

This paper was developed by Leslie Broun and Gardner Umbarger, DD Division members, and has been approved by the DDD Board on April 9, 2005 as an informative brief to be made available to its members. The Critical Issues Committee is open to a discussion of issues of interest to the membership – if you would like to develop an issue for consideration, please send your thoughts to stodden@hawaii.edu.

Division of Developmental Disabilities Issue Paper

Considerations on the Use of Medicine with People Who Have Autism Spectrum Disorder (ASD)

At some point in the life of a child with developmental disabilities, including autism spectrum disorders (ASD), families may be confronted with the issue of whether or not the use of medication is needed to improve their child's quality of life. This is often a very difficult decision for families to make. The use of medication for children with ASD and other developmental disabilities is an issue about which many people have strong opinions which may cloud, divert, or distort the crucial issue of whether the benefits of using the medication outweigh the risks associated with the use of psychotropic medications.

Children and adults with ASD may exhibit the following behaviors that can degrade their quality of life and require some form of intervention, including:

- Aggression that has moved beyond what can be tolerated or has become significantly less manageable.
- Self-injurious behavior that poses a threat to her/his health and safety and/or significantly interferes with the activities of daily living.
- Obsessions/compulsions that significantly interfere with the child's participation in the activities of daily living or safety.
- On-going, unsafe impulsivity that may include running, climbing, mouthing, or eating inappropriate objects.

Any of the above-mentioned behaviors can cause considerable distress at home, school, and/or other settings. When behaviors escalate to the point where quality of life is jeopardized, families may be forced to consider whether the benefits from the use of certain medications outweigh the possible side effects. When this occurs, the family should contact their child's physician and begin the dialogue on the appropriateness of medication and other treatment interventions for their child. Before the intervention is considered, however, there are some questions that must be considered:

- Have the behaviors been analyzed with a thorough multidisciplinary behavioral and environmental assessment?
- Has everything possible been done to ameliorate the behavioral difficulties both at school and at home, including but not limited to environmental accommodations, sensory sensitivities, etc?
- Has the input of appropriate resource personnel (e.g. behavioral therapists, psychologists, etc.) been accessed and utilized?
- Does the behavior occur across environments and seriously compromise (jeopardize) the health, safety, or quality of life of the child and/or those with whom he/she interacts?

It is important for families to feel that these broader questions have been answered to their satisfaction before making this serious decision.

Initial Considerations When Using Medication

Some people may feel that the use of medication is often a substitute for other equally effective methods in managing the challenges associated with ASD and other developmental disabilities. Some of the questions that families and teachers should ask include when considering the use of medication include:

- Is there adequate evidence that demonstrates the effectiveness of this medication as a treatment for the symptoms exhibited by the individual?
- What are the potential side effects or risks associated with that treatment?
- How can medication compliment other interventions to maximize the effectiveness of treatment?
- Are the benefits of treatment greater than the potential side effects associated with the treatment?
- Is the use of medication more effective and less expensive than other available treatments?
- To what extent will medication facilitate the child's participation in the community?
- How can medication improve the quality of life for their child?

As the child approaches adulthood, the family may also need to confront the issue of their child's use of commonly available stimulants and depressants such as caffeine, alcohol, and illegal substances to moderate the perceived effects of ASD. This practice can lead to significant personality and mood swings, compound the affective nature of ASD, and increase the individual behavioral challenges common to ASD. This use of prescription and non-prescription medications together can have potentially dangerous side effects that cannot be anticipated by families or physicians.

The Home/School Partnership

An open and honest relationship between families and teachers is critical when a child's behaviors have reached a level where either home or school interventions are unsuccessful in ameliorating a situation. Families bring the full spectrum of the child's life experience to the table, while teachers are able to give a more objective view on how behaviors impact the educational environment. Teachers can be valuable partners, both in providing information about the child's behaviors to families and doctors and, should medication be prescribed, in monitoring its effects. Decisions regarding medication should rightfully be limited to the families and physician. The teacher can facilitate this dialogue by providing information regarding the behaviors exhibited at school and the results they have witnessed once treatment has begun. The teacher can also act as a reliable ally to the family by being supportive and nonjudgmental of the family's decision.

In order to assist to the school in monitoring potentially dangerous side effects from these medications, it is important the family makes sure the school is constantly informed about the medication and dosages the student is receiving. The student spends a large proportion of his/her day at school, and any pharmacological contraindications or side effects need to be made aware to families and physicians. Teachers and schools need to be informed and aware of:

- The name of the medication, dosage, and administration times.
- The therapeutic purpose of the medication.
- The anticipated results of treatment.
- The potential side effects and what they look like.

- What accommodations are required by the student, e.g. rest periods, nutrition and hydration, decreased exposure to sunlight, etc.
- What to do in case of a medication-related emergency.

With families and teachers working together, the management of medication can become a viable process that enhances the quality of life for persons with ASD. When indicated, the use of medication can significantly alter and enhance a child's quality of life, enabling her/him to be able to live safely and access a broader range of activities available in the home, school and community.