

Wisconsin Council on Developmental Disabilities

No Easy Answers

Seeking consensus when considering
psychotropic medication for individuals
with developmental disabilities

Edited by Chris Heimerl & Howard Mandeville

COMMUNITY
SUPPORTED
LIVING SERIES



No Easy Answers

Seeking consensus when considering psychotropic medication
for individuals with developmental disabilities

June, 2001

**Report of a workgroup of the
Wisconsin Council on Developmental Disabilities
Edited by Chris Heimerl & Howard Mandeville**

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Table of Contents

Introduction	4
Psychotropics & people with developmental disabilities	7
Who is this person?	8
Inter-related elements of team support	9
What are psychotropic medications?	11
Six valid reasons for using psychotropic medications	14
Cautions & questionable uses of psychotropics	16
Assessing risks/benefits	18
Factors contributing to effective team support	19
Informed consent	22
Consulting with a prescribing physician	26
Appendix A:	
Behavioral assessment outline	31
Appendix B:	
Suggested outline for psychotropic medication monitoring	32
Appendix C:	
What to do when the team is feeling stuck	34
Appendix D:	
Glossary	35

Introduction

This monograph is the outcome of four meetings in which people representing developmental disabilities advocacy, family practice medicine, psychiatry, pharmacy, law, nursing, and community support met to discuss some of the practical, clinical, and legal issues associated with the use of psychotropic medications to treat people with developmental disabilities. The meetings were sponsored by the Wisconsin Council on Developmental Disabilities, Wisconsin Coalition for Advocacy, and the state Bureau of Developmental Disabilities Services. Our group represents a variety of perspectives that we hope will enhance the credibility of our conclusions and recommendations.

The purpose of this document is to provide information on the use of psychotropic drugs with people with cognitive disabilities. Our initial motive was to draw attention to our concern about the safety, well-being and civil rights of vulnerable people. Simply having this discussion deepened our understanding and allowed our perspective to evolve.

The content of this monograph represents a consensus reached in four meetings planned by Lynn Breedlove, Deborah DeRoos and Howard Mandeville. Lynn Breedlove facilitated the meetings. This is a summary of our discussions and reflects insights and viewpoints of the whole group. Chris Heimerl composed the report based on notes recorded by the meeting planners. The content of certain sections has a more individual imprint. The section titled “Six valid reasons for using psychotropic medications” is based on a written discussion piece contributed by Steven Zelenski, a psychiatrist and a participant in our group. The section titled “Assessing risks/benefits” also is adapted from Dr. Zelenski’s ideas. The section on “Factors contributing to

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effective team support” is based on insights initially offered by Paul White, a behavioral consultant at Community Ties, a Waisman Center program. The chapter titled “*Informed consent*” was written by Roy Froemming. Pharmacist Don Marek updated the examples of psychotropic medications in November 2000 and

also wrote the “*Questions to ask*” and “*For any prescriptions, remember*” items found in the section “*Consulting with a prescribing physician.*”

The basis of Appendix A, “*A behavioral assessment outline*”, was developed by Chris Heimerl, as was Appendix C, “*What to do when the team is feeling stuck*”.

Work group conclusions

- ◆ People with developmental disabilities aren't immune to the kinds of problems that are reasonably treated with psychotropic medication.
- ◆ Medications can be used both beneficially and harmfully.
- ◆ People who are nonverbal and/or have challenging behaviors are especially vulnerable to inappropriate administration of psychotropic medication.
- ◆ Mobilizing a team to assess the usefulness of these medications for particular individuals, to monitor their use, and to organize complementary interventions and support goes a long way to insure that medications will be used appropriately to the benefit of the individual.
- ◆ Our ideas about the capacity of current support systems to respond to the preferences of the person receiving support, to establish functional teams, to organize thorough and accurate information and communicate it clearly to prescribing physicians, guardians, and others represent a highly optimistic point of view. We acknowledge the high levels of stress and crisis that often oppress caregivers and people with disabilities alike and limit their sense of what is possible. However, we believe it is useful to present an approach that represents the best of what we see in current practice, hold it out as

an ideal, and urge readers to take these ideas and adapt them to existing circumstances, constraints, and opportunities.

- ◆ Physicians are in a better position to make good decisions about their prescription of psychotropic medications if they have a mutually trusting and informative relationship with their patients and the people who know them and are involved in their support.
- ◆ In order to be effective advocates for people with disabilities who use prescribed psychotropic medications and to be useful consultants to prescribing physicians, we need to know the person and be able to represent the unique qualities of the person to all who contribute to decisions that affect the person's life. We also need to know some basics about the medications and their side effects, about the interaction with other medications, food, etc., about the role of other nonpharmaceutical interventions, about the right of the person to participate in the decisions about medication, the person's legal rights to give informed consent, and the responsibility of the guardian to be an active advocate and participant in planning and monitoring.

Psychotropics & people with developmental disabilities

The use of psychotropic medications with individuals with developmental disabilities approaches 45% by some estimates. This includes individuals residing in community support models and those residing in large institutions. It is a subject rich in mythology, recrimination, bias, and conjecture. Opinions regarding individuals with developmental disabilities and the use of psychotropic medication range from concern that we are poisoning a generation, to the belief that pharmacology is the single most effective tool for enhancing quality of life. While for any individual either instance may be true, we believe that psychotropic medication is neither inherently good nor bad but must be viewed as one of many viable tools to enhance quality of life when used for valid reasons.

This monograph provides information on psychotropic medication and suggestions for building effective team support. The graphic on page eight illustrates our understanding of what facets of the person need to be understood in order for support to be useful. The graphic on page nine illustrates the understanding that the elements of effective team support are fluid, interactive and simultaneous. The central ideas of this monograph stand on the beliefs stated at the right.

The co-authors of this document (who are listed in the Introduction) represent diverse backgrounds, experiences, settings, and points of view. Our intention is to enhance understanding of a team approach to effective evaluation for the use of psychotropic medication. We have included definitions, examples and justifications that we expect will contribute to your confidence and proficiency in considering this difficult and, at times contentious, aspect of support. This monograph, with its attached appendices, may be viewed as an introductory source of information about supporting the safe and effective use of psychotropic medication by individuals with developmental disabilities. While primarily

addressing adults with developmental disabilities, we hope parents, guardians, and care providers of children will find it helpful as well.

Beliefs:

- ◆ All individuals with developmental disabilities are unique with singular characteristics, preferences, desires, capacities, and interpretations of their world. We assert the value of each individual's life and affirm each person's right to effective and equitable support and treatment.
- ◆ Collecting information, making decisions, and monitoring medication use are best accomplished by a comprehensive team approach. Each person assuming a significant role in the individual's life has important contributions to make.
- ◆ Individuals with developmental disabilities share an equal or greater risk with the general population of acquiring mental illness and other psychiatric disorders which may require short or long term intervention, including psychotropic medications.
- ◆ There are clearly defined circumstances when the use of psychotropic medication could be considered for any person. These circumstances ought to be consistent whether or not the recipient has a developmental disability.
- ◆ While the effects of medication can be intrusive, so can other strategies to influence individuals. Withholding potentially helpful medication can be a disservice.
- ◆ The use of psychotropic medication is most effective within the context of—and as a complement to—broader support and lifestyle issues. A multi-faceted approach to challenging and complex individuals is preferred over seeking any single panacea, medical, behavioral or other.

Who is this person?

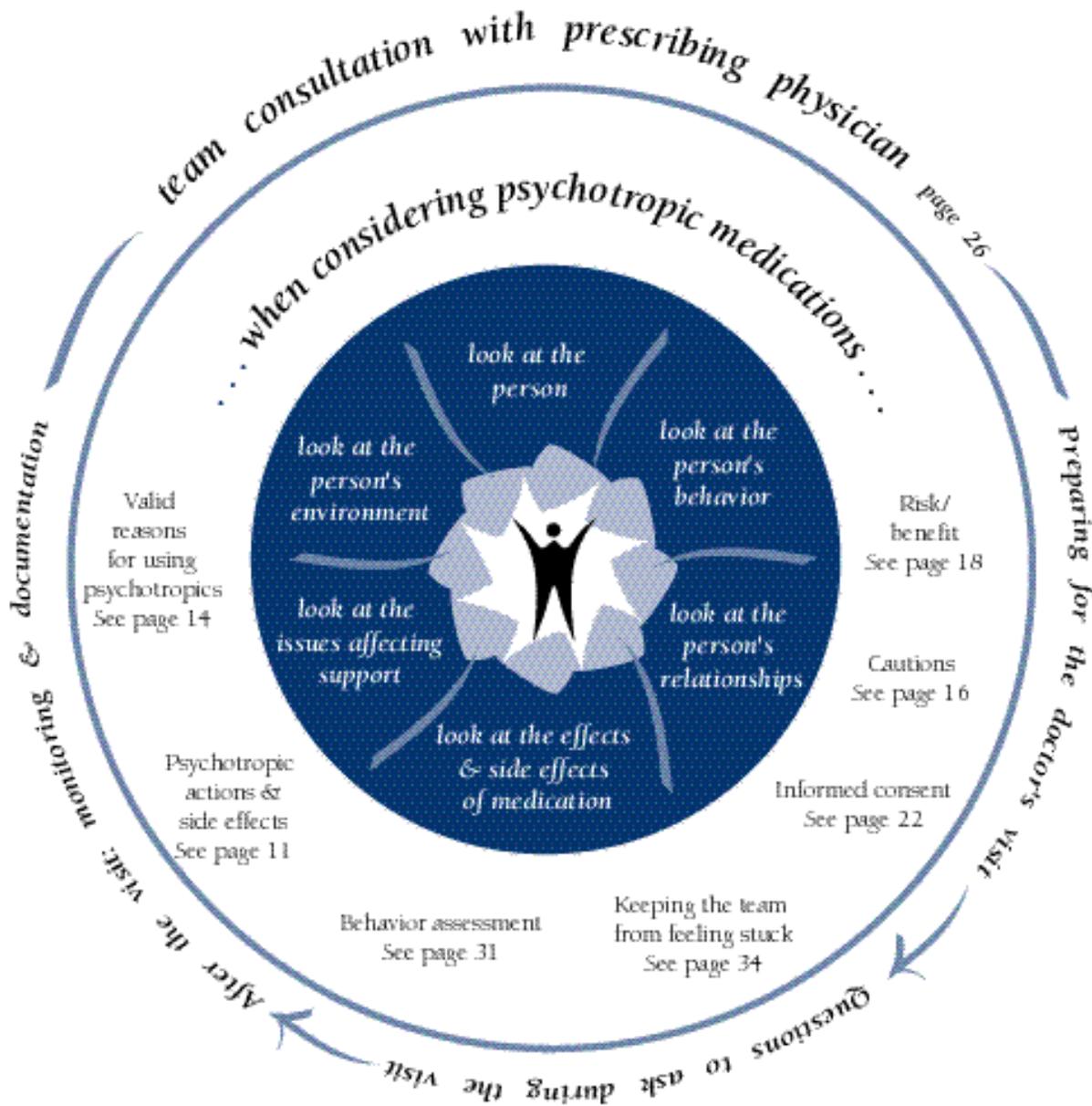
All individuals are unique with singular characteristics, preferences, desires, capacities and interpretations of their world.

A wholistic understanding of the person includes an understanding of these facts and of their relationship with each other and with other people, places and circumstances in the person's life.



Inter-related elements of team support

Use this visual guide to remind yourself that supporting a person who relies on psychotropic medications is not a linear, sequential process, but a wholistic set of simultaneous and inter-related activities and judgments.



What are psychotropic medications?

The word “psychotropic” originates from Greek psyche meaning “the mind” combined with tropos meaning “tending to turn or change.” “Mind influencing” is therefore an appropriate definition. Psychotropic medications are drugs specifically designed and intended to alter:

- Abnormal thoughts (specifically processes such as hallucinations, delusions, distortions, and paranoia);
- Abnormal moods (specifically feelings, states of pleasure or displeasure);
- Behaviors (specifically those dangerous behaviors arising from paranoid or grandiose delusions or previous traumatic events).

They are designed and intended to treat, manage, or control symptoms of psychiatric disturbances or “illnesses of the mind.”

The psychotropic medications most frequently considered include, but are not limited to the “families” of drugs listed on the following page. The examples given are not exhaustive. They reflect those most often used with individuals with developmental disabilities within each family. They are listed by generic name and proprietary or brand names. It should be noted that each drug has a therapeutic dosage range that minimizes toxicity. The relative effectiveness of different medications cannot be determined simply by comparing prescribed doses in milligrams.

The terms anti-psychotic, neuroleptic, or psychiatric are often substituted for psychotropic. Medications that modify thought processing and behavior work by affecting neurotransmitters, which are chemical substances in the brain that mediate nerve impulses. This is an emerging area of medical knowledge and many new advances materialize each year. For example, several new anti-depressants have been released that affect the neurotransmitter serotonin. Also, medications previously used for other purposes, such as anti-

convulsants, like valproic acid, and blood pressure medicines, like clonidine, have been helpful psychotropic medications for some individuals because of their effect on neurotransmitters.

This is distinguished from psychoactive medication which may have an effect on the mind, but is designed and intended for another purpose. For example, pseudoephedrine is intended as a decongestant, but makes some people feel stimulated and sedates others.

Another class of drugs important for consideration because of its extensive use with individuals with developmental disabilities, but not considered psychotropic, is the class of anti-parkinson drugs, most notably, trihexyphenidyl (Artane), amantadine (Symmetrel) and benzotropine (Cogentin), which are used to control extrapyramidal symptoms (unusual, involuntary muscle movements) which may be caused by antipsychotic drugs.

The scope of “**No Easy Answers**” does not extend to include a highly technical review of the chemistry of psychotropic medication. The prescribing physician, the pharmacist who fills the prescription, or a local librarian can give references to publications designed for non-physicians that describe the effects of prescription medicines. Steven Zelenski will field questions from readers about psychotropic medications and connect people making inquiries with pertinent publications, research reports and journal articles available from the statewide Human Resource Information Center at Central Wisconsin Center. Here is how to reach him:

**Steve Zelenski, Central WI Center for the Developmentally Disabled, 317 Knutson Drive, Madison, WI 53704, 608/243-2315
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Examples of psychotropic medications:

The following list is current as of June 2001. It is not complete. New medications will enter the market. Medications for other conditions may be shown to have psychotropic properties. Listed psychotropics may be withdrawn from the market or be shown to be ineffective. Some medication may be useful in several of the categories listed. Some medications have non-behavioral and non-psychiatric uses.

ANTIPSYCHOTIC

<u>generic name</u>	<u>trade name</u>
* chlorpromazine	Thorazine
* fluphanzaine	Prolixin
* haloperidol	Haldol
* loxapine	Loxitane
* mesoridazine	Serentil
* molindone	Moban
* perphenazine	Trilafon
* pimozide	Orap
* prochlorperazine	Compazine
* thioridazine	Mellaril
* thiothixene	Navane
* trifluoperazine	Stelazine

ATYPICAL ANTIPSYCHOTIC

<u>generic name</u>	<u>trade name</u>
** clozapine	Clozaril
** olanzapine	Zyprexa
** quetiapine	Seroquel
** risperidone	Risperdal
** ziprasidone	Geodon

ANTIDEPRESSANT

<u>generic name</u>	<u>trade name</u>
Tricyclic-Tertiary Amines:	
amitriptyline	Elavil, Endep
clomipramine	Anafranil
doxepin	Sinequan, Adapin
imipramine	Tofranil
trimipramine	Surmontil
Tricyclic- Secondary Amines:	
*amoxapine	Asendin
desipramine	Norpramin
nortriptyline	Aventyl, Pamelor
protriptyline	Vivactil
Aminoketone:	
bupropion	Wellbutrin
Tetracyclic:	
maprotiline	Ludomil
mirtazapine	Remeron
Trizolopyridine:	
trazodone	Desyrel
Phenylpiperazine:	
nefazodone	Serzone
Phenethylamine:	
venlafaxine	Effexor
Selective Serotonin Reuptake Inhibitors:	
citalopram	Celexa
fluoxetine	Prozac
fluvoxamine	Luvox
paroxetine	Paxil
sertraline	Zoloft
Monoamine Oxidase Inhibitors:	
isocarboxazid	Marplan
phenelzine	Nardil
tranylcypromine	Parnate

ANTI-ANXIETY

<u>generic name</u>	<u>trade name</u>
Benzodiazepines:	
alprazolam	Xanax
chlordiazepoxide	Librium
clorazepate diK	Tranxene
diazepam	Valium
halazepam	Paxipam
lorazepam	Ativan
oxazepam	Serax
Non-benzodiazepines:	
bupirone	BuSpar
hydroxyzine	Atarax, Vistaril
meprobamate	Equanil, Miltown

ANTI-MANIA/MOOD STABILIZERS

<u>generic name</u>	<u>trade name</u>
lithium carbonate	Lithobid, Eskalith Lithonate
carbamazepine	Tegretol
divalproic acid	Depakote
valproic acid	Depakene

STIMULANT

<u>generic name</u>	<u>trade name</u>
dextroamphetamine	Dexedrine
methylphenidate	Ritalin
pemoline	Cylert

SEDATIVE/HYPNOTIC

<u>generic name</u>	<u>trade name</u>
amobarbital	Amytal
chloral hydrate	Noctec
ethchlorvynol	Placidyl
estazolam	ProSom
flurazepam	Dalmane
glutethimide	Doriden
pentobarbital	Nembutal
quazepam	Doral
secobarbital	Seconal
temazepam	Restoril
triazolam	Halcion
zaleplon	Sonata
zolpidem	Ambien

COMBINATION

<u>generic name</u>	<u>trade name</u>
chlordiazepoxide/ amitriptyline	Limbitrol
*perphenazine/ amitriptyline	Triavil
	Etrofon

MISCELLANEOUS/OTHERS

<u>generic name</u>	<u>trade name</u>
clonidine	Catapres
clonazepam	Klonopin
naltrexone	Trexan
propranolol	Inderal

* Associated with tardive dyskinesia (TD).

** The incidence of TD may be less with the atypical antipsychotics

Six valid reasons for using psychotropic medications

Any physician–psychiatrist or non-psychiatrist—is authorized to prescribe psychotropic medications. Any appropriate use of psychotropic medications will be with the intention of improving the person’s social functioning and relieving the person’s emotional pain. The rationale for valid use of psychotropic medication applies to any person and will fit within one of the following reasons:

Reason Number 1

To treat a clearly diagnosed primary psychiatric illness: Whether a potential recipient has a developmental disability or not, the criteria established in the Diagnostic and Statistics Manual of Mental Disorders (DSM-IV) or the International Classifications of Diseases (ICD-10), should be satisfied. At least the same depth and breadth of evaluation must be exercised. This becomes increasingly more difficult with more significant developmental disabilities where problems with speech, motor performance, cognitive ability and sensory integration interfere with standardized testing and mental status exams.

Reason Number 2

Medical conditions: Some conditions may have associated secondary psychiatric features. Examples include specific types of epilepsy which may lead to a variety of seizures and problematic behaviors. For example, temporal lobe seizures can appear as unusual behaviors. Use of appropriate psychotropic medication for this reason should continue until the primary condition is treated and the symptoms resolve, or until it is clear that, even with treatment, the

psychiatric symptoms will continue. Long term medication therapy will frequently be necessary in order to control symptoms.

Examples of other medically indicated uses are small doses of antipsychotic drugs prior to chemotherapy (for the antiemetic effect) or general anesthesia.

Reason Number 3

Emotionally distressing, extreme behavior that interferes with important aspects of a person’s life: This is perhaps the most contentious and challenging rationale. The risk of it being used as a “garbage can” to justify medication for a variety of unpleasant, obnoxious, even hurtful behaviors that serve clear functional means for an individual is inherent. This rationale should be accompanied by a comprehensive assessment of the behavior that includes a functional analysis. If such analysis is unavailable or yields unclear results—and

Use of medication in (some) circumstances is most clearly indicated when the individual with developmental disabilities who presents challenging behavior expresses a desire for the behavior to be controlled.

intermediate intervention is necessary for safety or continued inclusion in support efforts—short term psychotropic intervention may be considered. Use of medication in these circumstances is most clearly indicated when the individual with developmental disabilities who presents challenging behavior expresses a desire for the behavior to be controlled. When the person cannot clearly communicate intentions, discerning the appropriateness of medication is more complicated. Please refer to Appendix A for an outline of a behavioral assessment.

Reason Number 4

For empirical reasons, to address severe dysfunction that has been resistant to other intervention:

There are times when the use of psychotropic medication should be considered when addressing a chronic condition or characteristic (other than behavior) which significantly interferes with an individual's social functioning and quality of life, particularly when exhaustive habilitative, environmental and lifestyle adaptation interventions have not provided relief. If effective, the smallest dose should be sought, with occasional, systematic attempts to reduce or discontinue the medication. An example is using a mild anxiolytic to ease acute difficulty with transitions experienced by an individual diagnosed with Pervasive Developmental Disorder (PDD), even when an anxiety disorder diagnosis is not established.

Reason Number 5

To treat medication withdrawal or discontinuation symptoms:

There is a growing awareness that people may experience withdrawal difficulties from a variety of psychotropic medications, although they may be markedly softened with gradual reductions. These symptoms may include anxiety, agitation, unstable mood, self-stimulation, insomnia, expressiveness, sexual expression, property destruction, and self-injury. Another instance would be when—upon decreasing or discontinuing a psychotropic medication which masked severe tardive dyskinesia symptoms—a return to a small dose or alternative drug may be required. For a small group of individuals with developmental disabilities who exhibit chronic, severe self-injury, withdrawal from endogenous endorphins may be a factor needing psychotropic

medication intervention. Endogenous endorphins are naturally occurring neurotransmitters which have a narcotic-like effect. For some, withdrawal from alcohol, caffeine, nicotine or illicit drugs may require short term intervention.

Reason Number 6

For sedation during a medical procedure:

When the importance of a medical procedure is unquestioned and the procedure cannot be performed without sedation, a psychotropic may be used for its sedating effect. For some individuals these medical procedures may include dental work, diagnostic evaluations such as EEGs, EKGs, C-T scans or physical exams. If used for this purpose, an adequate dose to accomplish the desired sedation must be sought and balanced against the least potential side effects.

Cautions & questionable uses of psychotropics

Just as there are clear reasons to consider the use of psychotropic medications, there are also questionable ones, many of which suggest misuse of the drug and, potentially, abuse of the individual with developmental disabilities. We encourage the following to be considered even if one of the preceding reasons seems to be met. The following is a list of questionable uses which can be prevented, avoided or corrected. Subsequent chapters offer methods of support that reduce the likelihood that these problems will occur.

Caution Number 1

No re-examination of the original decision to prescribe psychotropics: When the initial rationale for prescribing a medication is not re-examined and when there is a lack of evidence for the continued need for long-term use of psychotropic medication.

Caution Number 2

Inadequate assessment: When psychotropic medication is prescribed without a thorough assessment and comprehensive reporting to the prescribing physician.

Caution Number 3

Haphazard prescribing: When psychotropic medications are prescribed in a reactive, haphazard manner, quickly discontinuing one and substituting another.

Caution Number 4

Prescribing psychotropics for the convenience of caregivers: When medication is used to make the individual more “manageable” for the convenience of individuals who provide support to the person. The expectation that psychotropic medication can preclude outbursts is unrealistic except at extremely high

doses. In fact, using psychotropic medication may make life more difficult for support providers as the individual changes in response to the drug. In many cases, moderate doses of antipsychotic medications (or any dose of benzodiazepines) may interfere with the learning processes which would enable the individual to change “unmanageable” behaviors.

Caution Number 5

Ignoring the message the person is attempting to communicate with behavior: When medication is used to blunt a behavior without recognizing what the person intended to communicate with the behavior.

Caution Number 6

Interpreting an understandable behavioral response as pathological: When medications are used to treat the response to an empty life rather than addressing the empty life. Many individuals with developmental disabilities who present challenging behavior are expressing appropriate anger, fear, sadness, loneliness, frustration, and other unpleasant, powerful emotions in the only way they know.

Caution number 7

Limiting autonomy: When the effects of medication or the methods used to monitor them unduly limit the person’s autonomy. When possible, the individual with a developmental disability must have a forum for expressing his/her reaction to the psychotropic medication. Do they feel better or worse? Does taking a particular medication enhance or detract from their notion of how they want to live?

Caution Number 8

Exceeding therapeutic range: When medication dosages are increased, beyond the therapeutic range, in response to a conclusion that a smaller amount didn't work (more medicine isn't necessarily better). The exception is when the treatment plan calls for an initial low dose with the intention of periodic, potential increases in dosage based on response.

Caution Number 9

Caregivers lacking knowledge: When the people empowered to administer and/or monitor the effective use of the medication lack the information about the person, the prescribed medication, and the reason for using it, as well as the necessary training to competently administer medication and monitor its effect.

Caution Number 10

Lax administration of prn medication: When medications prescribed on a prn (as needed) basis are administered by various people with minimal training working in different environments without adequate training, supervision, monitoring, or communication among various staff and provider agencies.

Caution Number 11

Using medication to mask abuse: When medications are used to mask signs of abuse, effectively silencing legitimate complaints. Emerging research indicates that 95% of individuals with mild or moderate cognitive disabilities who present aggressive behavior have been physically or sexually abused by peers, family members or caregivers.

Caution Number 12

Using medications as a substitute for appropriate support: When medications are used as a substitute rather than a complementary adjunct to thorough, meaningful habilitative programs and positive behavioral support.

Assessing risks/benefits

Even when the preceding valid reasons have been satisfied and the potential questionable uses of psychotropic medication have been avoided, we acknowledge that challenging decision-making remains. “Best answers” may elude us and change over time. Other factors will influence the likelihood that support (including effective use of medications) will be delivered in meaningful ways. Issues of funding, community/institution bias, aging parents, high staff turnover, inadequate pools of potential staff, access to psychiatrist time, interest and experience of psychiatrists, internists, nurses and other medical professionals regarding individuals with developmental disabilities raise pragmatic barriers to support.

In addition to evaluating each person, a risk/benefit analysis should be performed. Ideally, this will be undertaken with the participation of the potential recipient, when possible, and all relevant team members. When self-reporting of symptoms, mood, experience and response to a medication is not possible, consistent alternative observation criteria must be established.

While this analysis can be made fairly objective, ultimately it is a subjective decision which determines the course of action.

Therefore, it is particularly important that periodic evaluation be built into the process. This evaluation should consider and document initial concerns generating ambivalence, in addition to the risk/benefit analysis. This should also include criteria for increasing, decreasing or discontinuing a psychotropic medication.

When self-reporting of symptoms, mood, experience and response to a medication is not possible, consistent alternative observation criteria must be established.

Benefit analysis:

Define the desired outcome (relief of depression, improved opportunity for community placement, decreased self-injury, etc.)

Determine if the alternative means of achieving this outcome have been attempted and state reasons for failure or only partial success.

Determine how often to review the continuation of the intervention and what milestones need to be met for continuation.

Risk analysis:

Medication side effects:

- possible impact on physical functioning, emotions, behavior;
- short term, long term effects;
- transient, permanent effects;
- ability to monitor.

Cost of medication and required monitoring.

Likelihood of medication complications.

Cross medication or medication-food

Factors contributing to effective team support

Disability in itself should not be a reason for denying someone basic human rights. All adults have the human right to make decisions regarding their lives and their medical treatment. To accommodate limitations some adults with developmental disabilities may experience in decision making, a broader circle of people who know the person—a team—can be deemed responsible for examining issues prior to decision making. The team’s role is not to make decisions but to participate in thinking through issues, identifying options, organizing information, forming recommendations, and communicating with the person and family or guardian so informed decisions can be made regarding all support strategies, including the use of psychotropic medication. A team representing varied interests, relationships, and experiences with the individual makes it more likely that there will be a comprehensive perspective regarding the individual’s strengths, needs, and preferences. A team can provide mutual learning opportunities among team members. Teams also promote implicit accountability and shared responsibility for safeguarding an individual’s rights and access to meaningful support. Abuse and questionable use of psychotropic medication are less likely to be encountered when a team is involved.

Effective teams understand they are more than simply groups of people. They hold a collective understanding of who the person is, the nature of the presenting disability and a positive, realistic vision for short and long term support. They are responsible for recording and preserving their growing knowledge so that future participants understand the history and past efforts

Teams promote implicit accountability and shared responsibility for safeguarding an individual’s rights and access to meaningful support.

to successfully support an individual. A team promotes creative, thoughtful speculation, planning, and action over time. A team blends individual talents, gifts, and expertise across all relevant domains of the person’s life, and expands its capacity to adapt and change based on the experience of the individual supported. Recognizing the turnover of staff, teams can provide a measure of continuity as it is rare that all team members would leave simultaneously.

We acknowledge that this notion of effective team support presents an ideal and that many individuals with developmental disabilities lack a meaningful team. Often, however, the individual, caregivers, case managers, and family members are not starting a team from scratch. Many who have services funded by COP, CIP, or CSLA have participated in a person-centered planning process that has many of the components we identify as effective team support. For those who are already participating in such a planning and support process, our recommendations simply enhance and substantiate what has already begun for the person. We forward these characteristics of effective team support as desirable and worth the effort to strive for with individuals you support.

We also know that parents rarely have a cohesive team available to them and their son or daughter. Again, trying to enlist some of the most intimate adults in a person’s life to assist the parents in decision-making is worthwhile. We also acknowledge that even the best of teams struggle, at times, to reach consensus, to understand the person they support, and to persevere.

Effective teams consider the following factors when the use of psychotropic medication may be part of the person’s support and intervention plan:

The team looks at the person.

Who is this person? What would constitute a desirable lifestyle? The team repeatedly pursues these predominant questions. They begin by learning to listen to the person and those most intimately involved in the individual’s life. This listening involves deeply intuitive processes in addition to sensory experience. The team listens for clues about how the person perceives the range of choices and relationships they enjoy. They observe the routines and rhythms of the person’s life to understand what is affirming, exciting, pleasing and what is tiresome, irritating and debilitating. An effective team strives to understand how the person learns and how a person communicates—particularly in non-verbal ways.

As team members learn to listen, they incorporate their growing experience in a person-centered, family-based planning process that contains a means of recording and preserving knowledge and history.

The team looks at the person’s behavior

An effective team will attempt to understand what factors contribute to the likelihood of a particular behavior being exhibited. The team studies the timing, intensity, and frequency of behavior to establish its severity and resulting priority for intervention. In addition, the team will look for precursors: subtle indications of arousal that may precede a behavior and can serve as indicators of a need for early intervention. The team will attempt to interpret if—and what—communicative intent the behavior may satisfy. The team will search for factors

that strengthen, weaken, redirect or end challenging behavior. The team will establish what preceding events, situations, people, and environments increase or decrease the likelihood that behavior will be exhibited. They understand that behavior has meaning for the individual and may be an effective strategy for accomplishing desired outcomes, including: gaining attention, escaping or avoiding unpleasant situations, satisfying sensory arousal or attaining desired food, activities, and objects. The team will continuously pursue information and insights to determine whether the behavior we find to be provocative, frightening and challenging has a functional purpose which accomplishes desired ends more effectively than other strategies for the individual. If so, the team offers the person alternative skills that satisfy the perceived function. When behavior is an expression of intense emotion, remedies to the events, situations, people, and environments that elicit those feelings are explored and coping strategies, such as relaxation, may be taught.

There is a profound difference between searching for what makes an individual with developmental disabilities who presents challenging behavior feel angry, lonely or frightened, and seeking ways to get them to stop expressing those feelings. An effective team is clear about for whom the behavior is a problem and why. They also understand how the behavior may be related to the person’s disability. After careful consideration of the preceding issues, the team designs and clearly documents a plan for positive behavioral support. When necessary, a crisis intervention plan is in place with a review protocol and documentation that staff have the capacity to implement the plan.

The team looks at the person’s relationships.

What is the range and what characterizes the most important and intimate relationships of the individual with developmental disabilities? Do they satisfy the needs for relationship we all have? Who are the people who have been involved over time and do they offer continuous notions of security, comfort, and safety? Does this person feel loved by anyone? Is the person allowed to have an intimate relationship that accommodates the individual’s sexual expression? What are the expectations, demeanor and attitude of people who surround this person? Could establishing new or re-establishing past relationships influence this person in a positive manner? Has a therapeutic relationship been attempted? Is the impact of any current relationship having an adverse effect on the person’s quality of life? An effective team is always concerned with these questions, appreciating that a wide range of relationships is critical for ensuring a desirable quality of life.

The team looks at the person’s environments.

An effective team discovers and creates settings that are compatible with the individual’s activity level, sensory and cognitive capacity, interests, and preferences. These settings are modified to respond to and accommodate challenging behavior, presenting opportunities to exhibit behavior in valued ways or at least minimize the potential damage and stigma. The primary emphasis in all settings is teaching alternative independent and substitute skills rather than

behavioral control. Care is given to assure that basic physiological needs are addressed. Settings that provide varied, interesting activities are continually sought and presented to the person to nurture a growing number and range of skills and capacities. This includes settings within which the person feels a sense of mastery and contribution.

The team looks at issues of those providing support.

An effective team is concerned with the welfare of its members, including their resources for addressing feelings of fear, anger, frustration, and sadness that, at times, accompany their roles.

Family and staff training, support, and supervision are viewed as critical components of an effective plan. Is a balance established between encouraging independent problem-solving and providing group security? Is the stress they encounter interfering with their capacity to carry out positive ideas? Do the members reflect affectionate, respectful attitudes toward individuals with developmental disabilities and in their relationships with the person? Are their expectations compatible with the person’s abilities? An effective team delegates responsibilities according to the skills and interests of members rather than adhering to rigid role definitions.

An effective team delegates responsibilities according to the skills and interests of members rather than adhering to rigid role definitions.

The team learns where to find out about the effects and side effects of medication.

An effective team will have an outer ring of advisors who can supply needed information in areas in which the team lacks expertise. For

Informed consent

In order for a team to function as an effective and legitimate advocate for the person using psychotropic medications, its members need to value the right of the individual to participate in the decisions about medication and have the knowledge of the legal requirements regarding informed consent. The team can contribute to the planning process with its knowledge of the person, clinical expertise and insights about mobilizing effective support. But the team is not the decision maker regarding psychotropic medication. The person has the legal right and responsibility to make that decision unless adjudicated incompetent and in need of a guardian. When a person has a guardian, it is the guardian who is responsible for making informed decisions regarding medications. The team can be a great help to the person and the guardian by offering information and analysis and incorporating them into the working of the team in a way that makes sense to the person, the guardian and the team. The following questions and discussion can assist the team in understanding consent issues.

Who has the final say on whether psychotropic medication can be given in non-emergency situations?

Our society gives the individual the fundamental constitutional privacy right to decide what happens to one's own body, including whether to take a particular medication for a particular purpose. In non-emergency situations, physicians and service providers must get informed consent

before giving a person psychotropic medications. To be "informed," consent must be:

- **Voluntary.**
- **Based on specific information about benefits, side effects, and alternatives.**
- **Provided by a person who is competent to give the consent or by a court-appointed guardian. (For children under age 14, consent must be obtained from parent or guardian; for minors age 14 to 17, both the youth and a parent or guardian must consent.)**

Many adults with developmental disabilities can and should make medication decisions for themselves, with whatever assistance is needed to help them understand and consider the information provided. However, some adults who have not been declared incompetent by a court may not, in fact, be able to adequately understand the information given or to make a decision based on it, even with counseling, training and assistance. A "consent" from a person who is not competent to understand the decision being made is not a valid informed consent. In questionable cases, a guardianship petition may be needed: the court can either declare the person able to make medication decisions, or appoint a guardian to act as substitute decision-maker. A guardian may have general powers to make decisions, or the guardianship may be limited to specific areas, such as consent to medical care or consent to certain medical decisions.

... the team is not the decision maker regarding psychotropic medication. The person has the legal right and responsibility to make that decision unless adjudicated incompetent and in need of a guardian. When a person has a guardian, it is the guardian who is responsible for making informed decisions regarding medications.

For most adults who have been found incompetent by a court, the guardian has the final say as to whether the person will receive psychotropic medications. This puts the other members of the treatment team in the role of presenting the information the guardian needs to make the decision and assisting the guardian to evaluate alternatives.

Who is responsible for making sure consent has been obtained?

Like other aspects of the decision to use psychotropic medications, ensuring informed consent should be seen as a team responsibility. Some service providers act on the assumption that it is up to the physician to obtain informed consent. However, where a public or private developmental disabilities service agency is involved in arranging or dispensing medication, it may have an independent responsibility to ensure that informed consent has been given to the treatment it arranges or administers. The potential for liability increases where the provider knows that the prescribing physician did not consult the legally responsible decision-maker.

How involved should the guardian be?

In practice, different guardians will have very different preferences for level of involvement. Some may want to be integral parts of the treatment team. Others may only want to be involved in the final decision among options identified by the team. Some will want a clear recommendation from the team. Still others may want to delegate the entire decision to the team or prescribing physician. Some will be unresponsive or unreachable.

Guardian involvement is not simply a legal formality. It can have important consequences for the quality of treatment decisions and the effec-

tiveness of treatment. The guardian is often the person with the greatest knowledge of the person's history—including past adverse drug reactions. The guardian may be able to identify possible causes of behavioral change that may require intervention other than medication. Finally, the guardian and family may provide a significant safeguard during treatment by identifying changes in the person that may be side effects of medication.

To some extent, the appropriate level of guardian involvement depends on circumstances. The decision to initiate the use of major psychotropic medications, such as the major tranquilizers, calls for a high level of guardian attention. Such medication is generally proposed because of some significant behavioral changes. The guardian should be aware of these changes, possible causes, and alternative responses. Complete history and vigilance for side effects may be particularly important with new medications.

On the other hand, if the person is in a stable situation, the guardian knows and has confidence in the providers, and the issue is varying the approach to an ongoing issue that has been discussed in the past, such as substituting a new medication for one that has been ineffective, a guardian may feel that the providers are in the best position to make decisions, and that his or her involvement would not add anything to the quality of the decision.

Can a guardian delegate decision-making to a service provider?

The law does not clearly authorize guardians to delegate medical decision-making, and there may be some risk in relying on any delegated authority. The risk is particularly great where the guardian attempts to delegate decision-mak-

ing to a service provider who will also be involved in arranging or administering medication because the provider has the legal responsibility to get informed consent to treatment. By definition, a general consent to future treatment that does not include specifics on the nature of the treatment involved cannot be “informed.” It is doubtful that a guardian has the right to waive his or her ward’s right to informed consent prior to treatment.

One approach that may increase flexibility is to obtain consent to a treatment plan that includes a range of dosages or a series of trials of different medications, where a single summary of risks, benefits and alternatives can be done that is not either too superficial or too confusing to be useful.

What if the guardian and the team disagree?

If the team has a strong consensus that medication is needed, and the guardian refuses consent, the first response should be to talk through the alternatives and likely consequences again: this may convince the guardian, or it may result in a course of treatment that the team can agree offers some hope of success. A good faith effort to accommodate guardian concerns can help to develop trust in the long term, so that if other approaches do not succeed the guardian may agree to try medication. All of the approaches discussed in Appendix C are appropriate where the team and guardian are “stuck.”

If the team feels strongly that a guardian’s medication decision is contrary to the person’s best interests, it can request the court to review the

guardian’s decision. Sometimes counties will assist in these petitions as a protective service. In other cases, the court may respond to a letter requesting appointment of a guardian ad item to review the decision and report to the court. Some courts will only respond to formal petitions which may require the team to hire an attorney.

While consent must be voluntary and there can be no retaliation against the person or guardian for refusal of consent, providers also cannot be forced to provide treatment that they view as futile or against professional judgment. If guardian refusal leaves no viable treatment options, it is not considered legal coercion for the treatment facility to offer a choice between accepting some viable treatment option or discharge.

What if the guardian consents but the person actively refuses medication?

The Wisconsin Court of Appeals has held that a guardian does not have the power to authorize anyone to compel the person to take psychotropic medications, even where there is a protective placement order. While not addressed by the court, a guardian probably also lacks power to authorize the use of deception to give drugs to someone who has refused psychotropic medication.

If the team feels strongly that a guardian’s medication decision is contrary to the person’s best interests, it can request the court to review the guardian’s decision. A person can be forced to take medication over his or her objection if he or she has been civilly committed, and the court has made a finding that the person is not competent to refuse medications.

Commitment requires proof of some level of dangerousness and treatability that may not be

possible with some people with developmental disabilities. The law also provides for a limited guardianship for consent to psychotropic medications, under which a guardian can authorize compulsion. However, this law has several restrictions, one of which is that the person must have a chronic mental illness. For some people with developmental disabilities who do not have chronic mental illnesses there may be no clear legal mechanism for giving psychotropic medications over the person's objection.

What are the risks if medication is given without meeting all informed consent requirements?

There are sometimes substantial barriers to the team in ensuring compliance with informed consent requirements. Some guardians simply will not respond, and there may be no legal resources to obtain court oversight. Some physicians reject the concept; others reject the paperwork involved.

Any administration of psychotropic medications without a proper consent is technically an assault and can result in liability, both under general common law and under the patients' rights law in Chapter 51, Wisconsin Statutes. Damages will be greater if the medication produces severe or permanent side effects. However, the degree of risk will vary depending on the circumstances. In general, risk will be reduced if:

There is an ongoing, open relationship between the guardian and providers. A guardian who feels excluded from decisions is also more likely to respond to an adverse result with a lawsuit.

- The guardian is kept informed of substantial changes in the person's behavior or situation, and alternatives to use of medication are fully examined.
- A good faith attempt is made to inform the guardian of medications given and of benefits, side effects and alternatives (e.g. by giving or sending written information).
- A complete medical history is obtained to identify any past adverse reactions.
- All staff are trained to monitor the person closely for side effects.

For some people with developmental disabilities who do not have chronic mental illnesses there may be no clear legal mechanism for giving psychotropic medications over the person's objection.

Forcible administration of medication with knowledge that no legal authority exists meets the legal definition of abuse. Intentional or reckless abuse can result in criminal liability where the abuser is in charge of or employed by an adult family home, foster home or group home for children, community-based residential facility (CBRF), home health agency, nursing home, hospital or treatment facility for mental illness, developmental disabilities or alcohol or other drug abuse.

Consulting with a prescribing physician

We recognize that those prescribing physicians who are not psychiatrists may have little experience with psychotropic medication and even less with individuals with developmental disabilities. Many psychiatrists have little knowledge of the unique issues facing individuals with disabilities. Consistent access to a psychiatrist is not available for most individuals with developmental disabilities and their support providers. A survey sponsored by the University of Wisconsin-Madison School of Social Work found that nearly 80% of all licensed psychiatrists in the state of Wisconsin practiced primarily in Milwaukee or Dane counties. Elsewhere, the responsibility for prescribing and monitoring psychotropic medications is often undertaken by primary care physicians, neurologists, or other clinicians. The following is meant to serve as an outline of information the physician should have available to recommend the best possible medication option and to capably evaluate its use.

Collecting information

Prior to the visit:

It is important that the team frame the reason for seeking physician consultation as clearly as possible prior to the visit and that this is conveyed to the doctor. This assures there is not a mistaken assumption that the people on the team are expecting a pharmacological solution to the problem they have identified. For example, the goal of the visit may be exclusively to have a physical assessment done for possible

medical conditions or to review other medications to see if side effects might be contributing to a specific behavior. Alternatively, it may be to simply explore therapeutic options without initiating any treatments at the time of the appointment. In other cases, there may be an interest in starting medication as soon as possible, especially if there is concern about the safety of the individual or others. This, too, should be explicitly stated.

Document a concise history of the person's disability, including etiology when possible. An outline of developmental accomplishments, diagnostic testing and impressions with associated diagnoses should be presented.

Assemble a detailed description of the presenting concern. Include, when possible, the individual's impression of the problem. The description should include when the issue of concern began, whether it has been observed in the past, and whether it is an acute or chronic problem.

Documentation of the problems course is also helpful. Does it occur in cycles? Is it getting more frequent, more intense? Are episodes lasting longer with less time separating them? What has been attempted to address it to date?

When establishing a relationship with a new doctor, provide a thorough history of the person's medical status including medication history (particularly if difficulties such as tardive disorders or neuroleptic malignancy syndrome have been encountered), allergies, general health, physical exam results, metabolic and genetic screening when available, and special or

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Questions to ask:

What is this medicine being given for? A specific diagnosis or a particular symptom?

What is the brand name AND the generic name of this medicine? What are the differences in effectiveness of the two in the case of this medication?

How will we know if this medication is working the way it's supposed to? How long before we have an adequate trial?

Should this medication be given before meals? With meals? After meals? At bedtime?

What are the most common side effects of this medicine? Can we do anything to minimize side effects? What should the caregiver do about side effects if they do occur?

Should certain foods be avoided? Alcoholic beverages? Other drugs?

How long should this medicine be given?

What should be done if a dose is missed? Or if too much is taken?

acute care provided. Develop a description of the person's somatic and social functioning and note any recent changes, including: sleep patterns, sexual behavior, appetite and weight, repetitive or ritualistic activities, relationships, sensory capacities and experiences, energy and interest level, cognitive functioning, communication patterns, and mood. Update the information as circumstances change.

A brief social history including a description of the person's family and their interactions, including siblings, when available, is helpful. A more complete profile will incorporate a description of placements, education, program descriptions and history, instances or suspicion

of neglect and abuse, stresses, and a description of the individual's current system of support. An outline of the person's usual functioning, how they appear when doing well, preferred means of communication, skills, talents, interests, and appealing characteristics will assist the physician's understanding of the individual.

A more complete history of the person's and family's psychiatric history is a necessary component. Has anyone in the extended biological family experienced depression, obsessive compulsive disorders, a bipolar disorder, schizophrenia, personality disorder, alcohol or other substance abuse or dependency, or developmental disability?

When team members accompany an individual to an appointment and serve the role of surrogate reporter they should be prepared point out to the physician information about the nature and duration of their relationship with the individual, whether they represent a consensus in observation, impressions and opinions, and what role family or guardians play in decision making. Decisions about responsibility for informed consent should be available as well.

During the visit:

Team members may wish to ask the physician to assist them in determining the following:

- Has the person been given accurate developmental and psychiatric diagnoses? Are the target signs, symptoms and behaviors consistent with the diagnosis?
- Is the recommended psychotropic medication consistent with the diagnosis and is it substantiated in prevailing practice, research or literature?
- What benefit does the physician anticipate?

- What would be the consequences of not receiving the recommended psychotropic medication?
- How will the medication interact with other drugs (prescribed and over the counter) the person is receiving? (For example, Tylenol deactivates some antidepressants).
- What indications of adverse side effects that may accompany the use of the medication should team members be aware of?
- When should the effect of the drug begin to be seen and how will changes be monitored?
- Is the initial dose likely to change and, if so, how will that decision be made? What if a dosage is missed or too much is taken?
- Is the physician aware of additional resources or treatments to supplement the medication intervention?
- Has the physician been given the impression that the family, staff or the individual simply wants the medication to “fix” a problem that is not solely medical?

After consultation:

Following consultation a tremendous amount of work remains in monitoring the administration and responsible use of psychotropic medication.

Observations of changes in the individual and his/her response to the medication need to be performed by all team members and recorded. Information the physician will need to monitor the effectiveness of the medication, based on the preceding section, should also be gathered. It should be recognized that there is likely to be a considerable degree of uncertainty in diagnosis and treatment. It can be difficult

to predict how any person, with or without disabilities, will respond to a specific medication.

This means that after the consultation, the following should be considered:

- Does the medication seem to be accomplishing its intended purpose? This is especially important to assist the physician with decisions regarding dose adjustments and overall appropriateness of drug choice.
- Have changes in the person’s status been noted, including, judgment, orientation, memory, mood, problem-solving, motor abilities, sleep, diet, energy, interests, relating to others, and general behavior?
- Are tardive disorders and other side effects being assessed on a regular basis by someone skilled in doing so? Two potential resources for assessing side effects are the Rockland Research Institute (Simpson) Abbreviated Dyskinesia Rating Scale and the Dyskinesia Identification System Condensed Users Scale (DISCUS). Specific training is required to apply and interpret these tools. Typically, it will be clinicians such as physicians, nurses or therapists who will have the necessary training.
- Are there any noticeable changes in the person’s capacities, behaviors, emotions? Could the medication be contributing to these changes?
- Are regular follow-up appointments necessary and scheduled?
- Should lab work be scheduled?
- Is a training protocol being used as new team members join to assure continuity of care and consistent monitoring?

Following consultation a tremendous amount of work remains in monitoring the administration and responsible use of psychotropic medication.

Conclusion

The use of psychotropic medication is a very serious decision with high stakes for the recipient. Responsible support extends beyond the initial consideration and decision to use psychotropic medication. These are very potent and potentially dangerous drugs when not used appropriately. However, when the right medication at the right dose is introduced to an individual with a developmental disability, the benefit can be life-enhancing.

This process is only the beginning of evaluating whether medications are really being effective in providing the benefits of the intended use of the medications. The support team should know what they would like to achieve and then review the effects of the medications periodically to ensure that this benefit is occurring. Because support personnel change and thorough documentation is rare, the reason why the person takes the medication may be lost to history. It could also be that the person has been on the medication for a long time and no one really knows whether it continues to be therapeutic. Of course, people who are on the support team when the individual is first using the medications remember, but caregivers change and institutional memory is lost. Long term use of the same medication without anyone reviewing it is poor practice. It is recommended that medications be reviewed monthly when a person first begins taking a new medication and every three months to ensure that the effects of the medication continue to be beneficial.

Appendix B provides an outline incorporating the information in this chapter that could be adapted as a worksheet for monitoring the use of psychotropic medication.

For any prescription, remember:

- ◆ Prescribed medications should be used to treat a specific condition. They should not be saved after that condition has been treated.
- ◆ Medications should be stored in a cool, dry place, usually not frozen, and usually not in a bathroom or kitchen.
- ◆ Over the counter (OTC) medications can be very powerful. Always tell the physician what OTC medications are being used. Before adding a new OTC medication, consult with the dispensing pharmacist and inform the prescribing physician.

APPENDIX A:

Behavioral assessment outline

A behavioral assessment is an organized, repeated observation of an individual, complemented by the observations of others and specific data that helps in understanding an individual's behavior. The functional analysis component extends beyond the person's behavior to include environmental, activity and interpersonal issues which create the contexts within which the behavior occurs. Behavior does not occur in a vacuum; a wide range of factors and variables must be considered. A behavioral assessment can provide an empirical baseline to measure effectiveness. It also serves as a hypothesis against which various interventions can be tested. The following information should be part of an assessment used to predict successful intervention.

The person and the presenting problem.

1. Describe the person, including capacities, preferences, skills and information regarding the nature and extent of the disability. Include physical characteristics, cognitive abilities, communication abilities, and motor, perceptual, self-care, social, community, domestic and leisure/recreation skills.
2. Describe the behavior of concern, including frequency, severity, duration, intervals, and cycles. Say more than "an individual exhibits aggression." Be specific, e.g., "The individual strikes another's face with an open hand slap. The force of the slap is moderate as the strike is from very close range with only 6-9 inches of swing range. Each incident consists of a single slap, with four incidents each day on average over the last six months. There have been no days free of this behavior, with the worst day noting 10 incidents. The behavior has been reported for the last five years."
3. Describe past attempts to address the behav-

ior. Include attempts to suppress, change, manage, and control the behavior.

4. Discuss potential medical or other physiological concerns which may be related to the behavior.

Environmental factors.

Note environmental factors that influence the behavior, e.g., the type of setting, the activities available, the numbers and mix of individuals, noise levels, visual distractions, temperature, the individual's expectations about clothing, furniture arrangement, food and other elements of the environment, and time of day.

Antecedents and consequences.

Analyze the antecedents (preceding conditions) that seem to establish the occasion for the behavior and consequences (following events) that seem to maintain or motivate the behavior.

How and what the behavior accomplishes.

Analyze how and what the behavior accomplishes for the individual, as most behavior is purposeful. These functions may serve as motivating factors and are often inadvertently rewarded. Attention, asserting autonomy, signaling a powerful emotion, escape or avoidance from undesired stimuli, retaliation, communication, self-regulation, access to tangible items and entertainment are frequent motivating factors.

Interpersonal issues.

Examine interpersonal issues including the role others play in, willingly or unwittingly, provoking, maintaining or rewarding the behavior. Examine the nature of the person's relationships to assess the capacity and interest for mutual attachment, intimacy, and sexuality.

APPENDIX B:

Suggested outline for psychotropic medication monitoring

This outline is a list of suggestions to create a method for monitoring psychotropic medication effects that can be individualized to the person whose medications are being monitored and the organizational environment in which this support is provided...

This list is based on the chapter titled “Consulting with a prescribing physician”.

Before the consultation with the physician:

- Reason for seeking the consultation?
- Concise history of the person’s disability.
- Detailed description of the presenting concern.
- History of the person’s medical status including medication history. (Remember to include dosages of the medications)
- Social history including a description of the person’s family and their interactions.
- Family’s psychiatric history.
- Does the information represent a team consensus or only the individual reporter’s point of view?
- Obtain informed consent.

Other information to bring to the consultation:

- Name and birthdate of the individual.
- Address/city/state/zip/phone number of the individual.
- MA/Insurance number of the individual.
- Who is the individual’s guardian? If not self, bring the guardian’s phone number.
- Bring a list of the individual’s current diagnoses and medications the individual is currently taking (including doses).

Questions to ask the physician at the appointment:

- Developmental and psychiatric diagnoses. Are the target signs, symptoms and behaviors consistent with the diagnosis?
- Rationale for the selected medication for this person’s symptoms and diagnosis?
- What benefit(s) does the physician anticipate?
- What consequences if the prescribed psychotropic medication is not used?
- How will the medication interact with other prescription and non-prescription drugs used by the person?
- What side effects should the team members look for?
- When should the effect of the drug begin and what changes should be monitored?
- Will the initial dose change?
- What additional resources or treatments to supplement the medication intervention?
- Should the medicine be taken with food?
- Will the medicine interact with certain foods?
- How often should this prescription be checked by the doctor?
- Are there laboratory tests to schedule?
- When is the next appointment?

Other information to obtain/log at the consultation:

- Name/Clinic/Phone Number of the Prescribing Physician.
- Date of visit.
- Name of the medication, including its

dosage. Is the dosage fixed, or can the medication be administered on an as needed (prn) basis, as well?

- What is the generic name of the medication, and is it okay to use the generic instead of the brand name?
- Should the medicine be taken with food?
- Will the medicine interact with certain foods?
- How often should this prescription be checked by a doctor?
- Are there laboratory tests (blood serum levels, etc.) to schedule?
- When is the next appointment (date/time/clinic/doctor)?
- Has the informed consent been obtained? By whom?

After Consultation: Monitoring and documentation

- Does the medication seem to be accomplishing its intended purpose?
- Note changes in the person's judgment, orientation, memory, mood, problem-solving, motor abilities, sleep, diet, energy, interests, relating to others, and general behavior.
- Note side effects. Are tardive disorders and other side effects being assessed on a regular basis by someone skilled in doing so?
- Are there any noticeable changes in the person's capacities, behaviors, emotions?
- Are regular follow-up appointments and lab work necessary and scheduled and documented?
- Is documentation and training in place for new team members to assure continuity of care and consistent monitoring?

Issues to consider to put the effect of medication in the context of the person's life:

- Significant change in the person's environment (new home, housemate, etc.)?
- Significant change in support staff?
- Additional emotional stressors present (loss, grief)?
- Significant change in the person's physical health?
- Change in the person's sleeping pattern?
- Change in the person's target behaviors? Increase? Decrease?
- Change in the person's appetite?
- Change in the person's routine?
- Weight change?
- Change in the person's bowel or bladder function?
- Any noticeable physical change?
- Any noticeable emotional change?

The "Health Care Tool Kit" is a valuable resource to track medications and all health care concerns, including dentists. It is to be used by consumers, caregivers, healthcare providers and community support personnel. The toolkit contains color-coded forms that track medical interventions and concerns. It helps to support a system of communication between consumers and providers. The consumer, health care providers and support personnel keep their own forms for reference. The Toolkit is available from the WCDD for \$6.50 or \$13.00 for a camera-ready version for duplicating.

APPENDIX C:

What to do when the team is feeling stuck

Seek a second opinion.

This is true for any aspect of the individual's support, particularly in areas that involve a measure of subjective evaluation, such as interpreting behavior, diagnosing a mental health issue, or choosing a psychotropic medication. The team may choose to seek available, alternative resources to solicit another perspective on what may be influencing the person and possible responses.

Seek outside consultation.

This is related to the preceding suggestion but extends beyond seeking a second medical opinion about the person. This could include consulting with a specialist in team building, behavioral support, specific disability areas, resource allocation, or stress management.

Hold a mini-retreat.

Taking time to reflect on accomplishments and consider future directions may seem like an indulgent waste of precious time. A well-planned and facilitated gathering can encourage team members to assert their commitment to the individuals they support and discover creative, novel solutions to problems. Sometimes, the sense that there is no time to reflect is the caregiver's symptom indicating the need to step back and get a fresh perspective.

Revisit the team's planning process and results.

Do the assumptions about what really matters to the individual still hold true? Are the resulting supports still seen as the best responses to the needs assessed and the most likely to contribute to a meaningful lifestyle?

Pound the history.

Are there sources of information that may teach us more about what the individual has experienced prior the current team's tenure? Have past strategies, including the use of psychotropic medication been thoroughly explored?

Play what do we know?

The team may hold a brainstorming session designed to express as much as possible about the individual and check for agreement between team members.

Learn something new.

Each member of the team may commit to exploring a new way of understanding the individual by reading a book or professional journal, attending a workshop or conference, speaking with a respected peer or mentor, those with and without a disability.

Break the routine.

The team may wish to plan purposeful breaks in the usual rhythms, routines, and expectations. This could range from small changes such as a "day off" to a vacation.

Bring in someone new.

The team may wish to introduce a new person to the individual or consider providing greater opportunities for the individual to expand the person's current circle of friends.

Share a meal together.

This may seem trite, but the simple pleasure of eating and enjoying one another's company can be moving and rejuvenating.

APPENDIX D:

Glossary

anesthesia: Partial or complete loss of sensation with or without loss of consciousness as result of disease, injury, or administration of an anesthetic agent, usually by injection or inhalation.*

antecedents: Any occurrence or event prior to another.**

anticonvulsants: 1. Preventing or relieving convulsions. 2. Agent that prevents convulsions.*

antidepressants: An agent used to treat depression. Some chemical classes of antidepressants are tricyclic, monoamine oxidase inhibitors, and serotonin reuptake inhibitors.

antiemetic: 1. Preventing or relieving nausea and vomiting. 2. Agent that prevents or relieves nausea and vomiting.*

antipsychotics: medications which have sedating and calming effects, the major of which is to reduce psychotic thinking and behavior. (see neuroleptics)

anxiolytics: An antianxiety agent or drugs used to treat anxiety.

autism: A neurological condition characterized by severe problems in communication and behavior. Individuals with autism are unable to relate to other people in a typical manner.

benzodiazepines: Any of several chemical compounds used as sedatives and muscle relaxants.**

bipolar disorder: A condition with two extremes. Example: mania plus depression in the same individual within a short period of time.

chemotherapy: In the treatment of disease, the application of chemical agents which have a specific and toxic effect upon the disease-causing microorganism.*

diagnostic work: To determine the cause and nature of a pathological condition; to recognize a disease.* eg: EEGs, EKGs, C-T scans

dyskinesia: Defect in voluntary movement.* (see Tardive Dyskinesia)

endogenous: 1. Produced from within. 2. Biology Originating within an organ or part.**

endorphins: Any of a group of hormones with pain-killing and tranquilizing ability that are secreted by the brain.**

epilepsy: A disorder of recurrent seizures which are characterized by sudden, brief attacks of altered consciousness, motor activity, or sensory phenomena.*

etiology: The study of the causes of disease.*

interactions: drug-drug: A combination with a chemical or clinical response which differs from that anticipated from known effects of two agents when given alone. drug-food: A response which differs from the response of the drug when given without food.

motor abilities: Of, pertaining to, or designating nerves carrying impulses from the nerve centers to the muscles; Of or relating to movements of the muscles.** e.g. hand motions, walking.

narcotic: 1. Producing stupor or sleep. 2. A drug which in moderate doses depresses the central nervous system, thus relieving pain and producing sleep but which in excessive doses produces unconsciousness, stupor, coma, and possibly death.*

neuroleptic malignant syndrome: A rare side effect of antipsychotic medications which may occur shortly after starting the medication and is marked by very high temperature and muscle stiffness; potentially fatal.

neuroleptics: Word used interchangeably with antipsychotics, major tranquilizers. (see antipsychotics)

neurotransmitters: Chemical messengers that operate between adjunct nerve cells.

obsessive-compulsive disorder: Marked by an inclination to perform certain rituals repetitiously in order to relieve anxiety.*

Parkinson's Disease: A chronic nervous disease characterized by a fine slowly-spreading tremor, muscular weakness and rigidity; and a peculiar gait.*

personality disorder: A tendency for acting out with the results that there is little display of anxiety or sense of distress felt or expressed.

prn: From the Latin pro re nata, as circumstance may require; as necessary. Frequently used in prescription and order writing.*

psychostimulants: Drugs which have a stimulating effect on the central nervous system.

psychotropic drugs: Drugs which affect psychic function, behavior, or experience. Many drugs can be classified as being intentionally psychotropic, but many other drugs may occasionally produce undesired psychotropic side effects also.*

schizophrenia: A group of mental disorders characterized by disturbances of thinking, mood, and behavior.*

sedation: 1. Process of allaying nervous excitement. 2. State of being calmed.*

self-stimulation: Repetitive behavior that is self-reinforcing.

serotonin: An organic compound found in the brain which is believed to have a role in certain types of depression.

side effect: The action or effect of a drug other than that desired. Commonly this is an undesirable effect such as nausea, headache, or insomnia.*

somatic: 1. Pertaining to nonreproductive cells or tissues. 2. Pertaining to the body. 3. Pertaining to structures of the body wall, e.g. skeletal muscles (somatic musculature) in contrast to structures associated with the viscera, e.g. visceral muscles (splanchnic musculature).*

tardive dyskinesia: Slow, rhythmical, automatic stereotyped movements, either generalized or in single muscle groups. These occur as an undesired effect of therapy with certain psychotropic drugs, especially the phenothiazines.*

therapeutic range: Measurement of a low and high level of a chemical or drug in the blood which has the usual desired effect.

toxicity: The extent, quality, or degree of being poisonous.*transient (vs. permanent): not lasting for a long time; momentary; not permanent.

Tourettes syndrome: (Gilles de la Tourette's) Motor in coordination with involuntary repetition of a word or sentence just spoken by another or involuntary utterances of vulgar or obscene words.

withdrawal: Cessation of administration of a drug, especially a narcotic, or alcohol to which the individual has become either physiologically or psychologically addicted. Withdrawal symptoms vary with the type of drug used.*

*Thomas, Clayton L., M.D., ed., *Taber's Cyclopedic Medical Dictionary*, 14th edition. Philadelphia, PA: F.A. Davis, Co., 1981.

***The American Heritage Dictionary*, Second College edition. Boston, MA: Houghton Mifflin Co., 1985.