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Direct Service Staff's Perceptions of Psychotropic Medication in Noninstitutional Settings for Individuals with Developmental Disabilities

LeeAnn Christian
Western Michigan University

DIRECT SERVICE STAFF'S PERCEPTIONS OF PSYCHOTROPIC MEDICATION IN NONINSTITUTIONAL SETTINGS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

by

LeeAnn Christian

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LeeAnn Christian, Ph.D.

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Approximately 35-55% of individuals with mental retardation who live in the community are prescribed psychotropic and/or antiepileptic medication (Aman, Saphare, & Burrows, 1995; Singh, Guernsey, & Ellis, 1992). As more individuals with severe behavior challenges are transitioned from institutions into the community, these rates are likely to increase. Given these prevalence rates, it is important to determine whether staff who serve people with mental retardation are adequately educated about psychotropic medications. Previous studies (Aman, Singh, & White, 1987; Gadow, 1983; Singh, Epstein, Stout, Luebke, & Ellis, 1994; Singh et al., 1996) surveyed a variety of service providers in school and institutional settings and reported a pervasive lack of education and training regarding the use of psychotropic medication. Direct service staff may contribute substantially to the appropriate use and assessment of psychotropic medications for individuals with developmental disabilities,

particularly for those living and/or working in the community. Given direct service staff's unique role, it appears particularly important to determine their perceptions of psychotropic medication.

The purpose of the present study was to extend the work of Singh et al. (1996) by surveying direct service staff to determine their perceptions, knowledge, and opinions regarding the use of psychotropic medication in noninstitutional settings for individuals with developmental disabilities. Participants were 334 direct service staff employed by 15 noninstitutional residential and vocational agencies in California and Michigan.

Findings of the present study were similar to those of Singh et al. (1996). The knowledge and skills deficits of direct service staff represent a barrier to the appropriate monitoring and management of pharmacotherapy for individuals with developmental disabilities. Therefore, a systematic training program to educate direct service staff about psychotropic medications needs to be designed, implemented, and disseminated on a broad scale.

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CHAPTER I

INTRODUCTION

The use of neuroleptics to treat people with mental retardation began soon after Delay and Deniker (1952) discovered that chlorpromazine was an effective treatment for adults with psychiatric disorders (Gadow & Poling, 1988). Chlorpromazine, and other neuroleptics, were initially used to treat people with mental retardation because their problem behaviors resemble those of people with psychiatric disorders (Gadow, 1986). Most often, however, psychotropic medications are prescribed to individuals with mental retardation to control severe behavior disorders, such as physical and verbal aggression, self-injurious behavior, and stereotypy (Aman & Singh, 1988; Gadow, 1986; Gadow & Poling, 1988; Singh, Guernsey, & Ellis, 1992).

Surveys indicate that roughly 30 to 50% of adults with mental retardation residing in institutions receive psychotropic medications, most often neuroleptics (e.g., chlorpromazine, thioridazine, haloperidol), whereas 25 to 35% of those living in community settings do so (e.g., Aman, Sarphare, & Burrow, 1995; Aman & Singh, 1988; Gadow & Poling, 1988).

If antiepileptic drugs (which are psychoactive) also are included, these percentages increase by approximately 20% (Gadow & Poling, 1988). These data indicate clearly that people with developmental disabilities are one of the most heavily medicated populations in our society (Gadow & Poling, 1988; Singh et al., 1992).

When appropriately used, neuroleptics have proven therapeutically beneficial for a variety of disorders among individuals with mental retardation (Gadow & Poling, 1988). The most frequently prescribed neuroleptics for the treatment of behavioral and psychiatric disorders in people with mental retardation are chlorpromazine (Thorazine), thioridazine (Mellaril), and haloperidol (Haldol) (Gadow, 1986; Gadow & Poling, 1988; McGowan, 1995). The general behavioral effects of neuroleptics include the "suppression of spontaneous movements and complex behavior...[and the reduction of] initiative and interest in the environment, [and] displays of emotion or affect" (Baldessarini, 1985, p. 393).

In addition to their ability to alter mood, thought processes, and behavior, these medications also carry a significant profile of untoward effects that cannot be ignored. People with mental retardation have an increased likelihood of experiencing the adverse effects of psychotropic medications, especially if they have secondary health care problems

(McGowan, 1995). Some frequent adverse effects of neuroleptics are dry mouth, sedation, weight gain, allergic skin reactions, tardive dyskinesia, akathisia, and dystonia (McGowan, 1995). They also impair performance on tasks that require sustained attention, and there is a general decrease in cognitive performance and learning at higher doses (Hartlage, 1965).

Understandably, incidents in which individuals have received medication when the adverse effects clearly outweighed the beneficial effects have sparked attention from advocates of people with mental retardation (Gadow, 1986; Singh et al., 1992). A plenitude of lawsuits concerning the misuse and overuse of psychotropic medication within this population has caused drug treatment practices to be scrutinized closely (e.g., Washington v. Harper, 1990; Wyatt v. Stickney, 1971a, 1971b, 1972; Youngberg v. Romeo, 1982). Court cases have focused on a variety of issues, including: (a) the lack of methodologically sound research; (b) the way in which medication is prescribed and administered; (c) the incompetence of service providers; (d) the lack of involvement of direct service staff in treatment decisions; and (e) the lack of risk-benefit analyses (Lewis, Aman, Gadow, Schroeder, & Thompson, 1996; Singh et al., 1992).

Years of litigation summon us to remember that persons with mental retardation have the right to be free from "unusual or hazardous

treatment procedures," including chemical restraint (Wyatt v. Stickney, 1972, p. 380). Moreover, "institutions, physicians, and drug companies can be held legally and financially liable for injuries resulting from the use or misuse of psychotropic medication" (Singh et al., 1992, p. 668). Kalachnik (1988) states:

> ...as a result of litigation, legislation, and regulations, a set of basic clinical standards has developed governing the use of psychotropic medication...(a) delineation of specific target behaviors; (b) written informed consent; (c) use of minimal effective dose; (d) periodic attempts at dosage reduction; (e) integration of behavioral, educational, and medical intervents; (f) monitoring for side effects; (g) interdisciplinary assessment of the need for medication; and (h) periodic, data-based evaluations of drug efficacy. (p. 231)

At present, pharmacotherapy continues to be a controversial topic in the treatment of people with mental retardation and complaints of overuse, misuse, and polypharmacy persist (Lewis et al., 1996). Concerns about inadequate assessment, diagnosis, and treatment also continue, particularly for individuals with severe and profound mental retardation, who often present difficult-to-diagnose behavioral disorders (Mikkelsen, 1997). The likelihood of an over-reliance on drug treatment and polypharmacy appears to be especially high in such individuals (Mikkelsen, 1997). These patterns of drug use appear to reflect the fact that traditionally-trained psychiatrists and physicians have little exposure to the special needs of this population (Hauser, 1997).

Despite the lack of experience and training, psychiatrists and/or treating physicians are frequently called on to evaluate, diagnose, and treat people with mental retardation who exhibit severe behavior problems or people dually diagnosed with mental retardation and mental illness (Hauser, 1997; Silka & Hauser, 1997). Unfortunately, individuals with mental retardation often present significant language or cognitive impairments, which hinder the utility of traditional methods of psychiatric assessment (e.g., interviews, self-report) (Hauser, 1997). When these methods prove ineffectual, psychiatrists and physicians rely on interviews with those who have a long-term relationship with the individual, such as direct service staff. Responses obtained by these informants, however, may be blurred by variables unrelated to the individual's mental health status, including their own distrust of psychiatrists and prescribing physicians, their lack of training, their expectations regarding treatment, their anxieties, and their most recent positive or negative experiences with the individual.

Unsurprisingly, the controversy surrounding drug treatment for individuals with mental retardation has reportedly affected a widespread mistrust and suspicion of pharmacological interventions among parents, teachers, service providers, and advocates (Lewis et al., 1996). Consequently, knowledge of how the use of psychotropic medication is

perceived by individuals who are affected by pharmacological interventions is important (Poling & LeSage, 1995). In the case of drug treatment for individuals with developmental disabilities, those affected by the intervention might include the person with a developmental disability, parents and guardians, advocates, and direct service staff. If any of these individuals are dissatisfied with the goals, procedures, or outcomes of an intervention, it can have a significant impact on the success and future use of the intervention (Poling & LeSage, 1995).

Although it is important to determine the perceptions of all individuals affected by an intervention involving drug treatment, it appears especially important to determine the perceptions of direct service staff. These individuals typically spend more time interacting with their consumers than others do. Furthermore, direct service staff may have the greatest impact on treatment outcomes because they are responsible for implementing and monitoring treatment, often with minimal supervision. Moreover, as noted previously, psychiatrists and prescribing physicians frequently rely on the information provided by these staff when making treatment decisions.

Given the unique role of direct service staff, it is important to determine whether they are adequately educated about the beneficial and adverse effects of psychotropic medications. At minimum, a cursory

knowledge of the effects of psychotropic drugs is desirable, given the prevalence with which they are prescribed and the pervasive effects they may have on behavioral adjustment, learning, performance, and physical health (Aman & Singh, 1983). Determining the perceptions, knowledge, and opinions of direct service staff regarding the use of drug treatments may contribute substantially to the appropriate use and assessment of psychotropic medications for individuals with developmental disabilities (Singh et al., 1992).

Only four studies have examined the perceptions, knowledge, and opinions of those individuals working most closely with persons with developmental disabilities (Aman, Singh, & White, 1987; Gadow, 1983; Singh, Epstein, Stout, Luebke, & Ellis, 1994; Singh et al., 1996). In the first survey, Gadow (1983) surveyed 536 special education teachers in Illinois regarding their training in pharmacotherapy and their personal encounters with students receiving medication for behavior or seizure disorders. Although most teachers reported contact with students who were receiving drug treatment, few had received formal training in the area of pharmacotherapy. The most frequently reported method for acquiring knowledge about drug therapy was the teacher's personal experience with students receiving medication. Overall, special education

teachers reported an inadequate knowledge of pharmacotherapy and desired further training in the area.

After the Gadow (1983) study, Singh and his colleagues conducted three related surveys. In the first, Aman et al. (1987) surveyed the caregivers of individuals with developmental disabilities to determine their perceptions, knowledge, and opinions about the use of psychotropic medication. Respondents were 227 nurses in two institutional settings in New Zealand where approximately 1075 individuals with developmental disabilities resided. Using a modified version of the Aman et al. (1987) survey, Singh and his colleagues (1994) subsequently surveyed 100 teachers of students with serious emotional disturbances and 100 teachers of students with learning disabilities to determine their perceptions, knowledge, and views regarding the use of psychotropic medication. Finally, Singh et al. (1996) further modified the Aman et al. (1987) survey and used it to determine the perceptions, opinions, and knowledge of professional staff (e.g., physicians, nurses, social workers, psychologists, and Qualified Mental Retardation Professionals). The staff were employed by four residential facilities in Texas, where more than 2000 individuals with mental retardation resided. With 377 respondents, this study represents the first large-scale effort to report data on the perceptions, knowledge, and opinions of professionals' regarding the use of

psychotropic medication for individuals with mental retardation in the United States.

In those studies using comparable surveys (Aman et al., 1987; Singh et al., 1994; Singh et al., 1996), noteworthy similarities existed among respondents regarding their perceptions, opinions, and knowledge of the use of psychotropic medication to treat individuals with disabilities. Perhaps most striking was the reported lack of training in the area of pharmacotherapy by respondents. Across all studies, 80-85% of respondents indicated receiving inadequate pre-service and inservice training in this area. Furthermore, when asked to choose important topics for additional training, side effects of medication, major clinical indications of drugs, and alternatives to drug therapy were among the top three or four chosen by all respondents.

When asked which behavioral or psychiatric disorders were likely to result in drug therapy, 87% of nurses (Aman et al., 1987) and 62% of professionals (Singh et al., 1996) rated aggression as most likely to lead to drug treatment. In contrast, Singh et al. (1994) reported that approximately 79% of teachers rated hyperactivity as the disorder most likely to result in drug treatment, with only about 33% rating aggression as likely to be treated with medication. This difference may be a function of the teachers' probable increased exposure to students with

hyperactivity disorders compared to that of nurses and other professionals working in institutional settings for individuals with mental retardation. Social withdrawal was uniformly rated as unlikely to result in drug therapy; across the three surveys 87-92% of respondents so rated it.

Physicians were perceived as highly influential in making medication decisions by 75-86% of respondents in all surveys (Aman et al., 1987; Singh et al., 1994; Singh et al., 1996). Nurses' responses differed, however, from those of other respondents in that 95% of the nurses rated charge nurses as more influential than physicians in the decision-making process. All other respondents rated physicians as more influential. It is noteworthy that the nurses were from New Zealand, which has a unique medical service delivery system (Aman et al., 1987).

All respondents were asked to rate the influence of various assessment methods on medication decisions under current and ideal conditions. Global impression (i.e., an overall subjective estimate about behavior by parents, doctors, or others) was perceived as the most influential assessment method in current practice by 82% of nurses (Aman et al., 1987) and by approximately 76% of teachers (Singh et al., 1994). Another subjective method, informal diary (e.g., case notes/narratives describing behavior), was perceived as influential by 80% of nurses and approximately 43% of teachers. Although behavioral

observation was rated as influential under current conditions by 83% of professionals, one-third (67%) also rated global impressions as an influential assessment method (Singh et al., 1996). Under ideal conditions, however, all respondents indicated that objective assessment methods (i.e., rating scales, behavioral observations) should be more influential when making medication decisions.

Respondents' knowledge regarding the side effects of psychotropic medication also was assessed in all three studies (Aman et al., 1987; Singh et al., 1994; Singh et al., 1996). More specifically, respondents were asked the extent to which side effects were thought to detract from the beneficial effects of psychotropic medication. Respondents in all studies perceived sedation as the side effect that most detracted from the therapeutic effects of drug therapy (48% in Aman et al., 1987; 45% in Singh et al., 1994; and 30% in Singh et al., 1996). Changes in attention span and interference with learning also were consistently rated as side effects that reduced the benefits of drug treatment among respondents.

In summary, these studies, which span more than a decade, indicate: (a) a pervasive lack of education and knowledge regarding the use of psychotropic medication among all respondents; (b) a prevailing reliance on subjective, unreliable assessment methods for making treatment decisions; and (c) a general lack of involvement of direct service

staff in treatment decisions (Aman et al., 1987; Gadow, 1983; Singh, et al., 1994; Singh, et al., 1996). Encouragingly, they do indicate a predominant interest among respondents in increasing their knowledge of pharmacotherapy and in increasing their participation in making treatment decisions. In addition, respondents appeared to understand the importance of using objective assessment methods when determining the effectiveness of drug treatment and advocated for their use under ideal conditions. A dichotomy, however, clearly continues to exist between what is and what ought to be in the management of pharmacotherapy for individuals with disabilities.

All of these studies contribute to our knowledge about the perceptions, opinions, and knowledge of individuals who are affected by pharmacological interventions (e.g., teachers, caregivers, professionals). They also provide information regarding the processes by which psychotropic medications have been managed in the treatment of behavior problems for individuals with disabilities in school and institutional settings. Singh and his colleagues (1996) have made perhaps the most significant contribution in this area by presenting the first large-scale study about professionals' views and the medication practices in institutional settings within the United States. Additional research, however, is required if we are to learn about the perceptions and

knowledge of the direct service staff who routinely work with individuals with developmental disabilities in noninstitutional settings.

Purpose of the Present Study

The purpose of the present study was to extend the seminal research of Singh et al. (1996) in two substantial ways. First, it surveyed direct service staff to determine their perceptions, knowledge, and opinions regarding the use of psychotropic medication to treat the behavior problems of individuals with developmental disabilities. Second, it targeted direct service staff employed by noninstitutional residential and vocational agencies.

As of June 30, 1995, approximately 50% of all persons with developmental disabilities lived in noninstitutional settings with 6 or fewer residents (Prouty, Lakin, & Smith, 1996). As increasing numbers of individuals with developmental disabilities are going to school, living, working, and socializing in their local communities, it is important to determine the ways in which decisions concerning psychotropic medication are made and the methods used to assess the effect of these medications in noninstitutional settings.

Although many standards have been put forth by federal legislation to protect the rights of institutionalized individuals receiving psychotropic

medication, it is not forgone that these requirements also safeguard the rights of individuals residing in the community (Rinck, Guidry, & Calkins, 1989). Therefore, how psychotropic drugs are used outside institutions merits especially careful attention.

The staff surveyed were full-time employees of 15 noninstitutional residential and vocational agencies throughout California and Michigan. Residential settings included group homes, semi-independent residential programs, and supported-living arrangements. Vocational settings included sheltered workshops, day treatment and activity centers, supported employment arrangements, and vocational rehabilitation services. To our knowledge, this study represents the first survey of direct service staff working with individuals with developmental disabilities who live and/or work as integrated members of their community.

CHAPTER II

METHOD

Participants

Participants were 334 full-time direct service staff whose primary job duty was working with individuals with developmental disabilities in residential and/or vocational/day settings (e.g., job coaches, residential aides, community support staff). Full-time employment was defined as working 30 or more hours per week. The participants were employed by 15 service providers in Michigan and California. Service providers, and therefore participants, represent a convenient, not random, sample. Specifically, agencies were selected by contacting directors with whom the author had a professional relationship, by asking those directors for the names of other directors, and by reviewing a resource directory book describing community-based agencies in Southern California. Participant characteristics are presented in Table 1.

Table 1

Participant Characteristics

Characteristic	Summary
Number of Agencies	15
Vocational/Day Only	8
Residential Only	3
Both	4
Number of Surveys	
Returned	363
Used in Analysis	334
Role of Staff	
Residential Staff	126
Vocational/Day Staff	187
Both	21
Gender of Staff	
Male	93
Female	180
Unreported	61
Age of Staff	
20-25 yrs	98
26-30 yrs	77
31-35 yrs	41
36-40 yrs	38
41-45 yrs	22
46-50 yrs	21
51-55 yrs	18
56+ yrs	5
Unreported	14

Table 1—Continued

Characteristic	Summary
Ethnicity	
White	199
Black	44
Hispanic	21
Asian/Pacific Islander	21
American Indian	4
Other	17
Multiethnic	16
Unreported	12
Education	
Some High School	9
H.S. Diploma/GED	71
Some Undergraduate Classes	104
Undergraduate Degree	76
Some Grad Classes	36
Graduate Degree	30
Unreported	8
Mean Years of Experience	5.4 yrs.
Range	1 mo. to 31.5 yrs.

Procedures

HSIRB Approval

Copies of Human Subject Institutional Review Board approval letters are in Appendix A.

Recruitment

Recruitment of participants was done by mailing or hand-delivering a packet of information to 22 directors of residential and vocational/day agencies serving individuals with developmental disabilities in California and Michigan. The recruitment packet included: (a) a cover letter introducing the investigators; (b) a brief proposal describing the rationale for the research, the methodology, and the benefits of participating in the project; (c) a copy of the survey; (d) a sample endorsement letter; (e) a self-addressed, stamped envelope to return an endorsement letter. A copy of the recruitment packet is in Appendix B.

Distribution and Collection of Surveys

Upon receiving an agency's letter of endorsement and after obtaining HSIRB approval, the agency's director was asked to identify the number of direct service staff who met the following inclusion criteria: (a) worked full-time (30 or more hours per week); and (b) worked directly with individuals with developmental disabilities as their primary job responsibility.

The investigator then mailed or hand-delivered the appropriate number of surveys to the director of each participating agency. Included with the surveys was a letter thanking the agency for endorsing the

research project and a set of instructions detailing the survey distribution and collection process. The instructions included: (a) a description of the two options by which the agency was asked to distribute, collect, and return surveys; and (b) a script, describing the purpose and procedures of the study that was to be read to the direct service staff immediately prior to distributing the surveys. A copy of the thank you letter and instructions is in Appendix C.

A large envelope or box also was provided to each agency for the collection of completed surveys. The collection envelope or box was pre-stamped and pre-addressed with the investigator's name and address as both sender and receiver to insure anonymity to the participating agency and its staff. The agency was instructed to seal the envelope or box and place it in the mail after completing the distribution and collection process.

Materials/Instrumentation

Data were collected using a 39-item survey which direct service staff completed independently. The survey was modeled after the instrument used by Singh et al. (1996). Items in the first part of the survey were related to the demographic characteristics of the participants. The second part of the survey included items related to the following

general areas: (a) the likelihood of various behavior problems leading to drug therapy; (b) the endorsement of behavior management techniques as an alternative to drug treatment; (c) the most frequently used or preferred assessment methods for evaluating drug effects; (d) the perceptions of the various side-effects associated with the use of psychotropic medications; and (e) the adequacy of training on drug-related issues. Additional areas included (a) the acceptability of using psychotropic medications to treat various behavior problems, (b) the endorsement of implementing behavior management techniques prior to or in combination with drug treatment, (c) the adequacy of training in behavior management, (d) the frequency of interagency communication regarding medication issues. A copy of the survey is in Appendix D.

Coding/Reliability

To ensure anonymity to participating agencies and their staff, completed surveys were assigned a random number upon receipt and were identified and identifiable only by this number. The investigator and three other graduate students hand-coded the surveys. See Appendix E for a sample data sheet and a copy of the coding instructions. Interobserver reliability was conducted on 20% (n=72) of the surveys. Reliability checkers independently coded every fifth survey returned and

then compared their data with those of the primary coder. Interobserver agreement was calculated by dividing the number of agreements by the total number of agreements and disagreements and multiplying by 100. Interobserver agreement ranged from 92% to 100% across samples with a mean of 99% for the 363 surveys. The primary coder and the reliability checker evaluated all disagreements and a joint decision was made as to the proper code for the item in question. Procedural reliability was not conducted, therefore, it is not known whether the 15 participating agencies distributed and collected surveys in accordance with the provided instructions.

After the surveys were hand-coded and interobserver agreement was conducted, the data were entered into a Microsoft Excel 7.0 spreadsheet. The computer spreadsheet was compared to the hand-coded sheets to check the accuracy of the data input. Any errors in data input were corrected.

CHAPTER III

RESULTS

Of the 1130 surveys distributed, 363 surveys were received; of these, 334 (30%) were included in the analysis. Surveys were not included in the analysis if respondents failed to report their current role or if they reported that they were not direct service staff. The sample consisted of 126 residential staff, 187 vocational staff, and 21 staff who identified themselves as both residential and vocational staff. They had worked with individuals with developmental disabilities for an average of 5.4 years. Of the 334 direct service staff, 93 were males, 180 were females, and 61 did not identify their gender.

A total of 167 items could be scored on each survey, however, not every item was scored on each survey. Calculations for each item were based on the number of respondents who scored it. The number of responses for each item varied, with a mean of 276 and a range of 53-334. Questions 38 and 39 were open-ended and had the lowest number of responses (n=119, n=53, respectively). The mean ratings and standard deviations for each survey item are presented in Appendix F. For some survey items, respondents had the opportunity to expand their answer by

writing in the additional space provided. These write-ins were incorporated into the data analysis and are presented in Appendix G.

Respondents were asked to rate numerous survey items using a five-point Likert scale (1=never; 5=always). To facilitate comparisons with the findings of Singh et al. (1996), ratings were categorized as they were in that study. Scores of 4 (usually) and 5 (always) were combined for presentation into one category and were considered to indicate "acceptable" or "likely." Scores of 1(never), 2 (seldom), and 3 (occasionally) were combined into a second category and were considered to indicate "unacceptable" or "unlikely."

Acceptability of Drug Therapy

Respondents were asked to rate the acceptability of drug therapy to treat behavior problems under various conditions. As shown in Table 2, most respondents deemed drug therapy acceptable for individuals in life-threatening situations (83.5%) and for individuals with whom all other treatment options had been exhausted (79.9%). In contrast, 24.6% of respondents ranked drug therapy as acceptable for children.

Table 2

Acceptability of Drug Therapy to Treat the Behavior Problems of Individuals With Developmental Disabilities*

Circumstance	Percentage Reporting Drug Therapy as Acceptable
For individuals in life-threatening situations	83.5
For individuals for whom all other treatment options have been exhausted	79.9
For individuals who cannot choose treatment for themselves	44.1
For adults	42.1
For children	24.6

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

Disorders Leading to Drug Therapy

Table 3 shows the perceived likelihood of specific behavior problems or psychiatric disorders leading to the use of psychotropic medication. More than two-thirds of direct service staff perceived self-injurious behavior, delusions/hallucinations, and aggression as likely to lead to pharmacological interventions (72.9,72.8, and 67.0%, respectively). In contrast, a majority of respondents rated withdrawal, acting out, and hyperactivity as unlikely to lead to drug treatment (79.3, 61.6, 59.2%,

respectively). Ratings were divided almost equally for anxiety with physical agitation, other psychiatric disorders, and depression or sadness.

Table 3

Likelihood of a Specific Behavior Problem or a Psychiatric Disorder Leading to Drug Therapy*

Behavior	Likely	Unlikely
Self-injurious behavior	72.9	26.2
Delusions/hallucinations	72.8	24.2
Aggression	67.0	30.9
Anxiety with physical agitation	54.2	43.2
Other psychiatric disorders	53.7	42.1
Depression or sadness	48.0	49.7
Hyperactivity	39.0	59.2
Acting out	36.0	61.6
Withdrawal	16.0	79.3

*Percentages for likely were calculated by adding ratings of "usually"(4) or "always"(5). Percentages of unlikely were calculated by adding ratings of "never"(1), "seldom"(2), and "occasionally"(3).

Treatment Alternatives

Table 4 shows respondents' opinions about the treatment options for various behavior problems and psychiatric disorders. For each behavior problem or psychiatric disorder listed, respondents were asked: (a) whether behavior management techniques should be attempted before drug therapy; (b) whether behavior management was a suitable

Table 4

Utility of Behavior Management Techniques and Drug Therapy in the Treatment of Specific Behavior Problems and Psychiatric Disorders*

Behavior Problem or Psychiatric Disorder	Beh. Mgmt. Before Drug Therapy	Beh. Mgmt. Alternative to Drug Therapy	Beh. Mgmt. Combined w/ Drug Therapy
Acting out	87.1	75.9	53.7
Aggression	83.3	63.3	61.9
Withdrawal	79.0	62.3	42.0
Hyperactivity	75.7	53.5	50.2
Anxiety with physical agitation	74.3	51.3	59.5
Self-injurious behavior	68.4	45.0	70.9
Depression or sadness	63.5	44.1	52.6
Other psychiatric disorders	60.7	34.4	56.7
Delusions/hallucinations	57.1	36.5	60.6

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

alternative to drug therapy; and (c) whether behavior management techniques should be combined with drug therapy. More than 50% of the respondents were of the opinion that behavioral interventions should be attempted before drug therapy for each of the behavior problems and psychiatric disorders listed, with acting out (87.1%) and aggression (83.3%) being the highest rated. Interestingly, less than 50% of the respondents viewed behavior management techniques as suitable

alternatives for 5 of the 9 items, with delusions/hallucinations (36.5%) and other psychiatric disorders (34.4%) being rated lowest. More than 50% of respondents reported that behavior management techniques should be combined with drug therapy for all disorders, except withdrawal (42.0%). For 3 of the 9 items (self-injurious behavior, other psychiatric disorders, and delusions/hallucinations), respondents indicated that behavior management techniques combined with drug therapy were viewed as useful, while for those same items, behavioral intervention was not viewed as a suitable alternative to drug treatment.

Choice of Assessment Methods

As shown in Table 5, respondents rated behavioral observations and global impressions as the most influential assessment methods when making decisions regarding medication issues. The perceived influences of assessment methods under current and ideal conditions were ranked in the same order, with the exception of the rating scale for psychiatric disorders which was perceived as more influential than the rating scale of social behavior under ideal conditions.

Table 5

Perceived Influence of Assessment Methods on Medication Decisions Under Current and Ideal Conditions*

Type of Assessment	Current	Ideal
Behavioral observations	73.1	83.4
Global impressions	66.3	76.4
Informal diary	57.6	71.3
Rating scale of social behavior	43.8	57.6
Rating scale for psychiatric disorders	43.7	60.8
Standardized tests	27.5	38.1

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

Roles in Current and Ideal Assessment Practices

As shown in Table 6, psychiatrists and prescribing physicians were perceived as most influential in the selection of drug assessment methods under current and ideal conditions. Psychologists were ranked by 67.4% of respondents as usually or always influential under current conditions and by 72.7% under ideal conditions. Although not perceived as highly influential under either condition, direct service staff ranked themselves as more influential under ideal conditions (38.4%) than under current conditions (17.8%). Noticeable differences under current and ideal conditions also existed for parents (44.5% vs. 58.0%), directors of

residential services (22.8% vs. 35.4%), and directors of vocational services (18.1% vs. 30.5%).

Table 6

Perceived Influence of Professionals in Selection of Drug Assessment Methods*

Professional	Current	Ideal
Physician/psychiatrist	92.0	91.0
Psychologist	67.4	72.7
Interdisciplinary team	53.1	58.8
Parents	44.5	58.0
QMRP	39.4	44.0
Case Manager	32.7	40.0
Social Worker	28.6	37.3
Director Residential Service	22.8	35.4
Director Vocational Service	18.1	30.5
Direct Service Staff	17.8	38.4

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

Influence of Professionals Regarding Medication Decisions

Consistent with their perceived influence in the selection of assessment methods, psychiatrists and physicians also were perceived as having the most influence in decisions to initiate or discontinue drug therapy (85.4% and 84.5%, respectively). Direct service staff perceived themselves as least influential in the decision-making process (6.5% and

8.1%, respectively). As Table 7 shows, there were no notable differences for those ranked as influential in decisions regarding the initiation and the discontinuation of drug treatment.

Table 7

Perceived Influence of Professionals in Decisions to Initiate or Discontinue Drug Therapy*

Professional	Initiate Treatment	Discontinue Treatment
Physician/psychiatrist	85.4	84.3
Psychologist	51.9	42.0
Interdisciplinary team	37.2	31.6
QMRP	27.8	24.6
Parents	20.9	23.7
Social Worker	15.9	15.8
Director Residential Service	12.4	14.0
Direct Service Staff	10.6	13.9
Director of Vocational Service	6.5	8.1

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

Knowledge of Side-Effects

Half the respondents (50.5%) rated tiredness/sedation as a major side effect detracting from the beneficial effects of psychotropic medication because of its common occurrence, with dry mouth (31.2%) and changes in attention span (26.5%) being ranked as the next two commonly occurring

side effects. As presented in Table 8, less than a third of respondents perceived 10 of the 11 listed side effects as occurring so commonly that they detract from the beneficial effects of medication. Interestingly, 19.4% of respondents rated motor problems associated with medication onset, and 16.5% rated tardive dyskinesia as commonly occurring side effects

Table 8

Extent to Which Side Effects of Prescribed Medications Occur so Commonly That They Detract From the Beneficial Effects of the Drugs*

Side Effects	Detract from Beneficial Effects of Drugs
Tiredness, sedation	50.5
Dry mouth	31.2
Changes in attention span	26.5
Behavioral irritation	25.3
Marked weight change	25.0
Depression or sadness	24.8
Interference with learning	21.2
Excitability	20.2
Motor Problems associated with the onset of treatment	19.4
Tardive dyskinesia	16.5
Skin reactions	12.2
None	9.0

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

that detract from the benefits of psychotropic medication. Also of interest is that 9% of respondents reported that no side effects of prescribed medication occurred so commonly that they detracted from the beneficial effects of the drug.

Interagency Communication

Table 9 indicates the frequency of interagency communication regarding medication issues. A majority of respondents (ranging from 50.5% to 66.2%) reported that interagency communications occurred when medications were initiated or discontinued, when there were changes in medications, or when problems were noticed.

Table 9

Frequency of Interagency Communication Regarding Medication Issues*

Issues	Your agency's communication with other agencies	Other agencies' communication with your agency
New medication prescribed	63.2	53.7
Medication changes	60.9	50.7
Medication discontinued	60.0	50.5
Problems noticed	66.2	56.4

*Percentages calculated by adding ratings of "usually"(4) or "always"(5).

Assessment of Drug Effects

Most respondents (91.9%) reported that consumers' behaviors were assessed for drug effects. Assessments were reported as occurring primarily on a monthly (39.5%) or weekly (22.3%) basis. Interestingly, 4.7% of respondents reported that they did not know how frequently behaviors were assessed for drug effects. The person reported as primarily responsible for these assessments was the physician or psychiatrist (72.8%). Direct service staff were reported as the primary person responsible by 32.9% of respondents and the psychologist by 28.3%. Approximately half the respondents (51.9%) selected two or more people as being responsible for the assessment of drug effects. This is heartening considering recent trends toward a multidisciplinary approach in the mental health field.

Training Issues

As shown in Table 10, approximately two-thirds of respondents indicated that they had received "too little" training in the area of drug therapy, whereas one-third reported inadequate training in the area of behavior management. A significant number of direct service staff, however, desired additional training in both drug therapy (88.4%) and in behavior management (83.3%). Respondents did not appear to prefer a

particular training format. Instead, respondents rated workshops (47.8%), inservices (43.1%), and continuing education courses (42.1%) as equally acceptable training venues. These percentages equal more than 100% because 25.6% of respondents selected two or more training formats as desirable. Basic mechanisms of drug action, side effects of medication, and the effects of drugs on behavior management techniques were chosen by respondents as the three most vital topics for additional training. These were followed by alternatives to medication, assessment of drug effects, drug interactions, major clinical implications, drug withdrawal effects, and legal issues.

Table 10

Amount of Instruction/Training About Drug Therapy and Behavior Management Techniques Provided by Agencies

Instruction	Drug Therapy	Behavior Management
Preservice training		
Too little	68.8%	33.0%
Just right	30.2%	66.0%
Too much	1%	1%
Inservice training		
Too little	68.8%	30.7%
Just right	30.2%	68.7%
Too much	1%	1%
Additional training		
Desired	88.4%	83.3%

Professional Consultation

When asked whether direct service staff should be involved in discussions about initiating, changing, or discontinuing medication, 34.0% of respondents said they should always be involved, but only 3.9% indicated that they always were involved. It is encouraging to note, however, that 40.5% of respondents did report that direct service staff occasionally or usually were involved in such discussions.

The respondents also reported that physicians and psychiatrists did not typically consult with direct service staff regarding medication issues, but did do so with management level staff within their agency (71.6%). When asked whether direct service staff consulted with physicians and psychiatrists regarding medication issues, 75.3% of respondents reported that they did not do so, however, 61.5% did report that consultation with management level staff did occur within their agencies. Although respondents consistently indicated a general lack of direct contact with prescribing physicians and psychiatrists, it appears that management level staff within most agencies act as intermediaries between direct service staff and physicians and psychiatrists.

Administration of Medication

Those listed as primarily responsible for administering medications were direct service staff (67.3%), consumers (30.3% reportedly self-administer), nurses (14.7%), and parents/caregivers (10.1%), with 22.2% of respondents selecting two or more choices. Many respondents indicated that within their agency, direct service staff administered medications and consumers self-administered their own medication. Interestingly, nearly half the respondents indicated that they administered medication, yet more than two-thirds report too little training (68.8%) in the area of drug therapy.

CHAPTER IV

DISCUSSION

Findings of the present study are comparable to those of Singh et al. (1996). Respondents in the present study rated self-injurious behavior, delusions/hallucinations and aggression as most likely to lead drug therapy. These findings were akin to the ratings of professionals surveyed by Singh et al. (1996), who rated aggression, delusions/hallucinations, and self-injurious behavior as most likely to lead to drug treatment. Similarly, respondents in both studies rated withdrawal and acting out as least likely to result in drug therapy. Direct service staff rated behavioral intervention as a suitable alternative to drug therapy for acting out and aggression, which again is consistent with the findings of Singh et al. (1996).

Of particular interest in the present study are respondents' ratings regarding the utility of behavior management techniques and drug therapy in the treatment of various disorders. In almost all cases, respondents reported that behavioral intervention should be attempted before drug therapy is implemented. More than half the respondents reported that a combined pharmacological-behavioral treatment approach

was preferable for all disorders except withdrawal. Respondents also perceived a combined treatment approach as having more utility than a behavioral approach alone when treating self-injurious behavior, delusions/hallucinations, depression, and other psychiatric disorders. This finding is of particular interest because a pharmacological-behavioral approach is representative of recent trends in treatment (Lewis et al., 1996). An integrative treatment approach combining pharmacotherapy and behavior therapy has been mandated by various regulatory bodies and has evidently taken hold within the agencies surveyed in the present study.

It is heartening that, consistent with professionals' ratings (Singh et al., 1996), direct service staff rated behavioral observation as the most influential assessment method used to make medication decisions under current and ideal conditions. Perhaps this is a reflection of the adequate training in behavior management that respondents reportedly are receiving. Hopefully, as more rating scales are created for specific use with people with developmental disabilities, the use of other objective assessment methods will be evidenced in this area (Rosenquist & Bodfish, 1997).

As was found in all previous studies (Aman et al., 1987; Gadow, 1983; Singh et al., 1994; Singh et al., 1996), psychiatrists and physicians

were perceived as most influential in the selection of assessment methods and in making medication decisions by respondents in the present study. Direct service staff perceived themselves as least influential in both situations. It is noteworthy that respondents in this study perceived parents as having a more influential role in making treatment decisions than did the respondents surveyed by Singh et al. (1996). This may be indicative of the more frequent involvement parents generally have in the lives of their non-institutionalized children.

Direct service staff reported that tiredness/sedation, dry mouth, and changes in attention span are the major side effects that detracted from the beneficial effects of psychotropic medication. Again, these results are consistent with other studies (Aman et al., 1987; Singh et al., 1994; Singh et al., 1996). Of particular interest is that respondents' ratings of motor problems and tardive dyskinesia were consistent with recent estimates of the frequency of neuroleptic-induced movement disorders (Bodfish, et al., 1997). It also is noteworthy that 9% of respondents did not perceive any of the 11 side effects as occurring so commonly as to detract from the beneficial effects of the prescribed medication. Although surprising given the well-documented history of the adverse effects of neuroleptics, about the same percentage of professionals rated all 11 side effects as tolerable (Singh et al., 1996).

Consistent with the findings of Singh et al. (1996), 91.9% of respondent in the present study reported that consumers' behaviors were assessed for drug effects. Direct service staff indicated that assessments were typically conducted on a monthly basis by the psychiatrist or treating physician. Approximately half the respondents selected two or more people as being responsible for carrying out the assessment. This may indicate that an interdisciplinary approach is being implemented within some agencies. Furthermore, one-third of direct service staff indicated that they were involved in carrying out the assessment. This is a much higher rate of involvement than reported by the professionals surveyed by Singh et al. (1996). This finding is understandable given that direct service staff in noninstitutional settings regularly work without constant supervision.

Although the professionals surveyed in that study worked in institutions, it is unsurprising that similar results were found among direct service staff working in noninstitutional settings. Direct service staff, regardless of the setting in which they work, are unlikely to have a broader knowledge base than those who oversee their work and most influence the policies and procedures within their employment setting (e.g., directors, psychologists, Qualified Mental Retardation Professionals, case managers). Also unsurprising is that direct service staff appear to

perceive issues similarly and hold similar opinions to those in authority positions.

In the present study, the acceptability of drug therapy to treat behavior problems, an issue not addressed by Singh et al. (1996), clearly depended on the presenting circumstances. Less than half of respondents perceived drug therapy as an acceptable treatment strategy for individuals with developmental disabilities unless they were in life-threatening situations or all other treatment options had been exhausted, at which time it was considered acceptable by almost all respondents. This indicates sensitivity to the particular needs of those individuals with developmental disabilities who exhibit behavior problems, rather than an unconditional acceptance of drug treatment as a "cure-all."

Interagency communication, another issue not addressed by Singh et al. (1996), reportedly occurs on a consistent basis according to respondents in the present study. This is encouraging because many individuals with developmental disabilities who are living and/or working in the community are likely to be receiving services from multiple agencies (e.g., residential, vocational). Assessing and monitoring drug effects in individuals who are served by a variety of agencies surely is a difficult task. Nonetheless, an evaluation of drug effects on behavior

across environments is advantageous when making medication decisions, and requires constant interagency communication.

Although its results are suggestive, the present survey has several limitations. First, service providers, and therefore participants, represented a convenient, not random, sample from two states. Therefore, the results may not generalize to other agencies or to other states. Future research should, if possible, utilize randomly selected participants from a greater number of states.

Second, these data are self-reported by direct service staff. It is not possible to determine the accuracy of these data nor is it known whether biases among staff existed. In the future, the accuracy of some data may be determinable by obtaining more information about the participating agencies. For example, the following questions could be asked of agency directors: What services are provided? Are adults and children served? Does a drug policy exist and if so, what is it? What kind of training do staff receive? Answers to these and other questions would have been helpful in determining whether staff were accurately reporting what transpires within their agencies and/or would have indicated inconsistencies.

A third limitation is that the survey may not have been as user-friendly as intended. It was rather long (12 pages) and the language used

may have been too technical for some respondents. Feedback was received from a few service providers indicating that some staff did not finish the survey because the language used was too difficult. A more user-friendly survey should be considered in future research endeavors.

The issue of using language that was too technical for respondents also has ramifications for the development of a training program in pharmacotherapy. If direct service staff experienced difficulty in completing this survey, a training program that uses similar terminology may be ineffectual. In the present study, 23% of respondents reported having undergraduate degrees, 31% had some undergraduate courses, and 21% had high school diplomas. The developers of training materials certainly should consider the education level of its intended audience.

Another possible limitation of the study is that only 30% of the surveys were returned, which was a lower return rate than anticipated. It was not possible to follow-up with agencies during the study to ensure that surveys were returned because it would violate the agencies' anonymity. Therefore, it is not clear that 1130 direct service staff actually contacted the survey. The 30% return may not accurately reflect the ratio of surveys returned to surveys distributed.

In summary, the findings of this and previous studies (Aman et al., 1987; Gadow, 1983; Singh et al., 1994; Singh et al., 1996) indicate a

pervasive lack of training in the area of drug treatment throughout the service delivery system for individuals with developmental disabilities, including mental retardation. The knowledge and skills deficits of service providers represent a barrier to the appropriate monitoring and management of pharmacotherapy to treat individuals with developmental disabilities. Therefore, attempts to better educate service providers, particularly direct service staff, about psychotropic medications are merited. Although some staff undoubtedly receive adequate training and are able to participate as effective members of an interdisciplinary team, the present study illustrates that a systematic training program needs to be designed, implemented, and disseminated on a broad scale.

As noted earlier, approximately 35-55% of adults with mental retardation who live in the community reportedly are treated with psychotropic and/or antiepileptic medication (Aman et al., 1995; Singh et al., 1992). As more individuals with severe behavior challenges are transitioned from institutions into the community, these rates are likely to increase. The right to be free from "unusual or hazardous treatment procedures" (Wyatt vs. Stickney, 1972, p. 380), including inappropriate use of psychotropic drugs, does not appear to be protected as vigilantly for individuals with developmental disabilities who live in the community as for those in institutions. Rinck et al. (1989) reported the following:

> When a psychotropic was ordered in an institution, most states (90%) required that the behavior for which the medication was being prescribed be explicitly stated. Similarly, about 96% of the states reported that provisions for evaluating the effects of these medications were included in the treatment or habilitation plan. For 90% of the states, behavioral changes had to be noted in the medical record. The percentages for persons in community facilities were significantly lower (58, 62, and 56, respectively). (p. 660)

Additionally, in 1987, 21 states reportedly had various regulations regarding the practice of polypharmacy (prescription of more than one psychotropic medication) for persons in institutions, whereas only eight states had similar regulations for individuals living in the community (Rinck et al., 1989).

In the past, individuals with the most severe behavior challenges remained institutionalized while those with less severe problems were integrated into the community. This trend has changed as more institutions throughout the United States are closing their doors (Prouty et al., 1996). An increasing number of individuals with developmental disabilities are living, working, and socializing in their communities, including those with the most challenging behaviors. The fact remains, however, that severe behavior problems account for many failed community placements (Lakin, Hill, Hauber, Bruininks, & Heal, 1983). Therefore, it is imperative that the treatment of behavior problems among individuals with developmental disabilities be managed carefully, particularly when that treatment includes psychotropic medication.

When properly prescribed and monitored, psychotropic drugs may afford individuals the opportunity to live as integrated members of society. When not properly prescribed and monitored, however, such drugs may cause untold misery. Therefore, how psychotropic medications are used outside institutions warrants considerable attention.

Although psychiatrists and prescribing physicians ultimately control how drugs are used, they frequently rely on the information provided by nonmedical staff, such as direct service staff, when making treatment decisions. Consequently, direct service staff may have the greatest impact on treatment outcomes because they are responsible for implementing and monitoring treatment, often with minimal supervision. Educating direct service staff, therefore, is especially valuable as it may contribute substantially to the appropriate use and assessment of psychotropic medications for individuals with developmental disabilities living and/or working in the community.

Appendix A

Protocol Clearances From the Human Subjects Institutional Review Board

Human Subjects Institutional Review Board

Kalamazoo, Michigan 490[illegible]

WESTERN MICHIGAN UNIVERSITY

Date: 5 June 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re. HSIRB Project Number 97-05-15

This letter will serve as confirmation that your research project entitled "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" has been **approved** under the **exempt** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-38 3

WESTERN MICHIGAN UNIVERSITY

Date: 13 June 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 9 June 1997 have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

WESTERN MICHIGAN UNIVERSITY

Date: 19 June 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 16 June 1997 (addition of Goodwill Industries and Behavior change associates as research sites) have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

WESTERN MICHIGAN UNIVERSITY

Date: 30 June 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project [illegible] Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated [illegible] June 1997 (addition of Westview Vocational Services as a research site) have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek approval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-38

WESTERN MICHIGAN UNIVERSITY

Date: 15 July 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 23 June 1997 (addition of Peppermint Ridge and Jewish Vocational Service as research sites) have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

Kalamazoo, Michigan

WESTERN MICHIGAN UNIVERSITY

Date: 22 July 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 21 July 1997 (addition of Toward Maximum Independence, Inc. as a research site) have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-3899

WESTERN MICHIGAN UNIVERSITY

Date: 25 July 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair Richard A. Wright

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 24 July 1997 (addition of Community Mental Health of VanBuren County as a research site) have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Human Subjects Institutional Review Board

Kalamazoo, Michigan 49008-5456

WESTERN MICHIGAN UNIVERSITY

Date: 8 August 1997

To: Alan Poling, Principal Investigator
LeeAnn Christian, Student Investigator

From: Richard Wright, Chair

Re: Changes to HSIRB Project Number 97-05-15

This letter will serve as confirmation that the changes to your research project "Direct Service Staff Perceptions of the use of Psychotropic Medications in Residential and Vocational Settings for Individuals with Developmental Disabilities" requested in your memo dated 6 August 1997 (addition of Residential Opportunities Incorporated as a research site) have been approved by the Human Subjects Institutional Review Board. *In addition, the minor revisions requested by the executive director at that site have also been approved for use at that site only.*

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 3 June 1998

Appendix B

Recruitment Packet

Kalamazoo, Michigan 49008-5052
616 387-4498

WESTERN MICHIGAN UNIVERSITY

Dear Service Provider:

We are beginning the process of conducting a research project for which your agency's participation would be greatly appreciated. The research project entails distributing surveys to full-time direct service staff who are employed by various residential and day programs throughout California and Michigan. The survey is designed to determine direct service staffs' opinions, perceptions, and knowledge regarding the use of psychotropic medications to treat the behavior problems of individuals with developmental disabilities.

Herewith you will find a brief proposal describing the rationale for this research, the methodology, and the benefits of participating in the project. We have also included a copy of the survey for your review. It can be referred to as you decide whether or not to participate in this research project. we would ask, however, that the survey not be shown to direct service staff within your agency at this time.

If your agency chooses to participate in this survey, we ask that you send us a letter of support. After receiving the letter of support from your agency we will submit it to Western Michigan University's Human Subjects Institutional Review Board for its approval. In an effort to save you time, we have included a sample letter which could be typed on your agency's letterhead and mailed to us in the self-addressed, stamped envelope enclosed.

We also would like to take this opportunity to assure you that completed surveys from your agency will remain anonymous. We are interested only in state-to-state differences, not agency differences. Therefore, we have set up a distribution and collection system which ensures that we can determine from which state the completed surveys were returned, but not from which agency.

If you have questions which are not answered satisfactorily in this packet, please feel free to contact us at (616) 387-8331. We appreciate your consideration of this matter and hope your agency decides to participate in this research project. Thank you for your time.

Sincerely,

Alan Poling, Ph D
Professor, Western Michigan University

LeeAnn Christian, M S.
Doctoral Student, WMU

[illegible] Applied Behavioral Sciences
[illegible] Psychology

[illegible], Michigan 49008-5052
616 387-4492

WESTERN MICHIGAN UNIVERSITY

RESEARCH PROPOSAL

Principle Investigator: Alan Poling, Ph.D., Western Michigan University

Student Researcher: LeeAnn Christian, M.S., Western Michigan University

Participants: Full-time direct service staff working with individuals with developmental disabilities in day and/or residential settings.

Proposed start date and length of study: Research will commence upon approval from the participating agencies and from the Human Subjects Institutional Review Board at Western Michigan University. The anticipated start date is June, 1997. It is expected that the survey will take staff 20-30 minutes to complete. Depending on the distribution and collection process used by each agency, the duration of participation for each agency is estimated to range from 1 week to 2 months.

Working Title of Study: Direct service staff perceptions of the use of psychotropic medications in residential and vocational settings for individuals with developmental disabilities

Description of Research:

Introduction

The use of drugs to treat behavioral problems in individuals with developmental disabilities has received much attention in recent years (e.g., Aman & Singh, 1988; Aman & Singh, 1991). Surveys indicate that roughly 30 to 50% of adults with mental retardation residing in institutions receive psychotropic medications, whereas 25 to 35% of those living in community settings do so (e.g., Aman, Sarphare, & Burrow, 1995; Aman & Singh, 1988; Gadow & Poling, 1988). If anticonvulsant drugs (which are psychoactive) are also included, these percentages increase by about 20%.

Given the high prevalence of psychotropic drug use in individuals with developmental disabilities, and reports that these medications are sometimes misused by caregivers (Singh, Guernsy, & Ellis, 1992), it is important to determine the ways in which decisions concerning medication are made and the ways in which the effects of these medications are assessed. Knowledge of the way these medications are perceived by individuals who are affected by such interventions is also important. In the case of drug

treatments for individuals with developmental disabilities, those affected by the intervention might include the person with a developmental disability, parents and guardians, advocates, and direct care staff. If any of these individuals are dissatisfied with the goals, procedures, or outcomes of an intervention, it can have a significant impact on the success and future use of the intervention (Poling & LeSage, 1995).

Although it is important to determine the perceptions of all individuals affected by an intervention involving drug treatment, it appears especially important to determine the perceptions of direct care staff. These individuals typically spend more time interacting with their consumers than anyone else. Direct care staff have the greatest impact on the success or failure of an intervention because they are responsible for its implementation, often with minimal supervision. Determining the perceptions, knowledge, and opinions of direct care staff regarding the use of drug treatments also may contribute substantially to the appropriate use and assessment of psychotropic medications for individuals with developmental disabilities.

Few studies have been conducted to determine the perceptions, knowledge, and opinions of individuals working with persons with developmental disabilities. No studies, to our knowledge, have attempted to determine the perceptions, knowledge, and opinions of direct care staff in non-institutional residential or vocational settings. Aman, Singh, and White (1987) surveyed nursing staff in large institutions and Singh et al. (1996) surveyed professional staff working in institutional settings. Singh, Epstein, Stout, Luebke, and Ellis (1994) surveyed teachers of students with serious emotional disturbance or learning disabilities in public school settings. Findings of these surveys consistently indicated a general lack of education pertaining to the use of medications in the treatment of behavior problems, a dissatisfaction among the respondents with their level of knowledge and the availability of training in the use of medications, and a recognition of the importance of incorporating more objective assessment measures of drug effectiveness and side-effects.

The purpose of the present study is to survey direct service staff in several residential and vocational settings throughout California and Michigan to determine their perceptions, knowledge, and opinions regarding the use of psychotropic medications to treat behavior problems in individuals with developmental disabilities. Staff from a variety of residential settings will be included in this survey (e.g., group homes, semi-independent residential programs, supported-living arrangements). Vocational settings will include a variety of facility-based and community-based programs (e.g., sheltered workshops, day treatment activity centers, supported employment programs). Respondents will include only full-time staff whose primary responsibility is to work directly with individuals with developmental disabilities (e.g., job coaches, residential aides, program aides).

Method

The investigators will mail or hand-deliver a pre-specified number of surveys to the director (or another person designated by the director) of each participating agency. Along with the surveys will be a set of instructions which will detail the process that the director (or appointee) is to follow as he or she distributes and collects the surveys. A script, describing the purpose and procedures of the study will also be included and will be read to all staff by the director (or appointee) immediately prior to distributing the surveys

to the direct service staff. A large envelope or box will also be given to the agency for staff to use when they have completed the surveys. Each agency will designate a location for distributing and collecting surveys (e.g., distributed at a regularly scheduled staff meeting and collected in the envelope by the mail boxes in the agency's main office). Upon receipt of the above materials and depending on the distribution and collection process used by each agency, the duration of participation for the agency is estimated to range from 1 week to 2 months. The distribution of the survey, including reading the script prior to handing out surveys to the staff, is estimated to take 5 minutes. It is estimated that each staff will take 20-30 minutes to complete the survey.

The collection envelope or box will be pre-stamped and pre-addressed with the investigators' names and address as both sender and receiver to insure anonymity to the participating agency and its staff. The director (or appointee) will be instructed to seal the envelope or box and place it in the mail after the distribution and collection process is completed. Upon receipt of completed surveys, the investigators will identify the state from which the surveys were returned by looking at the postmark on the envelope or box. The surveys will be coded in the top right-hand corner with the abbreviation of the state from which they were returned (i.e., CA, MI) and the envelope or box will be destroyed. Surveys will be filed by state code to insure that a particular survey cannot be traced back to a specific agency or individual.

Conclusions' Benefits Of Research

After all completed surveys have been returned and the data has been summarized and analyzed, the findings will be shared with the participating agencies. This information is expected to be of benefit to participants because it may provide useful information about direct service staffs' perceptions, opinions, and knowledge of the use of psychotropic medications. These findings may influence a change in policy or training within an agency.

Of longer-term and more general benefit to the participants is our plan to use the findings of this research to design a comprehensive training program for direct service staff regarding the use of psychotropic medications. Pilot work in the design and implementation of such a training program is expected to be done in collaboration with the agencies that participate in the current research project. Due to the usual turnover in staff, it is not possible to guarantee that participating direct service staff will directly benefit from a training program implemented in the future. However, it will benefit the direct service staff employed by the agency at the time the training program is implemented, whether or not they participated in the current research project.

In conclusion, the completion of the current research project will help us meet our short-term goal, which is to determine the perceptions, knowledge, and opinions of direct service staff regarding the use of psychotropic medications. As future research emerges from the findings of this study, we will be better able to meet our long-term goal: To better serve individuals with developmental disabilities who are receiving psychotropic medications.

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College of Arts and Sciences
Department of Psychology

Kalamazoo, Michigan 49008-5052
616 387-4498

WESTERN MICHIGAN UNIVERSITY

NOTE: This version of the survey has been provided to help you decide whether your agency would like to participate in this research project. It should not be distributed to staff until it is approved by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University (WMU). Upon approval from the HSIRB, a stamp from the HSIRB will be placed on the survey under the WMU letterhead. Under the HSIRB stamp will be an informed consent paragraph for each staff to read prior to deciding whether or not she/he would like to participate in this research project.

SURVEY CONCERNING DRUG THERAPY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Sex (circle) M F

1. Circle your current role:

   residential direct service staff vocational direct service staff both

2. Circle all that apply to the agency in which you are employed:

   residential program serves adults

   vocational/day-activity program serves children

3. Age: (Check one)

   ____ 20-25 years ____ 41-45

   ____ 26-30 ____ 46-50

   ____ 31-35 ____ 51-55

   ____ 36-40 ____ 56+

4. Racial/Ethnic Group: (Check one unless you are multicultural, then check all that apply. (optional) For this question, you are multicultural if you have parents from more than one of the broad racial/ethnic categories listed below)

_____ White, non-Hispanic
_____ Black, non-Hispanic
_____ Hispanic
_____ Asian or Pacific Islander
_____ American Indian, Eskimo, or Aleut
_____ Other

5. Level of education: (Check one)

_____ some high school
_____ high school diploma
_____ some undergraduate courses
_____ undergraduate degree
_____ some graduate courses
_____ graduate degree

If you have a college degree, what was your major? _____

6. For how many years have you worked with individuals with developmental disabilities?

_____ (Years)

In this questionnaire the term "prescribed drugs" is meant to include these drugs:

a. **Major tranquilizers (e.g., Thorazine, Mellaril, Haldol)**
b. **Minor tranquilizers (e.g., Valium, Librium)**
c. **Antihistamines (e.g., Vallergan, Atarax)**
d. **Antidepressants (e.g., Tofranil, Elavil)**
e. **Stimulants (e.g., Ritalin, Dexedrine)**
f. **Anticonvulsants (e.g., Tegretol, Depakene) but only when used for behavior control (not epilepsy).**

---

7. Are you currently working with consumers who are taking prescribed drug(s) to treat behavior problems or
have you in done so in past year?

_____ Yes If yes, how many consumers? _____

_____ No

Please circle <u>one</u> for <u>each</u> item.

8. In general, I believe it is acceptable to use prescribed drugs/drug therapy to treat behavior problems...

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. with adults with developmental disabilities	0	1	2	3	4	5
b. with children with developmental disabilities	0	1	2	3	4	5
c. with individuals with developmental disabilities who cannot choose treatment for themselves	0	1	2	3	4	5
d. with individuals with developmental disabilities who are in life-threatening situations (e.g., severe self-injurious behavior)	0	1	2	3	4	5
e. after all other treatment options have been exhausted	0	1	2	3	4	5

9. When it is suggested that one of the consumers in your agency should be tried on drug therapy, who usually recommends this approach?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Physician/Psychiatrist	0	1	2	3	4	5
b. QMRP	0	1	2	3	4	5
c. The Interdisciplinary Team	0	1	2	3	4	5
d. Psychologist	0	1	2	3	4	5
e. Parents	0	1	2	3	4	5
f. Social Worker	0	1	2	3	4	5
g. Director of Residential Service	0	1	2	3	4	5
h. Director of Vocational Service	0	1	2	3	4	5
i. Direct Service Staff	0	1	2	3	4	5
j. Other (Specify) _____	0	1	2	3	4	5

10. When discontinuation of prescribed drugs is suggested for a consumer in your agency, <u>who usually</u> recommends this change?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Physician/Psychiatrist	0	1	2	3	4	5
b. QMRP	0	1	2	3	4	5
c. The Interdisciplinary Team	0	1	2	3	4	5
d. Psychologist	0	1	2	3	4	5
e. Parents	0	1	2	3	4	5
f. Social Worker	0	1	2	3	4	5
g. Case Manager	0	1	2	3	4	5
h. Director of Residential Service	0	1	2	3	4	5
i. Director of Vocational Service	0	1	2	3	4	5

11. Some common types of behavior problems and affective disorders are listed below. We would like to know what types of disorders or problems most commonly lead to drug treatment.

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b.	Aggression to others or property damage	0	1	2	3	4	5
c.	Social withdrawal (isolation from peers)	0	1	2	3	4	5
d.	Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e.	Anxiety plus physical agitation	0	1	2	3	4	5
f.	Depression, sadness	0	1	2	3	4	5
g.	Delusions, hallucinations	0	1	2	3	4	5
h	Self-injurious behavior	0	1	2	3	4	5
i.	Any diagnosed psychiatric disorder	0	1	2	3	4	5
j	Other (Specify) _____	0	1	2	3	4	5

12. For the same problems as above, to what extent should behavior management techniques be attempted before a drug treatment is implemented?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b.	Aggression to others or property damage	0	1	2	3	4	5
c.	Social withdrawal (isolation from peers)	0	1	2	3	4	5
d.	Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e.	Anxiety plus physical agitation	0	1	2	3	4	5
f.	Depression, sadness	0	1	2	3	4	5
g.	Delusions, hallucinations	0	1	2	3	4	5
h.	Self-injurious behavior	0	1	2	3	4	5
i.	Any diagnosed psychiatric disorder	0	1	2	3	4	5
j.	Other (Specify) _____	0	1	2	3	4	5

13. For the same problems as above, to what extent do you see behavior management techniques as a suitable alternative to drug treatment?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b. Aggression to others or property damage	0	1	2	3	4	5
c. Social withdrawal (isolation from peers)	0	1	2	3	4	5
d. Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e. Anxiety plus physical agitation	0	1	2	3	4	5
f. Depression, sadness	0	1	2	3	4	5
g. Delusions, hallucinations	0	1	2	3	4	5
h. Self-injurious behavior	0	1	2	3	4	5
i. Any diagnosed psychiatric disorder	0	1	2	3	4	5
j. Other (Specify) _____	0	1	2	3	4	5

14. For the same problems as above, to what extent should behavior management techniques be combined with drug treatment?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b. Aggression to others or property damage	0	1	2	3	4	5
c. Social withdrawal (isolation from peers)	0	1	2	3	4	5
d. Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e. Anxiety plus physical agitation	0	1	2	3	4	5
f. Depression, sadness	0	1	2	3	4	5
g. Delusions, hallucinations	0	1	2	3	4	5
h. Self-injurious behavior	0	1	2	3	4	5
i. Any diagnosed psychiatric disorder	0	1	2	3	4	5
j. Other (Specify) _____	0	1	2	3	4	5

For the next four questions, we are interested in the way changes in medication are <u>currently</u> being assessed in the agency in which you work, and, also, how you think they <u>should</u> be assessed in the best of all possible worlds.

15. Please rate the following types of assessment in terms of their <u>current</u> influence on decisions relating to medication of consumers in your agency.

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Global impressions (overall subjective estimate about behavior by parents, doctors, or others)	0	1	2	3	4	5
b. Informal diary of behavior (e.g., case notes, narratives)	0	1	2	3	4	5
c. Behavioral observations	0	1	2	3	4	5
d. Rating scale of social behaviors	0	1	2	3	4	5
e. Standardized tests (e.g., IQ, personality)	0	1	2	3	4	5
f. Rating scales for psychiatric disorders (e.g., for depression)	0	1	2	3	4	5
g. Other (Specify) _____	0	1	2	3	4	5

16. In the <u>ideal</u> situation, with plenty of staff and resources, what methods do you think <u>should</u> be utilized for making decisions about medication?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Global impressions (overall subjective estimate about behavior by parents, doctors, or others)	0	1	2	3	4	5
b. Informal diary of behavior (e.g., case notes, narratives)	0	1	2	3	4	5
c. Behavioral observations	0	1	2	3	4	5
d. Rating scale of social behaviors	0	1	2	3	4	5
e. Standardized tests (e.g., IQ, personality)	0	1	2	3	4	5
f. Rating scales for psychiatric disorders (e.g., for depression)	0	1	2	3	4	5
g. Other (Specify) _____	0	1	2	3	4	5

17. <u>At present</u> who generally decides which assessments should be undertaken for making decisions about medication?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Physician/Psychiatrist	0	1	2	3	4	5
b. QMRP	0	1	2	3	4	5
c. The Interdisciplinary Team	0	1	2	3	4	5
d. Psychologist	0	1	2	3	4	5
e. Parents	0	1	2	3	4	5
f. Social Worker	0	1	2	3	4	5
g. Case Manager	0	1	2	3	4	5
h. Director of Residential Service	0	1	2	3	4	5

18. In the ideal situation, who should decide which assessments are to be undertaken for making decisions about medication?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Physician/Psychiatrist	0	1	2	3	4	5
b.	QMRP	0	1	2	3	4	5
c.	The Interdisciplinary Team	0	1	2	3	4	5
d.	Psychologist	0	1	2	3	4	5
e.	Parents	0	1	2	3	4	5
f.	Social Worker	0	1	2	3	4	5
g.	Case Manager	0	1	2	3	4	5
h.	Director of Residential Service	0	1	2	3	4	5
i.	Director of Vocational Service	0	1	2	3	4	5
j.	Direct Service Staff	0	1	2	3	4	5
k.	Other (Specify) _____	0	1	2	3	4	5

19. If a consumer is on medication:
   a. Is his/her behavior assessed for drug effects? ____Yes ____No
   b. If yes, how often?
      ____ Weekly ____ Annually
      ____ Monthly ____ Every 2-3 years
      ____ Semi-Annually ____ Other (Specify) _____
   c. Who carries out the assessment?
      ____ Physician/Psychiatrist ____ Psychologist
      ____ Direct service staff ____ Interdisciplinary Team
      ____ Case Manager ____ Other (Specify) _____
      ____ Nurse _____

20. To what extent do you believe the following occur as side-effects of prescribed medications so commonly that they detract from the beneficial effects of the drugs?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Tiredness, sedation	0	1	2	3	4	5
b.	Marked weight changes	0	1	2	3	4	5
c.	Interference with learning	0	1	2	3	4	5
d.	Skin reactions	0	1	2	3	4	5
e.	Behavioral irritation	0	1	2	3	4	5
f.	Excitability	0	1	2	3	4	5
g.	Depression, sadness	0	1	2	3	4	5
h.	Motor problems beginning with onset of treatment (extra-pyramidal symptoms, e.g., parkinsonian reaction)	0	1	2	3	4	5
i.	Long term motor problems (more than 3 months, e.g.,	0	1	2	3	4	5

21. Preservice Training: Check the amount of instruction/training about prescribed drugs/drug therapy you have received as part of your formal training at the agency in which you are currently employed.

____ Too little

____ Just right

____ Too much

22. Preservice Training: Check the amount of instruction/training about behavior management techniques you have received as part of your formal training at the agency in which you are currently employed.

____ Too little

____ Just right

____ Too much

23. Inservice Training: Check the amount of instruction/training about prescribed drugs/drug therapy you have received in inservice training at the agency in which you are currently employed.

____ Too little

____ Just right

____ Too much

24. Inservice Training: Check the amount of instruction/training about behavior management techniques you have received in inservice training at the agency in which you are currently employed.

____ Too little

____ Just right

____ Too much

25. Would you like to receive additional inservice training regarding drug therapy as it relates to your consumers?

____ Yes

____ No

26. Would you like to receive additional inservice training regarding behavior management techniques as it relates to your consumers?

____ Yes

____ No

27. If yes to item 25 or 26, specify what form this inservice training should take.

_____ Workshop

_____ Inservice Lecture

_____ Continuing Education Course

_____ Other (Specify) _____

28. How necessary is continuing inservice education about drugs/drug therapy for direct service staff who serve persons with developmental disabilities?

_____ Not at all necessary

_____ Necessary

_____ Extremely necessary

_____ Other (Specify) _____

29. Rank order the three most vital topics regarding drug therapy that you wish you could learn about in an inservice program (1=most important, 2=second, 3=third)

_____ Major clinical indications

_____ Side effects

_____ Drug interactions

_____ Legal issues

_____ Basic mechanisms of drug action

_____ Drug withdrawal effects

_____ Alternatives to medication

_____ Assessment of drug effects

_____ Effects of drugs on behavior management techniques

_____ Other (Specify) _____

30. Does your agency have a policy on drug therapy (i.e., prescription drugs)?

_____ Yes

_____ No

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
31. Do you think you as a direct service staff <u>should</u> be involved in discussions about beginning, changing, or discontinuing medications for your consumers?	0	1	2	3	4	5

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
32. <u>Are</u> your views taken into account before your consumers' medication is begun, changed, or discontinued?	0	1	2	3	4	5

33. How often does your agency communicate with other agencies or individuals (e.g., residential or day programs, parents, guardians) when issues arise regarding your consumers' medication regimen?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. When a new medication is prescribed	0	1	2	3	4	5
b. When a medication change is made (e.g., dosage)	0	1	2	3	4	5
c. When a medication is discontinued	0	1	2	3	4	5
d. When a problem is noticed (e.g., side effects, changes in behavior)	0	1	2	3	4	5

34. How often do other agencies or individuals (e.g., residential or day programs, parents, guardians) communicate with your agency when issues arise regarding your consumers' medication regimen?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. When a new medication is prescribed	0	1	2	3	4	5
b. When a medication change is made (e.g., dosage)	0	1	2	3	4	5
c. When a medication is discontinued	0	1	2	3	4	5
d. When a problem is noticed (e.g., side effects, changes in behavior)	0	1	2	3	4	5

35. Are you consulted by the doctor/psychiatrist regarding the medication of your consumers?

____ Yes

____ No

If no, is someone within your agency consulted (i.e., supervisor, director)?

36. Do you consult with the doctor/psychiatrist regarding the medication of your consumers?

____ Yes

____ No

If no, do you consult with someone within your agency who, in turn, does so?

____ Yes (Specify title) _____

____ No

37. Who administers prescribed medication if a consumer in your agency has to take medication?

____ Direct service staff

____ Nurse

____ Consumer self-administers his/her own medication

____ Other (Specify) _____

38. If you controlled the way prescribed drugs are administered to consumers in your agency, what changes (if any) would you make? Be as specific as possible and please write clearly

_____

_____

_____

_____

_____

_____

39. Any additional comments you would like to make?

_____

_____

_____

_____

_____

AGENCY LETTERHEAD

DATE

Richard Wright, Chair
Human Subjects Institutional Review Board
Western Michigan University
Kalamazoo, MI 49008

Dear Chairman Wright:

LeeAnn Christian has submitted a research proposal entitled "Direct service staff perceptions of the use of psychotropic medications in residential and vocational settings for individuals with developmental disabilities" to be implemented with the full-time staff employed by NAME OF AGENCY The project, as proposed, is relevant to the population of staff employed and consumers served and appears to pose no risks to either We support the implementation of this research project and may benefit from the results obtained.

Sincerely,

NAME
TITLE
NAME OF AGENCY

Appendix C

Thank You Letter and Instructions for the Survey Distribution and Collection Process

College of Arts and Sciences
Department of Psychology

Kalamazoo, Michigan 49008-5052
616 387-4495

WESTERN MICHIGAN UNIVERSITY

Date

Dear **(Director's Name)**,

Thank you for endorsing our research project titled, "Direct service staff perceptions of the use of psychotropic medications in residential and vocational settings for individuals with developmental disabilities." We appreciate **(name of agency)** participation and have made every effort to make the process of distributing, collecting, and returning the surveys as easy as possible. We do not want this to be a burdensome task for you or your staff.

Herewith you will find instructions for the distribution and collection of surveys, a script to read to your staff prior to distributing the surveys, and **(number)** copies of the survey concerning drug therapy for people with developmental disabilities. Also included is an envelope or box in which completed surveys should be collected. The envelope or box has already been pre-stamped and pre-addressed with the researchers' address. After all completed surveys have been collected, we ask that you securely seal the envelope or box and place it in the mail.

Prior to distributing the surveys to your direct service staff, please carefully read the enclosed instructions. By following these instructions, you will ensure that the surveys are distributed and collected systematically. It will also insure that your staffs' rights are upheld and that your agency and its staff will maintain anonymity.

If you have questions or would like to discuss further the processes for distributing, collecting, and returning the surveys described below, please don't hesitate to call us at (616) 387-8331. You can also fax your questions to (616) 387-8330 or email them to X95CHRISTIA1@wmich.edu. You may also contact the Chair, Human Subjects Institutional Review Board at (616)387-8293 or the Vice President for Research at (616)387-8298 if questions or problems arise during the course of this study.

Thanks again for participating in this research project. As soon as the surveys are collected from all participating agencies, the data will be summarized and analyzed. The results and conclusions of the research will be shared with you at that time.

Sincerely,

Alan Poling, Ph.D
Professor, Western Michigan University

LeeAnn Christian, M.S.
Doctoral Student, Western Michigan University

Instructions/Procedures for the Distribution and Collection of Surveys

A. Option 1: At a Mandatory Staff Meeting or Inservice

1. At a regularly scheduled staff meeting or inservice, set aside approximately 30-40 minutes on your agenda in which you can distribute and collect surveys. When you reach that part of the staff meeting do the following:

    a. Tell the staff that you will be reading them a script which describes the purpose and procedures of a survey being conducted by researchers from Western Michigan University.

    b. Read the script as it is written and please repeat any or all of it if staff request that you do so.

    c. Prior to handing out the surveys, announce that an alternative activity is being assigned for those staff who do not wish to participate in the survey. If materials are needed for the alternative activity, hand them out to everyone at this time. Try to assign a reading or writing task so all staff will be engaging in a similar activity. Under no circumstances should you ask staff if they want to participate or not. Staff should not be "singled-out" as participant and non-participants in the research project; participation is anonymous and voluntary. By providing an alternative activity, the risk of coercion or pressure to participate is reduced or eliminated. This is extremely important!

    d. Distribute the surveys to all staff. Remind them to read the informed consent paragraph on the first page of the survey to insure that they meet the inclusion criteria and to insure that their decision to participate is an informed one.

    e. After the surveys are distributed, announce that staff should place completed surveys in the collection envelope or box which is **(announce location)**

    f. Tell the staff it should take approximately 20-30 minutes to complete the survey.

    g. After everyone who had chosen to do so has completed the survey, place the collection envelope or box in a secure place until you seal it and place it in the mail.

***NOTE: Option 1 is the preferred method. Although it requires 30-40 minutes during a staff meeting or inservice, it is a shorter and less cumbersome process than Option 2 which follows.

B. Option 2: Separate Distribution and Collection Times

1. At a regularly scheduled staff meeting or inservice, set aside approximately 10 minutes on your agenda in which you can distribute surveys. When you reach that part of the staff meeting do the following:

   a. Tell the staff that you will be reading them a script which describes the purpose and procedures of a survey being conducted by researchers from Western Michigan University.

   b. Read the script as it is written and please repeat any or all of it if staff request that you do so.

   c. Distribute the surveys to all staff. Under no circumstances should you ask staff if they want to participate or not. No staff should be "singled-out"; participation is anonymous and voluntary

   d. Remind the staff to read the informed consent paragraph on the first page of the survey to insure that they meet the inclusion criteria and to insure that their decision to participate is an informed one

   e. Tell the staff it should take approximately 20-30 minutes to complete the survey.

   f. After the surveys are distributed, announce that staff should place completed surveys in the collection envelope or box which is **(announce location)** by **(due date)**.

   g. At close of business on *(due date)*, place the collection envelope or box in a secure place until you seal it and place it in the mail.

**NOTE. Option 2 may be more difficult and time consuming because staff might forget about the survey, lose the survey, or forget to place it in the collection envelope or box by the due date. If it is not feasible to implement Option 1, the following recommendations are made to simplify the process described in Option 2.

1. Set a relatively close due date (i.e., one or two weeks).
2. Set a due date that coincides with another job duty or activity in which staff are required to be in the office (e.g., pay day, next staff meeting).
3. Place the collection box in a highly visible area (e.g., near staff mailboxes).
4. Have extra copies of the survey readily available.
5. Post a few notes around the office reminding staff of the due date.

SCRIPT

(To be read to staff prior to distributing surveys)

You are invited to participate in a research project entitled, "Direct service staff perceptions of the use of psychotropic medications in residential and vocational settings for individuals with developmental disabilities." This project is being conducted by Alan Poling, Ph.D. who is a Full Professor in the Department of Psychology at Western Michigan University and by LeeAnn Christian, M.S. who is a doctoral student in the Department of Psychology at Western Michigan University. The project has been approved by the Human Subjects Institutional Review Board at Western Michigan University.

The purpose of this research is to survey direct service staff in several residential and vocational settings throughout California and Michigan to determine their perceptions, knowledge, and opinions regarding the use of psychotropic medications (e.g., haldol, thorazine) to treat the behavior problems of individuals with developmental disabilities. Staff from a variety of residential and day services will be surveyed. Only full-time direct service staff, whose primary responsibility is to work directly with individuals with developmental disabilities, are eligible to participate in the survey. Another purpose of this project is to fulfill LeeAnn Christian's Doctoral Dissertation requirement.

Many individuals challenged by developmental disabilities are prescribed behavior-modifying medications as a method for treating their problem behaviors. This project will attempt to determine the following: (1) the acceptability of using prescribed medications to treat behavior problems in individuals with developmental disabilities as viewed by direct service staff; (2) the current methods being used by agencies to assess the effectiveness of prescribed medication; (3) the amount of involvement direct service staff have in decisions regarding the use of behavior-modifying medications with the individuals they serve; (4) the training provided by agencies to their direct service staff; and (5) the need for further staff training in the use and assessment of behavior-modifying medications. After the research project is completed, the results will be shared with all agencies that participated in the survey. The researchers are also planning to use the results to design and implement a comprehensive staff training program on the use of psychotropic medications.

Your participation in this project entails completing a 39-item survey and returning it to the collection envelope or box. Participation is anonymous and voluntary. If you choose to participate, carefully read the informed consent paragraph on the first page of the survey. Placement of the completed survey in the collection envelope or box is viewed as giving your consent to include the information in the results of this research project.

Please remember, this is not an assignment that you have to complete as part of your regular job duties. You have the right not to participate. Choosing not to participate will have no impact on your employment status. If after reading through the survey, you choose not to participate, please work on **(announce alternative task and hand out materials to all staff if applicable)**. If you chose to participate, but feel uncomfortable answering particular questions, you have the right to skip those questions. You also have the right to withdraw from participation at any time while completing the survey. If you would like to withdraw, do not place your survey in the collection envelope or box, and begin working on **(alternative task)**.

At this time, I will hand out the surveys. Remember to read carefully the informed consent paragraph on the first page before deciding whether you would like to participate in this project. If you choose to participate, please place your completed survey in the collection envelope or box which is **(announce location)**.

Appendix D

Survey Concerning Drug Therapy for Persons With Developmental Disabilities

College of Arts and Sciences
Department of Psychology

Kalamazoo, Michigan 49008-5052
616 387-4498

WESTERN MICHIGAN UNIVERSITY

SURVEY CONCERNING DRUG THERAPY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

The purpose of this study is to survey direct service staff in residential and vocational settings in California and Michigan to determine their perceptions, knowledge, and opinions regarding the use of psychotropic (behavior-modifying) medications to treat the behavior problems of individuals challenged by developmental disabilities. Another purpose of the project is fulfill LeeAnn Christian's Doctoral Dissertation requirement. Only full-time direct service staff, whose primary responsibility is to work directly with individuals challenged with developmental disabilities, are eligible to participate in the study. Your participation in this study is voluntary and anonymous, and it entails completing a 39-item survey which is estimated to take 20-30 minutes to complete. To insure anonymity, you will NOT be asked to provide your name or the name of the agency in which you are employed. After completing the survey, you will be asked to place it in a collection envelope or box. Anonymity to all participating agencies and their staff is also insured by pre-stamping and pre-addressing the collection envelope or box with the researchers' address. The director of your agency will seal the collection envelope or box and will place it in the mail. Upon receipt of completed surveys, the researchers will identify the state from which the surveys were returned by looking at the postmark on the collection envelope or box (the envelope or box then will be destroyed). The surveys will be coded by state (CA or MI) and will be filed only by state code to insure that a particular survey cannot be traced back to a specific agency or individual. Participation in this study is strictly voluntary. It is not an assignment that you have to complete as part of your regular job duties. You have the right NOT to participate. Choosing not to participate will have NO impact on your employment status. If, after you read this, you choose not to participate, you can dispose of the survey. If you choose to participate, but begin to feel uncomfortable answering particular questions, you have the right to skip those questions or to withdraw from the study. If you want to participate, but choose not to answer all the questions, place the partially completed survey in the collection envelope or box when you are finished. If you choose to withdraw, dispose of the survey. Placement of a survey in the collection envelope or box is viewed as giving consent to include the information you provide in the results of this research project. The participants may contact Alan Poling, Ph.D. at (616)387-8328 or LeeAnn Christian, M.S. at (616)387-8331 if questions or problems arise during the course of this research project. The participants may also contact the Chair, Human Subjects Institutional Review Board at (616)387-8293 or the Vice President for Research at (616)387-8298 if questions or problems arise during the course of the study.

If you choose to participate in this study, the survey begins on page 2.

SURVEY CONCERNING DRUG THERAPY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Sex (circle) M F

1. Circle your current role:

   residential direct service staff vocational direct service staff both

2. Circle all that apply to the agency in which you are employed:

   residential program serves adults

   vocational/day-activity program serves children

3. Age: (Check one)

   _____ 20-25 years _____ 41-45

   _____ 26-30 _____ 46-50

   _____ 31-35 _____ 51-55

   _____ 36-40 _____ 56+

4. Racial/Ethnic Group: (Check one unless you are multicultural, then check all that apply. (optional) For this question, you are multicultural if you have parents from more than one of the broad racial/ethnic categories listed below)

   _____ White, non-Hispanic _____ Asian or Pacific Islander

   _____ Black, non-Hispanic _____ American Indian, Eskimo, or Aleut

   _____ Hispanic _____ Other

5. Level of education: (Check one)

   _____ some high school _____ undergraduate degree

   _____ high school diploma _____ some graduate courses

   _____ some undergraduate courses _____ graduate degree

   If you have a college degree, what was your major? _____

6. For how many years have you worked with individuals with developmental disabilities?

In this questionnaire the term "prescribed drugs" is meant to include these drugs:

a. **Major tranquilizers (e.g., Thorazine, Mellaril, Haldol)**
b. **Minor tranquilizers (e.g., *Valium, Librium*)**
c. **Antihistamines (e.g., Vallergan, Atarax)**
d. **Antidepressants (e.g., Tofranil, Elavil)**
e. **Stimulants (e.g., Ritalin, Dexedrine)**
f. **Anticonvulsants (e.g., Tegretol, Depakene) but only when used for behavior control (not epilepsy).**

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7. Are you currently working with consumers who are taking prescribed drug(s) to treat behavior problems or have you in done so in past year?

_____ Yes If yes, how many consumers? _____

_____ No

Please circle one for each item.

8. *In general, I believe it is acceptable to use prescribed drugs/drug therapy to treat behavior problems...*

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. with adults with developmental disabilities	0	1	2	3	4	5
b. with children with developmental disabilities	0	1	2	3	4	5
c. with individuals with developmental disabilities who cannot choose treatment for themselves	0	1	2	3	4	5
d. with individuals with developmental disabilities who are in life-threatening situations (e.g., severe self-injurious behavior)	0	1	2	3	4	5
e. after all other treatment options have been exhausted	0	1	2	3	4	5

9. When it is suggested that one of the consumers in your agency should be tried on drug therapy, who usually recommends this approach?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Physician/Psychiatrist	0	1	2	3	4	5
b. QMRP	0	1	2	3	4	5
c. The Interdisciplinary Team	0	1	2	3	4	5
d. Psychologist	0	1	2	3	4	5
e. Parents	0	1	2	3	4	5
f. Social Worker	0	1	2	3	4	5
g. Director of Residential Service	0	1	2	3	4	5
h. Director of Vocational Service	0	1	2	3	4	5
i. Direct Service Staff	0	1	2	3	4	5
j. Other (Specify) _____	0	1	2	3	4	5

10. When discontinuation of prescribed drugs is suggested for a consumer in your agency, who usually recommends this change?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Physician/Psychiatrist	0	1	2	3	4	5
b. QMRP	0	1	2	3	4	5
c. The Interdisciplinary Team	0	1	2	3	4	5
d. Psychologist	0	1	2	3	4	5
e. Parents	0	1	2	3	4	5
f. Social Worker	0	1	2	3	4	5
g. Case Manager	0	1	2	3	4	5
h. Director of Residential Service	0	1	2	3	4	5
i. Director of Vocational Service	0	1	2	3	4	5
j. Direct Service Staff	0	1	2	3	4	5
k. Other (Specify) _____	0	1	2	3	4	5

11. Some common types of behavior problems and affective disorders are listed below. We would like to know what types of disorders or problems most commonly lead to drug treatment.

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b. Aggression to others or property damage	0	1	2	3	4	5
c. Social withdrawal (isolation from peers)	0	1	2	3	4	5
d. Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e. Anxiety plus physical agitation	0	1	2	3	4	5
f. Depression, sadness	0	1	2	3	4	5
g. Delusions, hallucinations	0	1	2	3	4	5
h. Self-injurious behavior	0	1	2	3	4	5

12. For the same problems as above, to what extent should behavior management techniques be attempted before a drug treatment is implemented?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b.	Aggression to others or property damage	0	1	2	3	4	5
c.	Social withdrawal (isolation from peers)	0	1	2	3	4	5
d.	Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e.	Anxiety plus physical agitation	0	1	2	3	4	5
f.	Depression, sadness	0	1	2	3	4	5
g.	Delusions, hallucinations	0	1	2	3	4	5
h.	Self-injurious behavior	0	1	2	3	4	5
i.	Any diagnosed psychiatric disorder	0	1	2	3	4	5
j.	Other (Specify) _____	0	1	2	3	4	5

13. For the same problems as above, to what extent do you see behavior management techniques as a suitable alternative to drug treatment?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b.	Aggression to others or property damage	0	1	2	3	4	5
c.	Social withdrawal (isolation from peers)	0	1	2	3	4	5
d.	Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e.	Anxiety plus physical agitation	0	1	2	3	4	5
f.	Depression, sadness	0	1	2	3	4	5
g.	Delusions, hallucinations	0	1	2	3	4	5
h.	Self-injurious behavior	0	1	2	3	4	5
i.	Any diagnosed psychiatric disorder	0	1	2	3	4	5
j.	Other (Specify) _____	0	1	2	3	4	5

14. For the same problems as above, to what extent <u>should</u> behavior management techniques <u>be combined</u> with drug treatment?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Acting out (irritability, shouting, temper tantrums)	0	1	2	3	4	5
b. Aggression to others or property damage	0	1	2	3	4	5
c. Social withdrawal (isolation from peers)	0	1	2	3	4	5
d. Hyperactivity (restlessness, trouble paying attention, inability to sit still)	0	1	2	3	4	5
e. Anxiety plus physical agitation	0	1	2	3	4	5
f. Depression, sadness	0	1	2	3	4	5
g. Delusions, hallucinations	0	1	2	3	4	5
h. Self-injurious behavior	0	1	2	3	4	5
i. Any diagnosed psychiatric disorder	0	1	2	3	4	5
j. Other (Specify) _____	0	1	2	3	4	5

For questions 15-18, we are interested in the way changes in medication are <u>currently</u> being assessed in the agency in which you work, and, also, how you think they <u>should</u> be assessed in the best of all possible worlds.

15. Please rate the following types of assessment in terms of their <u>current</u> influence on decisions relating to medication of consumers in your agency.

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. Global impressions (overall subjective estimate about behavior by parents, doctors, or others)	0	1	2	3	4	5
b. Informal diary of behavior (e.g., case notes, narratives)	0	1	2	3	4	5
c. Behavioral observations	0	1	2	3	4	5
d. Rating scale of social behaviors	0	1	2	3	4	5
e. Standardized tests (e.g., IQ, personality)	0	1	2	3	4	5
f. Rating scales for psychiatric disorders (e.g., for depression)	0	1	2	3	4	5
g. Other (Specify) _____	0	1	2	3	4	5

16. In the ideal situation, with plenty of staff and resources, what methods do you think should be utilized for making decisions about medication?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Global impressions (overall subjective estimate about behavior by parents, doctors, or others)	0	1	2	3	4	5
b.	Informal diary of behavior (e.g., case notes, narratives)	0	1	2	3	4	5
c.	Behavioral observations	0	1	2	3	4	5
d.	Rating scale of social behaviors	0	1	2	3	4	5
e.	Standardized tests (e.g., IQ, personality)	0	1	2	3	4	5
f.	Rating scales for psychiatric disorders (e.g., for depression)	0	1	2	3	4	5
g.	Other (Specify) _____	0	1	2	3	4	5

17. At present who generally decides which assessments should be undertaken for making decisions about medication?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Physician/Psychiatrist	0	1	2	3	4	5
b.	QMRP	0	1	2	3	4	5
c.	The Interdisciplinary Team	0	1	2	3	4	5
d.	Psychologist	0	1	2	3	4	5
e.	Parents	0	1	2	3	4	5
f.	Social Worker	0	1	2	3	4	5
g.	Case Manager	0	1	2	3	4	5
h.	Director of Residential Service	0	1	2	3	4	5
i.	Director of Vocational Service	0	1	2	3	4	5
j.	Direct Service Staff	0	1	2	3	4	5
k.	Other (Specify) _____	0	1	2	3	4	5

18. In the ideal situation, who should decide which assessments are to be undertaken for making decisions about medication?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Physician/Psychiatrist	0	1	2	3	4	5
b.	QMRP	0	1	2	3	4	5
c.	The Interdisciplinary Team	0	1	2	3	4	5
d.	Psychologist	0	1	2	3	4	5
e.	Parents	0	1	2	3	4	5
f.	Social Worker	0	1	2	3	4	5
g.	Case Manager	0	1	2	3	4	5
h.	Director of Residential Service	0	1	2	3	4	5
i.	Director of Vocational Service	0	1	2	3	4	5
j.	Direct Service Staff	0	1	2	3	4	5
k.	Other (Specify) _____	0	1	2	3	4	5

19. If a consumer is on medication:

a. Is his/her behavior assessed for drug effects? _____Yes _____No

b. If yes, how often?

_____ Weekly _____ Annually

_____ Monthly _____ Every 2-3 years

_____ Semi-Annually _____ Other (Specify) _____

c. Who carries out the assessment?

_____ Physician/Psychiatrist _____ Psychologist

_____ Direct service staff _____ Interdisciplinary Team

_____ Case Manager _____ Other (Specify) _____

_____ Nurse _____

20. To what extent do you believe the following occur as side-effects of prescribed medications so commonly that they detract from the beneficial effects of the drugs?

		Not Applicable	Never	Seldom	Occasionally	Usually	Always
a.	Tiredness, sedation	0	1	2	3	4	5
b.	Marked weight changes	0	1	2	3	4	5
c.	Interference with learning	0	1	2	3	4	5
d.	Skin reactions	0	1	2	3	4	5
e.	Behavioral irritation	0	1	2	3	4	5
f.	Excitability	0	1	2	3	4	5
g.	Depression, sadness	0	1	2	3	4	5
h.	Motor problems beginning with onset of treatment (extra-pyramidal symptoms, e.g., parkinsonian reaction)	0	1	2	3	4	5
i.	Long term motor problems (more than 3 months, e.g., tardive dyskinesia)	0	1	2	3	4	5
j.	Dry mouth	0	1	2	3	4	5
k.	Changes in attention span	0	1	2	3	4	5
l.	None	0	1	2	3	4	5
m.	Other (Specify) _____						

21. Preservice Training: Check the amount of instruction/training about prescribed drugs/drug therapy you have received as part of your formal training at the agency in which you are currently employed.

_____ Too little

_____ Just right

_____ Too much

22. Preservice Training: Check the amount of instruction/training about behavior management techniques you have received as part of your formal training at the agency in which you are currently employed.

_____ Too little

_____ Just right

_____ Too much

23. Inservice Training: Check the amount of instruction/training about prescribed drugs/drug therapy you have received in inservice training at the agency in which you are currently employed.

_____ Too little

_____ Just right

_____ Too much

24. Inservice Training: Check the amount of instruction/training about behavior management techniques you have received in inservice training at the agency in which you are currently employed.

_____ Too little

_____ Just right

_____ Too much

25. Would you like to receive additional inservice training regarding drug therapy as it relates to your consumers?

_____ Yes

_____ No

26. Would you like to receive additional inservice training regarding behavior management techniques as it relates to your consumers?

_____ Yes

_____ No

27 If you answered yes to item 25 or 26, specify what form this inservice training should take.

____ Workshop

____ Inservice Lecture

____ Continuing Education Course

____ Other (Specify) _____

28. How necessary is continuing inservice education about drugs/drug therapy for direct service staff who serve persons with developmental disabilities?

____ Not at all necessary

____ Necessary

____ Extremely necessary

____ Other (Specify) _____

29 Rank order the three most vital topics regarding drug therapy that you wish you could learn about in an inservice program (1=most important, 2=second, 3=third)

____ Major clinical indications

____ Side effects

____ Drug interactions

____ Legal issues

____ Basic mechanisms of drug action

____ Drug withdrawal effects

____ Alternatives to medication

____ Assessment of drug effects

____ Effects of drugs on behavior management techniques

____ Other (Specify) _____

30. Does your agency have a policy on drug therapy (i.e., prescription drugs)?

____ Yes

____ No

If yes, please state the policy: _____

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
31. Do you think you as a direct service staff should be involved in discussions about beginning, changing, or discontinuing medications for your consumers?	0	1	2	3	4	5

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
32. Are your views taken into account before your consumers' medication is begun, changed, or discontinued?	0	1	2	3	4	5

33. How often does your agency communicate with other agencies or individuals (e.g., residential or day programs, parents, guardians) when issues arise regarding your consumers' medication regimen?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. When a new medication is prescribed	0	1	2	3	4	5
b. When a medication change is made (e.g., dosage)	0	1	2	3	4	5
c. When a medication is discontinued	0	1	2	3	4	5
d. When a problem is noticed (e.g., side effects, changes in behavior)	0	1	2	3	4	5

34. How often do other agencies or individuals (e.g., residential or day programs, parents, guardians) communicate with your agency when issues arise regarding your consumers' medication regimen?

	Not Applicable	Never	Seldom	Occasionally	Usually	Always
a. When a new medication is prescribed	0	1	2	3	4	5
b. When a medication change is made (e.g., dosage)	0	1	2	3	4	5
c. When a medication is discontinued	0	1	2	3	4	5
d. When a problem is noticed (e.g., side effects, changes in behavior)	0	1	2	3	4	5

35. Are you consulted by the doctor/psychiatrist regarding the medication of your consumers?

_____ Yes

_____ No

If no, is someone within your agency consulted (i.e., supervisor, director)?

Yes (Specify title) _____

36. Do you consult with the doctor/psychiatrist regarding the medication of your consumers?

____ Yes

____ No

If no, do you consult with someone within your agency who, in turn, does so?

____ Yes (Specify title) _____

____ No

37. Who administers prescribed medication if a consumer in your agency has to take medication?

____ Direct service staff

____ Nurse

____ Consumer self-administers his/her own medication

____ Other (Specify) _____

38 If you controlled the way prescribed drugs are administered to consumers in your agency, what changes (if any) would you make? Be as specific as possible and please write clearly

_____

_____

_____

_____

_____

39 Any additional comments you would like to make?

_____

_____

_____

_____

_____

Please return the survey to the collection box or envelope.

Thank you for participating!

Appendix E

Sample Data Sheet and Coding Instructions

Survey #	State	Sex	Q1	Q2a	Q2b	Q2c	Q2d	Q3	Q4	Q5	Q6	Q7	Q7a	Q8a	Q8b	Q8c	Q8d	Q8e	Q9a	Q9b	Q9c	Q9d	Q9e	Q9f	Q9g
4053	1	9	0	1	2	1	2	0	2	2	30	0	3	2	0	2	3	3	5	1	1	2	2	2	1
4719	1	9	0	1	1	1	2	9	9	9	24	0	99	2	2	2	2	99	4	9	2	2	2	0	2
4810	1	0	2	1	2	1	0	2	9	2	3	1	0	0	0	4	0	0	0	0	0	0	0	0	0
4945	1	2	0	1	0	1	2	0	0	99	60	0	3	3	3	3	5	4	4	5	5	4	3	4	2
4177	1	1	0	1	0	1	0	0	0	2	48	0	6	4	4	4	5	4	5	4	4	4	3	2	2
4258	1	1	0	1	0	1	0	2	1	2	156	0	4	4	4	4	5	4	4	4	4	9	3	9	9
4275	1	1	0	1	0	1	0	1	0	99	24	0	4	99	9	9	4	4	4	4	4	9	9	9	9

Coding Instructions for Survey

Q's	Codes								
State	0 = CA	1 = MI	9 = missing						
Sex	0 = Male	1 = Female	9 = missing						
Q1	0 = Residential	1 = Vocational/ Day	2 = both	9 missing	Note: If a 9 is scored, do not score the rest of the survey. It does not meet the criteria for inclusion				
Q2a-d	0 = not circled	1 = circled	9 = missing						
Q3	0 = 20-25	1 = 26-30	2 = 31-35	3 = 36-40	4 = 41-45	5 = 46-50	6 = 51-55	7 = 56+	9 = missing
Q4	0 = White	1 = Black	2 = Hispanic	3 = Asian/ Pacific Islander	4 = American Indian, etc	5 = Other	9 = missing		
Q5	0 = some H S	1 = H S diploma/ GED	2 = some under-grad	3 = under-grad degree	4 = some grad	5 = grad degree	6 = wrote in major	9 = missing	
Q6	# of months	NR = missing or uninterpretable							
Q7	0 = yes	1 = no	9 = missing						
Q7a	# of consumers	NR = missing							
Q8a-e	0 = not applicable	1 = never	2 = seldom	3 = occasion-ally	4 = usually	5 = always	9 = missing		
Q9a-j	0 = not applicable	1 = never	2 = seldom	3 = occasion-ally	4 = usually	5 = always	9 = missing		
Q10 a-k	0 = not applicable	1 = never	2 = seldom	3 = occasion-ally	4 = usually	5 = always	9 = missing		

Q's	Codes							
Q11a-j	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q12a-j	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q13a-j	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q14a-j	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q15a-g	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q16a-g	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q17a-k	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q18a-k	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing	
Q19a	0 = yes	1 = no	9 = missing					
Q19b	0 = weekly	1 = monthly	2 = semi-annually	3 = annually	4 = every 2-3 years	5 = other	9 = missing	
Q19c	0 = physician	1 = direct service staff	2 = case manager	3 = nurse	4 = psychologist	5 = ID team	6 = other	9 = missing

Q's	Codes						
Q20a-m	0 = not applicable	1 = never	2 = seldom	3 = occasionally	4 = usually	5 = always	9 = missing
Q21	0 =	1 =	2 =	9 =			
	too little	just right	too much	missing			
Q22	0 =	1 =	2 =	9 =			
	too little	just right	too much	missing			
Q23	0 =	1 =	2 =	9 =			
	too little	just right	too much	missing			
Q24	0 =	1 =	2 =	9 =			
	too little	just right	too much	missing			
Q25	0 =	1 =	9 =				
	yes	no	missing				
Q26	0 =	1 =	9 =				
	yes	no	missing				
Q27	0 =	1 =	2 =	3 =	9 =		
	workshop	observe/ lecture	combination	other	missing		
Q28	0 =	1 =	2 =	3 =	9 =		
	not at all necessary	necessary	extremely necessary	other	missing		
Q29a-j	0 =not ranked	1 = must important	2 = second	3 = third	9 = missing/ no data/ invalid		
Q30	0 =	1 =	2 = wrote in	9 = missing			
	yes, * if policy stated	no	unknown				
Q31	0 =	1 =	2 =	3 =	4 = usually	5 = always	9 = missing
	not applicable	never	seldom	occasionally			
Q32	0 =	1 =	2 =	3 =	4 = usually	5 = always	9 = missing
	not applicable	never	seldom	occasionally			

Q's	CODES						
Q33a-d	0 = not applicable	1 = never	2 = seldom	3 = occasion-ally	4 = usually	5 = always	9 = missing
Q34a-d	0 = not applicable	1 = never	2 = seldom	3 = occasion-ally	4 = usually	5 = always	9 = missing
Q35a	0 = yes	1 = no	9 = missing				
Q35b	N/A = coded 0 on Q35a	0 = yes	1 = no	9 = missing if coded 1 on Q35a and not scored in Q35b			
Q36a	0 = yes	1 = no	9 = missing				
Q36b	N/A = if coded 0 on Q36a	0 = yes	1 = no	9 = missing if coded 1 on Q36a and not scored in Q36b			
Q37	0 = direct service staff	1 = nurse	2 = consumer/self-advocates	3 = other			
Q38	0 = answered	9 = missing					

NOTE: For all items with a space for write-ins (e.g., Q9j, Q10k), code it and place an * next to the code to indicate that there is a write-in. For example, if a respondent circles 3 for Q9j and writes in "nurse", you would code it 3*. We will input write-ins in a separate file for now. After collecting all the surveys, we'll see if there are similar answers across surveys. If there are, we'll probably add columns to the spreadsheet accordingly. If a response to an item is uninterpretable (e.g., more than 1 item circled, can't read comment), code it as 99.

Appendix F

Mean Ratings and Standard Deviations

Survey Question	N	Mean	SD
Sex	273	n/a	n/a
1	334	n/a	n/a
2	334	n/a	n/a
3	320	n/a	n/a
4	321	n/a	n/a
5	326	n/a	n/a
6	328	n/a	n/a
7	329	n/a	n/a
8a	320	3.4	0.9
8b	304	3	0.9
8c	317	3.4	0.9
8d	322	4.2	0.8
8e	322	4.1	0.9
9a	312	4.3	0.8
9b	158	3.1	1.2
9c	222	3.2	1.2
9d	259	3.6	1
9e	259	2.9	1
9f	237	2.6	1.1
9g	208	2.4	1.1
9h	213	2.2	1
9i	237	2.2	1.1
10a	298	4.33	0.76
10b	157	3.13	1.14
10c	226	3.05	1.23
10d	288	3.49	1.05
10e	253	2.93	1.09
10f	228	2.59	1.1
10g	230	2.66	1.09
10h	206	2.39	1.13

Survey Question	N	Mean	SD
10i	214	2.14	1.06
10j	234	2.3	1.14
11a	307	3.07	1.08
11b	311	3.78	0.89
11c	293	2.58	0.98
11d	308	3.15	1.01
11e	302	3.5	0.87
11f	304	3.4	0.95
11g	300	3.97	0.94
11h	310	3.99	0.86
11i	296	3.58	0.99
12a	324	4.49	0.9
12b	322	4.34	0.92
12c	316	4.26	1.06
12d	317	4.15	1.03
12e	312	4.12	1.04
12f	310	3.86	1.17
12g	309	3.64	1.26
12h	312	3.96	1.17
12i	307	3.79	1.19
13a	313	4.02	0.91
13b	318	3.74	1
13c	308	3.74	1.01
13d	310	3.53	1.01
13e	305	3.53	1.01
13f	304	3.32	1.09
13g	300	3	1.27
13h	305	3.32	1.14
13i	295	3.18	1.12
14a	311	3.66	1.16

Survey Question	N	Mean	SD
14b	318	3.87	1.03
14c	307	3.37	1.2
14d	313	3.59	1.12
14e	306	3.77	1.04
14f	307	3.64	1.1
14g	307	3.79	1.13
14h	307	4.02	0.99
14i	296	3.77	1.07
15a	276	3.88	0.88
15b	273	3.67	1.01
15c	276	4.03	0.87
15d	253	3.36	1.08
15e	251	2.9	1.18
15f	257	3.38	1.14
16a	296	4.2	0.98
16b	294	4.07	1.02
16c	299	4.38	0.82
16d	285	3.74	1.1
16e	282	3.14	1.32
16f	290	3.76	1.12
17a	282	4.52	0.63
17b	173	3.52	1.13
17c	228	3.57	1.14
17d	253	3.91	0.97
17e	257	3.42	1.14
17f	233	3.04	1.12
17g	243	3.07	1.16
17h	220	2.79	1.2
17i	223	2.51	1.16
17j	242	2.4	1.19

Survey Question	N	Mean	SD
18a	285	4.55	0.66
18b	174	3.59	1.29
18c	250	3.79	1.22
18d	267	4.1	0.99
18e	267	3.7	1.21
18f	248	3.06	1.25
18g	261	3.13	1.28
18h	237	3.08	1.29
18i	237	2.93	1.28
18j	253	3.13	1.41
19a	297	n/a	n/a
19b	256	n/a	n/a
19c	283	n/a	n/a
20a	291	3.52	0.84
20b	282	2.97	0.93
20c	276	2.93	0.88
20d	282	2.61	0.89
20e	282	3.01	0.92
20f	283	2.88	0.86
20g	280	2.95	0.9
20h	271	2.82	0.94
20i	270	2.65	0.98
20j	274	3.14	0.92
20k	266	3.11	0.85
20l	106	2.31	1.06
21	314	n/a	n/a
22	315	n/a	n/a
23	314	n/a	n/a
24	316	n/a	n/a
25	318	n/a	n/a

Survey Question	N	Mean	SD
26	318	n/a	n/a
27	297	n/a	n/a
28	310	n/a	n/a
29	213	n/a	n/a
30	264	n/a	n/a
31	312	3.7	1.2
32	282	2.4	1.2
33a	276	3.8	1.16
33b	268	3.79	1.2
33c	269	3.76	1.18
33d	272	3.89	1.09
34a	271	3.59	1.16
34b	267	3.52	1.16
34c	264	3.49	1.21
34d	269	3.68	1.08
35	303	n/a	n/a
36	304	n/a	n/a
37	306	n/a	n/a
38	119	n/a	n/a
39	53	n/a	n/a
Mean	276	3.41	1.05
Range	53-334	2.2-4.52	0.63-1.41

Appendix G

Write-in Answers on Surveys

Write-in Answers on Surveys
Ordered by randomly assigned survey numbers
(spelling and grammatical errors were not corrected)

5	19.c. QMRP
	27. client relations
	35.b. supervisor
	36.b. supervisor
7	19.b. daily
	30. given as ordered by MD – recorded daily
	35. area manager
	36. area manager
8	high school diploma; didn't finish survey after Q13
10	38. be sure that all other possibilities have been exhausted before administering drugs
13	30. I do not directly participate
14	5. MAA
	30. I can't she said yes
	35.b. Larry supervisor
	38. I would use as little as possible
19	5. liberal arts
	35.b. director
	36.b. director
22	19.b. unknown/varies
23	35.b. supervisor
	36.b. supervisor
	37. sometimes
28	5. child development
31	35.b. home coordinator/assistant
	36.b. assistant
34	5. psychology
	35.b. manager
	36.b. manager
	38. educate direct service staff on the types of medications and the effects. Better communication between all caregivers so that behaviors are anticipated prior to prescribing medication
43	19.c. parents
	30. must be approved by ID team must be assessed quarterly by HR committee
	35.b. RN/QMRP
	36.b. RN
53	9.j. vocational staff
	10.k. vocational staff
	27.k. vocational staff
	18.k. vocational staff
	19.b. semi-weekly, weekly, and monthly for some
	30. that behavior mod techniques be tried to the ground until all hope is lost before drug therapy
	37. parents when visiting home

38. I would investigate any alterior motives ie: is it the home coordinator or other staff that may just have a personality conflict pushing for the medication I would have meds in dosage interval packages and dated so theft of drug would be noted.
39. I generally fell using meds for behavior mod is confused with behavior control. But in a present situation, the use of psychotropics for a consumer I work with has surprisingly eased tempers, allowed this person to calm quicker and have time to decide the consequences of aggression to objects/others and is more pleasant.

54 38. Make sure everything is explained in detail about meds and the side effects and changes also how to administer prescribed drugs.

56 19.b. daily

58 some high school; didn't finish survey after Q9

59 5. psychobiology
35.b. possiby supervisor
36.b. senior/supervisor

60 37. parent

62 20.m. benefits usually outweigh risks
35.b. home coordinator; asst. home coordinator
38. More info on each drug. Med counts between shift. Signout's for controlled substances. Less assess to med cupboard (only med passer having key).

64 30. med count, and med times, and 2nd check meds
36.b. home manager
38. If I could change it I wouldn't give them any drugs unless it was a life or death situation. But if needed it will be done.
39. Yes, I think you should have these surveys and more often. Good luck with your studies. I hope it would help all direct staff workers and consumers.

69 35.b. case manager/nurse
36.b. case manager/nurse

70 30. when drugs are administered @ program it is properly logged and given @ appropriate times
35.b. reg. dir./area manager
36.b. reg. dir./area manager

71 29. all the above
36.b. as a day program I would consult with the residential program
38. I believe in a team approach. I appreciated it when the doctor/psychiatrist listens to direct care staff (the people who know our consumers best) and take time to explain reasons for medication as opposed to other treatment, and side effects.
39. The consumers I work with in this program appear stable, there have been no reasons to be concerned about meds or med changes. But in the past, as surragate mother for 6 children appreciated the doctor/psychiatrist who truly cared about our consumers and allowed me to be involved in the decision making process.

75 13. depends
19.b. don't know
33. unknown
34. unknown

83 5. sociology
19.a. I am unaware of what is assessed when considering drug effects
35.b. occasionally
36.b. hardly ever. only if vigorously pursued
38. Prescribe drugs only after all behavior modification has been exhausted.
39. Drugs are prescribed far too often. As direct care staff, I am never involved in that aspect, and I think that's a gross error on the part of other direct care staff.

97 5. p.e.
19.b. not sure how often

35.b. supervisor
36.b. case manager

99 5. sociology
35.b. supervisor
36.b. supervisor
37. home staff

103 35.b. case manager
36.b. case manager

116 30. We do not administer prescription drugs
36.b. occasionally manager/director
38. close monitoring of behavioral changes which affect mental performance/job related performance

119 19.c. employment training specialist
30. no drugs are administered without a doctor's note
39. our agency requires updates on medication every 6 months

122 19.b. doctor visits
30. side effects and possible behaviors are shown to the supported staff in case of 911
36.b. parents
37. family
38. I may not be so quick to prescribe dangerous drugs without thorough evaluation first

127 38. I would like better control as far as our agency being notified of our consumers current meds or changes in meds for safety purposes

129 35.b. supervisor
36.b. supervisor

130 some undergraduate courses didn't finish survey after Q20

140 5. management
19.b. quarterly
37. home care provider

148 5. psychology
35.b. case manager -informed no one consulted

154 5. philosophy
35.b. supervisor
36.b. supervisor
37. doctor
38. will consult with doctor
39. more relationship with parents/careprovider and doctor

157 5. psychology
35.b. manager
36.b. manager
38. I would first make behavior assessment on the individual. Providing that no other therapy would benefit the consumer (behavior modification, art therapy, gestalt therapy, etc.) then further assessment should occur; administered drugs
39. I'm against any type of drug unless it is necessary

158 5. psychology
17. don't know
19.b. don't know
35.b. manager
36.b. manager
38. more drug information available to the staff - especially about meds taken at home, not during direct service hours.

159 5. accounting

38. due to drug interactions I feel the person administering medication should sign for them and be held responsible for consumer taking it at the right time. I do not feel headache relief medicine should be administered unless caregiver is notified.

164 5. psychology
30. behavioral management committee(BMC) - dd taking psychotropic drugs for behavior management
37. home provider/parents

166 5. sociology
30. before any prescription drugs are prescribed an assessment on indiv must be done

170 30. to prompt consumers to take medicines correctly what the doctor has told them

174 5. AA - general
30. prot. and checklist, casefile
37. group home

177 36.b. supervisor

178 19.b. depends on what drug
19.c. not sure
35.b. nurse
36.b. nurse
38. Our consumers see a doctor they don't even know except for their 3 month checkup. So I would like to see the doctor be more involved in consumers life.
39. some questions were confusing the way there were written

179 5. psychology

183 5. psychology
35.b. coordinator
36.b. coordinator

184 19.b. varies

190 35.b. home coordinator
37. if in behavior plan
38. Reduce the amounts of adverse effects of some psychotropes to reduce fatigue and encorrage more activity

199 h.s. diploma didn't finish survey after Q10

204 19.a. don't know, not being informed from home
35.b. don't know
36.b. program director
39. it would good to have regular interactive conference among direct care staff and home, doctors, mainly to focus discussion on medications

205 30. we administer those drugs prescribed by the home agency
35.b. program manager
36.b. program manager
38. changing doses more slowly and consult with those who directly work with the individual

206 19.b. seems to rely on anectotal infor/troubleshooting - no formal protocols have been observed by me
19.c. usually a combo/often in response to direct staff reports
30. only authorized personnel Ph.D/M.D./psych make any changes regarding
33. unknown by me
34. unknown
35.b. unknown but I reasonably suspect there is
36.b. supervisors
38. train direct service staff regarding meds (effects, side effects)

212 35.b. supervisor

213 30. speak to psychiatrist first
35.b. director
36.b. manager

214 35.b. director

216 36.b. assistant home coordinator
38. they are adminstered fine
39. As direct care staff I feel it is my job to monitor behaviors of residents which may result from drug/behavior therapy. But I do not feel as though I'm an educated enough about medication to give suggestions or recommendations of prescribed drugs.

220 38. to give them as small a dose as possible

226 19.b. daily
30. in service

227 38. making the staff make observations after meds are administered. maybe try more behavioral techniques, use a placebo to wee out the actual medication

232 5. psychology

235 5. medical technology
37. residential staff
38. only used if absolutely necessary. Kept to minimum seek alternatives

237 36. activity therapist

248 35.b. director
36.b. director

253 38. suggest to physician and parent

258 35.b. home coordinator
36.b. home coordinator, asst. home coordinator

265 5. psychology
didn't finish survey Q16-38
39. I would have loved to help you with your survey, but a 12 page survey is a bit excessive. Also, it is hard to concentrate on 10 part questions when I have 6 developmentally disabled clients being noisy and displaying maladaptive behaviors.

273 5. fire science

274 19.b. unknown
35.b. director
36.b. director
38. only let qualified person do it

275 5. creative writing

277 5. sociology
30. the policy at the company I were at is, is to if it helps the client and he/she is on a behavioral management program in addition to drug.
35.b. executive director
36.b. executive director
38. I would not currently change the system of administrating the drugs, but I would use the input of every staff that is working with these individuals. Plus more education on the medication.

278 30. service team approval
38. To give as little as possible. Sometimes I feel some of our residents have been held responsible for behaviors they showed in the past as long as 5yrs or longer and it sticks with them so medication does to.

279 38. before any changes are made there should be contact with all the people that are close to the person on a daily basis and have all noticed changes

283 5. communications

287 5. sociology
35.b. not sure
36.b. not sure

288 36.b. home coordinator

293 didn't answer Q11-30
39. The questions were very hard to follow. I felt that they were leading and too wordy.

Sometimes I didn't understand what was being asked of me so I couldn't answer many questions. It seemed to me a lot of questions were repetative and unrealistic. I am in no way uneducated about the clientelle I serve and these questions seemed redundant.

295 19.c. parents

296 5. psychology
35.b. supervisor
37. caregiver at home
38. the dosage and getting more information on the product for side effects

298 5. business
19.b. varies by consumer and med
35.b. nurse
36.b. psychologist
38. the psychologist seems to be the only one listened to at med reviews - even if he/she hasn't seen the consumer or know about what their actual behaviors are - direct care staff is not listened to very much and our opinions and observations are often not solicited. We are sometimes not allowed into the med reviews - direct care staff, the people who actually work with and see the consumers everyday should be given more input into medications.

301 36.b. supervisor
37. doctor
38. consult with doctor
39. doctor and psychiatrist, and consumers work together

308 30. all clients shall be free of chemical restraints
37. FM, QMRP
39. Please increase staffs salary – we love our job but are very underpaid

309 38. more input from direct care staff since they are with them most of the time

313 5. social work
19.b. every 2-3 months with psychiatrist, weekly by direct staff
19.c. sometimes (written by psychiatrist & ID team)
30. close monitoring if person with DD is prescribed med for behavior i.e. behavior management team. Justification, documentation of need, frequent 2-3 months reassessement of need
38. When a consumer is physically aggressive towards others. I feel medication is justified to stop aggression. However behavior plan should be developed and med decreased as quickly as possible. Hurting others should not be an option. i.e. injuries continue as behavior plan is being experimented with.
39. I think our agency does a good job. Prescribing psychiatrists use lowest doses and length of treatment that they feel is possible. They are always looking to use less medication.

314 36.b. director

316 5. psychology
19.b. don't know
35.b. executive director
36.b. program manager
38. for the direct service staff to be more involved with medication change and side effects because we see what occurs to the consumer

319 5. secondary education
36.b. supervisor

321 36.b. supervisor

322 5. psychology
19.c. residential staff

331 30. too lengthy
36.b. senior

332 30. community care licensing
35.b. program manager

36.b. program manager
333 5. biomed
35.b. home coordinator
36.b. home coordinator
38. not educated enough in these matters
334 h.s. diploma didn't finish survey after Q14
337 30. state side effects, the effects
38. Whoever passes medications should be qualified to pass prescribed drugs, give client less dosage as possible so client is not in their own world.
39. I feel any staff that is sick or has doctors excuse they should not use the point system against the staff that [agency name] is currently using to punish staff who calls off sick who has a doctors excuse I feel it is unfair to staff and clients.
341 38. None – I would because it's left up to the doctor
358 35.b. careprovider
36.b. careprovider
359 38. board and care homes are doing a fairly good job at this task now. no changes
369 5. health education
30. policy book being rewritten at present
35.b. supervisor/manager
37. family, occasionally
38. educate more
370 35.b. supervisor
371 35.b. nurse
36.b. nurse
372 19.b. varies
27. unknown
38. no changes
373 5. social welfare
19.b. depends on behavior, individual
19.c. in cooperation with parents under instructions of physician
28. especially to those who work with persons on medication
35.b. program supervisor
36.b. contact person
375 5. public admin
378 35.b. assistant home coordinator, home coordinator
36.b. assistant home coordinator, home coordinator
383 27. bi-monthly inservices/updates
30.b. unsure as to specifics
35.b. assistant home coordinator
36.b. assistant homecoordinator
38. Side effects, drug interactions would be explained as well as exact reason for med.
388 19.b. daily
391 5. social psychology
35.b. home coordinator
397 5. psychology
19.b. depends on psychiatrist evaluation
400 37. home/group home
403 35. b. case manager/psych
38. before prescribing a drug, the doctor needs to have a serious consultation vs. 5 min.
406 5. journalism
38. would require behavioral data to be collected to determine if drug therapy would help
407 30. we do not administer drugs
35.b. program manager

36.b. program manager
414 5. health science
38. I never administered prescribed drugs to consumers in my agency. If I do, I just followed the directions from the doctor
416 35.b. records
38. no drugs will be taken in the day program
39. I think that drugs should be taken or given by a nurse or someone with medical experience and training
417 5. psychology
37. residential direct staff
419 5. science
30. only the doctor can prescribe the drug and the RN follows through
420 35.b. supervisor/support coordinator
424 35.b. unknown
39. always alternative to drugs
425 30. don't know
38. none
428 5. finance
30. all medication for consumers must be controlled and unaccessible to anyone except the consumer and/or job coach. current emergency sheets on all consumers are required to denote drugs, dosages, and times
38. all drugs prescribed for consumers should have side effects notes accompanying dosages given to direct service staff (job coaches) for administering to consumers
434 5. vocational education/humanities
35.b. supervisor
36.b. supervisor
38. I believe all variable need to be looked at and have input from job coach directly working with consumer
440 39. Didn't have a clue what half of this ment or wanted
445 5. AA data processing
9. don't know
10. don't know
15. don't know
16. don't know
17. don't know
18. k. individual themselves/ not sure otherwise
19.a.b.c. don't know
20 don't know
33. don't know
34. don't know
35.b. supervisor
39. Would like to know the reason for med and/or side effects and what kind of withdrawal they may have so I could be better understand the effects it will have on their moods and/or physical being and help them to deal with these things.
447 5. sociology
39. it's easy to overgeneralize for these surveys. Obviously the use of medication for a consumer should be situation specific
448 19.b. every so often
35.b. program manager
37. lead support specialist
449 35.b. parent/case manager
36.b. case manager
456 30. all clients shall be free chemical restraints

37. Facility Manager/QMRP
459 5. law
36.b. supervisor
38. consult with doctor
460 30. Stated in service plan. approved by parents/guardian, approved by team
35.b. home coordinator
36.b. medication assistant
38. A registered nurse should be the one responsible for passing oral medications. I believe a two-day medication course is not enough experience for knowledge to pass medications to consumers
464 5. business
didn't finish survey after Q16
465 36.b. psychiatrist
466 5. history
35.b. QMRP, case manager
36.b. QMRP, case manager
467 5. psychology
469 19.c. consumer
38. would make sure what meds there taking and what there for
471 35.b. supervisor
36.b. supervisor
38. make the direct care staff involved with any changes with any thing as well as the medication
472 35.b. records
38. no drugs will be taken in the day program
39. I think that drugs should be taken or given by a nurse or someone with medical experience and training
480 30. agency prefers consumers not take meds during day program if at all possible
486 9.j. all
10.k. doctor
17.k. all
38. would not have any resident on meds during his/her day program due to being loss, stolen, overdose. if the resident has behaviors and is on meds would not take him/her off so fast if they needed it or not needed it.
39. FYI. Being at my job for 5 yrs, people who care for residents sometimes have to find other jobs due to the pay. also people who are sick should not be punished using the point system. making sure the resident really needs to be on meds before getting an order for him/her
489 5. art/fine arts
35.b. nurse
36.b. nurse
38. clearly be aware of side effects and report
494 5. liberal studies/psychology
35.b. manager
36.b. manager
496 5. linguistics
502 15.g. psychiatrist opinion
18.k. home provider
19.a. aims
30. must be prescribed by a doctor
37. home provider
38. exclude family physicians from prescribing "behavioral" meds
509 35.b. home coordinator

36.b. home coordinator
38. I would look more to direct care staff for important information regarding consumer's medication needs.

518 39. more training

519 19.c. all the above
35.b. supervisor
36.b. nurse

521 18.k. client if possible
19.b. if new med weekly and monthly then semi-annually
19.c. reviews case and quality of life and long term effects vs. natural herbs (next to psychiatrist); imp and collects data (next to psychologist)
38. I would like to see every avenue taken to address problem first. If quality of life is not good do to being out of control and not knowing how to regain good quality of life and they can not get control them something or someone needs to interfere if for them

523 14.j. if drug treatment has been mandated I believe it should always be hand in hand with behavior management

529 9.j. IPP
10.k. IPP
11.j. IPP
14.j. prompting
15.j. prompting
38. need home to tell staff of medication effects and drug withdrawal effects

532 5. sociology
10.k. most of the time we won't know
11.j. self talking
37. direct care staff eg; job coach. it is rare
38. care providers all other agency staff "should" notify or update in writing any changes in consumer medication. we have a form we send to significant agencies usually they ignore our requests they never return it. some have said why you need to know, even after lot of explanation.

537 5. psychology
38. inform day program staff. ask direct care staff for their input research all options

538 5. psychology
30. staff cannot give drugs but they can make drugs available (ex. lay pills on table)
38. I would like to give the consumer medication they are prescribed instead of just laying them on the table
39. I would like to give over the counter meds for headache and other minor ailments as needed

539 36.b. supervisor if problem to group home staff
38. I would like to see behavior techniques utilized first. Also I would like to have the consumer monitored by a professional throughout the day. Behaviors change from home to work. Drugs should not be given because a consumer "acts out" at home. He/she may be fine at work.

545 19.b. esp. when med changes occur
30. my position does no require medication monitoring
37. group home staff

547 5. sociology
16.g. psychiatrist
35.b. supervisor
36.b. supervisor
38. to get a second opinion regarding any drugs to be prescribed by a psychiatrist

549 5. communication disorders

550 35.b. home coordinator

36.b. home coordinator
38. direct service staff needs to have more input

551 38. meds should be updated with agencies on a regular basis via the parents or careproviders

555 5. public administration
30. prompt consumers taking medication as their doctors prescribed

556 5. psychology
35.b. senior

558 28. not that applicable to our consumers
39. no medications at my site that we administer or work in conjunction with

559 9.j. RN
10.k. RN
17.k. RN
18.k. RN
35.b. home RN
36.b. home RN
37. home manager and/or assistant manager
38. training/education of meds and side effects are understood by staff and management. Have in place a side effect checklist for daily use by staff, and to be reviewed by manager daily, RN weekly. Have the home RN review medication more and her assessments. Review each med monthly with staff (purpose side effects and problems noted)
39. I feel medications are serious and need to be monitored more by RN and staff need to really understand the purpose.

562 5. sociology
30. Our agency requires a class on distributing meds which contains little information on specific medication.
35.b. home coordinator
38. Offer a drug guide book that is complete and up to date. Offer classes if staff would like to ask questions and get answers regarding their clients' meds.
39. Question14. Some should be combined and some I feel behavior management techniques don't do the job unless you've got a lot of behaviorally trained staff (see the "seldom" responses). Also you need to define QMRP.

568 30. med count and med times and 2nd check
36.b. home manager
38. Would really prefer not to pass drugs if at all possible. Don't care for the responsibility. But if I have to, I will and do.
39. yes, survey should be done more often. And I hope this will help all of DCWs and consumers

571 35.b. administrator
37. consumer or parent

574 19.b. depends on drug and reason for prescription
36.b. home coordinator
38. Direct care staff need to become more educated on drugs, their effects, side effects.

581 5. psychology
15. I don't know
17. I don't know
19.b. I don't know
33. I don't know
37. caretaker
38. I would want the doctors or psychiatrists to notify the agency about medication changes

582 35.b. everyone
36.b. QMRP, nurse, and ps
38. I would not give such heavy doses that they make the client sleep all day and miss out on life.

39. I believe that workshops for DTS on all levels should be taught on a regular basis because consumers change just like we do.

584 36.b. area manager

588 35.b. case manager, supervisor

589 5. psychology major; sociology minor

591 5. psychology
19.b. not sure – not directly involved enough to know
35.b. case manager
36.b. case manager
39. I do not often become involved directly with consumers in relationship to drug treatment. I often work really briefly with consumers and then someone else becomes involved. My input is welcome however if I have any.

596 35.b. activity therapist if it happens here
36.b. activity therapist
38. Watch the procedures. more things are to relaxed here. No one is responsible for med book.
39. This was a good survey a little confusing at times and a little vague.

600 5. psychology
19.b. I don't know
35.b. staff nurse
36.b. staff nurse
38. I wouldn't make any changes in the way they are administered

606 5. psychology
19.b. not by us
35.b. instructor

613 9.j. RN
10.k. RN

614 5. psychology

615 5. liberal arts
19.b. every 3 months
35.b. don't know
36.b. case manager
38. ask for input from all people who care for or deal with the person - direct care staff, residence, van driver, coach, job trainers, case managers, etc. Make it easier to get any changes to people who need to know (coaches and job trainers especially)
39. like to see closer monitoring of medication side effects, behavior changes and a whole lot more communication of changes, etc.

619 5. sociology
19.c. day and night staff observe behavior change
35.b. manager or supervisor

620 30. Must take a course on medications before handling prescription drugs.
35.b. supervisor
36.b. supervisor
38. for the first month of a new staff passing meds I would have supervisors so if they had any questions about the med or the effect it could be answered or any other questions about meds. It's better to be familiar with the meds you are going to be passing to the residents then not.
39. I enjoyed taking this course and participating in any way I can.

624 38. 1) better communication from doctor to staff 2) better in house communication 3) more info about meds we give and what they are for

626 17.k. nurse
19.c. QMRP, facility manager
36.b. nurse

627 5. fine arts

38. I lack the medical background to make these sorts of decisions for the consumers
39. There were several questions that I had to leave blank because I have no way of knowing the answers. but there was no place to check on the survey if the answer is unknown

629
5. psychology
19.b. none
37. parents
38. monitor the side effects, have the parents talk to caretakers regarding side effects

631
17. don't know
19.c. all of the above
36.b. case manager
38. one person admin. all drugs certified

632
35.b. unsure

638
5. english/psychology
38. The use of alternative therapies not involving medication such as behavior modification techniques, extinction, schedules of reinforcement, etc.
39. I would hope that the researchers understand how individualistic the human service field has become and that this research will help to further understand how behavioral medications impact the lives of adults with disabilities.

641
36.b. supervisor

648
5. rehabilitation counseling
30. drugs are prescribed by physician/psychiatrist
35.b. nurse
36.b. nurse

650
5. sociology
35.b. medical supervisor
36.b. medical supervisor

651
5. psychology
9.j. individual if capable
10.k. individual if capable

652
5. social work
30. there must be a description of drug and its affects in the consumers' file

653
35.b. supervisor, nurse
36.b. nurse, supervisor
38. a nurse should be the only one to pass their meds because she and doctor etc. knows everything about meds and they are certified to do so staff shouldn't be responsible
39. I don't believe staff should pass out their meds. They are very important to them so the nurse should pass them out

656
5. psychology
35.b. director
36.b. supervisor

659
5. BA in psychology; MPA
20.m. sexual frustration
30. consent is required for psychotropics, changes in drugs person must have a behavior management plan or active psychiatric condition
35.b. home manager, case manager
39. there are occasional problems when a community physician, as well as CMH psychiatrist, prescribes psychotropic medication. There needs to be one person only responsible for medication prescription

662
30. We are required to attend health and medications class which teaches us basic handing and implications of prescribed drugs.
35.b. supervisor
36.b. supervisor
38. I would be looking for ways to discontinue the meds that have debilitating side effects to

the consumer.
39. Certain psychotropic medications are necessary for certain individuals. For someconsumers there are alternatives to medications that would benefit them more that should be implemented on a trial basis to determine what is most appropriate for that individual.

664 28. only necessary if they do not understand
30. have to be given at designated times everyday
35.b. supervisor
36.b. supervisor

674 15. don't know
19.c. don't know
33. don't know
34. don't know
35.b. regional center
36.b. maybe regional director
38. have direct care staff be more involved in the decision making process on whether or not a consumer should be on meds. This can only happen if we are better educated on pros and cons of each med

675 5. criminal justice
35.b. supervisor
36.b. supervisor
37. home

678 37. we do not dispense medications of any kind
39. This agency needs a better way to track medications (new, changes, etc.) prescribed by our consulting psychiatrist

679 5. recreational mgmt/therapeutic recreation
37. medication must be taken at home when applicable
38. not changing meds on individuals so much

680 30. we must know and have written every med consumer is on
36.b. supervisor

681 5. liberal arts, spanish
undergraduate degree, didn't finish survey after Q13

682 5. psychology
38. no changes consumers are supervised taking the meds

683 5. psychology
35.b. supervisor

684 9j. client
10.k. client
19.b. depends on consumer
19.c. behavior assessment team
h.s. diploma didn't finish survey after Q19

693 5. psychology
19.a. not a tech. assessment
38. none, however consumers who are unable to self monitor prescription intake should not be given meds to take independently, this is a common practice

695 5. psychology
39. I don't know who has final say in which drugs nor who is notified

696 14. when all else fails management/drug treatment maybe the answer but this would be case by case
35.b. nurse, case manager, home
36.b. nurse, case manager
39. I feel a lot of these questions could not be answered truthfully, they are not yes, no, maybe questions

698 35.b. home coordinator
36.b. home coordinator
699 35.b. program manager
36.b. program manager
702 5. psychology
30. there is a policy to lengthy to write
35.b. manager
36.b. manager/supervisor
37. parent, doctor
38. more intercommunication between staff and management
707 36.b. manager
708 19.b. always monitored by direct staff
36.b. home coordinator
716 36.b. home coordinator
38. I'd be a little more aware about alternatives before prescribing meds and I'd be a little more careful to train direct staff exactly what individual drugs consumers take are for and do.
720 5. psychology
35.b. supervisor
38. have effects assessed more often; more contact with psychiatrist, etc.; more staff education re: prescribed drugs
725 5. management
35.b. careprovider
36.b. careprovider
729 38. I would first of all give some training to DSS or have a CNA give the medication
39. It's very important that we receive the training to give the meds also we need to be listened to
731 30. in the employee hand training course
35.b. director
37. careprovider
38. just advising
39. good relationship with careprovider and doctor of consumers
739 5. criminal justice
35.b. SCIP staff, director?
38. I would not make any changes, they do a good job doing it
39. I think that behavioral management a lot of the time goes with drug therapy but the best idea would be to do it without drug therapy
741 5. psychology
19.b. don't know
didn't finish survey after Q30
743 5. psychology
744 19.b.c. don't know
36.b. manager
746 9.j. consumer
10.k. consumer
16.g. consumer
30. case-by-case situations outlined in pre-specified area of field packet
38. more communication among those involved regarding changes in prescriptions, dosages, etc. I'd like to be consulted when issues to see if I can do some kind of behavioral program changes
748 5. psychology
didn't finish survey after Q10
753 5. computer science
757 35.b. team leader

36.b. nurse

759 30. all clients shall be free of chemical restraints
37. facility manager, QMRP
39. the direct care staff need to get more and less rules

760 some undergrad courses didn't finish survey after Q12

763 35.b. supervisor

773 5. psychology
36.b. senior, supervisor
37. where they live

780 5. sociology
27. someone going out to field with the people
38. to be more informed about he specific drug taken by a consumer

789 35.b. supervisor

793 9a. individual choice if they can make it
11.j. consumer feels and can determine if they are in need of medical managed care
13.j. if consumer feels its necessary for them and can help them better cope with daily situations high school diploma didn't finish survey after Q14

794 15. don't know
16. don't know
36.b. case manager, supervisor

802 30. what is best for consumers well being
36.b. home manager

809 30. Had to take training class on how to pass prescriptions and to follow protocol if there's problems with medication
35.b. home coordinator/case manager
38. I wouldn't change anything because they are prescribed for a reason and have to be administered the way the doctor thinks they should and the way it will better benefit the consumer.

813 5. psychology
15.g. regular psychiatric visit
16.g. psychiatric regular visits
17.k. senior staff
18.k. consumer
35.b. senior or director
36.b. senior/supervisor
37. parents
38. The supported living section of [agency name] has a great setup on med count and inventory. I wouldn't change anything. The vocational support usually does not deal with consumer medications.

815 5. sociology
30. the person is not overmedicated for the purpose of behavior modification
36.b. residential supervisor

819 5. psyc/span
35.b. supervisor
36.b. supervisor
38. I would make it a more available option for extreme cases. It seems to be an inhumane last resort instead of a practical therapy.

820 5. psychology
38. I would involve all people currently involved in treatment of the client in any decisions being made on behavioral treatment plans, but not necessarily all medical changes.

824 5. humanities/psychology
30. protocol is written and followed for each consumer taking medication regarding their medication if taken during nonservice hours

38. I don't know. My consumer takes her medication during nonservice hours.

826 5. biology
36.b. supervisor
38. doctor
39. psychiatrist, doctor, consumer, parent

827 5. liberal arts
30. must have doctors prescription in order to give them while in program
35.b. supervisor, manager
36.b. manager

828 5. psychology
19.b quarterly
19.c. parent
30. community care licensing policy, lengthy and documentation should occur on all drugs taken
35.b. program manager, case manager
36.b. program manager, case manager
38. would need to learn more about the effects of drugs to answer question. drugs administer well at this time.

830 30. is not to administrate medication to consumers
35.b. area manager
36.b. house parent
38. I would make sure the counts of behaviors is accurate with staff before changing dosage. I would try to decrease more than increase medication if possible.
39. I think all individuals working with people with disabilities should be notified when medication is changed such as house parent, residential staff, parent, legal guardian, area manager, job coaches, and substitutes, etc.

834 19.b. 1/4
30. drugs are a last resort

835 19.b. quarterly
35.b. nurse
36.b. nurse

836 30. behavior management committee
36.b. case manager
38. more input from direct care staff

837 5. spec. ed
38. administration of medication is well controlled under present plan

840 9.j. nurse
17.k. RN
18.k. RN
30. follow CMH policy - Allegan Co.
35.b. home manager
38. less meds (for one's who don't need it) no other changes

845 5. psychology
39. as direct service staff I have not been involved in consumer's drug therapy

850 35.b. director
36.b. director, nurse

854 5. psychology

855 36.b. director or care facility

866 some graduate courses; didn't finish survey after Q12-38
39. I feel medications are abused

867 some undergraduate courses didn't finish survey after Q19

872 19.b. don't know

876 5. psychology

38. I would try to involve every person that the consumer comes in contact with.

877 19.b. quarterly
19.c. all parties give information to the psychiatrist after assessing
30. must follow BMC guidelines and BMC monitors each case quarterly
38. each consumer would have a choice of which doctor to go to. doctors who spend 10 minutes on their patients every 3 months would go out of business.

880 5. sociology
35.b. home coordinator
36.b. home coordinator
38. I would have designated persons passing meds. When just anyone on shift (although med trained) passes meds too many errors can occur.

881 36.b. coordinator

885 18.k. client

886 5. counseling psychology
9.j. BMC

889 5. marriage family counseling
38. If I had the opportunity to administer any prescribed medication to a consumer, I would apprise everyone, who is directly involved in the decision making process on the individual, to be educated on how to give the medication to the consumer.
39. There is a predisposing factor in which everyone should take into account of, and that is high levels of prescribed medication can cause physical and mental reprecusion on any person psychomotor ability thus easily neurological damage on that individual.

892 35.b. [supervisor's name]
36.b. [supervisor's name]
38. That all other alternative to drugs was used and that drugs be used mainly as a last resort

894 35.b. supervisor
36.b. senior/supervisor

897 5. accounting

901 30. receive the medication from careproviders or caretaker with the labeled bubble jacket or bottle, keep in the locked cabinet and taking it out the time the consumer need to take it

902 35.b. med. coordinator

903 5. psychology
16.g. autonomy of client
19.b. depends on service team and regarding past history and well being of client
19.c. service team!
27. behavior management colegiate level with hands-on experinece
30. approval by service team we follow the direction per individual
36.b. home coordinator
37. sometimes per individual
38. whatever the service team decides

909 9.j. nurse
10.k. nurse
30. they try all other means that is available before using drugs on them
35.b. nurse, QMRP, supervisor
38. I don't think I would change anything. I think they do a good job for the drugs prescribed
39. to them

911 5. communicative disorders

913 35.b. programmer

920 35.b. supervisor

922 5. psychology
35.b. executive director

923 5. biology and psychology

19.b. 3 months
19.c. BMC
30. if a person with a developmental disability is prescribed psychotropic medication, the appropriateness of drug therapy is reviewed every 3 months by BMC

924 35.b. supervisor

927 5. Psy/sociology
19.b. varies

928 5. psychology
18.k. consumer

929 35.b.home manager, nurse, assistant home manager
36.b. hm, ahm, nurse

930 30. data collection is important entire ID team is involved in decisions to change meds
38. vitamins and holistic approaches would be used in conjunction with behavioral management plans and medication
39. my facility is rare they consult everyone involved in client's life before making any drastic changes

936 19.b. daily
19.c. direct care provider
30.b. consent, informed, distributed by I-team
36.b. house director
38. The way it is being done is adiquit
39. Meds are not the only answer to problems our recipeants have

937 30. I'm not sure of the wording
35.b. regional director, specific area manager
36.b. when needed area manager, regional director may get involved
37. individual house manager
38. to have a job coach directly involved in the decision making process of meds. although a job coach doesn't have the legal right to advise, if educated continuously we could give our opinions/observations as direct care staff
39. education continuing is critical to dealing with this avenue of our clients

941 35.b. don't know
36.b. case manager
38. I do not feel that the choice of medication should be left to people (professionals, doctors, social workers, etc.) that only see these people 30 minutes per month. The direct care staff work or live with these people all day, everyday, and need to be consulted more

942 29. types of drugs and uses
30. follow 5 "R's"
38. only 1 change, staff should be fully informed of the use of needs in an oral manner so that all have a working knowledge of the med and what to look for

944 35.b. home coordinator
36.b. home coordinator

945 5. BSW
18.k. client
36.b. home coordinator, asst. home coordinator

946 35.b. manager
36.b. manager

948 35.b. care provider
36.b. care provider

950 35.b. LPN/RN
36.b. LPN/RN

953 38. I feel it is necessary to have medications in a locked box at all times. Especially when that consumer is around other consumers and it is possible that another consumer can take someone else's meds.

954 19.b. biweekly
35.b support coordinator
36.b. nurse
957 36.b. supervisor
967 5. psychology
9.j. court ordered
10.k. consumer
19.c. parents
30. consumers must be able to self medicate
36.b. supervisor
38. I would prefer not to be responsible for administering another persons medications
39. Medication therapy should be considered a last resort, but a necessary treatment in most cases where dual diagnosis exists
968 5. police academy
39. we need as direct care staff to know what changes a client would come about with upping or lowering doses and what signs to look for when either is necessary
970 12.j. elopement
35. Dorothy - regional director
38. first I'd see if the drug could be assessed with a behavior management program. If not, then use the least amount of drugs to compensate the behavior
972 38. Consumers in our agency live independent. Our work with them is not to control drug use but to assist them in skills that will allow them to integrate and function appropriately in society
974 9.j. case manager
10.k. case manager
15.g. staff
some undergraduate classes didn't finish survey after Q15
979 11.j. high blood pressure
35.b. supervisor
36.b. supervisor
984 5. psychology
19.b. when changes are noted
19.c. residential caretaker
30. we are not involved at all in the prescription or administration of drugs during program hrs.
37. meds taken at home only/not during program
985 5. counseling/therapy
30. what the doctor orders that is least restrictive
38. everyone who works with an individual would know what drug and why plus know all about the drug
987 35.b. supervisor
36.b. supervisor
988 35.b. RN
36.b. RN
38. I would have the direct care staff carefully monitor the effects of drugs and have the physicial personally find out the effects by interviewing the direct care staff, either face-to-face, by phone, or a written questionnaire
993 5. computer systems admin
996 19.b. depending on what med.
998 5. psychology

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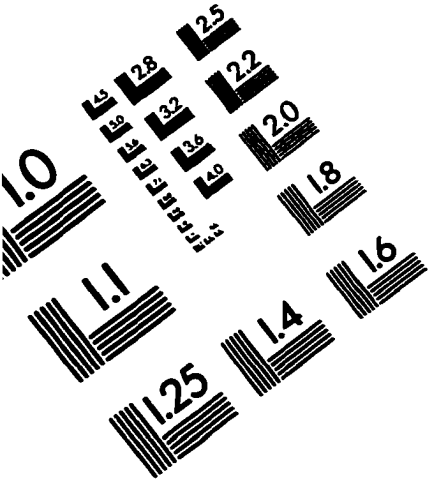
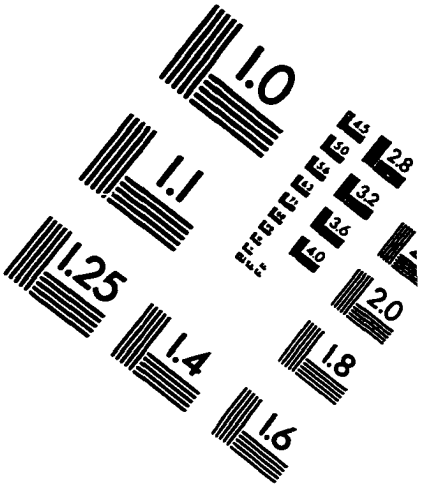
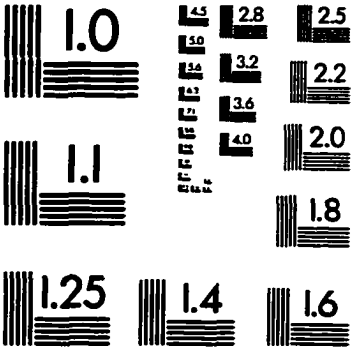
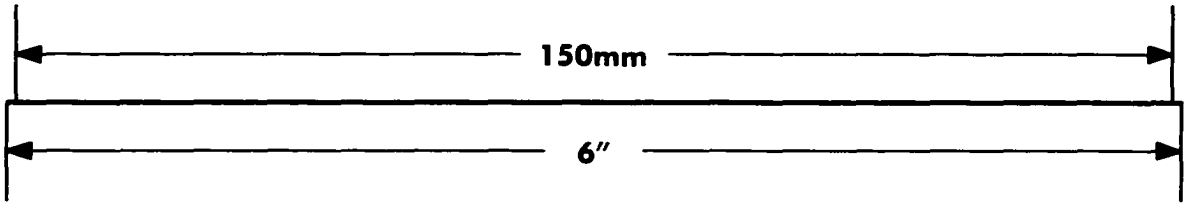
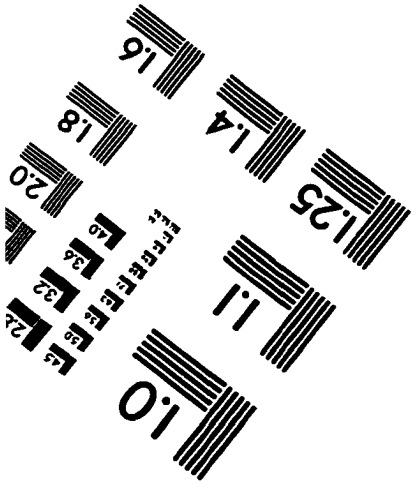
IMAGE EVALUATION TEST TARGET (QA-3)

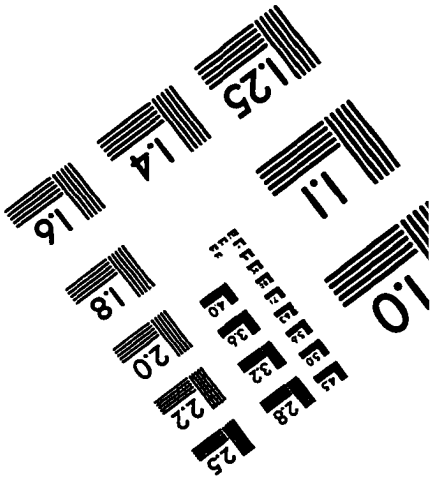












APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989