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• Original short papers describing current research, including current or proposed projects or the results of completed studies;
• Reviews of the literature in specialized areas;
• Health care, including preventive medical recommendations based on assessment of the literature and considered opinions on what constitutes state-of-the-art practice;
• Editorial statements reflecting opinion on the state of the field;
• Book reviews and longer book review articles;
• Bibliographic compilations and/or lists of current research studies in various specialties;
• Abstracts of recently-published research studies with critical commentary;
• Letters to the editor;
• Statements/suggestions regarding research directions that may be most promising, or for which there appears a significant current need.

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Don C. VanDyke, Siraj Siddiqui, Jeanne Liston, Dennis Harper, and Dianne M. McBrien
University Hospital School
Division of Developmental Disabilities
The University of Iowa Hospitals and Clinics
Child Health Specialty Clinics

Down Syndrome clinics often need to develop creative ways to serve regional families, especially when they need to serve an entire state. In a rural state such as Iowa, traveling clinics may help to meet the needs of widely dispersed families and their children. Such clinics can help to educate families and local professionals, as well as provide optimum health care for this unique population.

Down Syndrome Clinics

During the last decade, the number of clinics serving children with Down syndrome has dramatically increased both at home and abroad. Formerly rare in this country, Down syndrome clinics can now be found in a number of states including: Alabama, Arizona, California, Colorado, Florida, Georgia, Illinois, Indiana, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Jersey, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, Texas, Virginia, Washington, D.C., and Wisconsin (Van Dyke et al., 1995). International clinics include facilities in South America, Mexico, Canada, Europe, and Japan (Van Dyke et al., 1995; Cohen, 1996). Some of these new clinics are designed specifically for adults with Down syndrome (Chicoine et al., 1994; Chicoine et al., 1995). These facilities provide medical care — with a strong emphasis on preventive health care — targeted to the adult and child with Down syndrome population and their unique medical issues (Rogers et al., 1992; Pueschel et al., 1995; Rondal et al., 1996; Cooley et al., 1992; Cohen, 1996; Chicoine et al., 1994).

Iowa is a rural state with 93% to 95% of its land under active cultivation or other agricultural usage. Of its population of approximately 3.3 million, about 750,000 people reside in 8 cities of more than 50,000; the remainder live in rural areas. Iowa’s Down Syndrome Clinic is located at the University Hospital School (UHS) which forms part of the University of Iowa Hospitals and Clinics, a large university teaching hospital and major tertiary referral center for Iowa and the Midwest. The University of Iowa Hospitals and Clinics are located in Iowa City, a college community of approximately 80,000 in the eastern part of the state.

Traveling Clinics

Shortly after the clinic was established in 1993, it became apparent that many families faced obstacles in attending evaluations there. Distance often played a factor; families on the extreme western and eastern edges of Iowa often had to drive hundreds of miles and arrange for overnight housing in Iowa City. Finances also played a role; some parents could not easily take time away from the workplace or the farm. Others had no reliable transportation.

In an effort to meet the needs of these families, a traveling clinic was developed. The two-part clinic model consisted of an educational component for parents and professionals and a clinical evaluation component. The clinic was staffed by representatives of the following disciplines: education, medicine, nursing, nutrition, psychology, and speech and language pathology. Occasionally the team was augmented by professionals from genetic counseling and physical therapy, as well as a parent representative.

Since 1993 the traveling clinics have been held 2-6 times per year, usually on a monthly basis with an average of 4 times per year. The average clinic serves 13-14 patients and families. The distance traveled by the clinic staff ranged from approximately 100 miles to 400 miles. The team typically travels to the clinic location on the evening prior to clinic to present a 2 hour educational conference to families and local professionals. The clinic on the following day usually lasts 7 to 8 hours.

The direct operational costs per clinic range from a low of $300 to a high of $2,300. Professional and support staff salaries are not considered direct costs and thus are not reflected in this figure. The wide disparity in cost is related to distance traveled by clinic staff; long distance clinics are reached by chartered plane, which adds considerably to the cost of the clinic.

Educational Programs

Educational programs are held the evening before clinic. Each educational program is individualized on the basis of requests from the local Area Education Agency (AEA) and from parents. The programs consist either of 2 hours of informal presentations by team members or of one hour of informal presentations followed by one hour of small group discussion. Presentations offer general information on such topics as medical issues, sexuality, speech and language issues, augmentative communication, behavioral management, educational issues, attention deficit hyperactivity disorder, and hearing disorders. Small group discussions may focus on more specific issues such as thyroid dysfunction, atlantoaxial instability, nutritional issues, and full inclusion. Each presentation is accompanied by a handout. A general packet of information is also handed out to all parents attending the educational program and the clinic. The packet contains information on medical, educational, behavioral, and sexual issues.
Clinical Evaluation

The clinic serves both new and follow-up patients. Evaluations typically address medical, educational, speech and language, and behavior concerns. Other services include case management, nursing, and nutrition; physical therapy and genetic counseling are sometimes offered as well. A detailed report is prepared following each visit, containing individual reports from each professional evaluating the patient. The report is sent to the parents, who can request that copies by released to referral sources, the AEA, service delivery agencies, other specified care providers, and other family members. Recommendations and follow-up are coordinated by the nurse manager for each clinic.

Clinic costs per patient range from $29 to $202. Billing to families is on a sliding scale; many patients incur no direct costs. No patient or family is denied services due to financial issues. The clinic is operated under the sponsorship of Iowa Mobile and Regional Child Health Specialty Clinics (CHSC). As the state's Title V agency, CHSC serves Iowa's children with special health care needs and their families. The variety of CHSC services includes direct clinical services, clinical consultation, care coordination, family support, and parent training. CHSC operates through the Iowa Department of Public Health Maternal and Child Health Program with consultation from the U.S. Department of Health and Human Services. The agency is chiefly funded by the federal Maternal and Child Health Services Block Grant, with additional funding provided by state appropriations from the Iowa legislature.

References


Book Review

Barry M. Mitnick, Ph.D.
Book Review Editor

“High Expectations of Myself”

Jason Kingsley and Mitchell Levitz,
Count Us In: Growing Up With Down Syndrome.
$19.95, hardback (sold out); $10, paperback

“So I make my own expectations. I have high expectations of myself; I expect to get a good job. Good training ... good apartment, good wife, good social life, and good everything.” — Jason Kingsley (p. 169)

Not long ago, such a statement would have seemed utterly fanciful: People with Down syndrome simply could not expect any of that. Indeed, people with Down syndrome were not held capable of expectations at all. In this compelling autobiographical conversation between two young people with Down syndrome and various of their significant others, Jason Kingsley and Mitchell Levitz break all the traditional stereotypes. They provide a compelling testament of the changing expectations that both society and people with Down syndrome hold of their life possibilities.

In the last year, Down Syndrome Quarterly has featured reviews of recent books about the experience of Down syndrome written from the perspective of a mother [Marilyn Trainer, Differences in Common: Straight Talk on Mental Retardation, Down Syndrome, and Life (March 1996)] and a father [Michael Bérubé, Life as We Know It: A Father, A Family, and an Exceptional Child (DSQ, December 1996)]. In Count Us In, we have an account from the viewpoints of the people with Down syndrome themselves.

The book was assembled from more than fifty transcripts of conversations between Jason and Mitchell, often moderated by a parent or grandparent. In addition, essays and other short written pieces were contributed by the young men. The material was sorted into chapters dealing with such topics as their friendship, the experience of having Down syndrome, school, having fun, girls and sex, marriage and children, important people in their lives, religious beliefs and the experience of loss and grief, politics and world affairs, independence, and future plans. Although constructed from a number of pieces, many of which were originally oral, the book succeeds as a whole. The distinct personalities and interests of the two authors shine through the text.

Nigel Hunt’s journal [The World of Nigel Hunt: The Diary of a Mongoloid Youth (New York: Garrett Publications, 1967)] has long been a hard-to-find curiosity in the literature on Down syndrome. At the time it appeared, skeptics doubted that a young man with Down syndrome could write his own story. After the now twenty-year-old revolution in special education that demonstrated the academic capabilities of people with Down syndrome, the skepticism faded. But despite many accounts of people with Down syndrome with impressive life achievements, and many books and shorter pieces about specific individuals and their lifestyles and accomplishments, accounts like Nigel Hunt’s have remained virtually unknown. Indeed, though the disability movement in general has made rapid strides toward legitimizing and institutionalizing self-advocacy in a variety of settings, the written record by people with Down syndrome has remained skimpy.

Count Us In begins to change that. Jason and Mitchell provide a uniquely compelling testament. It is lyrical and even poetic in sections; it has humor, bite, and irony; it has vivid imagery; it gives a sense of time, place, and historical perspective. It is also clearly and deliberately uncorrected in grammar and syntax; parts are repetitive, just as real-life conversations overlap in content. Most importantly, this book conveys a powerful sense of Jason and Mitchell as thoughtful, capable individuals.

Not surprisingly, the book has won a number of awards, both from the Down syndrome and disability community and from mainstream book award programs. It has been translated into Japanese and further translations are anticipated. The book is clearly serving both an informational role, conveying very tangibly what people with Down syndrome can do, and an inspirational role as a model for what young people with Down syndrome may hope to accomplish.

From the point of view of professionals interested in Down syndrome, we may also ask if the story of Jason and Mitchell offers implicit suggestions for approaches to education, therapy, support services, or the like that might increase the chances for success. Although the authors take great pains in providing material that clearly distinguishes Jason and Mitchell as distinct individuals, certain common features of their experience seem striking. Some aspects seem to reinforce modern views of approaches to optimizing the development of people with Down syndrome; some I would offer as speculative.
Developmental influences flow primarily through principals and only secondarily through agents. In the most munificent modern environment of developmental disability, individuals are surrounded with skillful and well-meaning agents: special teachers, therapists, social workers, psychologists, administrators of special programs, vocational training providers, and so on. But normal life is not a life of being prodded and processed by such agents. The most important influences, and the most valued ones, come through life relationships with principals, not agents: family, friends, co-workers in a stable work environment. During their school years, Jason and Mitchell were clearly embedded in enormously supportive, cross-generational family settings, and much of what was educationally and socially valuable to them was transmitted not through agents at arm's length in classrooms, but through parents, grandparents, siblings, and friends. The agents were there, and were valuable — both young men cite psychologists, school administrators, teachers positively. Although essential, these agents were ultimately secondary in the developmental process.

They enjoy a diversity of activities, not just a diverse environment. Jason and Mitchell are players; they are very active participants in their own development. They do lots of things: There is an almost incessant string of travel and public events; encounters with new and impressive people, whether politicians, entertainers, people active in the Down syndrome community, or new friends; athletic activities, often with friends; school and extracurricular activities; family activities; and so on. They are pushed and stimulated by doing, not just by observing.

Their participation in events yields a pervasive sense of efficacy and achievement, and a positive self-image. Both Jason and Mitchell are not shy in declaring their accomplishments. For example, both young men are proud of the acting they have done; both are proud of the public recognition and awards they have received. In addition, both are quick to declare that they made things happen. For example, Jason says that Chris Burke became an actor through contact with him. Mitchell describes his Congressional lobbying for disability legislation and his role in the film “EMPLOYABILITY” shown during one such Washington effort: “I feel that I had achieved a lot....The film will definitely make a difference.” (pp. 140-141) There is a pervasive sense of confidence in being able to do things — most anything, in fact, and an understanding of an almost Piaget-like instrumentality in the causation of events. They talk confidently and assuredly of being married someday, of being parents themselves, of driving cars. Sometimes they even set goals: marriage or driving at 21 or 23. They discuss calling DS “Up Syndrome,” or at least, as Mitchell suggests, “Change Syndrome,” because “we can’t change the disability but we can change the way we feel.” And Jason declares, “You can realize now: You can do everything yourself from now on.” (p.44)

Their activities produce events that are memorable, vividly-recalled landmarks of the past. Jason and Mitchell have done some pretty impressive things, after all: The acting on Sesame Street and The Fall Guy, a special recognition from the New York State Legislature, an interview by Jane Pauley for Dateline, keynote speeches to conferences, jet skis in Puerto Rico and Cancun, the list seems endless. Both have flags that flew over the U.S. Capitol, courtesy of their Congressman; both received several awards or distinctions in school. They wrote this book. The things that Jason and Mitchell do impress not only others; they also impress themselves. It would be hard not to learn from such adventurous, exciting experiences. People recall emotion-laden events, and these young men have had plenty of them.

They benefit from creative and persistent parents. The Levitz and Kingsley families were national pioneers in changing perceptions and practices regarding people with Down syndrome. In the early years they persevered courageously against then-professional advice and have served as models for the parents that followed. They acted to change service systems, to improve public services, to modify educational settings. The Levitz family organized their own Down syndrome parent group. These parents were also consistently creative in their approaches to their children, providing educationally rich and developmentally challenging home environments. The story of Emily Kingsley immersing baby Jason in Jello and in styrofoam as part of infant stimulation is oft-cited; both Jason and Mitchell were raised in environments that delighted in verbal exchange, in the use and manipulation of words, in reading.

They are educated in settings that are adapted or altered or substituted to fit their needs. One size does not, indeed, fit all. Rather than take available services as a given, the Levitz and Kingsley families continually sought out settings that were most appropriate to their children at each stage of their development. Thus we see a string of settings all calculated to fit the child, from Infant Stim to Montessori to various forms of inclusive and special classroom settings. When things don’t work, they are adjusted or changed, so that the world is made to adapt to the child, not the other way around.

Family members serve as important instruments for delivery of basic cultural knowledge about the world as well as guardians of high standards and validators of the importance of continuing education. Besides their parents, both Jason and Mitchell have close relationships with grandfathers who work with them, take them on outings, and introduce them to ideas in science, art, and music, as well as to potentially life-long avocations such as stamp-collecting and fishing. For example, Mitchell recalls how his grandfather insisted that he spell words correctly (p. 106). Perhaps because these educational experiences have been based in such close, loving relationships, the young men recall much of what they were taught in this way.
They are taught in ways that emphasize sorting/categorization, sequencing, and enumerating/elaborating. Readers may be struck by the ability of both young men to group and list things, to trace sequences of events or logical trails, and to elaborate and develop points or issues. On such methods, cf. Pat Oelwein’s Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers, reviewed in DSQ, September 1996. They also show an excellent recall for groups or types of things, and for distinctions among things. For example, after Mitchell’s mother talks about the value of communications skills in conveying information, Jason says “There’s many other kinds of information — called spoken information, written information, and reading information.” (p.148) He goes on to discuss the benefits of these in turn, if with some overlap. Jason’s grandfather notes that they enjoyed word games, and Jason says, “Like spelling games, puns, homographs, homophones...” (p.113) His grandfather reminds him that they made a scrapbook of leaves and Jason replies, “We made a book of the leaves: oak, red oak, maple, white maple...” (p. 112) And then again, about knots, Jason notes, “square knots, overhand, slip knots.” (p. 112) Mitchell lays out issues in the presidential election. In addition to the Americans with Disabilities Act, he cites the “economy, jobs, health care, the environment.” (p. 136). The ability to make abstract, conceptual sense out of the chaotic phenomena of everyday living and to make practical applications of the sortings imposed by formal studies is a compelling sign of an active intelligence at work. It is, as well, another indicator of the extent to which these two have mastered their environment, not succumbed to it.

They grow up, both in home and school settings, in loving, personalized environments, in which they feel centrality, not marginality. Both Jason and Mitchell appear to have received lots of loving attention from parents and other family members; many family activities were influenced by their presence in important ways. As already noted, grandparents took them to museums, to shows, to the beach; helped them with homework; taught them art and science and politics. In school and the community they are kids that everyone knows. They are not without problems in school, but they seem valued and largely included in activities, including sports, especially in high school. Mitchell worked as assistant to the dean of students in his high school and received the dean’s award for service at his graduation. Mitchell writes that “people make me feel important in life...” (p. 17) The centrality is unmistakable.

They are provided with mechanisms to work out their problems, and they are encouraged to use these mechanisms. There is a lot of discussion about problems and dealing with problems. Both Jason and Mitchell talk to a psychologist regularly. The dean of students is helpful with problems. Grandparents are there to discuss problems that are tough to discuss with parents. Indeed, both Jason and Mitchell are encouraged to identify and work out problems rather than ignore them.

Family and other social settings encourage the acknowledgment and discussion of feelings. Emotions are treated seriously and with respect. Too often the feelings of the developmentally disabled are treated as if they were artifacts of the disability rather than of people capable both of deep emotion and of making valid judgments about that emotion; not so here. Much of the book deals with such issues, often in tender and sensitive ways. The chapter on religion and on grief is particularly touching. Mitchell describes how important his Bar Mitzvah was to him; Jason writes a beautiful card to his late grandmother “in heaven, calmly relaxing angel.” (p. 120)

Inclusion with nondisabled peers and friends, and with the ordinary interests, activities, and avocations of the general population, is frequent and substantial. Although their academic programs do not appear to feature total inclusion in regular classes with regular curricula throughout their middle and high school years, both young men appear to have been well-integrated into high school. Mitchell receives a standing ovation at graduation. Mitchell prefers to “hang around” kids without disabilities (p. 48) and looks forward to marrying a girl without a disability (p. 79). He notes that his friendship with Jason should not be based on their common disability, but “on the way we feel about each other and how both of our families got involved...” (p. 33) Both Jason and Mitchell anticipate independent lives with real jobs and independent or relatively independent (group) living arrangements among the general population.

Family, school, and social life encourage the development of individual differences and personal identity and expression. Mitchell and Jason spend a lot of time talking about their differences and their special interests and experiences, including their differing career aspirations, their choice of courses in school, and their preferences in entertainment and sports. They even discuss their differing positions on the candidates in the 1992 presidential election. Mitchell observes that “People can change, people can realize you are an individual and an identity is important to you, to your family, even to your community. People consider you an individual with rights. People respect you for who you are. Not just your disability. The person who you are makes it. That’s what counts... We are individuals and they are counting us in.” (p. 14)

Of course, the story of Jason and Mitchell is just beginning, both for the authors of this book and for those other Jasons and Mitchells who now enjoy "high expectations" of themselves. The challenge will be for society to meet those same expectations.
News from the Down Syndrome Medical Interest Group (DSMIG)

William I. Cohen, M.D.
Bonnie Patterson, M.D.
Co-Chairs

Mission The Down Syndrome Medical Interest Group (DSMIG) was founded in early 1994 with the express purpose of serving as a forum for professionals addressing aspects of medical care of persons with Down syndrome. DSMIG wishes to promote the highest quality care for children and adults with DS 1) by fostering and providing professional and community education; 2) by disseminating tools for clinical care and professional support; such as the Health Guidelines for Individuals with Down Syndrome; 3) and by engaging in collaborative clinical research regarding issues related to the care of individuals with Down syndrome.

For further information, contact either co-chair: Bonnie Patterson at 513-559-4691 or Bill Cohen at 412-692-6546. If you are interested in being added to our mailing list, please send your name, professional title, agency, address, telephone number, fax number, and email address (if any) to William I Cohen MD, Down Syndrome Center, Children’s Hospital of Pittsburgh, 3705 Fifth Avenue, Pittsburgh, PA 15213. (412-692-6546; fax 412-692-5679; email: cohenb@chplink.chp.edu).

As this issue goes to press, members of DSMIG are preparing to meet at the National Down Syndrome Society’s International Research Conference on Cognition and Behavior. Members of DSMIG who will be participating include: Drs Don van Dyke, Charles Epstein, Sig Pueschel, David Patterson, Bob Pary, Libby Kumin, Dennis McGuire, Ira Lott, and George Capone, among others.

A working meeting of DSMIG will precede the International Conference, focusing on a variety of issues. In addition to the preparations for the revision of the “Health Care Guidelines” the proposed agenda includes planning for research activities in a number of areas, including nutritional interventions.

A summary of the meeting will be published in the December issue of Down Syndrome Quarterly.

Comment on Editorial: Vitamins and Down Syndrome

Jesús Flórez
University of Cantabria
Santander, Spain

In her “Editorial: Vitamins and Down Syndrome” (DSQ, 2: 11-13, 1997), Dr. Mary Coleman discusses some studies on vitamin A and E in Down syndrome, and concludes that the level of other fat-soluble vitamins in Down syndrome awaits scientific study. She omits the paper by Del Arco et al. entitled “Vitamin D status in children with Down syndrome” (J. Intellect Disab Res, 1993; 36: 251-257). The authors studied the serum levels of the active vitamin D metabolites 25-hydroxyvitamin D, 1,25-dihydroxyvitamin D and 24,25-dihydroxyvitamin D in 21 children with Down syndrome in Cantabria, a northern region of Spain located at 44° N latitude. Serum calcium, magnesium, phosphate, alkaline phosphatase, parathormone and osteocalcin were also determined. The average levels of Vitamin D metabolites were comparable to those of an age-matched group in both winter and summer times and no child with Down syndrome showed values below the normal range.

1Correspondence: Professor Jesús Flórez, Department of Physiology and Pharmacology, University of Cantabria, Avada, Herrera Oria s/n, 39011 Santander, Spain
Abstracts/References

David Smith, M.D.
Abstracts Editor

AGING

Comments: With an N of 307 they found that the mean age at onset of dementia was 56 years. Prevalence was 11% between ages 40 and 49. All patients over 70 had dementia.

BIOCHEMISTRY


Comments: A review.

CARDIOLOGY

Comments: German. An editorial.

DENTAL

EDUCATION & THERAPY


ENDOCRINOLOGY

EPIDEMIOLOGY

GASTROENTEROLOGY

GENETICS


Comments: A review


Comments: Consanguinity did not affect the rate of Down syndrome.

HEMATOLOGY


MISCELLANEOUS


Comments: They conclude that adults with mental retardation with and without Down syndrome need exercise programs.

NEUROLOGY
Comments: A review
Comments: A letter
Comments: A letter

NUTRITION

Comments: Raises the question of whether or not aluminum should be limited in the diet of people with Down syndrome.

OPTOMETRY

ORTHOPEDICS
Comments: Another case of late diagnosis 15 weeks!

OTOLARYNGOLOGY
Comments: Includes a discussion of post-exubation stridor and special considerations for intubation of individuals with Down syndrome.

PRENATAL DIAGNOSIS

Comments: German. Looks at cost-effectiveness of the triple test in Austria.
Comments: A urine test may replace the serum triple screen if this study is correct. See below.
Comments: And they report that a urine test is not as good as the triple screen. See above.


Comments: French. A public health approach?


Comments: A letter.


Comments: Health professionals do not understand prenatal screening tests well enough to give women the information they need to give informed consent.


Comments: Sixty-nine (4%) of 1715 amniocenteses had a chromosomal abnormality. One half (2%) had Down syndrome.


Comments: An editorial.


PSYCHIATRY


UROLOGY

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