

A Center for Adults and Adolescents with Down Syndrome:

Twenty Years of Experience

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Abstract

The Lutheran General Adult Down Syndrome Center was developed in January of 1992 in an effort to better support adults with Down syndrome. The Center was established to provide comprehensive health care using a community-oriented primary care model.

Twenty years later, the multidisciplinary approach of the Center has continued to be effective in the management of a variety of patient care needs. Quality of care indicators and patient satisfaction data are provided to assess the progress of the Center.

Keywords: Adult Down Syndrome, Clinic, Health Care, Psychosocial Care

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Introduction

In April of 1994, *Mental Retardation* published an article entitled “Development of a Clinic for Adults with Down Syndrome,” which discussed the development and early operation of the Lutheran General Adult Down Syndrome Center (ADSC). The article was written to provide information about the model used by the Center to care for adults with Down syndrome (Chicoine, McGuire, Hebein, & Gilly, 1994). The present article reports on and assesses the progress of the Center through descriptions of its expansion over the past twenty years. It discusses the process that has occurred over time to meet the evolving needs and service requests of the patients and families. Another goal of this article is to answer two questions that are frequently asked of the Adult Down Syndrome Center staff:

- What was the process used to develop the Center?
- How can this process be replicated or modified to fit the needs and resources of other groups seeking to develop a center?

Development

The development of the Adult Down Syndrome Center came primarily at the urging of parents representing the National Association for Down Syndrome (NADS), a parent-driven advocacy organization that represents individuals with Down syndrome and their families in the Chicago metropolitan area (Chicoine, McGuire, Hebein, & Gilly, 1994). Responding to families’ dissatisfaction with the limited number of resources available for

adults with Down syndrome, NADS surveyed its members to determine the specific psychosocial needs (National Association for Down Syndrome, 1989) and health care needs (National Association for Down Syndrome, 1990) of this community. Respondents indicated a range of desired services, including more readily available health care and health screening, a physician and mental health professional knowledgeable in the treatment of adults with DS, and assistance in the transition from pediatric to adult medicine. Respondents also expressed concerns about financial issues and the lack of social and job opportunities outside of the school system. In addition to administering the surveys, NADS established a fellowship that would provide clinical and psychosocial consultation services for families with adults with DS. The Family Study and Service Program, a clinical program of the Illinois University Affiliated Program in Developmental Disabilities at the University of Illinois at Chicago, provided these services. The results of the surveys and the experiences of the Family Study and Service Program suggested that a comprehensive clinic for adults with DS was needed, and in 1990 the Lutheran General Hospital's Department of Family Practice agreed to develop such a clinic. The Adult Down Syndrome Center served its first patient in January of 1992.

The Center Today

When the Center opened, patients were seen two mornings a month. It is now a full-time practice in which patients are seen not only at the Center but also at group homes, patient homes, nursing homes, and work sites. Over 5000 unique patients have been seen since 1992. In 2010, there were 7,554 patient visits at all sites. The insight gained from these

patient experiences has led to the development and evolution of the model created when the Center was established twenty years ago. The evolving nature of the model has insured that it continues to be effective in the management of a variety of patient needs. For example, the Center opened initially with the intention to compliment the services of the patients' primary physicians. However, shortly after the Center opened, it became clear that families were looking for primary care as well. Additionally, the initial age minimum was eighteen but, after feedback provided by parents and guardians indicated that pediatric clinics were not adequately addressing some of the issues faced by children as they reached middle school and high school, the minimum age was lowered to twelve. These issues included the opportunities and challenges presented by greater inclusion in schools and recreational activities. Another example of the evolution of the Center is the adjusted out-of-state policy. After much consideration and discussion, the Center stopped accepting new patients from outside the State of Illinois. Although existing out-of-state patients continued to be seen at the Center, additional out-of-state patients are no longer accepted. A major component of the successful patient care at the Center has been the development of an ongoing, consistent relationship with the patients, their families, and their communities. The Center learned that relationships were much more difficult to maintain with patients coming from a greater distance which hindered the level of care provided.

Some of the tenets on which the Adult Down Syndrome Center model is based include:

- Health is defined as being more than the absence of disease; it involves physical, mental, and spiritual well-being.

- Developing an understanding of how physical health problems contribute to mental health issues and evaluating patients for these connections are essential to providing quality health care.
- The mission of the Center is to enhance the well-being of adults with Down syndrome by providing comprehensive, holistic, community-based health care services by a multi-disciplinary team (Chicoine & McGuire, 2010).

As indicated, although the initial purpose of the Center was to complement the existing services provided by primary care physicians and other service providers in the community, some families expressed interest in receiving primary care. Patients now utilize the Center in one of three ways that fit their specific and unique needs. Some patients utilize the Center as their primary care facility. Other patients have an outside primary physician and visit the Center annually. Lastly, a number of patients have an outside primary physician, are seen annually at the Center, and return for follow-up care for specific health needs, most commonly related to psychosocial issues. For all patients, the Adult Down Syndrome Center addresses the interconnected areas of physical and mental health. An informal review of available services for people with Down syndrome revealed that the Center is the only medical facility in the United States designed specifically to serve the primary health care needs of people with Down syndrome.

It is important to note that the model developed and utilized by the Adult Down Syndrome Center is one model – but not the only – for a comprehensive health care

clinic. As other clinics have been established, different models have developed based on the answers to the following questions:

- Will the services include primary care and/or specialty care?
- Will the Center serve only people with Down syndrome or people with other intellectual disabilities as well?
- Will it be aligned with a university, a community hospital, or a public health center?
- Will the Center also provide mental health services?
- What will be the relationship, if any, with a parent group?

The ADSC Team

The Adult Down Syndrome Center staff includes: two physicians, a nurse practitioner, a registered nurse/clinical coordinator, a certified medical assistant, and a licensed practical nurse who provide medical services; a PhD-trained social worker who provides psychosocial services; a registered and licensed dietitian who provides nutritional counseling; two patient advocates; a community relations specialist; a patient representative who schedules appointments and provides reception services; and a practice manager who coordinates the services offered by the Center. The Center is also supported by the administration of Advocate Medical Group and the Development office that performs the fund-raising activities.

A Visit to the Center

Prior to an initial visit, an information packet containing a medical and social questionnaire and a release of records form is sent to the parents or guardian of the patient in order to obtain the previous medical history of the patient. During a visit to the Center, one of the physicians or the nurse practitioner evaluates the physical health of the patient by taking a complete medical history, performing a physical examination, and performing or ordering screening tests. This information is recorded into the electronic medical record in a format customized for adults and adolescents with Down syndrome. Immunizations can be completed at the Center, and close proximity to Lutheran General Hospital allows phlebotomy and blood tests, audiology, X-ray, and other lab needs to be met easily and quickly. A meeting with the dietitian is also available. A visit to the Center includes an evaluation by the social worker and the psychosocial team, who assess psychosocial issues and concerns specific to adults and adolescents with Down syndrome. The social worker gathers information from the patient and accompanying family members, guardians, and agency staff about activities of daily living, communication methods, social skills and support, and other related information. At the end of the visit, appropriate follow-up appointments can be scheduled. A comprehensive summary report is mailed to patients and their families, agency staff, and any other individuals who assist in the care of the patient.

Patient-Centered Medical Home

The Adult Down Syndrome Center is committed to delivering primary care, coordinating care, maintaining strong communication channels, and providing resources to patients, families, and the community. As the idea of the patient-centered medical home (PCMH)

has developed, the goals of the Center and this model of care have often overlapped. While the ADSC is not recognized formally as a patient-centered medical home, the staff of the Center attempts to embody the PCMH philosophy through the care which is provided. According to the National Committee for Quality Assurance (NCQA), a patient-centered medical home is a model of care that seeks to establish a strong relationship between a patient and a primary care clinician who organizes and coordinates the involvement of other necessary qualified medical professionals (“Patient-centered medical home,” 2011). The medical home is not just a place but rather a family-professional relationship based on mutual respect (within the care provided at a primary care office or clinic). To achieve NCQA recognition as a PCMH, a facility must demonstrate fulfillment of a variety of criteria. Six standards describe the essential components of providing care: enhance access and continuity, identify and manage patient populations, plan and manage care, provide self-care support and community resources, track and coordinate care, and measure and improve performance. Each standard includes multiple elements, including one must-pass element that identifies an essential concept of a PCMH and must be met in order to receive official recognition as a PCMH. Table 1 indicates the NCQA PCMH standards and describes the services and protocols implemented by the ADSC to try to meet these standards.

As mentioned above, while the Adult Down Syndrome Center meets many of the criteria established by the NCQA, it has not yet sought or received formal accreditation. When assessing the ADSC in light of the NCQA PCMH standards, a few points need further clarification.

Customized Care – Colon Cancer Screening

The ADSC strives to provide care tailored to fit the needs of the population, adults and adolescents with DS, which it serves. A few goals of the Center include:

- Provide all the care that is necessary and beneficial but nothing more
- Avoid waste
- Avoid unnecessary testing and treatment that do not add a health benefit and could cause unnecessary risk

The Center's recommendation for colon cancer screening for adults with Down syndrome provides an example that illustrates the goals listed above. In the general population, the recommendation for colon cancer screening usually includes all people age fifty and older; however, this age can be younger in people with close family with colon cancer or colon polyps, people with inflammatory bowel disease, and people with certain genetic conditions associated with colon polyps. While the usual recommendations stipulate that many adults with DS seen at the ADSC should be screened for colon cancer, the studies which guide these recommendations generally do not include people with Down syndrome. Studies involving people with DS require additional IRB efforts and present greater challenges. Based on data and experiences gained from the patients seen at the Center over the last twenty years, the ADSC does not recommend screening colonoscopies for adults with Down syndrome (This recommendation is for *screening* colonoscopies. If there is an abnormality or symptom, patients are referred for diagnostic colonoscopies.). The Center has found that:

- The incidence of colon cancer is much less in people with Down syndrome. In general, solid tumors (including colon cancer) occur less frequently in people with DS (Hill et al, 2003).
- Most people with Down syndrome require significant sedation, and many even require general anesthesia, to complete a colonoscopy. People with DS have a greater risk of complications associated with anesthesia.

These experiences have indicated that the risks outweigh the benefits of a screening colonoscopy. As the life expectancy of people with DS continues to increase, there is the possibility that the incidence of colon cancer could also increase. If that occurs, the recommendation would be altered accordingly. However, at present, forgoing a colonoscopy or other screening method appears to be most effective in avoiding complications of testing, waste, and unnecessary testing and treatment. The Center is also investigating other possible assessment and treatment modifications due to the low incidence of diseases, such as coronary artery disease, breast cancer, and prostate cancer in adults with DS. Other modifications are being considered for the use of mammograms, cholesterol screening, and PSA testing.

Self-Care Process

An important piece of care in the patient-centered medical home is promoting self-care.

The ADSC promotes self-care by:

- Providing customized patient education material
- Helping patients develop schedules that involve healthy activity.

Though it may be challenging at first, once people with DS learn a self-care skill, they are capable of and take pride in maintaining this skill. The Center has found that this is aided by a common desire for sameness, order, and repetition and a strong visual memory that are seen in adults and adolescents with DS (Chicoine & McGuire, 2010). The use of pictures, schedules, lists, calendars, and other visual tools can help promote healthy behaviors. For example, a nighttime routine can be established by creating a schedule with accompanying pictures. According to Chicoine and McGuire (2010), “a photo of the person herself doing the activity (when appropriate) works best (rather than a schematic picture or a photo that shows someone else). It also helps to have the person participate in developing the schedule.” In addition, these visual tools have been successful methods for teaching people with DS, for example, about gluten-free diets. Celiac disease is more common in people with DS than in the general population so providing easily understood and accessible information on this topic is especially important. Gluten-free guidebooks with pictures can help people with DS make appropriate and healthy eating choices. Hands-on learning experiences have also been effective at the Center. For example, the Center established a group to promote healthy eating. ADSC staff asked participants to bring their own dinner to each meeting. The staff and participants would eat their meals and discuss healthy eating at the meetings. At the early meetings, the dinners tended to be “fast food” that had high caloric and low nutritional value. However, at successive meetings, the dinners that participants brought included healthier choices. Hands-on learning has also been implemented through the creation of the Fitness Team. It was started in 2004 to raise awareness of DS and to seek financial contributions for the Center through participation in long distance events such

as marathons and triathlons. By inviting patients and their families to participate in shorter events throughout the year, the Center encourages developing and maintaining healthy habits such as exercising.

Measuring Quality

As mentioned above, this article includes the performance data for the Adult Down Syndrome Center. Finding data which can be used as a comparison has been challenging due to the lack of other clinics of a similar magnitude that have reported quality data. The data included in table 2 compares the ADSC to established standards for the Department of Family Medicine at Lutheran General Hospital. Patient satisfaction data is also included in table 3. The Center regularly achieves the 99th percentile for the overall score. This data is gathered by Press Ganey and compared to Press Ganey data.

Looking Forward

Additional Challenges, Goals, and the Future

Funding remains one of the greatest challenges for the Center. Only about fifty percent of annual expenses are covered with net billing revenues; additional expenses are paid through the assistance of NADS, the Advocate Development Office, as charitable services provided by the Advocate Health System, and the generous donations of supporters. In addition to continuing to provide accessible, local, primary care that optimizes the health of ADSC patients, one goal of the Center is to continue to look for ways to support other health care providers and people at greater distances through video conferences, applications on smart phones, and other electronic resources. In October of

2010, a combination of state and federal money was given to the Adult Down Syndrome Center to build a larger facility (completion anticipated in spring 2012). Through the use of this additional space and technological improvements and the development of new programs, the grant money will help address the challenges and goals of the Center such as improving services, expanding educational programs, and developing electronic means of sharing information. It is the hope and plan of the Adult Down Syndrome Center that these changes and improvements will continue to advance the quality of care provided at the ADSC and other sites that serve the population of adults with Down syndrome.

Table 1

A Comparison of the NCQA PCHM 2011 Standards and the Adult Down Syndrome Center (ADSC)

NCQA PCHM 2011 Standards and Elements	ADSC
1. Enhance Access and Continuity	
A. Access During Office Hours*	<ul style="list-style-type: none"> ● Open five days a week from 8:30 am to 5:30 pm ● Evening appointments: one day each week or upon request ● Same-day appointments ● Outpatient care and inpatient care ● Visits to group and residential facilities, nursing homes, family homes, and work sites
B. Access After Hours	<ul style="list-style-type: none"> ● Answering service for after hours questions and advice (24/7 coverage)
C. Electronic Access	<ul style="list-style-type: none"> ● Electronic medical records ● Patient Portal (available in 2012)
D. Continuity	<ul style="list-style-type: none"> ● Can choose among two physicians and nurse practitioner
E. Medical Home Responsibilities	<ul style="list-style-type: none"> ● Provide information on the Internet <ul style="list-style-type: none"> ○ ADSC website with information about Center and its staff, patient forms, maps and directions, accepted forms of insurance, video tour of the Center, and resources about health problems common

	<ul style="list-style-type: none"> in adults with DS <ul style="list-style-type: none"> ○ Facebook page
F. Culturally and Linguistically Appropriate Services (CLAS)	<ul style="list-style-type: none"> ● Address language needs of patients through use of pictures and diagrams ● Communicate with both the patient and accompanying family members, guardians, aides, agency staff, etc.
G. Practice Organization	<ul style="list-style-type: none"> ● Weekly case management meetings ● Monthly staff meetings ● Defined roles for staff members
2. Identify and Manage Patient Populations	
A. Patient Information	<ul style="list-style-type: none"> ● Searchable electronic system (Clinicare) <ul style="list-style-type: none"> ○ Preferred name, date of birth, gender, preferred language, telephone numbers, address, e-mail address, legal guardians/parents, directives, etc.
B. Clinical Data	<ul style="list-style-type: none"> ● Research and scholarly activities: articles and studies <ul style="list-style-type: none"> ○ “Course of Alzheimer Disease in People with Down Syndrome” (Chicoine, Dominiak, McGuire, & Bilodeau, 2011) ○ “Effects of Donepezil on Cognitive Functioning in Down Syndrome” (Johnson, Fahey, Chicoine, Chong, & Gitelman, 2003) ○ “Health Issues for Adults with Down Syndrome” (Chicoine, McGuire, & Gratigny, 2003) ○ “Healthy Aging-Adults with Intellectual Disabilities: Physical Health Issues” (Evenhuis, Henderson, Beange, Lennon, & Chicoine, 2000) ○ “Overweight Prevalence in Persons with Down Syndrome” (Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998) ○ “Longevity of a Woman with Down Syndrome: A Case Study” (Chicoine & McGuire, 1997) ○ “‘Self-Talk’ in Adults with Down Syndrome: A Case Study” (McGuire & Chicoine, 1997) ○ “Predictors of BMI Among Adults with Down Syndrome: The Social Context of Health Promotion” (Fujura, Fitzsimons, Marks, & Chicoine, 1997) ○ “Depressive Disorders in Adults with

	<p>Down Syndrome” (McGuire & Chicoine, 1996)</p> <ul style="list-style-type: none"> ○ “Use of the Community Oriented Primary Care Model for a Special Needs Population: A Clinic for Adults with Down Syndrome” (Chicoine, McGuire, Hebein, & Gilly, 1995) ○ “The Development of a Clinic for Adults with Down Syndrome” (Chicoine, McGuire, Hebein, & Gilly, 1994) ○ “Hypothyroidism Presenting as Severe Psychological and Mental Dysfunction in an Adult with Down Syndrome” (Chicoine, 1993) <ul style="list-style-type: none"> ● Research and scholarly activities: books <ul style="list-style-type: none"> ○ <i>The Guide to Good Health for Teens and Adults with Down Syndrome</i> (Chicoine & McGuire, 2010) ○ <i>Mental Wellness in Adults with Down Syndrome: A Guide to Emotional Strengths and Challenges</i> (McGuire and Chicoine, 2006)
C. Comprehensive Health Assessment	<ul style="list-style-type: none"> ● Comprehensive, preventative, multidisciplinary care ● Medical history ● Physical and mental health assessment ● Appropriate immunizations and screenings ● Advance care planning
D. Using Data for Population Management*	<ul style="list-style-type: none"> ● Provide all the care that is appropriate but is not excessive and unnecessary ● Use of practices and templates modified to fit the specific needs of adults with DS <ul style="list-style-type: none"> ○ See text for further explanation
3. Plan and Manage Care	
A. Implement Evidence-Based Guidelines	<ul style="list-style-type: none"> ● Make plans and set goals with patients
B. Identify High-Risk Patients	<ul style="list-style-type: none"> ● Established criteria used for diagnosing conditions common in adults with DS such as Alzheimer disease
C. Manage Care*	<ul style="list-style-type: none"> ● Pre-visit preparations including previous medical history and health questionnaires ● Collaboration with patient and accompanying family members, guardians, aides, agency staff, etc. ● Written summary of appointment and care plan

	<p>sent to patient</p> <ul style="list-style-type: none"> • Assess care management needs and support • Follow-ups
D. Manage Medications	<ul style="list-style-type: none"> • Appropriate explanations of medications • Assessment of patient response to medication
E. Electronic Prescribing	<ul style="list-style-type: none"> • Medication interaction checking • Allergy checking • Dosing alerts • Formulary information • Generic alternatives for medications
4. Provide Self-Care and Community Support	
A. Self-Care Process*	<ul style="list-style-type: none"> • Education resources: patient education material, articles, books, Internet • Establish self-management plans and goals • Encourage developing and maintaining health habits <ul style="list-style-type: none"> ○ See text for further explanation
B. Referrals to Community Resources	<ul style="list-style-type: none"> • Parent Advocates • Community relations representative – serves as liaison to community support networks
5. Track and Coordinate Care	
A. Test Tracking and Follow-up	<ul style="list-style-type: none"> • This process has been implemented with a new version of the electronic medical record in 2011.
B. Referral Tracking and Follow-up*	<ul style="list-style-type: none"> • Center has established a referral network with strong communication among health care providers and patients • Tracking this process has been implemented with a new version of the electronic medical record in 2011.
C. Coordinate with Facilities/Care Transitions	<ul style="list-style-type: none"> • Appropriate paperwork sent and obtained when patients visit other health care providers or go to the hospital • System in place to share information with other facilities, government agencies, etc. with appropriate consent
6. Measure and Improve Performance	
A. Measures of Performance	<ul style="list-style-type: none"> • See quality of care data and patient satisfaction surveys
B. Patient/Family Feedback	<ul style="list-style-type: none"> • Patient satisfaction surveys • Patient Advocates <ul style="list-style-type: none"> ○ One of the Advocates is parent of an adult with DS who has experience-based appreciation for decisions faced by parents with children with DS

	<ul style="list-style-type: none"> • Maintain close relationship with NADS and other parent and family groups
C. Implements Continuous Quality Improvement D. Demonstrates Continuous Quality Improvement*	<ul style="list-style-type: none"> • Set and work to achieve goals • Evaluate progress at weekly and monthly meetings • Track results over time • Open and willing to try new methods to improve the Center
E. Performance Reporting	<ul style="list-style-type: none"> • This article includes the first published performance data
F. Report Data Externally	<ul style="list-style-type: none"> • This article includes the first published performance data
<p><i>Note:</i> * indicates a must pass element <i>Note:</i> NCQA PCHM 2011 Standards and Elements retrieved from “Patient-centered medical home” (2011)</p>	

Table 2
Adult Down Syndrome Center Quality of Care Data

Criterion	Result	Reached Minimum Requirement?
Use of Registries		
CIRRIIS Initiative Reporting Compliance – Early Completion ($\geq 50\%$)	90%	Yes
CIRRIIS Initiative Reporting Compliance ($\geq 90\%$)	90%	Yes
Roundtable Information Sessions		
Attendance – CII – Overview (≥ 1)	1	Yes
Attendance – Two Additional Information Sessions (≥ 2)	2	Yes
Office Manager Meeting Attendance (≥ 1)	1	Yes
Board Certification		
In Any Medical Specialty (= Yes)	Yes	Yes
In Primary Medical Specialty (= Yes)	Yes	Yes
Diabetes Care		
% Annual Eye Examinations ($\geq 50\%$)	67%	Yes
% Foot Exam Performed ($\geq 53\%$)	100%	Yes
% HbA1c performed ($\geq 81\%$)	100%	Yes
% HbA1c performed < 7 ($\geq 32\%$)	83%	Yes
% HbA1c performed > 9 or untested ($\leq 40\%$)	0%	Yes

% LDL performed ($\geq 79\%$)	100%	Yes
% of LDLs < 100 mg/dL ($\geq 46\%$)	50%	Yes
% of LDLs > 130 mg/dL or untested ($\leq 36\%$)	0%	Yes
Body Mass Index ($\geq 53\%$)	100%	Yes
Comprehensive Care ($\geq 20\%$)	67%	Yes
Hypertension Control < 130/80 mm/Hg ($\geq 26\%$)	100%	Yes
Hypertension Control < 140/90 mm/Hg ($\geq 49\%$)	100%	Yes
Nephropathy Testing ($\geq 63\%$)	100%	Yes
Depression Screening		
Depression Screening ($\geq 65\%$)	100%	Yes
HMO Quality		
HMO Quality Study Results ($\geq 66\%$)	100%	Yes
Average Length of Stay		
Milliman ALOS (Moderately Managed) – Practice Group Level (≤ 5.3)	4.2	Yes
Milliman ALOS (Moderately Managed) (≤ 5.5)	4.0	Yes
Milliman ALOS (Well Managed) – Practice Group Level (≤ 4.4)	4.2	Yes
Milliman ALOS (Well Managed) (≤ 4.6)	4.0	Yes
Generic Medication Usage		
Generic Drug Usage – Outpatient ($\geq 74\%$)	77%	Yes
ACL Outreach		
Outpatient Clinical Lab Usage (≥ 5)	683	Yes
Use of ACL for QI Registry Patients (≥ 1)	1	Yes
Peer Satisfaction		
Survey Completion – PCPs ($\geq 80\%$)	100%	Yes
<i>Note: Data collected from January 1, 2010 to December 14, 2010 and retrieved from the 2010 Clinical Integration Progress Report</i>		

Table 3
Adult Down Syndrome Center Patient Satisfaction Data

Question	All Sites Percentile	Region 5 Sites Percentile
Overall	99	99
Access	98	99
Courtesy of person scheduling appointment	98	98
Helpfulness on the telephone	99	99
Promptness in returning calls	97	97
Convenience of office hours	92	94
Ease of scheduling appointments	96	96
Courtesy of registration staff	99	99
Moving Through Your Visit	N/A	N/A

Speed of registration process	99	99
Waiting area comfort/pleasantness	97	96
Wait before going to exam room	98	97
Exam room comfort/pleasantness	98	97
Wait in exam room to see CP	97	97
Nurse/Assistant	98	98
Friendliness/courtesy of nurse/assistant	98	98
Concern of nurse/assistant for problem	98	97
Care Provider	99	99
Friendliness/courtesy of CP	96	97
CP explanations of problem/condition	97	98
CP concern for questions/worries	98	98
CP efforts to include in decisions	98	98
CP information about medications	98	99
CP instructions for follow-up care	99	99
CP spoke using clear language	94	95
Time CP spent with patient	99	98
Patients' confidence in CP	96	97
Likelihood of recommending CP	97	98
Personal Issues	99	99
Sensitivity to patients' needs	99	99
Concern for patients' privacy	99	99
Cleanliness of practice	95	94
Overall Assessment	98	98
Cheerfulness of practice	99	99
Care received during visit	99	99
Likelihood of recommending practice	98	98
<i>Note: n = 163, Data collected from January 1, 2010 to December 31, 2010, and gathered by Press Ganey</i>		

References

- Chicoine, B. (1993). Hypothyroidism presenting as severe psychological and mental dysfunction in an adult with Down syndrome. *Success Stories in Developmental Disabilities*, 11, 8-11.
- Chicoine, B., Dominiak, E., McGuire, D., & Bilodeau, J. (4 May 2011). Course of Alzheimer disease in people with Down syndrome. *Proceedings of the Advocate Research Forum at Lutheran General Hospital*.
- Chicoine, B. & McGuire, D. (1997). Longevity of a woman with Down syndrome: A case study. *Mental Retardation*, 35 (5), 477-479.
- Chicoine, B. & McGuire, D. (2010). *The guide to good health for teens and adults with Down syndrome*. Bethesda, Maryland: Woodbine House.
- Chicoine, B., McGuire, D., & Gratigny, S. (2003). Health issues for adults with Down syndrome. *Geriatric Advances*.
- Chicoine, B., McGuire, D., Hebein, S., & Gilly, D. (1994). Development of a clinic for adults with Down syndrome. *Mental Retardation*, 32 (2), 100-106.
- Chicoine, B., McGuire, D., Hebein, S., & Gilly, D. (1995). Use of the community oriented primary care model for a special needs population: A clinic for adults with Down syndrome. *American Journal of Public Health*, 85 (6), 869-870.
- Evenhuis, H., Henderson, C.M., Beange, H., Lennon, N., & Chicoine, B. (2000). *Proceedings from World Health Organization Conference: Healthy Aging—Adults with Intellectual Disabilities: Physical Health Issues*. Geneva, Switzerland.

Fujura, G.T., Fitzsimons, N., Marks, B., & Chicoine, B. (1997). Predictors of BMI among adults with Down syndrome: The social context of health promotion. *Research in developmental disabilities, 18* (4), 261-274.

Hill, D.A., Gridley, G., Cnattingius, S., Mellekjaer, L., Linet, M., Adami, H.O., Olsen, J.H., Nyren, O., & Fraumeni, Jr, J.F. (2003). Mortality and Cancer Incidence Among Individuals with Down Syndrome. *Arch Intern Med, 163*, 705-711.

Johnson N., Fahey C., Chicoine, B., Chong, G., & Gitelman, D. (2003). Effects of Donepezil on cognitive functioning in Down syndrome. *American Journal on Mental Retardation, 108* (6), 367-372.

McGuire, D. & Chicoine, B. (1996). Depressive disorders in adults with Down syndrome. *The Habilitative Mental Healthcare Newsletter, 15* (1), 1-7.

McGuire, D. & Chicoine, B. (2006). *Mental wellness in adults with Down syndrome: A guide to emotional strengths and challenges*. Bethesda, Maryland: Woodbine House.

McGuire, D., Chicoine, B., & Greenbaum, E. (1997). 'Self-talk' in adults with Down syndrome. *Disability Solutions, 2* (1), 1-4.

National Association for Down Syndrome. (1989). Family survey. Unpublished manuscript, National Association for Down Syndrome, Adult Issues Committee, Oak Brook, IL.

National Association for Down Syndrome. (1990). NADS Adolescent and Adult Health Survey. Unpublished manuscript, National Association for Down Syndrome, Adult Issues Committee, Oak Brook, IL.

Patient-centered medical home. (2011). Retrieved July 2011 from <http://www.ncqa.org/tabid/631/Default.aspx>.

Rubin, S.S., Rimmer, J.H., Chicoine, B., Braddock, D., & McGuire, D. (1998).

Overweight prevalence in persons with Down syndrome. *Mental Retardation*, 36 (3),

175-181.