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# SPECTRUM

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THE PERIODICAL FOR PROFESSIONALS IN THE FIELD OF AUTISM

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## Protection of Clients' Rights to Confidentiality

By Mark E. Weiss

*Princeton Child Development Institute*

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Spectrum is a semi-annual periodical for professionals who provide services to individuals with autism and their families. Our goal is to inform our readers of developments in the field of autism; to provide a medium through which Spectrum readers can exchange information and ideas; and to maintain awareness of and sensitivity to the issues that confront individuals with autism and their families, and the professionals who serve them.

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Protection of an individual's right to confidentiality is a crucial responsibility of all treatment providers. Effective strategies for ensuring this basic right to children and adults with autism parallel those employed for anyone receiving educational, therapeutic, or rehabilitative services. However, the behavioral characteristics of individuals with autism, e.g., severe receptive and expressive language deficits, require highly effective rights-protection procedures.

Professionals in human services have long considered the right to confidentiality an ethical responsibility, yet legal mandates to protect the rights of students in education programs, adjudicated individuals, or mental health patients were slow to develop. The courts traditionally did not address social service activities and if they did, they tended to side with program administration. Historically, clients were not considered to have rights to assert against institutions or treatment providers (Martin, 1975)

In the past, the rights of children received very little attention; issues of institutional exploitation, gross neglect, and sexual abuse were the primary areas of focus (Christian, Clark and Luke, 1981). One of the most significant pieces of Federal legislation to impact on the protection of children's rights was the Education for All Handicapped Children Act (P.L. 94-142, 1975), which asserted that it is unlawful to release information about students without the permission of parents. Subsequently, individual states established guidelines for access to information and records and developed procedural safeguards. In New Jersey, the Division of Developmental Disabilities through Division Circular #46, "Access to Client Records and Record Privacy" (reissued October, 1988), dictates specific policies and procedures to be followed by Division personnel and service providers.

Beyond legal mandates for the protection of client rights to confidential-

ity lies the challenge to treatment providers to implement effective day-to-day procedures. An important first step is defining standards of professional behavior. Typically, standards about confidentiality are included in professional codes of ethics. For example, the National Teaching-Family Association, a professional organization of group home treatment providers, has formulated standards of ethical conduct encompassing guidelines for a wide range of issues relative to the protection of "fundamental human rights", including standards concerning confidentiality. (National Teaching-Family Assoc., 1979).

Guidelines in such standards should include clear definitions of what information is confidential, the circumstances under which information should be communicated, to whom information may be released, and procedures for obtaining voluntary informed consent. Due to the severe behavioral deficits of many individuals with autism, consent must often be obtained from parents or legal guardians. Yet it remains the responsibility of intervention agents to "assist...

children in acquiring the linguistic and conceptual skills that will enable them to receive instruction about their rights... and to give informed consent" (McClanahan and Krantz, 1981). Written consent should specify the type of information to be released (e.g., medical records, diagnostic information or data on treatment programs), the individual, organization, or agency requesting it, and the intended purpose of use. Researchers and persons preparing professional presentations should follow specific guidelines to protect clients' rights to anonymity as well as confidentiality.

Having formulated written guidelines on confidentiality, it is incumbent on organizations and professionals to ensure that guidelines are effectively implemented. Some key factors in implementation are: (a) training, supervision, and evaluation of staff; (b) periodic

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review of written policies and procedures; (c) accurate and secure record keeping; (d) reviews by impartial professional evaluators and (e) data-based treatment programming.

### **Training, Supervision and Evaluation of Staff**

Pre-service and in-service training should address issues of confidentiality. It is important that training involve more than reading program policies and procedures. Role-plays that help trainees rehearse specific skills and ongoing supervision that includes specific professional feedback, can help ensure that confidentiality is maintained in a variety of situations. Further, staff performance evaluations may include measures of an individual's adherence to policies. For example, supervisors might observe and rate trainees' skills in maintaining confidential records and protecting confidentiality and anonymity when describing individualized programs to visitors.

### **Periodic Review of Written Policies and Procedures**

It is important to regularly reassess the effectiveness of guidelines. Are procedures easily interpreted? Are procedures specific? Do procedures reflect current legal mandates?

### **Accurate and Secure Record Keeping**

Accurate maintenance of records is imperative. Information should be correct and up-to-date. It is equally important that confidential materials be securely stored so that access is limited to people who are responsible for maintaining, monitoring, interpreting and translating information. In large programs it is advantageous to develop a management system that delineates specific staff responsibilities.

### **Reviews by Impartial External Evaluators**

For persons with autism, who are often unable to advocate for their rights, a formalized, regularly occurring process for external reviews is critical. Professional evaluators (with consent to

review materials) can do much to help protect clients' rights to confidentiality. They can provide feedback to staff regarding whether: (a) client records are written to protect confidentiality; (b) records are stored securely and properly; (c) records present objective vs. subjective information; and (d) the program provides adequate training and supervision of staff regarding confidentiality.

### **Data-Based Programming**

Confidential information should be objective and relevant to individuals' treatment objectives. Data-based programming allows interventionists to limit information collected to observed, measured behavior. Limiting treatment information files to objective data about an individual's progress towards agreed upon goals can prevent transmission of subjective information, conjecture, or unfounded conclusions.

### **Summary**

Protecting people's right to confidentiality must be an ongoing, systematic process involving clients, parents or guardians, program administrators, and staff. This important goal can be best achieved by channeling ethical concerns and commitments to clients into effective, accountable procedures that are practical and replicable.

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