

Development of a Clinic for Adults With Down Syndrome

Brian Chicoine, Dennis McGuire, Sheila Hebein, and Donna Gilly

Abstract: In an effort to better support the adults with Down syndrome that it serves, parents from the National Association for Down Syndrome, a parent organization, worked with staff members from The Family Study and Service program of the University Affiliated Program for Developmental Disabilities of the University of Illinois and the Department of Family Practice of Lutheran General Hospital to develop a clinic for adults with Down syndrome. The clinic was developed to provide comprehensive health care with an emphasis on preventative services. The multidisciplinary approach of the clinic has proved to be effective in the management of a variety of patient care needs. The most common health problems found were discussed.

In January of 1992, the Lutheran General Adult Down Syndrome Clinic opened and served its first patient. The opening came after several years of effort to improve the delivery of health care and supportive psychological and social (psychosocial) services for adults with Down syndrome. The development of the clinic came primarily at the urging of parents representing the National Association for Down syndrome (NADS). In the present article we have discussed the development and operation of the clinic and described the services provided. This information can serve as a model for others who are seeking to provide care for adults with Down syndrome. We hope that it will also encourage those who want to expand the services they provide to this patient population.

The NADS is a parent-driven advocacy organization that has been providing support services to individuals with Down syndrome and their families in the Chicago metropolitan area for over 30 years. Although the parents who belong to this association have been able to effectively help parents of children with Down syndrome, they have been frustrated by the limited availability of resources for adults with this syndrome.

Until the 1960s, adults with Down syndrome primarily lived in large institutions (Cooley & Graham, 1991; Merker & Wernsing, 1984). Consequently, health care and supportive services were viewed as a matter for institutions. However, during the past 20 to 30 years, more children with Down Syndrome have been raised by their parents, and now the majority of adults with Down syndrome live in the community, either with their families or in residential programs (Thomas, 1986). Many parents of sons and daughters with Down syndrome living in the community called on NADS to help them locate comprehensive health care and supportive services for their children. The organization

responded by identifying individual resources within the medical community to whom they could refer adults with Down syndrome.

In addition, NADS surveyed its members regarding the needs of adolescents and adults with Down syndrome and their families regarding psychosocial issues (National Association, 1989) and health care (National Association, 1990). The survey was included in an issue of the Association's newsletter, which is distributed to members and sent to 1,200 addresses; approximately 400 of these members are parents of adults with Down syndrome. Sixty-five responses were returned, all from the Chicago metropolitan area and, presumably, all from parents of a person with Down syndrome.

Regarding health care, parents expressed a number of needs, including health care availability and health screening. They were interested in obtaining regular physical exams and other health screening tests for their sons and daughters with Down syndrome to warn them of problems at an early stage or reassure them that certain findings are normal and/or did not need treatment.

Respondents also expressed the need for a physician knowledgeable in the treatment of adults with Down syndrome who would, therefore, be aware of problems (e.g., hypothyroidism) that occur more frequently in this population (Pueschel & Pezzullo, 1985) and less frequently (e.g., hypertension) (Pueschel & Pueschel, 1992). They were also concerned about the transition from pediatric to adult medicine. Although it may have been reassuring that their son or daughter had been cared for by the same physician for years, a physician who was knowledgeable about developmental disabilities, parents still expressed some concerns. The adults with Down syndrome and their parents were not comfortable seeing a physician whose office was clearly for children. The parents felt that many pediatricians were unfamiliar with questions addressing the unique needs of adults with Down syndrome.

Financial issues were another concern for both parents and physicians. Parents found it difficult to find a physician who would accept Medicare or Medicaid patients. Some pediatricians were unfamiliar with Medicare regulations as few of their patients require such funding.

Second, surveys of the psychosocial issues and concerns of NADS members showed that families were very concerned about the absence of viable social and job opportunities once their sons and daughters transitioned out of the school system into adult life. Some families reported that loneliness, withdrawal, depression, and weight management problems were frequent responses to this transition. They also reported verbal and nonverbal expressions of frustration and even despair among their adult sons and daughters, particularly when comparing their limited range of opportunities to siblings and others without developmental disabilities. Further, some families reported enormous difficulty locating mental health professionals with either the interest or experience to help ameliorate the painful or debilitating symptoms of this transition.

Three years prior to the opening of the Lutheran General clinic, the NADS Board responded to these issues and concerns by funding a fellowship that would provide clinical and consultation services for families with adults who had Down syndrome. The services were provided by the Family Study and Service Program (hereafter called the Family Program), a clinical program of the Illinois University Affiliated Program in Developmental Disabilities at the University of Illinois at Chicago to serve the needs of individual families, to define and document areas of general concern, and to assist in the development of and advocacy for more responsive social programs. Combining the support and advocacy network of NADS with the resources and experiences of the Family Program staff in both the clinical and developmental disabilities fields allowed a unique partnership that successfully increased the service options available to families of adult members. Since its inception, hundreds of families have been served directly by Family Program staff or through a network of service providers who were trained or identified by NADS and Family Program staff as knowledgeable and sensitive to the unique needs and concerns of adults with Down syndrome.

A review of the problems seen by personnel of the Family Program suggested that medical illnesses could be related to at least some of the psychosocial problems encountered. That possibility and a review of the survey information made it clear to NADS staff that a comprehensive clinic for adults with Down syndrome was needed, and they asked Lutheran General Hospital to develop such a clinic. In 1990, the hospital's Department of Family Practice accepted that challenge.

The availability of training for physicians in the care of adults with Down syndrome is limited. Therefore, the medical directorship was assigned to a member of the faculty of the Department of Family Practice (the first author) who had interest in and experience in caring for adults with developmental disabilities. Extensive review of the literature and regular conference attendance has increased the director's understanding of the care of adults with Down syndrome.

The next step in the development of this comprehensive health care clinic was for the medical director to review the aforementioned concerns of NADS members and the findings of the staff of the Family Program and then meet with their representatives to discuss a means for creating the clinic. The medical director was then asked to join the Adult Issues Committee of NADS, which included the Family Program fellow. This provided a forum for open discussion and eventual implementation of the Lutheran General Adult Down Syndrome Clinic.

One of the most important aspects of the clinic development, both to date and in the future, is the association with NADS. Input from NADS on patient questionnaire forms, research efforts, feedback from families, and many other operational and philosophical issues has helped keep the program focused on the needs of the patients and families and how to implement them. The input into this article by the third author, the executive director of NADS, reflects the regular input into the functioning of the clinic. In addition, the efforts of NADS members to inform the community about the clinic are

important. Forty-seven percent of the first 115 patients were NADS referrals. Table 1 lists the sources of all referrals.

Table 1
Referral Source of the first 115 patients Seen at
the Lutheran General Adult Syndrome Clinic Source

NADS	54
Clinic activities/publicity	24
Community agencies	18
University Affiliated Program	7
Physician	5
<u>Other</u>	<u>7</u>

National Association for Down Syndrome. Includes lectures at local meetings attended by community agencies and parents, advertising, and articles in hospital publications. Referrals came from the second author.

Cooperation with the patient primary care physician is also important. Although referral from physicians has not been a source of a large number of patients to date (see Table 1), follow-up with the primary physician on certain problems is important. This is especially true for patients who travel a great distance.

The key, again, to implementation of the recommendations was listening to the perceived needs as described by NADS and focusing on provision of those services, which helped (a) prevent duplication of services available to patients in their local areas and (b) keep down costs. In addition, it required discussions with multiple departments inside and outside of the hospital system describing the needs and development of a system to provide for them. For example, rather than trying to hold the clinic in the limited space near the hearing booth in audiology, the Audiology Department agreed to send an audiologist to the Family Practice Center with a portable hearing machine for hearing screening.

A major hurdle was cleared through the joint efforts of Family Program and NADS, which has continued to fund the fellowship at the Family Program (the position held by the second author). As a social worker with both clinical skills in counseling and knowledge of the available social support networks, he is an important element of the clinic services.

Recruitment of members of the audiology and nutrition departments who had experience working with children and adults with a variety of developmental and/or

chronic health problems was also important. Nursing personnel were sought who had a strong outpatient clinical background and a desire to serve the needs of patients, families, and other care providers. Extensive experience with adults who have Down syndrome, although desirable, was not mandatory. Good candidates were found for all the positions within the hospital system. In choosing candidates', the clinic director focused on the candidates' desire to serve the patients and their willingness to continue to learn and develop new ways to provide services.

The Lutheran General Adult Down Syndrome Clinic which opened in January 1992, incorporates the principles of a multidisciplinary approach to comprehensive medical care with an emphasis on preventive medicine and psychosocial adaptation. The clinic was designed to compliment the existing services provided by primarily care physicians and other service providers in the community.

The initial contact with the clinic is through a phone call taken by a certified medical assistant in the Family Practice Department. The needs of the adult with Down syndrome are discussed with the family member or the care provider and appropriate appointments are scheduled. An information packet is then mailed that includes a detailed clinic description, a medical and social questionnaire, and a release of records form to obtain previous medical data. After the returned information is reviewed by the clinic director, an effort is made to help the patient and his or her family or caregiver decide whether other consultations, lab tests, or x-rays will be necessary on the day of the clinic visit so appropriate appointments can be made. Further discussion and decisions regarding additional tests and consultations are made on the day the of the clinic visit.

The medical director evaluates each patient by reviewing the complete medical history and completing a physical examination. This information is recorded on forms tailored for adults with Down syndrome. Comprehensive care is provided, including pelvic exam and PAP smear, immunization update, and other minor procedures as necessary.

Each patient is then evaluated by the Family Program social worker, who assesses relevant psychosocial issues and concerns. Information is gathered directly from the patients and from accompanying family members or agency staff. This information includes the personal resources, skills, and attributes of the adult with Down syndrome; the availability of economic, educational, and recreational resources in the community; and the network of family, peers, and community supports. Assessment instruments include the Checklist for Psycho-social Concerns, which is administered in a structured interview with a family member or caregiver and the patient. This interview is an adaptation of the diagnostic criteria for depression and other potential problem areas taken from the Diagnostic and Statistical Manual of Mental Disorders--DSM-III-R (American Psychiatric Association, 1987) by the second author. It is suited to the unique needs and expressive limitations of adults with Down syndrome. A standardized instrument, the Developmental Diagnostic Profile, is also used to assess adaptive and living skills (Brown et al., 1986). When administered during yearly clinic visits, this

Profile is useful in assessing strengths in independent living skills. Changes in these living skills would indicate the need to evaluate for the possibility of early onset aging or dementia processes, both of which have been hypothesized to occur in this population, and to evaluate for reversible causes of the decline in skills.

An audiologist performs an audiogram for each patient and a nutritionist makes dietary recommendations. A modified version of the Down Syndrome Checklist (Ohio/Western, 1992) is used. Therefore, each patient has as a minimum the following labs: complete blood count, chemistry profile, thyroid uptake, and thyroxine and thyroid stimulatory hormone levels. Cervical spine x-rays are obtained if they have never been done or if the history or physical exam indicates a need for this procedure. Consultants in a variety of specialties are available.

The patient sees each health care provider on the same day at the clinic, and a brief verbal summary of the findings is provided to the patient and parents or caregiver. A written report documenting the findings and the recommendations for care, further consultation, additional testing, and follow-up is also provided. This includes a summary of the psychosocial evaluation detailing strengths, resources, problem areas, gaps in programs or services, and recommendations. This report is sent to the parent or caregiver, the primary physician, and other pertinent care providers. Follow-up clinic visits are available for further consultation with the clinic staff as needed.

At the end of the first 18 months, 115 patients had been served in the clinic. Many patients have been seen for routine physical exams with an emphasis on prevention and early detection of health problems. The most common problems encountered are outlined in Table 2.

Table 2

Most Common Health problems of first patients of the Lutheran General Adults Down Syndrome Center (N=115)

<u>Health problem</u>	<u>n</u>
Xeroderma	112
Cerumen	79
Tinea pedis	72
Impaired vision	68
Obesity	65
Onychomycoses	59
Impaired hearing	58
Folliculitis	48
Hypothyroidism	40
Strabismus	36
Hypercholesterolemia	37
Depression	34

Note: January 1992-July 1993.

The clinic has also been used as a referral source, particularly by NADS, community service agencies, and local residential facilities, for problems that have been difficult to diagnose or treat. These organizations have been the source of a number of referrals of adults with Down syndrome whose intellectual and functional capabilities seemed to have diminished. The effectiveness of the multidisciplinary approach of the clinic is well-demonstrated with this type of problem or concern. The patients presented with decreased self-care, loss of skills in activities of daily living, loss of verbal skills, loss of job skills, withdrawal, slow down in activity level, paranoid features, increase in talking to themselves, aggressive behavior, self-abuse, change in sleep patterns, weight change, and/or persistent forgetfulness. The diagnoses of 48 patients presenting with decreased level of function are shown in table 3. In addition, because Alzheimer's disease is felt to occur more frequently and at a younger age in some individuals with Down syndrome (Dalton & Crapper-McLachlan, 1986; Wisniewski, Rabe, & Wisniewski, 1987; Zigman, Schupf, Lubin, & Silverman, 1987), often the family or caregiver expressed concern that this was the cause of the diminishing skills. Although the population seen at the clinic to date has been fairly young (average age of 34 years), the etiology for the lower functioning has been found to be a diagnosis other than Alzheimer disease in almost all cases to date.

In addition, numerous patients have been seen who are healthy, well-adjusted, and living productive lives. The multidisciplinary approach of the clinic has provided a great deal of insight into these individuals as well. Some patients expressed a need to discuss the stress of daily life or assistance in finding suitable programs.

Table 3

Diagnoses of Patients (N=48) Presenting With Diminished Skills

<u>Diagnosis</u>	<u><i>n</i></u>
Depression	34
Adjustment reaction	13
Hypothyroidism	12
Dementia	2
Anxiety	2
<u>Other</u>	

Note: Some patients had more than one problem contributing to the decline, and, therefore, the sum of the diagnoses is greater than 48.

Includes one each of alcoholism, seizure disorder, hyperthyroidism, severe vision impairment, recurrent lung infections, menopause, severe nonsurgically corrected congenital heart disease, possible sexual

abuse, and sinus infection.

In response to psychosocial needs, services have been provided and coordinated between NADS, the Family program, and Lutheran General Hospital. Support groups led by a social worker focus on social, employment, and educational issues and provide an opportunity for adults with Down syndrome and other developmental disabilities to share concerns and to understand and appreciate normal and healthy aspects of their personalities. In addition, groups have addressed weight awareness issues. An exercise videotape has been produced featuring a physician and a nurse leading four young adults with Down syndrome in an exercise program, and an exercise class is currently being developed.

When problems arise, a variety of approaches are used. A growing network of contacts with community service organizations is being developed to assist in provision of employment training and placement, home medical care, and respite care. Employment issues are frequently a part of psychosocial problems. In addition, extensive discussions with families or residential facility care providers, home visits by the medical director and social worker, and assessments and appropriate referral to family therapists is provided. Support groups for families are also available, as is an extensive support network through NADS. Involvement with and evaluation of the home situation, whether it be the family or residential care facility, has been important in understanding potential areas of conflict and resources within the home setting that can be useful in problem resolution. Assistance with residential placement has been provided when appropriate and desired by directing individuals to appropriate community agencies and providing assistance in negotiating the system. When placement is appropriate and desired, further evaluation of the home setting and referral for additional assistance is sought to optimize the setting until placement is available.

The clinic is held twice a week, and up to 4 patients are seen in each session. Each patient spends between 3 and 4 hours at the clinic. Although the cost varies depending on the needs of the patient, the basic care as outlined is billed as approximately \$350 to \$450 and has been covered by Medicare, Medicaid, and the private insurance.

The costs of the clinic include several areas. Salaries and benefits for the physician and staff and office space are primarily provided by the Department of Family Practice. Physician services are billed in the standard fashion as are lab and X-ray. Audiology and nutrition services are also directly billed services. The social work services are generally not reimbursed and, therefore, are provided free-of-charge with the assistance of funds provided by NADS. Although only about 50% of the expenses are covered with gross revenues, further expenses are covered through the assistance of NADS, the Lutheran General Foundation, and as charitable services provided by the Lutheran General Health System.

A patient satisfaction survey is sent to each family or care provider after the clinic visit. Approximately one-half have been returned. The responses to date have been

predominately appreciative of having medical services tailored to the needs of adults with Down syndrome. Recommendations have been made and acted on regarding improving some areas of the clinic process. Another area of change based on the survey responses has been expanding availability of follow-up at the clinic. The original NADS survey suggested that people were looking for a clinic primarily to get an annual exam and not for ongoing care. Their intent was to continue ongoing care with their own physician. However, the patient satisfaction survey and discussions with families and care providers revealed that many were interested in on-going services. The needs were particularly centered on follow-up with the social worker and /or the physician. Therefore, the clinic was expanded to include these services. In addition, both the medical director and the social worker continue to serve on the Adult Issues committee of NADS and regularly seek input from the committee.

Research is an important part of the clinic services. Defining optimal care of adults with Down syndrome and evaluating its effectiveness has not been as thoroughly studied as it has with children who have Down syndrome (Thomas, 1986). A database of the associated health problems and the medical and psychosocial history is being compiled. An ongoing evaluation is also being conducted on the services of the clinic, the health care needs of adults with Down syndrome, and the effectiveness of the care provided.

The clinic also includes community education for adults with Down syndrome, their families, and other caregivers. Several talks have been provided by clinic staff for local organizations and residential facilities. In addition, the clinic serves an educational function for physicians, clinicians, and other providers in the community and for residents and medical students in the medical center. This is provided both by lecture and direct involvement by residents and students in the clinic.

A young woman with Down syndrome was recently hired to perform data entry and secretarial services for the clinic. She not only directly provides an important service to the clinic but also indirectly contributes to the educational component by demonstrating to the local community and others some of the range of skills that adults with Down syndrome can achieve.

After a direct request from and working closely with NADS, the Lutheran General Adult Down Syndrome Clinic was developed to better serve adults with Down syndrome. This population has the same basic health needs as the general population as well as some special ones; the clinic is a model to meet all of these. In addition, research in these areas is limited and, therefore, investigations will be undertaken through the clinic to evaluate health care and psychosocial needs. The clinic will also serve as a source of information for adults with Down syndrome and their families, practicing physicians-in-training, and others in the health care fields. The clinic is more than a model for providing good health care for adults with Down syndrome and for meeting these other goals. We hope that this information on the clinic will also provide a catalyst for further discussion on how to optimize the health care of adults with Down syndrome.

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Authors: BRIAN CHICOINE, MD, Medical Director; DONNA GILLY, CMA, Lutheran General Adult Down Syndrome Center, Department of Family Practice, Lutheran General Hospital, 1775 Ballard Rd., Park Ridge, IL 60068. DENNIS McGUIRE, PhD, Coordinator of Family Support Services, Family Studies and Services Unit, University Affiliated Program in Developmental Disabilities, University of Illinois, 1640 W. Roosevelt Rd., Chicago, IL 60608. SHEILA HEBEIN, BS, Executive Director, National Association for Down Syndrome, P.O. Box 4542, Oak Brook, IL 60522.