Understanding Common Issues That Affect Health Care

Jim, a 21-year-old man with Down syndrome, had been refusing to go to work for a week. He lived in an apartment with three other men with intellectual disabilities. Each man worked in the community and the routine was that a van picked them up each morning and took each of them to their place of employment.

The supporting staff reported that Jim was refusing to walk out to the van, and that he became upset when they encouraged him to go to work. Upon further questioning, we discovered that Jim had also been declining to participate in other activities and that he was sometimes seen limping (although he had not limped into the office).

The physical exam revealed a red, swollen joint on Jim's great toe. Jim stated that he had not reported his pain because in the past, when his hand had been red and swollen, he had been diagnosed with an infection and hospitalized for five days. This time he really wanted to go on the special recreation trip to St. Louis next week and didn't want to take a chance that he would be in the hospital and miss the trip. We diagnosed gout, treated Jim with an anti-inflammatory medication, and he enjoyed the trip to St. Louis.

As discussed in the Introduction, it is important to avoid attributing every change in a person with Down syndrome to "just the Down syndrome." People with Down syndrome (DS) can get a number of health problems that are not unique to people with DS and that often have a specific treatment. However, it is also necessary to understand some of the common characteristics of adolescents and adults with DS to better understand the health problems that may be present. This chapter briefly reviews these characteristics to help readers improve their ability to understand and care for individuals with DS.

The Interaction between Physical Health and Mental Health

There is an interaction between physical and mental health. This statement is neither a new concept nor uniquely true of people with DS. Physical health problems can have a psychological impact on all people. We may respond to an illness with fear, anger, depressed mood, anxiety, and other emotions. In addition, when we don't feel well, we may not function as well physically or mentally. This is also true for people with DS. However, the relationship between physical and mental health can at times be more complicated and more difficult to assess in adults with DS. This is discussed further in Chapter 5.

Communication Issues

One reason it can be more difficult to assess the relationship between physical and mental health in adults with DS is because communication challenges are common. Many people with DS have difficulties with expressive language. They may readily express their feelings nonverbally through a look of sadness, anger or anxiety, or through expressions of joy and exhilaration. However, it may be very difficult for them to verbally communicate the cause or source of their expressed emotions, particularly negative feelings. Caregivers are usually good observers and will often know that something is wrong, but they may not know what or why. Often the only

means that an adult with DS has to communicate the presence of a problem is through a change in mood or behavior. This may be especially true if a major problem or stress is involved, such as the loss of an important supervisor at a job, or the presence of a physical problem, with pain or discomfort.

When looking at behavior as a communication issue, it may be helpful to consider how "loud" the person's nonverbal or behavioral communication needs to be for others to "hear" it. Some professionals in the mental health field have discussed what they call the level of "selective deafness" that occurs in one's social environment (Minuchin and Fishman, 1981). For example, if there is a slight change in someone's mood or behavior, others may ignore it. If the problem persists, then the person's behavior may amplify until others "hear" that something is wrong. Not surprisingly, as someone experiences more pain or discomfort (whether physical, mental/emotional, etc.), his behavior may change (such as by becoming more agitated or restless) and become more obvious to others.

Once a problem is "heard" by significant others, the next step is to find the cause or source of this problem. This usually requires digging and detective work on the part of parents, caregivers, and any professionals who have been engaged to help solve the problem. At the Adult Down Syndrome Center, we look high and low for any clues to help explain the source of a change in behavior. We look for physical problems by conducting a thorough physical exam. We also ask about stress in the person's life. We seek out and talk to as many people, in as many settings, as we can to help explain a problem. This may include teachers in schools, staff in residential settings, supervisors at a worksite, etc. In short, we try to gather information from any source to help us find what the person is trying to communicate through a change in their behavior.

Due to the frequency of communication problems, we view any and all behavioral change in adolescents and adults with DS as a possible communication tool. Particularly if the person is nonverbal or has limited verbal skills, a behavioral change can be his means of communicating discomfort or a feeling of illness. Even some of our patients with excellent communication skills do not communicate their discomfort via spoken words or writing. The physical illness affects them mentally, and they communicate it through a change in behavior.

In cases like these, we like to think that it is not that our patients are not communicating well; it is just that we are not listening correctly. In short, we urge others to look very carefully at any behavior as a form of communication.

Why is this so important? People who may be unable to communicate the presence of a problem, whether or not they have good verbal skills, may be at greater risk for mental health problems. Their inability to communicate a problem may contribute to a condition described by a psychologist as "learned helplessness" (Seligman, 1975). Learned helplessness occurs when people do not get enough experience solving problems they encounter in their daily lives, and, as a result, tend to give up rather than try to meet the challenge. In other words, they have literally "learned to be helpless." This, in turn, often leads to a state of hopelessness and depression.

Ensuring that people with DS have a means to communicate the need for help, whether through verbal or nonverbal communication, may go a long way to help to prevent or reduce learned helplessness. Once people learn that they have a responsive environment and that they can communicate successfully when there are problems, this greatly increases the chance that they will use this strategy when faced with future challenges. Taking these differences into account can improve our ability to diagnose health problems and also develop treatment plans.

Pain

It is important to understand how pain affects people with DS when diagnosing and treating illnesses and injuries. For years we have heard family members say that their son, daughter, or sibling with DS does not feel pain in the same way as they do. They appear to have an increased pain tolerance. Although no studies of people with DS have proven this to be true, one study has demonstrated an increased pain tolerance in mice with trisomy 16 (Martinez-Cue et al., 1999). (Mice with trisomy 16 have many of the physical and medical characteristics of people with DS and are referred to as “a mouse model for Down syndrome.”) When these mice were subjected to painful stimuli, they had less of a response than the mice without the extra chromosome. This study demonstrated in the mice what families had been saying about people with DS for years.

It is also important to consider how a person’s difficulties with communication might contribute to an apparent increased pain tolerance. In other words, sometimes when an individual with DS is not expressing that he is in pain, the problem may be that he is not able to effectively communicate his pain to others, not that he does not perceive the pain.

Another issue that we have seen involves denial. It is usually in the form of refusing to acknowledge pain to avoid evaluation or treatment. A number of our patients, like Jim in the case example at the beginning of the chapter, have not told us of pain because “the last time I told you, you did (this test or that procedure).”

So, what is the best way to avoid missing painful episodes that need treatment? We recommend:

- Watch for subtle signs that something is wrong (facial expressions, holding an extremity differently, a change in appetite, etc.).
- Watch for behavioral changes, including changes in appetite, changes in mood, and changes in activity level.
- Consider the possibility that the person has a reduced ability to perceive pain.
- Consider communication issues, since symptoms may be misinterpreted if the person has difficulties in communicating. (Consider using pictorial representations of pain, a number scale, or something similar if you suspect communication issues.)

Self-Talk and Imaginary Friends

We have repeatedly heard at the Center that our patients with DS talk out loud to themselves, and many also have imaginary friends. Although this behavior concerns some parents and professionals, we urge caution when evaluating it. Too often the behavior is viewed as pathology when it is quite normal in most cases.

Many children in the general population talk to themselves at some time in their childhood and many have imaginary friends. For these children, the self-talk and imaginary friends usually continues up to the age when they are able to internalize their thoughts. Many people with DS continue to talk out loud to themselves and to have imaginary friends throughout their lives. This should not be considered odd or abnormal in teens or adults with DS, given that many of them continue to have intellectual functioning that is similar to a child's, at least in some respects.

Usually when an adult with DS continues self-talk or imaginary friends into adulthood, we view the behaviors as a social skill issue. Talking out loud in public settings can be upsetting to others and draw attention unnecessarily. We recommend that the adult be taught to use self-talk only in a private space, such as the bedroom or bathroom at home. (Be sure to note that stalls in a bathroom at work are *not* a "private space.")

If the adult can learn to use self-talk in a private space, there are many benefits (which we have described in detail in *Mental Wellness in Adults with Down Syndrome*). Briefly, the adult can use self-talk to direct his own actions, particularly with a new task—that is, to talk himself through the steps. Self-talk can also allow someone to review previous events and to plan for future events. It may help the person solve problems or express his feelings and frustrations and calm himself down. Some people use self-talk to help themselves learn new skills or to entertain themselves. For example, many people enact scenes from their workplace or school to practice needed skills or because they enjoy activities from these settings.

In addition, self-talk may actually play an important role in communicating the presence of a problem. The key is for others to be sensitive to this medium of expression. People with DS may be able to say things in or through their self-talk that they are not able to say directly to others, including parents or other caregivers. This might be because the person does not want to offend or disappoint others by directly telling them what is really on his mind, or because he does not feel comfortable confronting others or making direct comments.

Whether or not parents or other caregivers can understand the words expressed in the self-talk, they may still hear a change in tone or see a change in expression that provides a clue as to what the problem is. If the adult is angry or self-critical in his self-talk, this may be a clear message that something is amiss in his life. Angry self-talk may not be a concern if it only occurs occasionally as a means to vent frustration, and most of the self-talk is more positive. On the other hand, if more and more of the self-talk is negative, it is worth investigating to see if something is wrong. The person may be experiencing something in his day-to-day life that is disturbing or upsetting. For

example, there may be a conflict or problem at work or in the person's residence. Or the self-talk could be an indication of some type of physical pain or discomfort.

Again, self-talk is just one means for letting others know there may be a problem. We just need to be alert and open to this means of communication. See Chapter 8 of *Mental Wellness in Adults with Down Syndrome* for a more detailed discussion of self-talk.

The Groove

One of the more interesting and consistent findings at the Center is that people with DS have a need for sameness, repetition, and order in their lives. We call this a tendency for "grooves," because people's behavior tends to follow set patterns or grooves in their thoughts and actions. Like all patterns of human behavior, these grooves can be either productive and adaptive or unproductive and maladaptive. For example, people with DS can get stuck in "ruts" involving unhealthy eating habits and a sedentary lifestyle or they may get into the groove of having healthy eating habits and an active lifestyle.

The good news about people with DS is that because they tend to maintain set patterns or grooves, once a healthy pattern is established, they are often incredibly conscientious and reliable with maintaining these patterns. Time and time again, we have seen adults with DS stay with a pattern of healthy eating and physical activity, lose weight, and develop a sense of pride and self-esteem that comes from a healthy lifestyle. It also helps if they repeatedly hear from others how good they look. People with DS are often especially aware of, and sensitive to, praise and support from others.

One important thing for caregivers to consider is that people with DS may not be able to set up a healthy pattern of behavior on their own. However, once a program is established, they will often keep the schedule going, "come hell or high water." Parents and other caregivers will attest to the tenacity of people with maintaining a healthy (as well as an unhealthy) routine.

In short, we have all repeatedly heard that people with DS are "stubborn and set in their ways." If there is some truth to this, then why not use the tendency as a strength to develop and maintain routines and grooves that actually help people with DS feel better and live longer?

Memory

Researchers have consistently found that people with DS have difficulty remembering and acting on what they hear or what is told to them. On the other hand, we have found that people with DS tend to have exceptional visual memories and are very good visual learners. Consequently, they are far more likely to remember and respond to a request from others if shown rather than told what to do. Examples of the use of visual cues will be given in many of the case vignettes discussed throughout this book.

We have also learned at the Center that visual cues can be combined with a person's need for sameness and grooves to develop very effective problem solving strategies or to promote independence and adaptive behavior. For example, many people with DS are very reliable and conscientious about following a list of healthy foods, which they then check off at every meal. It may be even more reinforcing if they also use a calendar to mark their food choices at the end of the day and record their success with the plan. A calendar can be a very effective incentive in and of itself.

Grief

Grief is another issue to consider when trying to get to the bottom of a change in mental or physical health. We commonly see a delayed response to grief in adolescents and adults with DS. For a period of time (often about six months), many of our patients seem to be little affected by a death in the family or other loss. Only later does the person seem to grieve. It is not exactly clear why this delay occurs, but it may be that some people with DS take longer to really understand the magnitude or the permanence of the loss.

Interestingly, some of our patients have not initially appeared to grieve after a significant loss such as the death of a parent. Later, after another loss—often one that seems much less significant (e.g., the death of the turtle at the group home)—the person will experience and express the grief that he did not with the first and more significant loss.

We often see people with DS show their grief in alternative ways (not that there are only certain ways that grief can be experienced). As noted with other issues above, they may express their grief through changes in behavior. They may also express grief through physical complaints. It is important to understand these possible ways of expressing grief when assessing a person with DS who has experienced a loss. This may be true even (or especially) several months after the loss has occurred.

Developmental Age versus Chronological Age

Due to the intellectual disability associated with DS, a teen or adult's developmental age generally is lower than his chronological age. However, for many of our patients, this difference is not the same for all aspects of their personality. In other words, there can be unevenness. For example, some adults with DS may have the typical adult dreams and desires of getting married and getting an apartment but lack the skills to do this on their own. Others may want to work as cashiers in grocery stores, but be unable to handle money successfully because of difficulties understanding basic math concepts.

Sometimes this disparity between developmental and chronological age results in actions that affect an adult's health and well being—particularly if the person is allowed to make decisions and control aspects of his life when he doesn't have the skills or judgment to do so. Perhaps the best illustration of this problem we have seen involved four women with DS who were roommates in an apartment. Despite a high level of skill, three of the four were gaining significant amounts of weight. All were failing in their jobs (two of the four had excellent jobs in the community). All four were also showing signs of depression such as lethargy, listlessness, and fatigue.

These women were thought to be quite capable (and in most respects they were). They had been assigned intermittent supervision, and, as a result, had no supervision in their apartment after 11 p.m. The dramatic changes in their mood and behavior were a mystery until it was learned that all were staying up until very early in the

morning. Apparently they were watching beloved horror movies and binging on favorite junk food. This, of course, did not allow the women to get adequate sleep, and they were paying a steep price for their emotional and vocational functioning and weight management. All four of these women had excellent skills, but they all had a need for help in one key area—decision-making about going to bed at an appropriate time. Once the right supervision was arranged, this problem was solved.

Another common issue involving developmental delays is that receptive language skills are often greater than expressive language skills. Because of this, many people with DS have a fairly good sense of what is going on around them, and an understanding of physical, emotional, or environmental problems they are experiencing. But their expressive language difficulties may limit their ability to communicate problems to others. This communication may be especially important to caregivers who may help them to solve whatever problem they are facing.

This unevenness of communication skills may affect people with DS in other ways. For example, we have found that people sometimes assume that adults with DS who have more intelligible speech have greater abilities than they actually do. Despite excellent verbal skills, they may not be able to conceptualize and communicate the presence of more complex issues and concerns. For example, at least two of the women in the above example had excellent verbal skills but still were unable or unwilling to communicate that their problems were related to nightly movie and eating binges. In short, when an adult with DS has good intelligibility, parents and other caregivers may assume that the person can communicate problems and issues, when in fact this may be beyond his capability.

On the other hand, we have seen the opposite assumption for people who are nonverbal or limited in their use of verbal speech. These individuals may be assumed to have less skill or understanding than they actually have. As a result, people may ignore or discount the individual's nonverbal communication even when it is quite creative and explicit in describing the presence of a problem. For example, we have had people brought to us with what caregivers and other mental health professionals described as severe behavioral problems and even the diagnosis of "psychosis" because of "self-injurious behavior." In fact, the behavior may have been severe and disturbing to others, but often it was also a very clear way to communicate the presence of a problem (if we were able to listen to this). For example, several people who were hitting their heads were found to have problems such as severe sinus infections and major dental problems. The individuals were clearly showing the locus of the problem, if others had been listening.

Conclusion

On one hand, it is important not to fall into the trap of labeling all symptoms of people with DS as "just the Down syndrome." On the other hand, it is also very impor-

tant to understand that there are some common (albeit not universal) characteristics of people with DS. Understanding these characteristics will improve the ability to understand, diagnose, and treat health issues in people with DS.