

SCHOOL LEARNING AND SOCIAL/EMOTIONAL ADJUSTMENT

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Children with A-T, just as all children, have significant variability in their cognitive skills. There is variability from child to child, and each individual child will have specific areas of strength and weakness. Performances on tests of cognitive abilities have produced results that fall within *all* ranges of intelligence. Children with A-T often have a general slowing in their learning ability over time, resulting in lower test scores than those of other children of the same age. As a group, children with A-T do not have a loss of specific cognitive abilities as much as they become less able to acquire new knowledge. Thus, with passing time the child with A-T may seem to be more like a younger child in terms of understanding and interests. This is important to monitor so that academic and social expectations can be modified appropriately. The child often is sensitive to his/her areas of weakness and thus needs ample opportunity to utilize areas of strength.

Many activities become increasingly effortful for the child and fatigue will further affect performance. Modifications in work load help to ensure optimal use of time and energy for both social “fun” activities and productive “work” activities. Helping the child to recognize his or her energy limitations and to indicate the need for breaks is useful and also can increase the child’s control over the environment.

Psychological Evaluation Process

A comprehensive psychological evaluation may be worthwhile to determine the child’s individual profile of strengths and weaknesses. A typical evaluation begins with a parent interview to obtain information regarding school performance, adjustment issues and information processing skills. Psychological areas that can be assessed include cognition (problem-solving abilities in both the language and visual/perceptual domains), memory, attention, academic skills, and social and emotional functioning. The child is may be given a series of standardized tests to address areas of specific concern. The results of these tests are intended to provide information about cognitive strengths and weaknesses so that appropriate interventions can be undertaken.

Cognitive Abilities

Learning Problems

Children with A-T often develop learning difficulties at school that require accommodations in classroom goals and teaching strategies. There are many reasons for these difficulties. Abnormal eye movements impair reading. Tremor and ataxia interfere with writing and the use of the computer keyboard.

Slurred speech and the increased time that most A-T patients need to process information may give a false impression that the affected child is unable to answer the question. The energy and attention that are required to maintain sitting posture may detract from the concentration needed for classroom instruction. Superimposed on these problems is a slowing in the rate of development of cognitive abilities with age.

It is important to identify a child's individual profile of strengths and weaknesses in order to ensure that teaching strategies are geared to optimal learning. For example, although eye movement problems can make the visual tracking of letters and words in reading difficult, some children show strengths in specific types of visual/spatial organization. In this case, the use of certain kinds of demonstrations or visual input can be helpful in accompanying the presentation of verbal material.

Academic goals, as well as teaching strategies, need to be set in accordance with a child's own cognitive profile. It is important to recognize that this profile will change as the child becomes older, and that teaching goals and strategies may need to change as well. Goals that are set beyond a child's capacity will prove to be frustrating and contribute to poor self-esteem. Modifications of goals often can be made successfully within a regular class setting. A good measure of the appropriateness of goals is the success that the child is experiencing in class, regardless of the level of the work. Modifications in the classroom need to address problems related not only to learning but also to motor abilities and fatigue level. Although it is reasonable to strive for full-time attendance at school, work loads may need to be reduced, and children may need days off periodically or shortened school days. Other typical accommodations include additional time allowances, the use of computers, and oral rather than written testing. Modified testing can ensure that the child's knowledge of material is sampled but that additional work and repetition are avoided.

As they get older, most children find that a one-to-one assistant at school is invaluable. The school system may provide an assistant for physical safety reasons, but the role of the assistant can be much larger. For example, the assistant can facilitate school work by taking notes, reading directions and presenting information orally. Of course, it is important that the assistant strives to facilitate learning and classroom involvement without simply doing the work for the child. Classroom aides also can be useful in reducing demands that contribute to fatigue.

Classroom accommodations may not be sufficient to allow the child to be competitive with peers and achieve at his/her optimal capability level within the regular class setting *full-time*. It may be beneficial to provide resource help or other services outside of the class to ensure more individualized attention. Again, the goals should be success in relation to peers and positive experiences during school time.

Assessment of the child's cognitive profile and educational program also should lead to planning for a successful transition beyond high school. It is appropriate to encourage many young adults with A-T to pursue avocational and vocational goals. Some A-T patients have been successful in college with a program that includes reduced class loads and adequate support to handle the demands. Others have been successful in appropriate job settings.

Rate of Processing Information

Many children are slow to process information and may benefit from modifications in time allowances. They may need additional time in order to answer a problem in school or reply to a comment in a social conversation. It can be frustrating for a child to feel pressured or to be cut off before giving a response. Creating a safe environment in which the child is comfortable setting the pace is important. This can be accomplished by establishing a method of communication that allows the child to convey when he or she needs extra time. This can provide the child with more opportunity to be successful and interactive, as well as gain some control over the environment.

Reading

Reading is one of the activities that often becomes very effortful due to difficulties with eye movement. Enlarging print and covering lines above and below can make reading easier. Pointing to individual words can help with visually following text. Computer scanning technology can be useful. However, circumvention strategies become increasingly helpful as the child becomes older. Although it is important to work on reading skills, it also is important to emphasize other avenues for acquiring information, in part to reduce fatigue and frustration. These compensations are especially important when the child makes the transition from "learning to read" to "reading to learn." The child's ability to listen carefully often represents a relative strength. It may be more productive to read to the child or use books-on-tape or videos rather than require the child to read long passages.

Memory

Some children with A-T have trouble with memory and word-finding. For these children, it can be helpful to employ specific strategies such as visual imagery, grouping information into smaller units ("chunking"), organizing information into categories, using verbal rehearsal or practice, developing associations using cues of similar meaning or similar sound, using environmental cues and prompts, relating information to previous experience, linking events temporally, concentrating on key aspects of communications, or using multiple modalities when presenting and processing information.

Social and Emotional Adjustment

Handling the multiple demands of coping with A-T can be very stressful for children and families and can lead to difficulties with social and emotional adjustment. Families often adjust very well, but many have reported that

counseling services have been helpful in working through difficult issues.

Over time, the child with A-T is faced with the loss of certain skills, the loss of independence, and a progressive inability to “keep up” with peers. Handling these losses can be frustrating for the child and impact self-esteem. The child may feel powerless, which can result in reduced motivation and/or depression. Whenever possible, it is beneficial to allow the child the opportunity to make choices and exert control over the environment.

Children may encounter a variety of problems with peer relationships. Children with A-T may be misunderstood, identified as different, subjected to ridicule or become isolated from group activities. Individual friendships may change as children develop and those with A-T become more limited in their ability to participate in certain activities. For example, many parents have reported that children become frustrated and feel “left out” when they can no longer engage in activities such as bicycle-riding with their friends. Symptoms of anxiety, loss of self-esteem and depression are not uncommon, nor are other difficulties in social and emotional functioning. The dynamics of the entire family unit may change. Many issues must be confronted and can be extremely stressful to the child, siblings, other family members and close friends. A variety of adjustment problems may become evident as the family works to accept the diagnosis, to adjust to changes in the child’s abilities, and to cope with the implications of the prognosis.

It is helpful to handle such concerns openly but with developmentally appropriate information. Thus, answers to questions need to be tailored to the child’s level of understanding. A young child will be much more concrete than an older child and require different explanations. Also, children at different developmental levels will have different concerns and questions. It can be helpful to allow the child to take the lead in asking questions in order to avoid over-interpreting the depth of meaning intended by the child. Long-range implications of the diagnosis often are more troubling to the parents than the child. This is true particularly for young children, who are more focused on immediate concerns, such as why they require help with a task or why they are not allowed to participate in certain activities with peers. Our experience with A-T children has shown us that many are gratified with small improvements that are made possible with new techniques or aids. They often focus on *what they can do* rather than *what they cannot do*. Parents may gain comfort from recognizing the positive effect of concentrating on immediate, concrete matters rather than the long-range, “larger” concerns.

The primary difficulty with the young child is adjusting to “being different” from peers, especially when he or she is not able to engage in usual activities or begins to use adaptive equipment such as a wheelchair. Although frequently it is not possible to locate counselors with experience in treating families with A-T, counselors who are experienced in working with children with other handicaps, such as cerebral palsy, are well trained to deal with such peer-related issues. However, it must be remembered that there is one major difference between A-T and cerebral palsy. The child with A-T will suffer

from progressive loss of function; the child with cerebral palsy may or may not achieve new milestones over time, but he or she will not lose skills. At times it becomes necessary to discuss the situation openly with classroom peers to ensure that they are aware of the child's problems and have the opportunity to be supportive.

Older children may well become concerned about issues related to prognosis and the uncertainty that goes with the diagnosis of A-T. Symptoms of depression or anxiety are not unusual. Again, counselors who deal with other life-threatening illnesses, such as cancer, can provide appropriate help in coping with these issues.

Socialization also plays a role in the child's emotional adjustment. Successful peer relationships can offer stimulation, provide a distraction from problems, enhance self-esteem, and improve the overall quality of life for the child. Providing the child with adequate opportunities for social interactions and participation in extracurricular group activities becomes increasingly important as the child grows older and peers engage in activities that are difficult for the A-T child to manage. New interest areas may need to be explored, and activities that can offer success and positive involvement need to be developed. For example, a child who can no longer actively participate in a sport could become a manager or assistant. Activities that offer the opportunity to mentor or work with younger children can provide the experience of being a "helper" rather than the one always being "helped." Such an experience can be extremely gratifying and enhance a child's confidence and overall self-esteem.

The computer can be useful in developing interests and facilitating socialization. Computers also can provide access to games and activities that can be enjoyed with friends. Electronic mail can enhance socialization opportunities and facilitate the development and maintenance of friendships and contacts with family members. Also, the opportunity for children to communicate with other children with A-T can provide a network of support and a sense of relatedness.

In the midst of all of these A-T issues, it is important to remember that children with A-T also will experience "normal" developmental issues, such as separation, independence and sexuality. Children need to re-negotiate their relationships with parents and develop a strong sense of identity. For some, issues of developing or delayed sexuality become paramount. Counseling can be helpful in addressing these issues.

Summary

The primary goal of the psychological evaluation is to help develop an educational and social program that will increase the child's opportunity to experience success. Testing can identify areas of weakness that require additional intervention and areas of strength that can be utilized. Such information can be helpful in developing appropriate academic goals, selecting

extracurricular activities, and fostering positive social interactions. Experiencing success is crucial to a child's self-esteem and overall emotional adjustment. Thus, the psychological evaluation can assist in the development of a comprehensive approach to understanding and working with the child and family.

Fatigue Affects All Aspects Of Functioning

Fatigue

Comes From:

- √ Walking
- √ Sitting
- √ Eating
- √ Handwriting
- √ Speech
- √ Visual scanning
- √ Reading

Impacts Upon:

- √ Completing homework
- √ Participating in school
- √ Length of school day
- √ Involvement in extracurricular activities
- √ Interactions with friends
- √ Family activities
- √ Physical health
- √ Ability to cope with problems
- √ Overall emotional well-being

Reading Accommodations and Compensations

- √ Enlarged print
- √ Additional time allowances
- √ Covering lines above and below
- √ Pointing to words
- √ Computer scanning
- √ Having books read
- √ Tape-recording material
- √ Books-on-tape
- √ Discussions
- √ Videos