

**Adult Down Syndrome Center of
Lutheran General Hospital**
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Newsletter

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Recent Publications

Self Talk

The article "*Self Talk*" in *Adults with Down Syndrome* (McGuire, Chicoine and Greenbaum) was published in the July/August 1997 issue of Disability Solutions. We have found that 81% of our patients talk to themselves. Sometimes parents or caregivers are concerned that this behavior in persons with Down Syndrome is "not normal". One of our major motivations for writing the article was to prevent misinterpretation of self talk as a sign of psychosis. We believe that too often these conversations with self or imaginary companions have been equated with "hearing of voices" and treated with anti-psychotic medications. Since it is difficult to evaluate the thought processes of adults with cognitive impairment and limited verbal skills, we urge a cautious approach in interpreting and treating what seems to be a common and, at times, very helpful coping behavior for adults with Down Syndrome. For some parents and caregivers, the fact that "almost everyone with Down Syndrome does it" is reassuring.

Self-talk plays an essential role in the cognitive development of all children. It helps children coordinate their actions

and thoughts and seems to be an important tool for learning new skills and higher level thinking. In children without identified learning problems, the use of self-talk is progressively internalized with age. As self-talk is transformed into higher level thinking, it becomes abbreviated and the child begins to think rather than say the directions for his or her behavior. The intellectual and speech difficulties of adults with Down Syndrome may contribute to the high prevalence of audible self-talk reported to us at the Center. The usual transformation to internalized thinking from audible self-talk does not occur or does not occur as thoroughly.

In adults with Down Syndrome, self-talk may be used when they are alone and confronting new tasks, to vent feelings, or be a source of entertainment, especially when alone.

Our best advice about when to worry about self-talk is to listen carefully for changes in the frequency and context of the self-talk. When self-talk becomes dominated by remarks of self-disparagement and self-talk devaluation, intervention may be warranted. A marked increase in the frequency and a change in the tone of the self-talk may signal a developing problem. We have observed that self-talk is an important coping tool and only rarely should it be considered a symptom of severe mental illness or psychosis.

The full article is available at the Center.

Predictors of Obesity

Predictors of BMI Among Adults with Down Syndrome: The Social Context of Health Promotion (Fujiura, Fitzsimons, Marks and Chicoine) was recently published in Research in Developmental Disabilities. Diet, exercise, disability status and degree of social integration were evaluated with regard to body mass index (a measure of weight in comparison to height). A person being close to his/her ideal body weight was not found to be correlated with exercise or diet but instead was correlated with contact with friends and social opportunities. While we continue to encourage exercise and good nutritional habits, this study also leads us to encourage helping adults with Down Syndrome to participate in social opportunities and to have regular contact with friends.

In the general population, studies have found that despite whatever reason a person starts an exercise program, he is more likely to stay with it if it is fun. There is no reason to suspect that this should be any different in persons with Down Syndrome. Therefore, opportunities to be with friends and to have social gatherings probably help keep people with Down Syndrome closer to their ideal body weight at least partly because it gets and keeps them going. Perhaps the health benefits of riding an exercise bicycle all by oneself in the basement are no more enticing to a person with Down Syndrome than they

are to a person without Down Syndrome. Keeping activities fun and social keeps us all coming back.

Many of our patients love to dance. Other ideas include walking to museums, in malls, or in the forest preserves. If an activity seems too passive, try parking a little further away from the front door to encourage a little more walking or walk instead of driving. Turn off that TV and keep moving!!!!

This article is available at the Center.

Conferences

Dennis McGuire, Ph.D. and Brian Chicoine, MD presented in November at the National Down Syndrome Society's International Research Conference on Cognition and Behavior held on Amelia Island in Florida. They spoke on *Promoting Behavioral Competence in Adults with Down Syndrome*. To optimize behavioral competence, in their presentation they encouraged 1) assisting adults with Down Syndrome to optimize communication skills (not just verbal skills), 2) acknowledging self-talk as a common and potentially helpful coping strategy, 3) assisting people with Down Syndrome to develop as much control of their own life as possible (i.e. allow them to make their own choices as much as possible) and 4) optimize physical health.

Resource Center

The waiting room at the Adult Down Syndrome Center is in the process of

becoming multi-functional. It will continue to serve as a waiting room but is also becoming the Resource Center. Ann Jonaitis has catalogued the resources that are presently in the Center. The next step is to purchase an updated computer, books, videos and other educational materials. In addition, we are anticipating adding new chapters to our adapted Health Care Information book (a patient education book designed for our patients that is given to our patients at their annual complete physical.). A scanner and a digital camera are additional planned purchases to assist in developing improved and personalized patient education material. More information will be in future newsletters. As the resource center is developed, it will be a place where people can come to get further information; a place where people are welcomed even if they are not being seen as a patient that day.

Clinic Statistics

More than 600 different patients have been served at the Center since it opened not quite six years ago. We have gathered data, so far, on the first 602 people seen. Here are some interesting statistics:

Approximately 41% live at home with parents or siblings while the rest live in a residential facility, a foster home or a nursing home (for those who have developed other health problems).

91% live in Illinois. We have also seen people from Michigan, Maryland, Kansas, Indiana, Florida, Wisconsin, Iowa, Missouri, Ohio and Alabama.

300 have been women and 302 have been men.

88% of the people we have seen have problems with dry skin.

37% of the people we have seen have hypothyroidism (Under-active thyroid) and are on thyroid replacement medication.

Only 2 patients (a mere 0.3%) have hypertension (high blood pressure). It is interesting to compare that to the estimated 20 to 25% of the general population that have hypertension.

Only 10 of our patients are reported to have ever smoked cigarettes.

Holiday Greetings

The staff of the Adult Down Syndrome Center hopes you have a joyful and blessed holiday season and new year.

Mission Statement

The staff of the Center is presently developing a mission statement for the Center. Janice Smith, RN who is working on her Ph.D. in nursing has been working at the Center for the last several months and is assisting in this project. The Center's mission statement will grow from the mission statement of Advocate Health Care, the parent company of Lutheran General Hospital. An abbreviated version of the mission statement of Advocate Health Care follows:

The Mission of Advocate Health Care is to serve the health needs of individuals, families and communities through holistic philosophy rooted in our fundamental understanding of human beings as created in the image of God. The statement of values of Advocate Health Care serves as an internal compass to guide our relationships and actions: Equality, Compassion, Excellence, Partnership and Stewardship. The Philosophy of Advocate Health Care is grounded in the principles of human ecology, faith and community-based health care. These principles arise from an understanding of human beings as whole persons in light of their relationship to God, themselves, their families and the society in which we live.

Our Mission

The Adult Down Syndrome Center of Lutheran General Hospital grew from the

mission of this faith-based institution. The original goals included: providing for the health and psychosocial needs of

adults with Down Syndrome, providing community education programs and to teach professionals (both those in practice and those in training) about caring for adults with Down Syndrome. The clinic was developed as a result of a direct request of the National Association for Down Syndrome (NADS), a parent group serving the Chicago metropolitan area.

The clinic opened in January 1992 and at that time patients were seen two half days per month. Patients are now seen five days per week. It is the only center in the United States specifically serving the needs of adults with Down Syndrome. In addition to the medical and psychosocial services, the Center, along with NADS, also provides advocacy services, exercise programs, group discussions, music therapy and a mentoring program (see last months newsletter). We are also developing a resource center (as noted above).

It is through the generosity of Lutheran General Hospital of Advocate Health Care, Advocate Medical Group and other benefactors that the Center is able to provide not only the basic health and psychosocial services but these additional programs as well. We appreciate all who have contributed financially to the Center. If you can assist us in our mission, your generosity would be most appreciated.

