The Down Syndrome Association Gauteng

NOT SPEAKING UP FOR THEMSELVES

Acknowledgement:
Down Syndrome International (DSI)

Caregivers are often called upon to speak on behalf of the adult with Down syndrome (DS). Unfortunately, and with the best of intentions, caregivers may develop a habit of speaking too often for the person with Down syndrome, when he/she is able to speak for themselves. This can occur for many reasons related to both the caregiver and listener and the person with DS as speaker.

When parents or other caregivers act as interpreters, over time a type of "short-hand" of understanding develops. Having seen the person with DS respond to different situations over many years, they are often able to anticipate how he/she will respond and what he/she may want and need in a given situation. This is just part of being assumptions for the person that may not be correct.

Additionally, as people age and mature, they want to have more of a say in decisions affecting their lives. Even if the caregiver is correct in assuming what the person wants, he/she may still want to speak for themselves, just as we all do.

Another reason that "interpreters" may take over too much has to do with the difficulty that many people with DS have with the actual act of speaking. It takes a great deal of work and effort for many people with DS to conceptualise and then to successfully communicate their thoughts and opinions, even to familiar others.

As a result, it may be easier for the person with DS to let the caregiver speak for him/her, even when, the person with DS is asked a direct question, and then looks at the caregiver and either says or clearly indicates, that the caregiver should speak for him/her.

To better understand how and why this happens, it may be helpful, again to compare the difficulty people with DS have in communicating with the author's difficulty with communicating in Spanish. What the author found is that similar to people with Down syndrome, he was depending too much on his interpreter (his wife), even though he was often able to speak Spanish, if he took some time and effort.

Again, the reason for this is the same as for people with DS – because the act of conceptualizing and speaking is extremely hard work. In order for the author to converse in Spanish, he has to translate back and forth between English and Spanish, and then communicate clearly enough in Spanish to be understood by others.

This is a daunting task, given the author's limited vocabulary and his tendency to pronounce certain letters or words, or words differently than native language listeners are accustomed to, making comprehension far more difficult.

The person with Down syndrome has a number of similar hurdles to successfully converse with another. He/she has to understand the other's speech and formulate some thoughts or answers. This may take time because of a slower processing speed. After this, he/she must successfully communicate his/her thoughts, despite significant articulation limitations. This is often the part that is fraught with frustration and difficulty, even when others are familiar with his/her speech.

Aside from having moderate to severe articulation limitations, many people with Down syndrome also stutter, or they get stuck repeating the first word or phrase. Many people also tend to speak at a low volume, or they speak too fast or too slow. Perhaps most importantly the delay needed to process and respond to the other's speech may make them self-conscious or concerned that they may be trying the listener's patience.

Interestingly, self-consciousness is also a common problem for people speaking a foreign language. Both the persons with DS and the person speaking a foreign language may be concerned with how they sound, or how long they need to formulate their ideas.

This may make then hurry or force their speech, which may then interfere with the successful articulation of their thoughts. This, in turn, may make them less intelligible to the listener, making them feel even more apprehensive.

Over time, unproductive patterns may develop in which the person with DS, or the person trying to speak a foreign language, becomes more and more reluctant to speak to others. Often, they become increasingly dependent to one or small numbers of interpreters, which then affects their ability to deal independently with the world, and, of course, their sense of pride and self-esteem.

The good news is that people with DS will speak for themselves if given the opportunity and strong encouragement from others.

Returning again to the analogy of the foreign language speaker, recently the author was able to successfully communicate with a Spanish-speaking relative during a weeklong period while his wife (the interpreter) was out of town.

This took a great deal of effort on the part of the author and the aunt. They struggled with many different words and expressions, but the feeling of accomplishment from successful communicating was very exhilarating and greatly reinforced the author's intention to speak for himself in Spanish.

We see a similar process when people with DS are encouraged to talk for themselves, only the stakes are much higher. This is their *only* means to verbalize their thoughts and feelings and not a second language. We have found that both the speaker and the listener must make a concentrated effort for the person with DS to successfully speak for herself.

Similar to non-native language speakers, which is required for the person with DS to speak for him or herself is the following: - (Refer to Page 3) …

1. The listener starts the conversation, he needs to speak clearly and slowly enough for the person with Down syndrome to understand. He also needs to give the person with DS sufficient time to process the ideas communicated and to formulate an answer.

2. When the person with DS speaks, the listener has to be very patient.

3. As discussed previously, it helps to have an understanding of, or first-hand experience with the person's life and activities to increase comprehension of his/her speech. On the other hand, the listener still must be very careful when making assumptions about what the person is trying to communicate.

4. Attempts to finish the person's sentences based on prior experiences may not be constructive. Some people may want the help, but for many others this tends to inhibit their efforts to speak.

5. Just as the listener needs to be patient and receptive, the person with DS must be willing to communicate without automatically looking for help from his or her "interpreters".

This is strongly encouraged and when needed, parents or other caregivers should be gently blocked from jumping in too quickly to speak for the person with DS. The person with DS may also need coaching assistance to speak for him or herself in the presence of their parents or others. Once this process is set in motion, caregivers may simply need periodic reminders to back off and the person with DS may need encouragement to continue to speak for him or herself.

Again, the benefits of this approach are substantial, as there is perhaps nothing as important to self-esteem as to have your thoughts, feelings, and wishes listened to and understood. From experience, most parents or other caregivers will try to change this pattern, given some time and encouragement. Of course, if this is a habitual pattern, it can be hard to break. Additionally, some caregivers strongly resist relinquishing control of this and other aspects of the adult's life. Often other reasons are found of why this continues, even when people are aware of the negative consequences.

For example:

An elderly mother and her 35-year-old son, Daniel, came to the Centre for the first time because the son had pneumonia and some other health concerns. Daniel did not talk and his mother made a point of telling staff that he was non-verbal. After a year and many visits to the Centre, staff members were surprised to hear Daniel talk clearly for himself during a routine medical follow-up visit to the Centre. The mother explained that she had been afraid that Centre staff would "take him away" to live in a group home. She feared that this would leave her alone and without his help. Once she was assured that would not be the case, she let her son speak for himself.

Interestingly, Daniel's mother later became concerned about what would happen to her son if anything happened to her. She had enough trust in the Centre to ask for help in working with the appropriate agencies for residential placement. Fortunately, because of the mother's age, her son was a high priority for residential funding by the state. As per her wishes, a group home was located within a short distance from her home, which allowed him to visit her frequently.

In another family the problem was far more complex:

In this family, all but Carlos, the youngest of five children, a young man with Down syndrome, has moved out and established their own lives and families. His parents brought Carlos to the Centre when they were concerned about symptoms suggesting he was depressed. He refused to go to his workshop in the morning or to social and recreational activities in the evening. He had also developed a habit of whispering in a barely audible voice.

On examination at the Centre, the cause of the problem was found to be a long-standing conflict in his parent's marriage. After the last of his siblings left home, the marital conflict intensified. His father spent more time away from home involved in his work and his mother became over-involved in managing the young man's life and speaking from him. Carlos was very sensitive to the marital conflict and was sacrificing his own voice and life ambitions in order to reduce the conflict and tension in the relationship.

Our strategy was to try and refer his parents to counselling and to help this young man to move out of the middle of the parental conflict. The marital counselling was never started because the conflict was too entrenched. However, we were able to help Carlos move out of the conflict, and this in turn helped the parents to deal with their own issues. As part of the process, Carlos worked for months with Centre staff and several key siblings to articulate his own thoughts and desires for his life. This was a slow process at first because he spoke so quietly and he was initially very hesitant to move out of his parent's home. Fortunately, he was a man of strong character and his siblings and Centre staff appealed to his need for independence and growth.

The turning point came at an arranged meeting with his parents and siblings at the Centre. His parents had difficulty at first letting him talk, but he persisted, even though he still talked very softly but emphatically… that he was going to talk and that they were going to listen. He went on to explain that he wanted to move on with his life and that he wanted to live in a group home. After this, he was able to spend extended periods of time in the homes of several nearby siblings.

Fortunately, his siblings had started the process of applying for a group home some time before and a group home became available fairly quickly.

A short time after Carlos moved into his group home, he began to speak at a more normal volume and to resume all normal activities, such as going to work and to all social and recreational activities. For their part, his parents were able to get a divorce and move on in their lives as well. After five years, Carlos continues to live successfully in his group home and he has visited with both his parents in their separate residences without any additional problems.

When Communication Problems Become Behaviour Problems:

For non-verbal adults with Down syndrome, it may be extremely difficult to communicate more serious problems and issues. This may be especially true if the problems are something new or for which there is no prior history of communication to others. For example, one 29-year-old man with verbal language limitations was brought to the Centre by the family when he began hitting himself very hard in the head. On examination, it was determined that he had a painful sinus infection. He had been healthy for most of his adult years and had had little previous need to communicate physical pain to his family.

Sometimes people in the person's environment may fail to "hear" her communication. This may happen because no one is taking the time and effort to understand her nonverbal communication – for example, when a special caregiver-interpreter is absent or distracted by someone or something else. It may also happen if the person's skills and intelligence are underestimated, especially by inexperienced staff or professionals. These individuals may tend to discount or downplay the person's ability to understand and to communicate her thoughts, feelings and needs to others. Whatever the cause, we have found that when people are frustrated in trying to communicate a problem or need, they usually do one of two things:

1. They withdraw into depression and despair, or

2. They communicate their frustration and need through anger or aggressive behaviour (towards property, self, or others).

In our experience, withdrawal into depression may be potentially more dangerous. This is because it may go undetected for some time and because it may be more difficult for caregivers and sensitive professionals to get to the cause. This is particularly the case if the person seems to have given up and makes no effort to try to communicate the source of the problem.

Attention to psychological, social, biological, and medical issues is all important aspects in the diagnosis and treatment of mood disorders in people with Down syndrome. Therapy needs to be tailored to meet the unique aspects of the person's person ability and environment as well as the symptoms. If depression is suspected, it is imperative that the people diagnosing and treating the condition understand characteristics often seen in adults with Down syndrome, such as self-talk, strong visual memory, and others previously addressed.

Additionally, it is important to recognise that depressive symptoms may also be part of bipolar disorder. In adults with Down syndrome, this typically includes a rapid fluctuation between depressed and manic mood states.

The manic state may be characterised by agitation, over activity, and angry outbursts, which is similar to how this would be expressed in a child, rather than an adult in the general population. Moreover, mania, like depression may be a separate mood disorder, or it may be part of a bipolar pattern.

Understanding how mood disorders in adults with Down syndrome may differ from the text book definitions may significantly improve the diagnosis and treatment of depression, mania, and bipolar disorder.

The other way to communicate a problem, through anger and aggressive behaviour, is potentially more constructive, because the behaviour often gives stronger clues as to the cause of the problem. For example, when the man mentioned previously herein, him himself in the head, he communicated the source of his pain as his head.

The other benefit is that it is often a more successful way to get help. In an insensitive environment depression may be ignored, whereas aggression, particularly when directed at staff often gets quick attention.

On the other hand, there is a danger that uninformed staff or professionals may misdiagnose aggressive behaviour as a “behaviour problem”. While technically correct, this often means that there is a lack of understanding or interest in seeing the person’s behaviour as her primary means for communicating.

Viewed for the ‘behaviour problem” perspective, the treatment is often to chemically manage (sedate) the person rather than to try to uncover the source of the problem. Behavioural management techniques are also commonly used. These may be helpful, but also may be too restricting, especially if there is no attempt to uncover the cause of the person’s angry behaviour.

Unfortunately, these techniques may end up suppressing the person’s means for communicating and will often lead to more anger and despair. On the other hand, attempts to understand the person’s behaviour as communication can be very fruitful.

The principle outline to the treatment approach for mental illness is discussed as to how they are applied to specific mental health problems.

For each problem, assessment (and often reassessment), the use of specific medications, counselling, and other therapies, and an assessment for contributing (or causative) physical problems are described. Wherever possible, we provide examples of ways in which medications benefited patients with Down syndrome we have treated.