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Representing Institutionalized Mentally Retarded Persons

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The following article explores the need for increased legal advocacy for mentally retarded persons. Contrasting the services available to the mentally ill with the limited resources for the mentally retarded, the authors highlight the unique problems of this underrepresented population, and examine alternative forums for advocacy. In a practical, straightforward analysis, the article identifies barriers to effective representation, including the fundamental problem of lawyers' and advocates' reactions to institutionalized retarded persons' appearance and behavior, and the effect of these reactions on advocacy efforts.

The article is followed by a client interview form and guide that focus on the special problems of the mentally retarded. Although the guide is only one approach to improving the effectiveness of representation, it contains valuable information for both lawyers and advocates, and can also serve as an educational tool for institutional personnel.

The Need for Representation

Successful efforts to provide legal services to mentally retarded clients are a relatively recent development.[1] Even institutionalized mentally ill people found legal advocates at an earlier date.[2] Where progress has been made in securing rights for retarded persons — whether through litigation or legislation — it has often been as an afterthought in efforts on behalf of the mentally ill.[3] While the advent of developmental disability protection and advocacy agencies in each state has greatly expanded the legal resources available to retarded citizens, these agencies differ in the extent to which they provide legal advocacy.[4] The cutbacks in agencies funded by the Legal Services Corporation have brought a halt to expansion of legal assistance to retarded persons and may jeopardize those programs now in existence.

The relative novelty of providing legal representation to mentally retarded people, when combined with the increased competition for finite advocacy resources, may lead some to conclude that these clients should not be a high priority for legal advocates. Retarded clients who live in institutions may be particularly easy to ignore; it is not a novelty to observe that those who are out of sight may forfeit a prominent position in the mind. The probability of this result is made more certain by the omission of mandatory provisions for counsel at civil commitments and periodic reviews for the mentally retarded in the statutory structure of many states, provisions that often are in place for the mentally ill.[5] Finally, the number of attorneys who receive any introduction in law school to the legal problems of mentally retarded persons is very small.[6]

Abandonment of these clients in the 1980s would be catastrophic. Reduced state budgets are likely to lead to a decline in the quality of life in institutions, and we have abundant experience to suggest that such a decline will produce abuses of appalling magnitude.[7] Even in more prosperous times we have seen that deinstitutionalization may mean movement into settings which are less notable for their "lesser restriction" than for their "lesser cost."[8] There is reason to believe that these problems are on the rise. The successes of litigation for institutional reform and community placement have not been sufficiently widespread or entrenched to permit complacency or even a period of benign neglect.

The Setting for Representation

Ironically, available forums for legal representation are on the rise. Although the United States Supreme Court declined to order states to provide hearings for mentally retarded minors whose institutionalization was sought by their parents,[9] other opportunities for advocacy are increasing. Slowly but surely, state legislatures are beginning to insert due process language in statutes providing for residential placement.[10] Where the legislatures have not acted, courts are beginning to scrutinize the procedures afforded by the state.[11] An increasing number of states have enacted statutes specifying the rights of institutionalized mental patients,[12] and some of these statutes encompass mentally retarded persons as well.[13] Statutes providing for limited purpose guardianships on issues of treatment and habilitation may also provide a useful forum.[14]

The U.S. Supreme Court's recent decision in *Youngberg v. Romeo*[15] carries important new opportunities for advocacy on behalf of institutional residents. While declining to decide whether there might be a broader and more generalized right to habilitation, the Court found that specific liberty interests of institutional residents could give rise to a constitutional right to training. Mr. Romeo was entitled to that training that was linked to his liberty interests in free bodily movement within the institution and in physical safety.

In other cases, a similar linkage could be shown be-

tween needed habilitation and the ability to leave the institution for a less restrictive placement.[16] A concurring opinion holds open the hope of a right to freedom from institution-induced regression.[17] In all such cases, the teaching of *Romeo* seems to point toward individualized determinations of habilitation rights; to come within the holding of the case, the asserted right must be linked to a liberty interest of the individual resident. Whether this individualized approach will act as an impediment to class action litigation[18] remains to be seen, but it certainly holds open the opportunity for litigation tailored to the needs of a particular client.

We have not attempted an exhaustive list of the forums available for individual legal advocacy for mentally retarded residents of institutions. Other federal[19] and state[20] opportunities present themselves to the lawyer seeking the release of a client who is wrongfully institutionalized or whose needs are not being met by the facility in which he resides.

Interviewing the Client and Assessing His Needs

Perhaps the most significant barrier to effective representation of institutionalized retarded persons is their lawyer's visceral reaction to them. Typically, the residents of our public institutions are severely and profoundly retarded, and a disproportionate number have some form of physical handicap as well.[21] Few attorneys will have had prior experience in dealing with such people. If the client experiences seizures, wears diapers (adults), or is self-abusive, the lawyer may find that his or her emotional reaction hinders the provision of legal services which would be performed as a matter of course if the client were mentally (and physically) typical.[22] Even if the lawyer is not put off by the client's appearance or behavior, he or she may be unclear as to the appropriate procedure when the client lacks the ability to speak, or when the speaking ability is rudimentary.

These difficulties may contribute to confusion about the lawyer's proper role.[23] The attorney may see no point in seeking direction from a client who is mentally retarded. The temptation to be paternalistic is strong. Yet, where the client is able to express some preference about where he will live and under what conditions, the lawyer is ethically obligated to bring those wishes to the attention of the decision-maker.

Canon 7 of the ABA's Model Code of Professional Responsibility states, "A lawyer should represent a client zealously within the bounds of the law." Ethical Considerations 7 and 8, interpreting this canon, make it clear that the authority to make decisions regarding the merits of a case belong exclusively to the client. The lawyer should exert best efforts to ensure that the client has been informed of all relevant considerations, but the lawyer's power to usurp the client's preferences is expressly limited.

Ascertaining the client's preferences is not as simple a task with mentally retarded clients as it is in cases involving mentally typical people. In some cases, technological advances such as language boards may assist clients who lack the ability to speak.[24] But whether or not such aids are available or appropriate, the attorney must adapt his own communications to his client's ability to understand. Questions must be phrased simply and in words and concepts that the client understands.[25] For example, a client may be unable to discuss features of the proposed habilitation plan per se, but may be able to tell his lawyer what kinds of things he likes to do. Similarly, a client's expressed preference about his future residence ("I want to live with my brother," or "I want to live in [a particular city]") may give the lawyer important information about the services the client should receive while still in the institution, *i.e.,* habilitation designed to impart skills that will make the client's preference possible.

The lawyer may face a similar problem in ascertaining the client's current situation. The same disability that impairs the client's ability to tell his lawyer what he wants may also limit his ability to tell him what is happening to him in the institution. The findings of fact in cases like *Youngberg v. Romeo,*[26] *Pennhurst State School & Hospital v. Halderman,*[27] and *Wyatt v. Aderholt*[28] alert the lawyer to the kinds of hazards a client may face while residing in an institution. For example, with regard to abuse and neglect, the previously discussed problem of a client's language disability may be compounded by fear of retribution. The vulnerability of these clients makes it incumbent upon the attorney to be alert to possible problems in the client's life.

A final caveat is in order regarding information provided to the lawyer by members of the institutional staff. Staff members are typically the source of much valuable information. But even when the staff members are perceived as compassionate and competent professionals, the lawyer should bring a degree of skepticism to their information about the client. A staff member, especially above the direct care level, may be basing conclusions upon reliable hearsay. Diagnostic testing of institutional residents is particularly suspect; there may be incentives for institutions to claim that the bulk of their residents are severely or profoundly retarded; a higher functioning individual who has not been placed in the community may be a source of institutional embarrassment.[29] It is relatively commonplace in our experience to be told by a staff member that a particular client lacks a certain skill (*e.g.,* receptive language skills) when a casual observation by a layperson proves conclusively that this is untrue. It should also be noted that the professional skills of diagnosticians on the staffs of institutions are not uniformly high.[30]

We have outlined a few of the characteristics of these clients that may call for the lawyer to perform differently than in the case of a mentally typical client. Having discussed these exceptions, we must now belatedly emphasize the general rule: *Mentally disabled clients are more like mentally typical clients than they are dissimilar from them.*[31] As with many mentally typical clients, they may be unversed in the legal aspects of their problem, and nervous about discussing their situation with a lawyer. They may find it difficult to understand the role of the lawyer and distinguish it from the role

that other professionals play in their daily activities. In addition, like mentally typical clients, they may have difficulty, whether because of shyness, confusion, inarticulateness or a communication disability, in expressing themselves to their lawyer.

The lawyer can safely and profitably start from the rebuttable presumption that things that he or she would find disagreeable or unpleasant will have the same effect on the client. Starting from this premise may also assist the lawyer in dealing with the initial visceral reaction that he or she may experience in dealing with a mentally disabled client. It may be relatively novel for some clients to be treated as if their opinions and condition mattered to someone else, and introducing the client to this kind of treatment is not the smallest service a lawyer can perform.[32]

A Client Interview and Assessment Form

New Mexico's Protection and Advocacy agency represents institutionalized mentally retarded clients in a number of settings. More prominently, it is counsel for a substantial number of these clients in the mandatory periodic review hearings under the Mental Health and Developmental Disabilities Code.[33] Its lawyers also appear in hearings on petitions for plenary and limited guardianships. At these hearings, the issue is not only whether the client meets the statutory criteria for commitment, but also the adequacy of the individualized habilitation plan[34] and the availability and suitability of less restrictive alternative placements, as well as hearings on educational and other matters.

Early in the representation efforts, it became clear that a standardized method for collecting and organizing information gathered during client interviews was needed. In order to assist lawyers, paralegals and social workers in interviewing clients, an interview form and interviewer's guide were devised by the managing attorney. The agency's objectives were to hone the observation skills of the staff and to achieve consistency among interviewers. Consistency was required in order to ensure that any member of the staff could evaluate a file quickly, make comparisons of a client's reponse to different members of the staff, detect regression or improvement in a client's abilities and promote continuity if a new lawyer was assigned to the case.

The form and guide have been revised a number of times as the agency has grown and continuing legal representation has revealed weaknesses in information collection. These tools are proving helpful in eliciting relevant information for use in a variety of legal proceedings and also in standardizing the information on various clients within the agency. Advocates may find that they can adapt the approach to assist them in other advocacy settings. A copy of the form and guide follow this article.

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FOOTNOTES

1. *See,* Herr, "The New Clients: Legal Services for Mentally Retarded Persons," 31 *Stanford Law Review* 553 (1979).

2. *See, e.g.,* Litwack, "The Role of Counsel in Civil Commitment Proceedings: Emerging Problems," 62 *California Law Review* 816 (1974); B. Ennis, *Prisoners of Psychiatry: Mental Patients, Psychiatrists, and the Law* (1972).

3. *E.g., Wyatt v. Stickney,* 344 F. Supp. 373, 387 (M.D. Ala. 1972), *aff'd sub nom. Wyatt v. Aderholt,* 503 F.2d 1305 (5th Cir. 1974); *Dixon v. Attorney General,* 325 F. Supp. 966 (M.D. Pa. 1971); N.M. Stat. Ann. §§43-1-2 through 43-1-25 (Repl. 1979). Sometimes even defeats for the mentally retarded follow in the wake of defeats of the mentally ill. *Compare, Parham v. J.L.,* 442 U.S. 584 (1979), with *Secretary of Public Welfare v. Institutionalized Juveniles,* 442 U.S. 640 (1979).

4. The agencies also differ in the extent to which they actively serve a substantial number of clients who live in institutions.

5. B. Sales *et al., Disabled Persons and the Law: State Legislative Issues* 416-21 (1982); J. Ellis, R. Luckasson, K. Watson & E. Church, *Commitment of the Mentally Retarded: State Laws and the Need for Reform* (American Bar Foundation, in press 1983). In the past, such hearings as were conducted often became "rubberstamp" procedures. *See,* Kay, Farnham *et al.,* "Legal Planning for the Mentally Retarded: The California Experience," 60 *California Law Review* 438 (1972).

6. The major law school casebooks on mental health law provide almost no discussions of separate issues confronting mentally retarded persons. The only casebook which devotes major attention to this group is R. Burgdorf, *The Legal Rights of Handicapped Persons: Cases, Materials, and Text* (Paul H. Brookes, Publ. 1980).

7. *See, e.g.,* B. Blatt & F. Kaplan, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (1974).

8. Of particular concern is the trend toward moving residents of institutions for the retarded into nursing homes. *See,* Scheerenberger, "Public Residential Services, 1981: Status and Trends," 20 *Mental Retardation* 210, 214 (1982).

9. *Secretary of Public Welfare v. Institutionalized Juveniles,* 442 U.S. 640 (1979). For a suggestion that another result might have been preferable, *see, Teitelbaum & Ellis, "The Liberty Interest of Children: Due Process Rights and Their Application," 12 Family Law Quarterly* 153, reprinted in 2 *Mental Disability Law Reporter* 459 (1978).

10. J. Ellis *et al., supra* note 5. For a draft of the American Bar Association model statute for admission and consent to services, *see,* B. Sales *et al., supra* note 5, at 409-52.

11. *E.g., In re Hop,* 29 Cal. 3d 82, 171 Cal. Rptr. 721, 623 P.2d 282 (1981); *People v. Reliford,* 382 N.E.2d 72 (Ill. App. 1978).

12. Lyon, Levine & Zusman, "Patients' Bill of Rights: A Survey of State Statutes," 6 *Mental Disability Law Reporter* 178 (1982).

13. B. Sales, *et al., supra* note 5, at 849-64.

14. *E.g.,* N.M. Stat. Ann. §43-1-15 (Repl. 1979). Seeking the client's consent to his individualized habilitation plan may provide an opportunity to scrutinize the adequacy of the services he is receiving. *See,* Bennett, "Reviewing an Individual Habilitation Plan: A Lawyer's Guide," 4 *University of Arkansas at Little Rock Law Journal* 467 (1981).

(continued on p. 63)

CLIENT INTERVIEW FORM

Client _____
Case Number _____
Facility _____
Place of Interview _____

Date _____
Time _____
Day of Week _____
Interviewer _____

1) Physical Appearance:

2) Approximate Height: _____
   Approximate Weight: _____
3) Clothing/Diapers:

4) Age:
5) Health (*e.g.* injuries, sores, sunburn, coughing):

6) Teeth:

7) Medication:

8) Wheelchair/Eyeglasses/Hearing Aid/Helmet/Bed:

9) Ambulation:
10) Eye Contact:
11) Expressive Speech/Language Ability (What is client able to communicate?):

12) Receptive Speech/Language Ability (What is client able to understand?):

13) Client's Response to Interviewer:

14) Activity in which client was involved when interviewer arrived:

15) Activity in which other nearby residents are involved:

16) Activity of staff:

17) Expressed desires of client re:
   a) Substitute decision-making:

      Recognizes money:

      Understands uses of money:
      __small amount __large amount

      Connects illness or injury with seeing doctor or nurse:

      Understands medical questions:

      Consent:
      __capacity
      __information
      __voluntariness

      Has personal goals:
      __short range
      __long range

      Reaction to mention of proposed guardian:
      __positive
      __negative

   Expressed desires of client re:
   b) Residence

   c) Activities/Likes/Dislikes

18) Staff comments re:

   a) Health:

   b) Needs/Programming:

   c) Visitors:

   d) Activities/Likes/Dislikes:

   e) Abilities:

   f) Regression:

   g) Potential Placement/Change:

19) Recommendations of Interviewer
   __Oppose Guardianship
   __Consent to Full Guardianship
   __Consent to Limited Guardianship
   __Consent to Treatment Guardianship
   __Oppose Extended Commitment
   __Consent to Extended Commitment
20) Services which client appears to need, or which should be investigated more thoroughly:

_____
_____
_____
_____

INTERVIEW GUIDE

This interview guide is intended to help lawyers and advocates in their efforts to represent mentally retarded institutionalized patients. The guide is not intended to be all-inclusive; it should be used in conjunction with general interviewing techniques.

As in the case of an interview with any legal client, there are two primary purposes to an interview with our clients, that is (a) to establish a comfortable attorney-client relationship and (b) to gather information. Additionally, in these situations we will often be in the position of setting an example of the kind of respectful attitude which we expect other persons who deal with this client to exhibit.

The initial contact with the client will generally occur in the cottage or ward. It is important that you introduce yourself to the client and explain the purpose of your visit and your relationship to him. For example, with extended hand you might say, "Hello, Mr. Rand.* I am happy to see you. My name is _____. I'm your lawyer. I'd like to talk with you for a little while."

Meanwhile, a staff person will probably have assisted you in locating the client and finding a quiet place to conduct the interview. You should explain that you are Mr. Rand's lawyer and you need to discuss his case with him. You will also want to discuss some things with the staff person after you have completed your client interview. Creating as comfortable and quiet an environment as possible is important. However, try to avoid disrupting an activity or upsetting the client by taking him into a forbidden area (the staff office) or physically endangering him (by rolling his crib into another room, for example). Do not set yourself up for disruptions from other clients. It's probably a good idea to sit so that you can see as other residents walk toward you.

The information you will need to collect from this interview is extensive and of several varieties. The collection of the information will often require a great deal of creativity on your part as well as intense observation. We are dealing with clients who may never have had a lawyer before and in fact may only rarely have been asked to express an opinion or a desire. In addition to trying to get direction for the legal representation, we should attempt to determine if our client is healthy, physically comfortable, in need of anything (perhaps his eyeglasses need repairing or he has run out of writing paper or he needs to make a phone call), of if he wants to tell an "outsider" something he feels uncomfortable telling to a staff person.

The form should be used only as a guide. Individual clients will present individual concerns and the record of your interview should reflect these. This form is not the form we use to analyze data from the client's medical file or habilitation file. Therefore, all the data collected is *observational* data. (For example, a client may be described as toilet trained in his habilitation plan, but be wearing a diaper during your interview. There may be no record of prescribed medications, but you may see a staff member administer a pill or you may be told that "Mr. Rand can't be interviewed this afternoon. He just took his medication and won't wake up until 6:00 this evening.")

The client identification section includes the client's name, case number, facility, place of interview (did it occur in Cottage 3?), name of person conducting the interview, date, time of day (it may be important that a client is eating supper at 3:30), and the day of the week (Saturday activities may be justifiably different from Tuesday school activities).

The first nine items on the form concentrate on the condition of our client. Is he clean, disheveled, shaved, sunburned, injured? Is our client undersized for his age or of normal height? Some of our clients are overweight or underweight and we may need to investigate dietary changes. Is our client wearing clean, well-fitting clothing appropriate to the time of day, his gender, and the season? What is the approximate age of our client (this is a good question to ask of the person himself during the course of the interview). We need to observe the state of our client's health. Is he coughing, does he have swollen areas on the side of his head, an eye infection? Does he have teeth missing, or swollen gums or terribly bad breath, which might indicate an infection? Does he seem drowsy or is he shaking, both of which may be at-

*While the use of Mr., Miss, or Ms. is preferable in addressing legal clients, some of our more disabled clients may only recognize their first names. In such cases, it is acceptable to refer to them in this less formal manner.

tributable to overmedication. Is he wearing a sound amplifier or a helmet or a baseball cap (which might be a functional substitute for a helmet)? Is our client walking or sitting in a wheelchair or restrained on a bed? In many cases, direct questioning of our client is appropriate in the above items. For example, "Do you hurt?", "Do you brush your teeth?", "Why do you have this hat on?", "Can you walk?".

Items 10 through 13 concentrate on communication ability. Does our client look at you when you're speaking with him or does he keep his eyes closed or averted? Is he blind? Does he have oral language in English or Spanish? Does he use sign language (either his own version or the official American Sign Language)? Does he have a language board with a pointer or a head-directed light? Receptive communication ability is less easily determined than expressive ability. Since we cannot be sure of what many of our clients are hearing and/or understanding, rather than underestimate their abilities and chance not talking with them enough, we should overestimate and give them information even when we can't be sure that they are understanding us.

Item 13 is the place to record the client's response to you. Did he smile when you talked with him? Did he converse with you in an appropriate way? Did he reject all attempts to communicate with him? Was it impossible to break through the stereotypical behavior? Did he grab at you?

The activity occurring in the ward should be reflected in items 15 through 16. Was our client sitting in the corner doing nothing when you arrived? Were the other residents engaged in various forms of self-stimulation? Were the aides watching *General Hospital*? It may be significant that although our client wasn't doing anything, the other residents were putting puzzles together. After all, the staff may have directed him to sit quietly and wait for his lawyer as a matter of courtesy in order to save you time. (A quick glance at the other activities occurring in the ward will help determine the likelihood that that was indeed the case.)

Item 17 reflects the heart of the interview as it concerns the question of guardianship. Does the client know what money is? Can he recognize a dime when you show it to him? Some clients understand the use of small amounts of money but do not yet appreciate the value of large amounts. For example, Mr. Rand may understand that he can save $89 over a period of a few months and then buy a black and white television set, but he may not yet understand that when he inherits $20,000 from his grandmother he could make a down payment on a duplex.

Does our client express an understanding of the relationship between illness or injury and medical care providers? Does he like the doctor who has been treating him? Do the elements of legally adequate consent exist in this situation at this time?

Is our client able to express some desires concerning goals in his life? Is he enthusiastic about a short-term goal such as getting a Coke, but unresponsive when asked about his desires for his life when he graduates from high school?

Even when a client may not have been able to communicate his desires on any other dimension of the guardianship, he may be able to give us a clue when he hears the name of the proposed guardian. When asked whether he wants his mother to decide things for him, does he blurt out, "It's none of her damn business?" Does the mention of his brother cause him to make a punching motion? Perhaps a loving smile will be his response to discussion of his father. Although the response may not provide the entire basis for a litigation decision, any indication of his desires should be taken into account in some way.

Additionally, we will want to talk with our client about where he likes to live or where he'd like to move. (You should probably check the validity of this information with a question such as "Where do you live right now?"). It's also helpful to find out what our client likes to do so that we can later determine whether his habilitation plan addresses this preference. Does he say that he likes to swim or that he likes to visit his brother in another city or that he likes to go to dances? Is he being allowed by the institution to do the one thing which gives him pleasure?

Generally a staff person is nearby who may be able to give you some useful information. He or she should be able to tell you about any recent medical crises or a particular program which might be beneficial but is not available. A staff person should also be able to tell you whether or not the proposed guardian visits our client or corresponds with him. Since he or she is involved on a daily basis with the resident, the staff person will often describe the likes and dislikes of our client. In addition, you can get otherwise undocumented information on the abilities of our client; for example, "Eddy walks anywhere he wants to on campus" or "he makes a lot of money shining shoes for the staff" or "he runs away every chance he gets." A staff person who has worked at the facility for a long time may be able to describe our client when he or she first arrived. Of interest in that area would be indications of regression in our client's abilities. Some staff may also have thought about possible future placements, and may be willing to discuss these with you.

The interviewer is not being asked in question 19 to make *the* determination regarding legal action. However, the feeling of the person who participated in the face-to-face interview is valuable as the primary attorney analyzes the case. Any explanatory comments regarding your recommendation are also gladly received.

Likewise, question 20 should flag some areas that warrant further thought or investigation.

Remember, this person is our legal client. Therefore, when you are trying to resolve a dilemma concerning the way in which the interview should be conducted, ask yourself the question "How would I handle this with a mentally typical client?" It probably won't solve your dilemma, but it should at least point you in the right direction. ■