

## Promoting Mental Wellness in Teens and Adults with Down Syndrome

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In this plenary I discuss findings from a multi-disciplinary center serving the health and behavioral needs of over 4500 teens & adults with DS. The center was started 17 years ago at the urging of our local parent group, the National Association for Down Syndrome (NADS). NADS is one of the oldest and largest parent groups in the US and as such they had a large number of teens and adults who were underserved prior to the start of the Center. We may be described as “one stop shop” because we do primary care to mental health care. We have found this to be a very advantageous approach because behavioral/ mental health problems are often precipitated by health issues and vice versa.

This plenary will emphasize behavior health issues because that is my focus on the team. What we have learned is that people have a number of behavioral characteristics which are surprisingly consistent for the Center population. Additionally these characteristics may be a strength or a weakness depending on how they are viewed and promoted by the person with DS and by others. These characteristics include expressive language, “grooves” (obsessive compulsive tendencies), visual memory and visual cues.

Expressive language includes a number of key components including, intelligibility of spoken word, expression of thoughts and feelings, receptive skills and self talk

### Intelligibility of spoken word

Despite verbal limitations many people with DS are understood by close family and friends who are familiar with the persons’ articulation style as well as their interests and daily activities. Unfamiliar others may have difficulty understanding them and this may result in dependence on family or friends to act as “interpreters” when not understood by others. This in turn may create problems when important interpreters leave, such when a sibling leaves for college, a sensitive boss leaves a job site, or when parent dies or a long time caregiver leaves. In order to lessen the affect of this type of loss it is best to have multiple ‘interpreters’ in different settings (home, school, and work). It is also best to have total communication so that some communication is possible even when others cannot understand verbal language. Many people with DS are not shy and it may be possible for them to use their artistic and theatrical skills as mediums for expressing themselves when verbal language is not easily understood.

Interpreters can be very beneficial but there is also enormous benefit to the persons’ pride and self esteem to speak for them-selves. This may not be an easy task for two reasons. First, it may be difficult for caregivers to stay silent when the person with DS stutters or struggles with their speech. Caregivers also develop a type of ‘shorthand’ of understanding. They can predict what the person wants or needs based on experience. Despite this their assumptions about what the person with DS is thinking may be wrong and even if it is correct it is still best to let the person speak for themselves.

Secondly, many times people with DS will invite others to speak for them. We believe this is because verbal communication is quite tiring because of articulation limitations and a slower processing speed. One way to look at this is that for many people with DS verbal communication is like being in a foreign country trying to speak a foreign language. It is very difficult to communicate and be understood by others. Even normal conversation may lead to fatigue and exhaustion and people may be easily excluded from conversations. When excluded in social situations it is easy to see how people withdraw into fantasy play, day dreams and self talk.

In social situations and to encourage participation in important meetings (yearly staffings etc) caregiver interpreters may help to facilitate communication by paraphrasing the topic of the conversation in clear

understandable terms for the person with DS. Similarly it may help to give the topic and background of what the person with DS is trying to communicate to others. Despite the importance of this, interpreters need to be careful not to take the persons' voice. They should assist with the translations of actual statements only when needed. Additionally it is important to encourage others to be patient to allow the person with DS time to process the information, to formulate questions and articulate answers when needed.

### Expressing thoughts and feelings

Many people with DS are very open and honest in expressing feelings through non-verbal facial expressions and gestures but many have difficulty articulating thoughts and feelings verbally. As a result caregivers may have difficulty interpreting the cause or source of the persons' nonverbal expressions. This may limit their ability to identify and resolve problems or issues and it may make them at greater risk for mental health problems. The way to minimize this is to encourage people to find creative ways and means to communicate issues and concerns to others. For example many people are quite good with art and theater which can be used as a medium for expressing issues and concerns if others are open to this.

When it is clear that something has affected the person with DS and they cannot communicate why to others, it is important to become like detectives looking for causes and explanations in any and all areas of their lives, including health, environmental, sensory etc. This is why a multidisciplinary clinic is important and why good observations from families, staff, teachers and others are so important to better identify when problems occur and why.

### Receptive Language

Despite whatever expressive limitations people may have, many have excellent receptive skills. They can be very perceptive and will often have an uncanny sensitivity to the feelings and emotions of others (especially loved ones). The down side of this is that they may absorb conflicts and stress experienced by others and they are especially sensitive to anger. Therefore one thing to look for when people show some changes in mood or behavior is whether they are in environments where there is negative behavior or emotions expressed by others.

### Self talk & Imaginary friends

Despite the availability of many articles about self talk we have found that some people are still being treated with psychotropic medications for talking to themselves, even when there are not other mental health symptoms present. Self talk and imaginary friends are developmentally appropriate given peoples' intellectual and not chronological age. Self talk may point to the presence of a mental health problem but the self talk is usually a way to express the presence of a problem and not a problem in and of itself.

In fact self talk serves many adaptive purposes. It is a means to think out loud, review the day event's, it allows directed action (especially when doing a new task) and may allow planning for future actions or events. It may also help one to express feelings and frustrations.

Similarly many people have imaginary friends who they may communicate to as part of their self talk. An "Imaginary friend" may be an imagined person, a favorite movie character or recording artist, but it may also be a real person that people bring to life through their exceptional memory (discussed later). Fantasy play with imaginary others may be entertaining, soothing and relaxing. In some situations it may also complete with what is going on in people lives, particularly if reality is boring, or frustrating, such as in un-stimulating school or work settings.

We view self talk as a social skill issue and not as a mental health issue. As a social skill issue it may draw attention needlessly and it may be viewed as odd by others. It is best conducted in a private space (such as a bedroom) and not appropriate in the community or in work settings. While in public, as a temporary

measure, while people are learning where and when to practice self talk, it may be possible for people to talk into cell phones. (After all everyone else talks out loud on phones, why not people with DS?)

### Self talk and communication

As mentioned previously people may have difficulty understanding or articulating the cause or source of problems. Self talk may offer a window on peoples' thought processes and it may offer valuable clues to help families understand the presence of a problem in peoples' lives. For example many people will enact scenes of disturbing or conflictual events which they experience in the course of their day. A change in quality or quantity of self talk may then be a means to communicate real problems and issues in people's lives.

“Grooves” (obsessive compulsive tendencies and behaviors).

People with Down syndrome have a reputation for being “stubborn.” They may resist change and have rituals and routines which may be maddening to caregivers. We call this behavior “grooves” because people will often follow well worn paths or grooves in their daily lives and activities. Despite the negative reputation there are many benefits to grooves. It gives structure and order to peoples' daily lives. People organize their rooms and personal items. Many are careful with their appearance and grooming. Grooves increase independence at the home and worksite because people complete daily living and worksite tasks reliably when part of their daily routine. Grooves may also offer a way to relax during free time, such as by repeating a favorite activity in a quiet space (copying words, word search puzzles, needlepoint, and even rearranging and ordering personal items). Grooves will also allow people to project a clear and unambiguous statement of choice or preference. Doing things “just so” may be viewed by others as a little quirky, odd or persnickety but it is a statement the persons' own style and personality.

There are certain problems which may develop from grooves which are fairly easy to solve. For example: we have heard that some people working in restaurants do an exceptional job cleaning bathrooms. However they are so conscientious and meticulous that they ignore patrons who are waiting to use the facility. Restaurant owners have found a simple effective solution which is to have the bathroom cleaned before the restaurant opens or after they close.

We have also found that it is helpful to describe grooves as “on board equipment” to emphasize the fact that it grooves are part of the person's physical make up and not necessarily an attitude or behavior issue. For example, many times problems defined in the school and worksite as “behavior problems” may be solved if defined as a compulsive tendency or ‘groove’ and not a behavior problem. Following from this simply allowing people to finish one thing before moving on to something else may eliminate “oppositional behavior.”

### Grooves and stress

Under stress a normally productive ‘groove’ can become an unproductive obsession or compulsion. For example, Marlene, began to rearranging things in her room to be “just so,” which made her miss or be very late for beneficial recreation activities (which she enjoyed). This seems to have developed after she was assigned a stressful new job at her worksite. When a groove become unproductive in this way it may be like any other type of vulnerability which our bodies use to express stress (such as a through a headache, stomach ache, ulcer etc) . Stuck grooves may be reduced if the source of the stress is reduced. It is also important to not try to forcibly stop a stuck groove. This is like trying to stop a river and it will often intensify the behavior. It is often best to work gently with the stuck groove to establish new more productive pattern of behavior. For instance in the above example, as Marlene became more comfortable with her new job, her need to rearrange things became a little less rigid. Over time her parents were able to encourage her to spend less and less time arranging things in her room until she was eventually back on time for her evening activities. Visual cues may also help to reset stuck grooves as discussed below.

### Visual memory

We have found that people with DS have exceptional visual memory. They will often remember anything they see including people, places and events. It is not uncommon for people to remember activities 10, 20 years or longer in the past in great detail. Visual images from movies and television may also be remembered in detail. These visual images may be replayed over and over. The one major problem with this type of memory for people with DS is that they have no sense of time. Events are remembered as if happening “now,” with all the feelings and emotions of the original event. This may be good or bad depending on the original event. Good memories may include past events with family and friends favorite movies etc. Bad memories include past incidents of harm, danger, anxiety or other negative experiences. Because of this type of visual memory people with DS may be more susceptible to relive a past traumatic stress over and over. In many case it may also be possible fight “fire with fire” by using past positive memories (stimulated by pictures or other images) as a means to reduce the impact of negative memories and images.

Visual memory may also help to explain why phobias occur fairly frequently in persons with DS. If they have a bad run in with an animal, a storm etc, (even at a very early age) they may to relive the same fearful experience every time they encounter the animal, storm etc in their daily lives. In these instances it may be possible to desensitize the image through gradual exposure to “virtual image” such as a photograph rather than the real thing.

Visual memory may also help to explain why self talk and fantasy play may occur in the public space if the environment is experienced by the person with DS as boring or stressful. As discussed previously self talk & fantasy play should be conducted to a private space, such as ones bedroom. However, visual memory may allow people to escape to a rich internal world of movies and positive past memories when in a stressful or boring environment. The obvious solution is to make the environment less stressful and more interesting for the person with DS so they don't have a need to escape.

#### Visual Cues

Researcher have consistently reported that people with DS have auditory deficits but what is often not stressed is that people with DS have strong visual assets. What this means is that people may have difficulty remembering what is told to them but they will often remember everything they see (and I mean everything). People with DS are drawn to visual cues and images. They are visual learners. They love movies and pictures, and especially family pictures or movies. Not surprisingly then there is then an enormous benefit to use visual cues with this population such as through visual schedules or checklists, calendars, and visual images for learning tasks etc.

#### Combining different characteristics productively

One very productive way to use visual cues is to help to “reset” a stuck groove. As mentioned previously many people with DS have a tendency for repetitious behavior and routines which we have called “grooves.” These grooves are generally beneficial but they may also become unproductive when people are under stress. Dealing with a stuck groove we may try to identify and reduce stress associated with the stuck groove but if the behavior is a little too stuck or fixed it may also be possible to use visual cues to effectively “reset” the problem groove. Following this once a new behavior is introduced this then will form the basis of a new more productive routine.

For example, visual images can be designed to fit the needs of a family with an oppositional teenager. Susan a very energetic 13 year old had two parents who battled with her to get ready on time for school every morning. What is interesting is that she actually enjoyed school and wanted to go. Unfortunately she and her parents were caught in a teenage battle for independence over the wrong things, her daily living tasks. She should have been completing her own daily living tasks without prompting and this would help to allow her to become more independent not less. In fact she had no difficulty doing these tasks. But she and her parent were trapped in an unproductive pattern. The harder her parents tried to get her to do her morning tasks the angrier and resistant she became, thus short circuiting her own independence, growth and

maturity. Unfortunately too Susan had enough a tendency to get stuck in patterns because of a propensity for grooves and this further intensified the problem.

In order to change this pattern we simply set up a morning checklist which she was to complete and check on her own. When completed she would earn a simple but desirable reward of 10 cents per task. This money was then stored in a glass jar and she could use it to buy her favorite music. Additionally a calendar was used to document the completion of the day's task. This too would be marked by her and she would bring this to her next appointment at the center. Her tasks include the following steps:

- \_\_\_ Eat breakfast
- \_\_\_ Let dog outside
- \_\_\_ Make bed
- \_\_\_ Get dressed (look good!)
- \_\_\_ take Lunch
- \_\_\_ Take backpack with purse, wallet and key
- \_\_\_ Get on bus on time

What is interesting is that she felt that "The list" told her what to do and not her mom and dad. In a very short time the problem was solved.

In this plenary I discussed psychosocial findings from a multicenter. We have found that people with DS attending the Center have a number of behavioral characteristics which are surprisingly consistent including four expressive language issues, intelligibility, expressing thoughts and feelings, receptive skills and self talk. Additional characteristics also include "grooves" (obsessive compulsive tendencies), visual memory and visual cues. These characteristics may be strength or a weakness depending on how they are viewed and promoted by the person with DS and by others.