds may be insufficient to purchase the amount of consulting time needed to review every individualized habilitation program, and it may therefore be necessary to enlist the consultant's aid in devising a method of randomly selecting a subset of client programs for evaluation. In the latter case, the evaluation can retain its in-service training function as well as its protective function if the records are sampled not only by the evaluator but also by the staff member responsible for providing programs and collecting and recording data.

Finally, those who instigate and participate in this type of evaluation should acknowledge at the outset that not all findings will be positive. There are no perfect human services programs. However, it is only by disseminating complete evaluation data that the evaluation process serves a genuine protective function. And, if presented in their entirety, the data can contribute to the achievement of a broader goal—the development of a body of normative data on program operation and outcome that will eventually enable consumers, reviewers, and community representatives to make more informed and enlightened decisions about what constitutes a "good" or "poor" behavior change program for autistic children and youth.

Test-Retest Scores on Standardized Instruments. Traditional uses of standardized tests with autistic children and youth present a discouraging picture; a large majority of children are designated "untestable" on standardized intelligence tests such as the Stanford-Binet and Leiter, and they typically score between the second and third year on instruments such as the Vineland Social Maturity Scale (Rincover, Koegel, & Russo, 1978). In the present context, however, these traditional uses of standardized tests are perhaps less interesting than the possibility of employing them as repeated measures of the children's acquisition of new skills as they progress through a treatment program.

For example, the Peabody Picture Vocabulary Test, Vineland Social Maturity Scale, or Preschool Attainment Record may be administered to an autistic child upon his or her entry into treatment, and then periodically readministered in order to document the child's acquisition of language or social skills that were not displayed at the outset. Similarly, children may be initially tested and periodically retested on standardized measures of academic achievement (e.g., Key Math Test or Peabody Individual Achievement Test), so that their educational progress may be regularly reviewed. These test scores, like other measures discussed earlier, could contribute to the development of a body of normative data on treatment outcomes for autistic children, while simultaneously serving as a benchmark in the evaluation of individual service agencies.

Anecdotal Accounts of Children's Progress. The earlier emphasis on measurement of program processes and products notwithstanding, it often happens that not all consumers, board members, or community representatives have acquired a taste for data. These individuals may, however, be quite responsive to case studies. Thus it may be possible to substantially broaden the audience for the annual report (and concomitantly for the protective system) by including descriptive materials relevant to autistic children's progress.

Such case study information should be generated by describing the earliest and most recent data points on children's behavior change. This approach permits empirically inclined reviewers and evaluators to validate the written descriptions by tying them to the original data from which they were derived. Most programs for autistic children and youth seem to have favorite "success stories," and the telling of these is often important to parents, staff members, and members of the governing board, who should be encouraged to take active roles in the protection of children's rights.

Measures of Parent-Training Services. Many established and well-known programs for autistic children place heavy emphasis on parent-training activities (Freeman & Rivo, 1976; Hensley, Howlin, Berger,

Hershey, Holbrook, Rutter, & Yule, 1978; Lovaas, 1978; Lovaas, Koegel, Simmons, & Long, 1973; Nordquist & Wahler, 1973; Rincover & Koegel, 1977; Rincover et al., 1978). Given the severity of these children's problems and their difficulties in generalizing new skills, the ongoing involvement of parents can be critical to their survival in community environments. Trained parents, serving as at-home tutors and therapists for their own children, can significantly increase the total amount of intervention available, and can ensure continuity of program implementation. Thus, the provision of effective parent-training services contributes importantly to the protection of autistic children's rights, by maintaining children in "least restrictive" education and treatment environments (i.e., families and day schools, as opposed to institutional placements).

Process measures of parent-training services may include (1) number of parent-training meetings held, (2) number or mean number of parents in attendance at group training meetings, (3) number of individualized parent-training sessions, (4) mean number of individualized training sessions per family, (5) number of hours of individualized parent-training services delivered, and (6) mean number of hours of individualized training per family.

Some important outcome measures of parent training include the number or mean number of home instruction and treatment programs implemented by parents (employing the definition of "individualized program" advanced on p. 88). A variety of definitions of "individualized program" is possible, but one of the most straightforward is based upon the number or percentage of completed home data sheets submitted by families to the parents' trainers or home programmers. Including also a list of these home instruction and treatment programs implemented by parents in this outcome reporting will make an important contribution to the protective system, by enabling professionals, community representatives, and parents of referred children to examine home treatment goals and assess their appropriateness and social significance. In addition, if parents' data on home programs are regularly graphed or summarized, external evaluators and reviewers can employ the rating procedure described above, in order to determine the effectiveness of home programs in achieving child behavior change.

Measures of Community-Entry Services. Most persons acquainted with the problems of autistic children and youth agree that a "sink or swim" philosophy is not the preferred approach to helping them enter the mainstream. Typically, these children require extensive special programming if community entry is to meet with success. One strategy for helping them become integrated into public school classes was reported by Russo and Koegel (1977): after some pretraining sessions to establish tokens as reinforcers, a therapist attended the child's kindergarten classroom to

provide treatment. After ten weeks the classroom teacher was trained in behavioral techniques, and later was able to maintain the child's appropriate classroom behavior. Although some retreatment by the therapist was required at the beginning of first grade, the child's performance was maintained during her second and third grade years with different teachers. A primary advantage of this approach is that it may circumvent the extreme restrictions of stimulus control and generalization deficits that are characteristic of autistic children (cf. Koegel & Rincover, 1974).

An alternative mainstreaming strategy involves the provision of individualized programs of gradual transition from special treatment environments to "normalized" community settings. For example, children enrolled in the programs of the Princeton Child Development Institute who achieve readiness for community entry attend the Institute's special education classes for part of each day, and participate in normal pre-schools, in public school classrooms, or in after-school recreation programs for the remainder of the day. In these cases, transition programs include special monitoring and reporting procedures (e.g., school notes and direct observation of the children in community programs), as well as special instruction and therapy in the treatment environment or in the mainstream setting. As children's appropriate performances become more stable, the amount of time spent in normal settings is gradually increased, and the extrinsic reinforcers, such as tokens, are faded.

Since special programming appears critical to autistic children's successful community entry, it is essential to provide public reports on the availability and effectiveness of these services that try to help them move to and remain in "least restrictive" environments. Process measures of community-entry services include the number of children to whom transition services have been provided, as well as the number of individualized transition programs implemented. It is also relevant to report the number of training or consulting sessions provided to receiving personnel—such as public school teachers, scoutmasters, recreation directors, and others. And, finally, some measure of the number of hours of direct observation of the children participating in community programs is important. These data are critical to the development of child protective systems, because they document that children are not segregated from normal peers who may serve as role models, nor are they deprived of exposure to regular classroom curricula and materials (Russo & Koegel, 1977). In addition, such data offer evidence that human services agencies are not stable and self-perpetuating but instead encouraging of movement through and out of their programs.

Outcome data on community entry may be based upon out-of-house reviewers' evaluation of data on the children's performance in community settings, as described previously. Of course, the best outcome measure of community-entry services is the number of children who re-

ceive positive discharge from special treatment programs, and the number who continue to function effectively in the community. These considerations lead to a final area of measurement of instruction and therapy services.

Follow-up Measures. A now-classic discussion of generalization and follow-up measures (Lovaas et al., 1973) offers convincing evidence that autistic children discharged to non-treatment environments (such as state hospitals) lost what they had gained during treatment, whereas children discharged to their parents (who had been trained in behavior management procedures) maintained their new skills or showed further improvement. These data strongly suggest that parent-training and transition services are necessary conditions for follow-up measures to yield encouraging results.

This pioneer work by Lovaas et al. (1973) employed measures of self-stimulation, echolalia, appropriate verbal behavior, social nonverbal behavior, and appropriate play obtained before, during, and after treatment. Although these investigators used an automated button-panel with a direct computer hookup to measure frequency, duration, and interaction of target responses, agencies with lesser access to hardware may find that a procedure of time-sampling within intervals produces similar information with only minor revisions of the original protocols.

Not infrequently, social, economic, and political contingencies influence children's treatment in ways that render the interpretation of follow-up data difficult. In some cases, compliance with conditions of funding may prohibit a human services agency from rejecting a referred child who has been inappropriately diagnosed as autistic. And although it appears obvious that a child whose parents seek training will be in a better position vis-à-vis outcome than one whose parents reject it, and that a child removed from a program during the early months of intervention will fare less well on follow-up than one who completes treatment and pursues a planned program of community entry, many agencies may have little control over parent involvement or child tenure in their programs. Since such issues strongly affect outcome, it is incumbent on treatment agencies to develop reliable definitions of positive and negative discharge. Definitions of positive discharge often rest on performance data indicating that a child has achieved treatment goals and is able to display target skills in community settings as well as the treatment environment. Discharges may be defined as negative if, for example, (1) a youth has attained a chronological age that requires exit from the program, although performance data indicate that treatment goals have not been achieved, (2) a child develops a chronic illness or other severe handicapping condition requiring transfer to a medical facility, although treatment goals have not been met, (3) the child's parents fail to exhibit

a specified level of participation in training activities over a specified period of time, (4) parents or guardians request the child's discharge, although performance data indicate continued need for intervention, or (5) after extended enrollment in the program, data on the child's individualized programs show little or no progress in achieving treatment goals. Although differing program philosophies and differing referral and funding sources may require differing definitions of discharge, careful attention to discharge taxonomy should contribute to the understanding of follow-up data and should also facilitate the development of a body of descriptive data on post-treatment outcomes against which individual agencies can assess their follow-up results.

While the importance of direct observation of children's post-treatment performance cannot be underestimated, additional follow-up data may be obtained by asking parents, foster parents, or other responsible adults to periodically rate the child's performance with regard to each of their original treatment goals. For example, parents of children positively discharged from the Princeton Child Development Institute are interviewed three, six, twelve, eighteen, and twenty-four months post-treatment, and annually thereafter. During these interviews, parents are asked to assign satisfaction ratings to each of the target behaviors treated. This rating procedure appears to pick up low-rate or situation-specific behavior problems (e.g., sleep disruptions, feces smearing, attacks on particular persons) that might not occur during follow-up observation sessions but might be critical to children's ability to remain in "least restrictive" environments. A follow-up system providing early detection of such problems permits the delivery of consultation and re-treatment services that contribute to children's survival in community placements. Because of their potential contributions to the protection of children's rights, the presence of these follow-up systems should be noted in the annual report.

MEASURES OF EXTERNAL PROGRAM MONITORING

For the most part, programs for autistic children and youth may employ the same instruction and treatment strategies offered children with other handicapping conditions, although programming must often be more highly structured, systematic, and continuous. Under these circumstances many autistic children will respond well to intervention, but some, unfortunately, will not. These exceptions are encountered sufficiently often to merit considerable attention. Indeed, it appears that a characteristic of autistic populations—in comparison with other populations of disabled children—is their comparatively higher rate of failure to respond to a rather standard set of behavior management procedures,

such as positive reinforcement (Foxy, 1977; Foxy & Arin, 1973) and time-out from positive reinforcement (Plummer, Baer & LeBlanc, 1977). Acknowledging these treatment problems, the National Society for Autistic Children recently reported that autistic children's presenting behavior problems "may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies" (1978).

Aggressive behavior, self-injury, and excessive self-stimulation often head the list of difficult-behavior-management issues. It has been noted that when self-stimulatory behaviors decrease, other more appropriate behaviors may increase (Ristey, 1968), and some investigators have reported autistic children who did not exhibit discrimination learning or appropriate play behaviors until self-stimulation was suppressed (cf. Koegel & Covert, 1972; Koegel, Firestone, Kramme, & Dunlap, 1974). Such data have led some researchers to the hypothesis that "elimination of self-stimulatory behavior may be a necessary prerequisite to the establishment of new appropriate behaviors" (Koegel & Covert, 1972).

It is assumed, of course, that behavior reduction procedures will not be attempted by responsible researchers and professionals unless other avenues of intervention have been fully explored and documented as ineffective in producing a behavior change considered critical to a child's present welfare and continued progress. It is also evident that some punishment procedures are highly preferred over others, based upon the extent to which the variables included in a treatment package lend themselves to precise measurement and replication. Further, it is assumed that aversive procedures should be implemented only if informed and noncoerced consent has been obtained.

Apart from all of these important precautions, however, the continuation of particular interventions and indeed the continued existence of particular treatment agencies may ultimately rest upon how treatment processes are viewed and interpreted by community representatives. Because programs for autistic children must be highly structured, and because behavior reduction strategies must sometimes be employed, misunderstandings sometimes arise. Regular on-site contact with visitors, observers, parents, interns, members of governing and review boards, and others can serve both preventive and ameliorative functions by providing essential information about how treatment activities are perceived by persons outside the program. Positive feedback from persons external to the agency can offer social validation and the assurance that treatment strategies are viewed as meaningful and appropriate. Negative feedback from these community members can offer opportunities for error correction and program revision in order to ensure the maintenance of good community relationships.

In most cases, external monitoring is easy to arrange. Many parents,

educators, medical and nursing personnel, and members of the media find autism an intriguing and unfamiliar area, and frequently request opportunities to visit the treatment setting. High school and college students who are developing careers in psychology, special education, speech or occupational therapy, or other disciplines may welcome opportunities to intern in the program. And, finally, local professionals such as attorneys, advocates, social workers, and politicians often find that service on the agency's governing, advisory, or review boards contributes to their experience and credentials. The interest typically displayed by these individuals of diverse backgrounds recommends them as observers of program processes, and permits a variety of measures of external program monitoring.

Parents' Visits. Parents are especially important visitors because their observations of their own children's instruction and treatment programs helps guarantee that informed consent has indeed been obtained. Both the number of children whose parents have visited and the number of visits are easily reported.

Internships. Local high school and college students and community volunteers who wish to participate in on-site internships or field experiences can enhance the agency's programs in many ways—by serving as observers, data collectors, or teacher aides. In addition, since many of these young people will be preparing for human services careers, they are particularly valuable as program monitors; frequently, they approach internship experiences with a great deal of humanitarian concern for autistic children's rights and welfare, and tend to ask many questions and display interest in many different dimensions of program operation. Their presence in the treatment setting often places regular staff members in the roles of trainers and models demonstrating the correct implementation of instruction and therapy procedures for the benefit of the trainees. And since many undergraduate and graduate students earn academic credit for their on-site experiences, their participation in field-work seminars and their reports to faculty members may occasion informal (and cost-free) program review by professionals in the community.

Measures of interns' program-monitoring functions may include (1) number of students or community volunteers who participated in internships, (2) days of the week when interns were on site, and (3) number of hours of on-site observation completed. To the extent that interns' institutional affiliations and educational levels are perceived as related to program-monitoring capabilities, it may be useful to provide consumers with this information as well.

Visitors. Some programs regard visits as interruptions in the routine delivery of services; in programs for autistic children, however, outsiders' visits to the treatment setting may be turned to advantage by using them as opportunities for children to practice specific social skills, such as greetings, introductions, and descriptions of their usual activities. The presence of new faces offers chances to help children achieve stimulus generalization with regard to many different social interaction tasks. And visitors, like parents and interns, can contribute to program monitoring. Obviously, a program receiving only 2 visitors per year would be regarded quite differently than would a program receiving 200 visitors; consumers and community representatives would rightly perceive the former agency as closed and insular, and the latter as more open and concerned with community education and coordination of services.

Press Coverage. The mysteries of autism's etiology, the extreme disparities in skill levels displayed by some autistic children, and the extraordinary success of some lend themselves to human-interest stories. Media reporters, whose training encourages them to look beyond press releases and public statements, can serve as excellent program monitors. Thus, in the annual report that serves as a protective mechanism an additional measure that may be included is the number of times that newspaper, magazine, radio, and television coverage has been obtained. With sufficient attention to the process and outcome measures discussed earlier, it would ideally be unnecessary to report the ratio of favorable to unfavorable media presentations.

The measures of external program monitoring enumerated above are by no means comprehensive; it is also important to report, for example, on peer review processes and meetings of the agency's governing and advisory boards. Most of us have heard stories of human services agencies whose intervention programs were regarded as grossly inappropriate; in most cases, these "deviant" agencies tend to be clothed in secrecy and cut off from public review and feedback. Attention to external monitoring of program operation can help to ensure that services to autistic children remain consistent with local community norms and expectations, and are integrated with larger human services systems in the county and state.

CONSUMER EVALUATION

There is a rapidly growing literature on consumer evaluation (e.g., Clark, Greene, Macrae, McNees, Davis, & Risley, 1977; Minkin, Brauk-

nann, Minkin, Timbers, Timbers, Fixsen, Phillips, & Wolf, 1976; Stokes & Fawcett, 1977; Willner, Brauckmann, Kirgin, Fixsen, Phillips, & Wolf, 1977). Consumers, their representatives, and members of the larger community are increasingly being invited to participate in evaluating the social significance of treatment goals, the appropriateness of intervention procedures, and the importance of treatment results (Wolf, 1978). In this context, the Teaching Family Model of group home treatment delivers special attention, because it offers tested and readily adaptable strategies for obtaining consumer feedback (Lassiter, 1978; Phillips, Phillips, Fixsen, & Wolf, 1972; Schneider & Lassiter, 1978). Implementation of this evaluation paradigm involves asking the members of various consumer groups to respond to brief questionnaires, indicating their satisfaction or dissatisfaction with program services on Likert-type rating scales. This procedure yields a great deal of evaluation data at relatively low cost.

It is advantageous to use the broadest possible definition of "consumer," since this results in maximum feedback and—if the data are publicly disseminated via the annual report—maximum protection of children's rights. In programs for autistic children, the most immediate consumers of program services—the children themselves—are often unable to respond to evaluation instruments of the type under discussion, and must therefore be represented by parents, foster parents, guardians, or responsible relatives. Parents' sustained and intimate interactions with their children and their regular associations with program personnel give them an excellent vantage point from which to assess program operation and outcome. Representatives of referral and funding agencies (e.g., social workers in public agencies and personnel in the children's local school districts) are also primary consumers, and similar data may be obtained from them. Since neighborhood sentiment can potentially determine the initial development and continued operation of community-based programs, neighbors' feedback is also significant. Neighbors are in an optimal position to evaluate the program's impact on, and acceptance by, members of the local community.

Beyond these obvious consumer groups, there are several other groups frequently and extensively influenced by program quality. The appropriateness and effectiveness of program services directly affect members of the governing and review boards. Similarly, students participating in internships and teachers and therapists employed by the program are regular consumers of training services, as well as consumers of one another's work activities. These individuals, who observe the effects of policy decisions as well as the moment-to-moment implementation of instruction and treatment programs, are especially well qualified to evaluate program administration, co-workers' professional skills, and service delivery.

In sum, consumer feedback can be an invaluable program resource,

permitting ongoing revision of service delivery systems, correction of errors, and development of new services. Dissemination of consumer-satisfaction data via the annual report can contribute significantly to the protection of autistic children's rights.

CONSUMER DEMAND FOR SERVICES

Helping agencies should not be self-perpetuating but should provide specific services for which there is consumer demand. Reporting the number of referrals received and the number accepted or rejected per year assists in documenting the level of community need for the agency's services, and enables persons outside the program to evaluate the appropriateness of shrinkage, expansion, or maintenance of intervention activities. And because even the most well-meaning service providers have been known to become ensnared in bureaucratic entanglements to the detriment of their clients welfare, it is important to also report the mean number of days in the period from the time a referral is received to the time a decision on acceptance or rejection is made and communicated to the client or representatives. A relatively short mean time between receipt of referral and communication of decision shows that clients who may be badly in need of service are not being wait-listed and denied opportunities for early or rapid intervention.

Professional ethics binds service providers to offer intervention without regard to religious affiliation, race, or national origin. Beyond these obviously important considerations, agency policy may require that decisions on acceptance or rejection be made within specific parameters or age, gender, financial eligibility, place of residence, and so on. Reporting on receipt and disposition of referrals by age, sex, ethnicity, residence, religious preference, and similar variables can document that agency policy is being correctly implemented, and can simultaneously show that no subgroups within the referral pool are targets for discrimination. Nondiscriminatory decision-making on referrals can be further documented by public presentation of the reasons for rejection of referred children.

HELPING CHILDREN PROTECT THEIR OWN RIGHTS

Prior to intervention, most autistic children and youths display a virtual absence of self-protection resources. As children embark upon treatment programs that will help them learn to follow instructions, control undesired behaviors, engage in motor and verbal imitations activities, and begin to use functional speech, their learning experiences

should also include skill-building activities expressly designed to help them protect their own rights.

At the most basic level, language development programs should include training in the correct use of "yes" and "no," how to request and transfer information, giving accounts of everyday events, and expressing simple desires (cf. Lovaas, 1977). As children display increasing skill, training may broaden to include more detailed descriptions of activities and events, recall of events that are temporally more remote, and expressions of appropriate disagreement—e.g., "No, this is not a———," "No thank you," "I'd rather not," or "I don't think so."

Because many autistic children do not initially enjoy social contact, they are often excluded from the ongoing personal interactions that help normal children learn to attend to and report on their physical and emotional states. Consequently, autistic children may need special instruction on how to report illness or injury or how to communicate emotional affect, as in statements of happiness, pride, worry, anxiety, anger, fear, or affection. In addition, they may also need training in order to identify certain situations or events as "dangerous," "bad," "threatening," "illegal," or "punishing."

Before treatment, many autistic children have been passive recipients of care, rarely expressing preferences or making choices among objects, events, or activities. Therefore, training in decision making is often needed. Such instruction may begin at the level of asking children to make simple choices between a few visible objects: "What shall we have for snack—these cookies or this can of beets?" or "What do you want to buy with your tokens?" As children gain proficiency they should be encouraged to make more complex choices, such as where to go on an outing; what to buy with allowance money, or what to wear to a party. Decision-making skills should be gradually elaborated to lead toward participation in self-government (see Phillips et al., 1972).

As children acquire the requisite skills, they should also receive explicit instruction on day-to-day human rights. Even children in comparatively early stages of language development can learn to respond to questions about fairness, such as "Is it fair for Johnny to take your toys away?" "Would it be fair if you didn't get to play outside?" or "Is it fair for you to have a nice lunch?" Of course, children at more advanced levels of receptive and expressive language development should receive direct instruction in client rights and in review and appeal mechanisms. And, commensurate with their readiness, children's programs should include expanding contacts with community members and increasing opportunities to gain awareness and understanding of the roles of police officer, social worker, bank teller, physician, attorney, and advocate. Finally, programs for helping children protect their own rights should cultivate those skills that will ultimately enable some clients to partici-

pate in consumer evaluation of program services (cf. Phillips, et al., 1972; Quillich, 1978; Willner et al., 1977).

Conclusion

The above-described measures of program processes and products are by no means inclusive; many additional measures could contribute importantly to the protective system. For example, measures of staff performance—including praise rates, nag rates, teacher-generated opportunities for children's response, and minutes of transition time between scheduled instructional activities—could give program reviewers and community representatives additional information to be used in the evaluation of program services. Similarly, measures of information dissemination—such as listing community organizations in which program staff members regularly participate, number of professional meetings attended, number of presentations made at conventions, and number of manuscripts accepted for publication—may help others outside the program evaluate the extent to which program personnel share information, cooperate with other human services agencies, and keep abreast of current developments in their fields.

All such measures can serve a double protective function. First, they provide program staff with data-based feedback that facilitates program development and modification; and, second, they enable others to evaluate program processes and outcomes. Neither of these opportunities should be overlooked. Obviously, data are useful to program personnel only insofar as they are carefully scrutinized and subsequently utilized in program monitoring, troubleshooting, and making policy and clinical decisions. And it is equally obvious that data are useful to community representatives and external reviewers and evaluators only if they receive broad public distribution. Construction of the proposed system for the protection of children's rights is a worthwhile activity only if agency heads commit themselves to the widest possible dissemination of data, via the annual report or a similar vehicle.

Those who anticipate adoption of this protection system should be forewarned that maintenance must be programmed if the system is to remain viable and operative. Initial attention to the issues of when, where, how, and by whom data are to be gathered and recorded will have long-term positive results. In addition, teachers, therapists, home programmers, secretaries, and administrative assistants who feed data into the system will need initial and ongoing training in order to insure complete and correct data collection. Although the foregoing pages do not include discussions of reliability, most of the measures described above readily lend themselves to reliability estimates; presentation of levels of inter-

observer agreement on each of these variables will greatly enhance the overall credibility of the protective system. Last but not least, program administrators or their designees must plan to allot sufficient time for the preparation of the annual report that disseminates these data.

Although the proposed system undeniably involves certain costs in terms of materials, time, effort, and commitment, such costs can be regarded as a sound investment in preservation of the basic rights of autistic children and youth.

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