

## If People with Down Syndrome Ruled the World

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*This paper was originally delivered as a plenary address at the conference in Chicago in July of 2005, co-sponsored by the National Down Syndrome Society and the National Association for Down Syndrome. It was well received by the audience, and we have received many requests for a written form of the presentation. In this paper I will try to maintain the spirit and humor of the original.*

**If** I am going to describe what it would be like if people with Down syndrome ruled the world, it may be helpful to explain how I came by this information. I am the Director of Psychosocial services at the Adult Down Syndrome Center in Park Ridge, Illinois, a unique partnership between the National Association for Down Syndrome (NADS), Advocate Medical Group, and Advocate Lutheran General Hospital. Our multidisciplinary team has served the health and psychosocial needs of over 3000 teens and adults with Down syndrome since we started in January of 1992. Our patients have let us into their world, and what a rich and interesting world it is.



### Development of the Adult Down Syndrome Center

Before beginning, let me provide a little history. NADS, as the oldest Down syndrome parent organization in the country, had many members who had teen and adult age children. These families found there were few health or social services available to them. Sheila Hebein, Executive Director of NADS, was determined to develop resources for these individuals and their families. She recruited the Center's Medical Director, Dr. Brian Chicoine, and myself to help develop and then run the Center, and we continue to have a very close working relationship with NADS.

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Why us? Brian had some experience in his medical practice with persons with disabilities, but he also did not have a great deal of contact with people with Down syndrome. One could say I also had led a sheltered life.

Sheila's son, Chris, was probably the first person with Down syndrome I had ever met. Still, Sheila seemed to know this would work. The good thing about our lack of experience was that we were able to listen to the families and the people with Down syndrome without any preconceived ideas, assumptions, or biases.

We learned quickly that the families are the experts with regard to their sons and daughters-because they had to be. We view the information we have gathered from families as a repository of their wisdom. We hope this paper will be helpful to families who are searching for ways to improve the lives of their sons and daughters.

What would happen if people with DS ruled the world?

If people with Down syndrome ruled the world:

**Affection, hugging and caring for others would make a big comeback.**

Despite the fact that my family was not terribly affectionate, I have had a crash course in hugging at the Center. I am confident that if people with Down syndrome ran the world, everyone would become very accustomed to the joys of hugging. Fortunately for me, I had a head start. My wife is a native of Argentina, and I got some intense exposure to hugging when I landed in her country and found there were 6000 members of her family waiting to be hugged as we got off the plane.

**All people would be encouraged to develop and use their gifts for helping others.**

In our world, too often people with Down syndrome are "DONE FOR" by others, when in fact they are great givers. If they ran the world, their ability to minister to others would not be wasted.

**People would be refreshingly honest and genuine.**

People with Down syndrome are nothing if not straightforward and unpretentious. As the expression goes, "what you see is what you get." When you say to people with Down syndrome, "You did a good job," most will answer simply and matter-of-factly, "Yes, I did."

**We believe, too, that a stuffy high society would probably not do well in the world of Down syndrome.**

However, we believe that BIG dress up dances would flourish. People with Down syndrome love dressing up and dancing at big shindigs. They have a ball, and ...can they dance! (and by the way, who needs a date... "Just dance").

Most people we have met with Down syndrome also love weddings. This should not be a big surprise. They love getting dressed up, being with family and friends, having good food, and, of course, dancing until the wee hours of the morning. (Many people love it so much, they will chase the band down at the end of the night, begging them to continue.) Perhaps, too, part of the reason they love weddings so much is not just because of the food and dancing, but because in many cases the rules against hugging are temporarily suspended. This may give people a little piece of what I experienced in Argentina. Whoa! Can you imagine what the world would be like with so much affection unleashed?

**People engaged in self talk would be considered thoughtful and creative. Self talk rooms would be reserved in offices and libraries to encourage this practice.**

People with Down syndrome have a reputation for "talking to themselves." When conducted in a private space, self talk serves many adaptive purposes.

It is a wonderful means to ponder ideas and to think out loud. It allows people to review events that occurred in the course of their day. It allows people to solve problems by talking themselves through tasks. It allows them to plan for future situations. It is also helpful in allowing people to express feelings and frustrations, particularly if they have difficulty expressing their feelings to others. There is even evidence that athletes who do not have Down syndrome use self talk to motivate themselves. Certainly people without Down syndrome talk to their computer (particularly when it crashes), and likewise many people talk out loud when driving in Chicago. (Of course they may also make odd gestures as well; not recommended if long life is one of your ambitions.)

### **Order and Structure would rule**

We have heard that many people with Down syndrome are stubborn and compulsive. Now, I know what many of you are thinking..."Did you really have to bring that up?" I'm sorry, but—we do. What we hear is that quite a few people have nonsensical rituals and routines. They can get stuck on behaviors that can drive family members a little crazy.

Despite the irritations, there are also many benefits to these "obsessive compulsive tendencies." We actually have termed these tendencies "Grooves" because people tend to follow fairly set patterns, or "grooves," in their daily activities.

What are the benefits of Grooves? Many people with Down syndrome are very careful with their appearance and grooming, which is especially important since they often stand out because of their physical features. Grooves also increase independence because most people are able to complete home and work tasks reliably when these tasks are part of their daily routine. (And while they are not fast ... they are very precise.) For many with Down syndrome, grooves serve as a way to relax. Some people repeat a favorite activity in a quiet space, such as writing, drawing, puzzles, needlepoint, etc. Grooves also serve as a clear and unambiguous statement of choice (very important for people with language limitations). This may even be a way for teens with Down syndrome to define their own independence without getting into the same rancorous conflicts with parents as many other teens.

So given what we know about people with Down syndrome and grooves, how would they use this to run the world? Here is how:

- Schedules and calendars would be followed.
- Trains & planes would run on time.
- Lunch would be at 12:00. Dinner at 6:00.
- Work time would be work time.
- Vacation would be vacation.

At the Center, our receptionist, Shirley, will often have people at her desk pointing to the clock or their watches. Obviously, she hears about it when we don't take people back at their appointment time, but she also found that some people refuse to go back early: "Nope I am not going at 9:45, my appointment is at 10:00," nor does going over into the lunch period work. I am sure all of you have similar stories.

But there is much, much more:

- People would be expected to keep their promises.
- Last minute changes would be strongly discouraged (if not considered rude and offensive).
- Places would be neat, clean, and organized (not just bedrooms, but cities, countries, the whole world).
- Lost and founds would go out of business (even chaotic appearing rooms have their own sense of order).
- The "grunge look" would be out, way out.

- "Prep" (but not pretentious) would be very big.

In the world of Down Syndrome, there would be a great deal more tolerance for:

- Repeating the same phrase or question
- Use of the terms "fun" and "cleaning" in the same sentence
- Closing doors or cabinets that are left ajar (even in someone else's house)
- Arranging things until they are "Just so."

Despite their compulsions and grooves, people with Down syndrome rarely have the really 'bad habits' that so many of us have. In fact, out of approximately 3000 people we have seen at the clinic, we have not seen any drug addicts or gamblers and just two alcoholics and a very small number of smokers. However, we think that pop may be a common addiction in the world of Down syndrome, and of course some people are incurable savers and hoarders of just about everything, but especially paper products and writing utensils. Because of this, I could see maybe a Betty Ford Center for pop addicts and extreme paper hoarding.

**The words "hurry" and "fast" would be not be uttered in polite society. "Plenty of time" would take their place.**

At the Center, we frequently hear about pace, or how fast or slow people move. Quite often these issues are discussed in disparaging terms by harried and frustrated family members. In this world, people with Down syndrome have a reputation for having two speeds, slow and slower.

Therefore, in the world of Down Syndrome:

- Our current mode of dealing with time, also known as the "Rat race" (or rushing around like our hair is on fire), would not survive.
- Here and now would command a great deal more respect than it currently does.
- Stopping to smell the roses would not be just a cliché.
- Work would be revered, no matter what kind, from doing dishes to rocket science.

We have consistently seen respect and devotion to work by people with Down syndrome. This is such a strong characteristic for many that they don't want to stay home from work even if feeling ill. Perhaps more importantly, they value any kind of work.

Therefore, if people with Down syndrome ran the world:

- Speed would be far less important than doing the job right.
- Work would be everyone's right, not a privilege.

However, we think there would probably be no work conducted during the time that "Wheel of Fortune" is on TV.

All instruction would include pictures to aid visual learners.

Many studies have shown that individuals with Down syndrome have deficits in auditory memory. If they cannot remember verbal instruction, they may be considered oppositional or less competent in school, home, or work environments. Despite this, they have exceptional visual memory—they are visual learners. If they see something once, they can usually repeat it. They also have an exceptional memory for facts and figures of interest (favorite celebrities, movies, music, sports teams, etc).

If people with Down syndrome ran the world:

- School and work sites would have picture, written, and verbal instructions to accommodate different learning styles.
- Counselors would be able to use visual mediums to help solve problems.

### **What About News?**

If people with Down syndrome ran the world:

- Weather would be the only essential news item
- News would be more local ("A new McDonalds just opened up," or "A dance tonight," etc.). After all, what is more important than that?

### **What About Bad News?**

If people with Down syndrome ran the world, would there be wars or murders? We don't think so! There may be too many McDonalds but definitely not the wars or murders we have in our "civilized societies."

### **What About "Behaviors"...**

...and terms such as (the ever popular) "Incident reports," "Outbursts," "Unprovoked outbursts" (one of our all time favorites), and of course "Non compliance"?

We believe that in the world of Down Syndrome, anyone writing "incident reports" would have to go through sensitivity training, which would consist of someone following them around writing down everything they did wrong. Brian Chicoine and I both figure that we would have been on major psychotropic medications long ago if we had people writing up incident reports on us.

We have found that most people with Down syndrome are very sensitive to expressions of anger by others. I imagine they would do all they could to help reduce and solve conflicts between people.

Therefore if people with DS ran the world:

- Anger would only be allowed in special sound proof rooms.
- Trained negotiators would be available to everyone to help deal with any conflicts.
- The word "non compliant" would not be used (except as a very rude comment). It would be replaced by "assertive," as in "he or she is being assertive today."

### **What About Self Expression?**

- Art and music appreciation would be BIG.
- People would have time to work on paintings and other art projects.
- Acting and theatrical arts would be encouraged for all.

### **Dancing**

- You probably would not hear a great deal about exercise, but you may hear a phrase like, "Dancing tonight ... absolutely."
- The President's commission on physical fitness would probably recommend dancing at least 3 times per week.
- People would be encouraged to get married several times to have more weddings for more music and dancing.
- Richard Simmons and John Travolta would be national heroes.

### **Music**

- Elvis, The Beatles, and the Beach Boys would still be number 1 on the hit parade (Music of the 60's, 70's, and 80's would be BIG)
- Musicals would be very, very, very, big (such as "Grease," and "The Sound of Music")
- John Travolta would be the biggest star.

## **Television**

- Classic TV hits would be very BIG and take up at least half the TV schedules.
- "I Love Lucy," "Happy Days," "The Three Stooges," etc. would be very BIG.
- Wrestling would be very Big.
- "Life Goes On" would also be very Big and replayed regularly.

## **Movies**

- There would be fewer movies, but they would be replayed over and over.
- Movie theaters would allow people to talk out loud to tell what happens next.

## **No Secret Agents**

- People would not hurt the feelings of others and they would also not lie or keep secrets.
- Therefore there probably would be no secret service agents, spies, or terrorists.

The purpose of this article is to give back some of what we have learned to the families and people with Down syndrome who have come to the Adult Down Syndrome Center and who have been so giving and open with us. If people understand more of the special talents people with Down syndrome have, they may be more able to help them use and develop these talents to improve their lives. We also wanted to reassure families of younger children with Down syndrome who are concerned about their child's future that there is much to be optimistic about.