

Newsletter

Spring 1998

Editor: Brian Chicoine, MD

Welcome to our new employee

We have the privilege of welcoming Dennis McGuire, PhD. to the Advocate Medical Group. Dennis is not new to the clinic team; he has been here since the inception of the clinic in 1992 (and had been working with the National Association for Down Syndrome even before the clinic was developed). However, previously he was an employee of the Institute on Disability and Human Development at the University of Illinois, Chicago and his services were provided to the Center through federal and state grants. However, those funds have diminished and Dr. McGuire's availability to the Center was also decreasing. We now have the benefit of having Dr. McGuire at the Center full-time and he now has time to use his extensive counseling training to better serve the needs of our patients.

Clinic publications

"Longevity of a Woman with Down Syndrome: "A Case Study" was published in the December 1997 issue of Mental Retardation by Brian Chicoine and Dennis McGuire (vol. 35, No.5, 477-479).

Abstract: A case of a woman who is among the longest surviving people with Down Syndrome was described. The life expectancy of persons with Down syndrome has increased more than six-fold to 56 years since the turn of the century. The literature regarding life expectancy for persons with Down Syndrome was reviewed, and the implications regarding Down Syndrome and Alzheimer's disease were discussed.

"Ann" (as we called her in the article) lived to the age of 83. It is interesting to note that she showed no evidence of mental decline. Previous studies have found that all persons with Down Syndrome over the age of 35 have changes in their brains consistent with

the changes seen in Alzheimer's disease. However, our findings and the findings

of others suggest that not all persons with Down syndrome develop clinical Alzheimer's disease. Although we don't think the final answer is in yet with regard to the incidence of Alzheimer's disease in persons with Down syndrome, we suspect that it is no more common than in the general population. However, when it does occur in a person with Down syndrome, it tends to occur earlier (on average in the 50's rather than in the 70's or 80's), the decline is more rapid and seizures tend to be more common than in people in the general population who develop Alzheimer's disease. Our approach continues to be to aggressively look for a any potentially reversible cause when we see a person with Down syndrome who has a decline in level of function. Of those persons over 40 (the group most at risk for Alzheimer's disease) we were able to find a potentially reversible cause approximately 75% of the time when they presented with a decline in level of function.

The full article is available at the Center.

Thank you

Thank you to all who responded generously to our appeal in the December newsletter. We appreciate the kindness of families, friends, and Lutheran General employees who were able to help us with our mission. With the assistance of your generosity we strive to provide high quality clinical services and to learn more about caring for adults with Down syndrome and

disseminating that information. Thank you to all.

Lost and Found

We recently found a pair of eye glasses left by someone at the Center. Our efforts to find the owner have not been successful. Anyone missing a pair of eyeglasses?

Importance of History

Did you ever wonder why we have the forms for you to fill out and then still ask many questions when you arrive? History!!! Obtaining a good medical and psychosocial history is essential to providing good care to our patients. Medical students are taught that 90% of diagnosing a problem comes from a good history. Most of the rest come from the physical exam. The tests help make the diagnosis or confirm the diagnosis. Thank you for filling out the forms; for being part of the team to provide good health care for adults with Down syndrome.

Health Maintenance Checklist

What do we recommend for regular screening for our patients?

- >An annual physical exam
- >Annual thyroid function testing (blood test)
- >Hearing screening ever 1 to 2 years.
- >An eye exam by a eye doctor (optometrist or ophthalmologist) every 1 to 2 years.

Lateral neck x-ray(3 views) once in adulthood (repeat for any symptoms of Atlanta-axial instability)

- >Pap smear: starting at the age 21 or when become sexually active (if become

sexually active prior to age 21). Every year in sexually active women or those at three years for cervical cancer or every three years for those not sexually active and at low risk for cancer of the cervix >Cholesterol screening every 5 years, if cholesterol less than 200. (If greater than 200, further testing follows guidelines for treating elevated cholesterol).

Mammogram (these recommendations vary depending on where you obtain your recommendation) once between 35 and 40, every other year between 40 and 50 and annually after 50.

Colorectal cancer screening. Testing for occult blood annually after 50. It is also recommended to screen via flexible sigmoidoscopy every 4 years aft 50.

The recommendation for cholesterol, mammograms and colorectal screening come from data on the general population with a life expectancy of approximately 76 years of age. It is not exactly clear how they fit for persons with Down syndrome with an average life expectancy of 56 years. There are not studies that clearly show that for persons with Down syndrome there is benefit (improved longevity, finding disease early enough in its course to affect outcome) to warrant the discomfort and potential complications of the tests.

We generally recommend the same testing as for the general population until further study will guide us one way or the other. However, as you might guess,

compliance with some tests is more difficult for persons with Down syndrome, just as in the general population. Therefore, if the person requires sedation to perform the test, the risk of sedation may outweigh the benefit

to the test and therefore, it may not be recommended. Please consult us or another physician if you have any questions.

Weight management

Weight management is a frequent concern for persons with Down syndrome (and persons in the general population). Joan Medlen, R.D., editor of Disability Solutions, wrote a very nice article in the January/February 1998 edition. In her article, Weight

Management in Down Syndrome: The School Age and Adolescent Years", Ms.. Medlen describes some key elements:

- An attitude of complete acceptance. Persons with Down Syndrome need to know that relationships are not contingent on how much they weigh or what they eat.
- Model the expected behavior.
- Allow the person with Down Syndrome to make choices.
- Create opportunities for successful independence.

She recommends creating a list of a person's favorite foods and rearranging the list by food groups. This assists in structuring menu planning. Set up a snack choice system. Encourage appropriate serving sizes and food budgeting. Involve the person in menu planning.

Limiting sedentary activity is also important. Provide a framework that helps the person use his time wisely, discourages long periods of sedentary activity and encourages families (and friends) to spend time together.

She reminds us that healthy lifestyles don't just happen, they are taught. Joan Medlen has written a very good article to assist persons with Down syndrome and others as well with weight

management. A copy of Disability Solutions is available for review at the Adult Down Syndrome Center. Each edition I have read has been very interesting and full of information both for professionals and for patients, families and care-providers. You can contact Disability Solutions for a free subscription at 9220 S. W. Barbur Blvd. #119-179, Portland, OR 97219-5428.

Independence and self-determination are important issues for persons with Down syndrome (just as they are for everyone else). However, interdependence is also a very important concept. Ms. Medlen's article does a fine job on describing ways to encourage while at the same time providing opportunity for personal choice. In addition, the idea about modeling the expected behavior is important. If we bring an attitude of supporting each other (both people with Down syndrome and those without) rather than the person with Down syndrome always being the one being taught, we can all learn and benefit from the experience of sharing the common goal of improved health.

On the last pages we have provided a copy of the Activity Pyramid which is a way to begin to think about increasing activity in our daily lives and the Food Pyramid to help guide food selections.

Mission Statement

In a recent newsletter I discussed the effort we were undertaking to develop a mission statement for the Center. Thanks to all the staff at the Center and primarily to the effort of Jan Smith, RN, we have developed a mission statement,

philosophy and goals. Jan came to us about a year ago as part of her studies as she pursues her PhD in nursing. While she is not active at the Center now because she is working on her thesis, she continues to volunteer for us.

Mission statement

To enhance the well being of adults with Down syndrome by providing comprehensive, holistic, community-based health care services by a multi-disciplinary team.

Philosophy

We believe that:

- all individuals are worthy and deserving of comprehensive and compassionate health care.
- health is a state of physical, mental, and spiritual well-being.
- persons with Down syndrome should be provided the opportunity to be active participants in their health care.
- health promotion behaviors have a positive impact on the quality of a person's life.
- research, education, and the dissemination of information related to Down syndrome foster an understanding and acceptance of individuals with Down syndrome.

Goals/Values

- provide comprehensive and compassionate health care services reflective of standards of professional excellence and current research findings.
- Enhance the health of adults with Down syndrome.
- Encourage individuals with Down

syndrome and their families to develop health promoting behaviors.
-Foster an understanding and acceptance of individuals with Down syndrome.

Spiritual needs

by Janice Smith, RN, MS

Where's the Place for Me?

When my throat is tight
And there's no guiding light,
I look unto the west,
And challenge up the best,
When time turns against me,
And there's no light to see,
I wonder of a place that's free,
That's just the place for me. (1)

The above poem was written by a child, Ben, who was a resident of a hospital for adolescents and children with disabilities that Dr. Webb-Mitchell cared for in his pastoral ministry. In those precious words, Ben opened a window for us to view the spiritual struggle an individual with a disability faces as he tries to sort through his relationship with himself, his community and his God. Dr. Webb-Mitchell confirmed that addressing the spiritual needs of people is as great of importance to their health as meeting their physical, emotional and psycho-social needs.

Supporting the faith development of a child with disabilities within the context of formalized religion has been a challenge for parents. Historically, individuals with disabilities were faced with barriers that left them detached from formalized churches (2). The social myth that people with mental disabilities are not capable of participating as equals in the communion of faith needs to be

dispelled. Father Mike Solazzo, chaplain at Misericordia, Chicago, IL, stated that "Faith is grounded in relationships-our relationship to God-to-others. Therefore, it is something that is intuitive rather than cognitive. The person with mental impairments may have little capacity for cognitive reasoning, but great capacity for intuitive understanding. Faith is a matter of the heart; we are called to live from the heart and help others do the same. In regards to the people with disabilities, the heart is not disabled, feelings are not disabled, spirit is not disabled". Webb-Mitchell challenged churches to "imagine the person" rather than their disability(2).

In my time spent with the families and patients at the Adult Down Syndrome Center, as part of my doctoral studies in nursing at Rush University, I have developed an appreciation for the challenges encountered by families in providing for the holistic needs of their loved one with Down syndrome. At times, families are so busy with the work of caring for the immediate needs of physical care, residency and employment, that the person's spiritual needs can be overlooked or inadvertently placed as a lower priority. One parent described that a simple act such as attendance at worship services can require an inordinate amount of time and energy. She stated "I'd have to get him up at 5:30 AM just to get him ready for 9:30 AM services". Fear of embarrassing behaviors during services and perceived unreceptive attitude by pastors and members of the congregation were also identified as barriers to participation in church services (2). Programs for the religious education of children and adults with special needs, such as SPRED, in the Chicago Catholic

Archdiocese, REACH in the Joilet Catholic Archdiocese, and the SEEKERS, a Sunday Bible Study at College Church in Wheaton, IL For all children and adults, including people with disabilities, serve as models for the positive steps churches can take in providing for the spiritual well being of all members of their congregation.

Another important spiritual need for the individual with Down syndrome is to feels that they are making a contribution to society. As I spent time with patients at their work site, I witnessed the joy in individuals when they were doing work they found meaningful, and the despondency when they were asked to perform tasks they found boring and hollow.

Spiritual well being also depends on the individual with Down syndrome being welcomed as a integrated part of the community. I observed how easily patients can feel isolated and disconnected when they have little involvement with the world outside their home or work shop. Inactivity also contributes to physical health risks such as obesity. Continued participation in activities such as art, music, park district programs, Special Olympics and church groups is vital. Not only does it provide for socialization and enjoyment, it contributes to one's self esteem and sense of accomplishment. I will never forget when my friend's adult daughter with mental retardation died this past December and her dad placed her Special Olympics medal on her casket. He said that through the years she never lost the pride she had in that achievement.

A final conclusion I made was how much each of the patients and their families contributed to my own spiritual

well being. They opened their lives and their hearts to me and I am truly grateful. I look forward to continuing to explore the spiritual needs of adults with mental retardation as I conduct my dissertation research. Spirituality is an important dimension of a person's life. It is no less important for an individual with mental retardation.

Sources:

(1) Webb-Mitchell, B. (1993). God plays the piano, too: The spiritual lives of disabled children. New York: Crossroads.

(2) Webb Mitchell, B. (1996). Dancing with disabilities: Opening the church to all God's Children. Cleveland: United Church Press