synergy

PSYCHIATRIC WRITING WORTH READING

VOLUME 22 • NUMBER 9 • SPRING/SUMMER 2015

Memories and Meaning

BY WILLIAM F. KENNY

I think back to the earliest memories.

Images of my father playing catch with me merge with later glimpses of him returning home from work. He would usually call at noon to touch base with my mother and then arrive home around 5 PM. I remember how much I wanted to please him, show him that I could catch the fastest pitch he could throw at me. His stories were magical and took me into a land of enchantment. In those early years, my father embraced the world and brought laughter into our home.

My mother was the one who was always there, always comforting me during the night. I developed asthma early on and often awakened gasping for breath. She would sit me on her lap, calming me with soothing words as she enfolded me with her arms. Little wonder then that I would scream loudly and vehemently when they left me in the care of a babysitter. I was their first child and, for a while, the focus of all their attention.

I am not sure when and why it all began to change. Certainly the arrival of my younger siblings divided their attentions, but there was something else. A bitterness between my parents surfaced around the time I began school, and it smoldered fiercely over the coming years. My mother gained weight, looked weary, and began to drink. My father grew frustrated and angry. He had always needed to be the center of attention, having been the youngest and very spoiled child in a large Irish family. When I look back now, I can see how this undermined his ability to deal with life's later frustrations. He could not evolve with us as we grew into adolescence, and his need for self-adulation grew even stronger. Eventually, open fighting erupted between my parents. Often, I became the mediator and even protector of my mother.

It seemed that the only thing that gained their attention was my success in school. This was fine with me as it offered a way out. High school and university beckoned and I gradually spent more time away. Upon arriving at medical school in Canada, I faced a foreign country and a different culture. While there, I formed friendships and imbibed the differences. Yet, there remained the ties of home, religion, and upbringing. Further training in New York City sharpened my focus and led me to a residency in psychiatry.

As a young psychiatrist, I strained to make sense of new experiences that challenged old beliefs. The Catholicism I knew was conventional and rigid. The world I was encountering offered new ideas and confusing boundaries. Sexually, I was inexperienced and scared. Eventually, I sought refuge with a group of men who were wrestling with similar problems, and we experimented timidly with

continued ➤

INSIDE

Welcome to the Spring/Summer 2015 edition of *Synergy*.

We are proud to present an issue where all the contributors are members of the local Department of Psychiatry here at Queen's University.

Our cover essay by Bill Kenny is deeply personal and part of a much longer piece that develops themes of psychotherapy and meaning. If this edition's piece whets appetites, readers will be able to look forward to further installments of this work in subsequent issues as we'll be serializing Dr. Kenny's work.

Dr. Nasreen Roberts is just now stepping down from her long-held position as head of child and adolescent psychiatry in the department. In this issue, she reflects on a long and fruitful career in the field and measures its successes and challenges (a career that is far from over, I might add).

Our third essay is also reflective: Dr. Bruce McCreary examines the state of attitudes towards persons with developmental disabilities after a career of more than 45 years thinking about and advocating for his patients.

Finally, we proudly present poetry in our back pages. Bethmarie Michalska, a published poet and member of our department, has allowed us to publish "Glosa," as well as including some explanatory notes that will enhance the pleasure of the piece for many of us.

We hope you enjoy the prose (and poetry) and, as always, welcome your comments.

EDITORIAL BOARD

SYNERGY SUBMISSION GUIDELINES

Synergy invites submissions from members of the mental health community in Southeastern Ontario and beyond. We encourage articles on current topics in psychiatry. Our essays are scholarly in outlook but not number of footnotes. We strive to publish good prose and ideas presented with vigour. Articles range from 500 – 1000 words. Longer articles may be accepted.

Articles may be submitted in the form of a Microsoft Word document as an email attachment.

Queen's University
Hotel Dieu Hospital
Providence Care
Kingston General Hospital
Frontenac Community Mental Health Services
Ongwanada

our identities and relationships. There were no great insights or changes, but the yearning was there to find a way out.

When the war in Vietnam splashed across America, I was conscripted to fight in that foreign land. I remember arriving at the airfield in Saigon and being terrified. It took some time to become adjusted to the realities of the war, but it began the process of my liberation. While there, I read the existential philosophers, especially Karl Jaspers. His concepts of end points as defining our identities resonated with me.[1] The prospect of death and the shortness of life caused me to rethink my values and make the best of my allotted time. I was determined to grab hold of my future as a present reality.

On returning to America, my search quickened. I deepened my philosophical ideas and read more psychoanalytic literature. If I were to break the stalemate in my life, I decided I would have to undergo my own analysis.

He was a well-known New York analyst who had written several books. His intellect brought instant respect and calmed my fears. At first, I sat up facing him, and later lay on a couch while he sat behind me. I would leave work three times a week to drive into Manhattan and his Park Avenue office. I remember riding up in the elevator, looking at faces and wondering if any were his patients. Invariably, I would arrive some minutes early and spent time in his reception room imagining what went on behind the closed doors. I would imagine him in his room. It always seemed dark and forbidding. As I sat waiting, there was always the strong desire to please him. When he opened his door, I would be jolted out of my reverie. I was a vivid dreamer who sought instant answers. His silences only spurred my imagination. Sometimes I would reveal these dark images, but not always. Throughout, I cherished his knowledge and benefited from his insights. Most of all, I learned to trust my instincts and embrace my sexuality. For this I am eternally grateful.

However, I never felt that he cared for me. I was looking for the father I lost years ago but could not grasp any hint of feeling in that room. Eventually we had a falling out. I had been seriously ill and was unable to come to his office. Despite this, he insisted on charging me for the times that I missed. I felt hurt and angry but never really confronted him. However, I decided that I had to leave therapy. For all his brilliance, he remained an uncaring man.

I do not remember our last session, but it was several years before I finally relinquished his presence in my mind. I measured my success with his accomplishments. Towards that end I tried to write and organize conferences and meetings; his image took a prominent place in the back of my mind. Recently, I saw a picture of him in the *New York Times*. He was still active in his field and very involved in teaching. Surprisingly, he looked only a few years older than I. I had always pictured him as older and wondered whether he was still alive. To this day I have difficulty holding my patients accountable for missed appointments. From this experience, I know that they think about me more than they are willing to acknowledge. I also know that the most important issue in therapy is whether I care about them.

continued ➤

I continued reading the psychoanalytic literature. For many years, I was inspired by the teachings of Harry Stack Sullivan.[2] His insight that the real work of therapy took place between therapist and patient seemed to equalize the playing field. I focused more on how and why I was reacting to the patient. The British Object Relations School clarified and brought to the forefront the patient as a three-dimensional person and not a bundle of instincts.[3] André Green pointed to the dark and hidden soul in each of us.[4] My experience with borderline patients and their frail psyches showed just how damaged people can be and just how desperate their longing. Christopher Bollas,[5] in his groundbreaking book, *The Shadow of the Object* (1989), brought home the need to understand the unspoken emotions that were frozen in time. He, along with Heinz Kohut,[6] taught me that understanding, acknowledging, and reacting were the bedrock of therapy. For many years, I believed that my role was that of an impassioned observer of my patients' history, experiences, and dreams. Some responded well to this approach while others offered strong resistance. Ironically, many of the latter did quite well without seeming to accept my formulations of the roots of their problems.

Charlene was a young woman who came to me in great despair. This was many years ago during my first year as a psychiatrist. After an initial and halting history, Charlene became quite silent and remained that way for the next three months. She would arrive on time for the sessions but would not say a word. I tried everything and ended up talking about myself just to fill the time and space. I could sense her great pain and distress but never knew just what she was thinking. It was very painful for me while I struggled in vain to reach her. When Charlene left treatment suddenly and without notice, I felt confused, embarrassed, and futile. After a few months I was able to let go of this strange woman. Then, to my great surprise, I received a short note from her. Charlene apologized for leaving so abruptly and explained she had left for the west coast of the United States and thanked me profusely for helping her in ways that I never truly grasped. She ended by writing that therapy had changed her life dramatically and that she was forever grateful. When I look back and think of others, it seems that my effort to understand and reach out to my patients was the one thing that they needed.

In the last year of my therapy, I met the woman who was to be my wife. We were kindred souls who saw the world as a place to reach for our dreams. Over the years she has been that constant presence in my life, sustaining me in both good and bad times. Her love and understanding has made me feel both special and challenged. She has filled that deep hole in my life while expecting that I be there for her. She needed me to be the man that I always was but could never realize. I had to grow into our relationship and respond to the reality of her love for me. In the process, we built a life and family together that is firm, tender, and lasting. This has given me the platform to embrace the world more openly and with more confidence. I am no longer that small child crying in the night for his mother. There is clarity to my vision. I see other people as they are: fellow travelers on the dusty road. In my work, I am able to approach intimacy yet set boundaries with my patients. This is crucial, since my aim is not to possess the other but rather to set him or her free.

The path to individuality can take a circuitous route. When I started my residency in psychiatry in New York City, I met a fellow resident who changed my life. At that time I was quite alone, shy, and intense. Bob, in contrast, was voluble, outgoing, and joyous. He was full of contradictions: a strict Catholic who would stray and then return to the fold of the Church. We often clashed intellectually, but I was drawn to him and his wide circle of friends. This was a group that looked out onto the world with confidence and verve. In the ensuing years, I became a social animal though still remaining somewhat on the fringe of life. The war in Vietnam and marriage brought inward changes while I gained confidence in my ability to participate in the social flow of life. The friends that I met through Bob have been a constant in my life, and over the years we have celebrated time's passing. I shudder to think what my life would have been if I had never met him. Two years ago this man who was so full of joy and adventure died suddenly of a rapidly disseminated cancer. At his memorial I tried to express my sense of loss:

Gone, gone, gone. The pied piper of our dreams
Ripped from us by a God indifferent to our prayers
We had hoped for a miracle that never came
While he knew instinctively the end was near
In the hospital, he spoke of doctors, tests and drugs
Yet, always came back to the reality we avoided.
Family and friends surrounded him with their love
But we left and the nights were long and so alone

This man, this brother, our constant comrade
Strode through our lives with the force of a lion
While we struggled, he roared. The future beckoned
With images he created and we laughed along
Willing to believe that life could be enchanting.
In his presence we forgot ourselves and were less alone
This was his great gift to us, his love for us, his friends.
He was never happier than to be among us, confronting
Our conceits, regaling our fears, half smiling to himself.
With him the future always seemed possible, within our grasp.

He is gone now and there is an aching in our soul
For the man who so enriched our lives
His stories, his laughter, his merriment are gone now
And emptiness invades our memories
How can this be? Where is the meaning, the future?
We search for him in our dreams in hopes of peace
And hear again his roar. Life is for the living not the dead.
To love despite fear, to enjoy despite pain, to sing again
This is his final gift to us his forever friends.

William F. Kenny, MD, FAPA, is a Vietnam Veteran; former Director, Orange County Mental Health Center, 1972-78; former Director, Greenwich Hospital Mental Health Services, 1978-2000; and has been married for 46 years. He is the father of 2 children and spent 4 years in psychoanalysis in NYC.

REFERENCES

1 K Jaspers, *Way to Wisdom: An Introduction to Philosophy*. New Haven: Yale University Press; 1954.

2 H S Sullivan, *The Interpersonal Theory of Psychiatry*. New York: Norton; 1953.

3 R Fairbairn, *From Instinct to Self: Selected Papers of WRD Fairbairn*. Ed, E Fairbairn. Northvale, NJ: Jason Aronson, Inc; 1994.

4 A Green, *On Private Madness*. London: The Hogarth Press, Ltd; 1986.

5 C Bollas, *The Shadow of the Object: Psychoanalysis of the Unthought Known*. New York: Columbia University Press; 1989.

6 R R Lee and J C Martin, *Psychotherapy After Kohut: A Textbook of Self Psychology*. Hillsdale, NY: The Analytic Press; 1991.

Reflections on a Career in Child and Adolescent Psychiatry

> *"How soon can a child go mad? Obviously not before it has got some mind to go wrong and then only in proportion to the quantity and quality of mind which it has."*
>
> —Henry Maudsley, 1895[1]

BY NASREEN ROBERTS

Introduction

At the close of the 19th century, Henry Maudsley, a pioneering British psychiatrist, posed the above question, which, in some measure, was answered at the beginning of the 20th century. In 1909, the world's first Child Guidance Clinic was established to study biological aspects of brain functioning including IQ, social factors, attitudes, and motivations of delinquents.[2] In 1923, the Maudsley Hospital, a London postgraduate teaching and research psychiatric hospital, added a children's department. However, it took another 7 years to establish the first academic child psychiatry department at the Johns Hopkins Hospital in 1930, where Leo Kanner was the first physician to be identified as a "child psychiatrist". Kanner first used the term "Child Psychiatry" for his text book, introducing the term and the specialty to the English-speaking academic community. [3]

Although work continued across the developed world to provide care for children and adolescents, it was not till the 1950s that child and adolescent psychiatry became distinct from pediatrics and adult psychiatry. In 1952, The American Academy of Child Psychiatry (AACP) was formed, and in 1959, child psychiatry was approved as a subspecialty in the Unites States. The first batch of 101 child psychiatrists passed their subspecialty exams in 1960. *The Journal of the American Academy of Child Psychiatry* was launched in 1962, granting the field its own publication. The first child epidemiological study was conducted in 1964 by Michael Rutter, the Isle of Wight study. This was followed by similar studies in the United States and Canada, where the Ontario Child Health study (1980) became a model for evidence-based research. In 1986, the AACP voted to expand its name to the American Academy of Child and Adolescent Psychiatry. In Canada, the Academy of Child Psychiatry was established in 1980, but it was not till 2009 that child and adolescent psychiatry was given subspecialty status by the Royal College of Physicians and Surgeons of Canada, requiring additional training and an examination; the first subspecialty examination was held in 2013.

Over the last 30 years research has established that children can and do develop mental illnesses, and that some of the major adult mental disorders have their beginnings in childhood. And we have established that it is true, the disorders are "in proportion to the quantity and quality" of not just the mind but also the brain.

Research has established the role of nature and nurture in the genesis of disorders in children and adolescents. Despite promising developments in the fields of genetics and epigenetics, we must, nonetheless, ensure we keep in mind resilience and plasticity so as not be "dazzled into mistaking biology for destiny," in the words of Leon Eisenberg.[4] Meanwhile, heated debates continue over the diagnosing of children, with loud recriminations about over-diagnosis from one camp, and equally loud assertions by others that we are underdiagnosing and thus not intervening early enough to prevent adverse outcomes. These debates are made difficult as it is only since DSM III-R (1987) that we started to develop a classification system where a standard set of criteria was applied to diagnosing a child, and it is since DSM IV (1994) that there has been a comprehensive list of disorders which start in childhood. Most recently, DSM V has caused much furore as many see it as pathologizing even normal developmental behaviors. Perhaps this is so. But in my experience, well-trained child and adolescent psychiatrists who have had a sound grounding in child development and what constitutes a normal range of behaviors in the context of a child's culture and subculture, can distinguish disorder from a variation of the norm.

Initial Career Choice

I was fortunate to have joined child and adolescent psychiatry in the early 1980s. This was an exciting time to join as the field was wide open and there was room for testing novel ideas in every aspect of the biopsychosocial domains – in assessment, diagnosis, and treatment as well as reviewing the training for child and adolescent psychiatrists. It is during this time that research into psychopharmacology accelerated, providing us with empirical evidence for the use of medication in children and adolescents.

Why have some of us chosen a career in child and adolescent psychiatry? I approached a number of early, middle, and late career child and adolescent psychiatrists from different settings and different countries to share their reasons for choosing their speciality. I was expecting divergent responses depending on career stage and age, but I was surprised to find a consensus for our choice: (1) a mixture of discovering a fascinating field of research and practice as well as the good fortune of meeting excellent preceptors; (2) curiosity about children and their families – "I always found the children and families that I worked with endlessly fascinating, and the experience of success in our work together truly moving"; and (3), we all share a sense of optimism in entering a field that afforded us the opportunity to witness change in patients and families, indeed, in believing that the possibility of change was greater as children and adolescents were still developing. This sense of optimism is shared by clinicians, educators, and researchers alike; we felt we were "entering a discipline which was beginning to throw off the shackles of untested theory-driven practice and beginning to embrace practice on theories that were underpinned by rigorous testing of hypotheses". In all this we are grateful for the advances in technology and ongoing research which have informed and brought us into the 21st century better equipped to understand and serve our patients.

continued ➤

continued from page 7

Rewards

Looking back at 35 years of child and adolescent psychiatry, I see the rewards in many different areas. Child psychiatry afforded me the privilege of finding the right clinical match for my personal strengths in specializing in emergency child and adolescent psychiatry. I, like many of my colleagues, acknowledge our debt to children and their families for allowing us into their lives and thereby witnessing the changes and resilience in them. One of the most gratifying aspects of child and adolescent psychiatry is the impact of one's interventions. "By intervening we can truly make a difference in their clinical trajectory and development when their minds are still plastic." I have been astounded and humbled to witness very impaired boys and girls and their families confronting and trying to overcome the impairments caused by their short- or long-term mental illness.

A surprising and unexpected reward over the last 5 years is that social media has allowed adolescents I treated in the past, who are now adults, to contact me to tell of their progress, what part of their encounter with me was a turning point for them and their parents and, importantly, how it impacts on their own parenting.

I have been fortunate to have many clinical, administrative, and academic rewards. Working in academic departments I have had the invaluable experience of working with multidisciplinary teams (at times a challenge), which provide a rich tapestry of theoretical knowledge, philosophies, and expertise to ensure the best possible comprehensive care. Child and adolescent psychiatry has grown during my career so we have a better understanding of the complex relationship between genetics, brain physiology, and the socio-cultural environment. I have been rewarded by having time and support from my colleagues, departments, and universities to generate ideas, test them, and then see them implemented. Post graduate education has been a serendipitous reward for me: I never saw myself as a teacher; in fact, I was the teacher's bane as a student myself, yet this aspect of my work has grown on me. I have had tremendous enjoyment and stimulation from the curiosity of residents and fellows and been rewarded by trainees, who were either ambivalent or not considering child psychiatry as a career, to go on to become child and adolescent psychiatrists. Being involved in postgraduate teaching at a provincial and national level afforded me the satisfaction of influencing the developments in the child and adolescent psychiatry curriculum and training. Lastly, I did not set out to be an administrator, and I did not feel I had the patience or diplomacy this took, yet having arrived into this necessary part of my position, I have reaped the benefits of being able to influence hospitals, departments, and the Ministry of Health to support and fund new clinical programs that have proven to be effective.

Challenges

Rewards would not be rewards if we did not have to deal with the accompanying challenges. In child and adolescent psychiatry, the chronic shortage of child and adolescent psychiatrists globally and in Canada has made it very difficult to recruit child psychiatrists. There are simply too few of us, which results in long waitlists for care and the ensuing understandable dissatisfaction of patients and their families. There are efforts underway to address this shortage but it will take time, especially with the additional year of training and another exam for certification. For me, the inadequate resources in health, education, and social services have been an ongoing challenge and the least acceptable one. We are a first-world country, and I feel we should be able to provide the optimal (not minimal) level of care to our most vulnerable group of children. Despite the rhetoric, we see very slow and small changes at policy and funding levels to address this sad state of affairs. Access can only be improved if we have enough staff to service the ever-growing need, especially of patients who have complex comorbidities that make for longer-term needs.

Another major challenge is the stigma associated with mental illness. This is pervasive but much more noticeable in child psychiatry as the barriers it creates to accessing and utilizing treatments lead to my failure to engage a child and the parents or caregivers. The lack of knowledge and awareness in the parents and even the educators can pose a serious challenge in engaging and treating a child or adolescent. Residents rotating through our service have frequently commented on the impotence of the psychiatrist in the face of parental noncompliance and, at times, frank hostility. I have found it frustrating when this leads to my inability to convince an adolescent or parent to accept treatment even in the face of clear evidence of the problem and the availability of effective treatments that will change the trajectory of their and their child's lives.

A substantial challenge lies in the fact that many of the children and adolescents we see need some changes in their family system, in their schools, and in their neighbourhoods. We need a concerted plan that addresses all these areas to bring about change, even as we struggle with each person's or system's own hierarchy, philosophy, and understanding of the problem and its solution. For me, getting all these various players to work together is immensely time consuming and frequently frustrating; I find myself asking why it is, when we are talking about the same child and the same problems, we are not working together to get all the pieces in place to help change the outcome. As I frequently explain and state, just medication or just counseling does not work if what makes for a troubled journey in the school or home cannot be altered at the same time.

continued ➤

continued from page 9

Child and Adolescent Psychiatry in the 21st century – who will want us, who will need us

I have paraphrased the title of Dr. Quentin Rae-Grant's 1986 article to assist me in organizing my thoughts for demonstrating child and adolescent psychiatry to those interested in exploring it or even joining us.[5] Rae-Grant was a Canadian scholar, educator, and pioneer of Canadian child and adolescent psychiatry whose scholarly article noted that one of the main challenges for child psychiatry would be to develop more efficient ways of using the skills of the child psychiatrists. He felt we required a more flexible metaphor for training and practice with competence in the different schools of theory and of therapy. He signaled the importance of the consumer movement and the impact of better informed parents and public on our future practice. He discussed the importance of developing a parsimonious and selective approach ("lean thinking," in 2015 jargon) to the use of scarce professional time.

I do not wish to get up on my soap box, but I would be remiss if, despite this optimism, I did not comment on the breakdown of cohesive communities, dissolution of families, and lack of social and emotional supports which have all contributed to our arriving at parenthood, even one that is planned, under-equipped to deal with anything but a truly well-behaved, articulate, self-regulated child (in fact a little adult). We have demonized and pathologized children's behaviour without considering their age and developmental stage; we seem to overlook the fact that self-actualization takes time and that children need not just love but consistency, structure, predictability, and expectations which are commensurate with their age. This applies across the board, whether a child has or will develop a major psychiatric disorder or a temporary glitch in adjusting.

Conclusion

From a historical perspective, child and adolescent psychiatry answered Maudsley's question: we have established that a child can certainly have a mental disorder with just his brain and not only when he has a mind. We agree with his assertion "in proportion to the quantity and quality of mind (brain really) which it has," but with a caveat that the brain is still developing and this plasticity gives us hope for change. (It is this possibility of making a real and, in some cases, a lasting change that attracted me to this subspecialty.) Personally bearing witness to the developments over the last 40 years, as a trainee and then faculty, I have seen each decade bring some new theory, some new therapy, some new fad to be tried and replaced by something else based on new evidence and a different perspective. My training was eclectic but heavily influenced by psychodynamic theory and behaviorism; our present state is perhaps one of integrated understanding distilled from all the previous theories. We have the privilege of deciding how we work now with a clearer understanding of the role of the complex biopsychosocial factors that contribute to the psychiatric disorders and their treatments in children and adolescents.

I have had the luxury of witnessing the evolution of child and adolescent psychiatry from a child of a lesser god to "al nino del oro" of psychiatry. As a scientist, I have been rewarded for clinical research and seen the results used to implement changes for better service. As an active clinician, I have had the highest honour of watching children and families overcome adversity, stigma, and long held beliefs to arrive at a better understanding and solutions. If I have helped change the trajectory of even one child and family I have contributed to a better world. I can honestly say even in the autumn of my career that there is not a single day I have gone to work wishing I did something else. Each day brings a new challenge which I find stimulating and rewarding to overcome. In the coming decades all the research in genetics, neuroimaging, and other new techniques will not only affect our work with children, but also determine the type and number of professional organizations that will be needed to treat children and adolescents with mental illnesses. What is important is that we are training child and adolescent psychiatrists who are well-equipped and cognisant of the exciting possibilities in clinical work, teaching, and research. We have followed the sage advice of Dr. Rae-Grant – we have streamlined our role within the multidisciplinary team with parsimony. We are using technological advances to ensure we communicate effectively with the "consumers". Our trainees, children of the cyber age, well-versed in the power of social media, are better situated than their predecessors in the 80s and 90s to address children's and parents' needs in a manner that improves use of our services. Our training curriculum has been adjusted to keep up with the latest evidence-based knowledge and the needs of our times.

Nasreen Roberts, MBBS, MRCPsych(UK), FRCPC, MSc(Epid) received her psychiatry training in London, UK. She emigrated to Canada in 1981 as lecturer at the University of Ottawa, where she pioneered the Urgent Consult service for expedited risk assessment for children presenting to the emergency rooms. Dr. Roberts was then Head of child and adolescent psychiatry emergency and crisis services at the Hospital for Sick Children in Toronto. Since 2000, Dr. Roberts has been at Queen's University. She is a Professor and holds the Chair and Head of the Division of Child and Adolescent Psychiatry since 2009.

REFERENCES

1 W L I Parry-Jones, "The history of child and adolescent psychiatry: its present day relevance," *J Child Psychol Psychiatry* (1989) 30(1): 3-11.

2 J E Schowalter, "A History of Child and Adolescent Psychiatry in the United States," *Psychiatric Times* (2003) www.psychiatrictimes.com/articles/history-child-and-adolescent psychiatry-unitedstates/page/0/3#sthash.

3 J E Schowalter, "Child and Adolescent Psychiatry Comes of Age, 1944-1994." In R W Menninger and J C Nemiah (eds.), *American Psychiatry After World War II – 1944-1994*. Washington, DC: American Psychiatric Press; 2000, p. 461-480

4 L Eisenberg, 'The past 50 years of child and adolescent psychiatry: a personal memoir," *J Am Acad Child and Adolesc Psychiatry* (2001) 40(7): 743-748.

5 Q Rae-Grant, "Child psychiatrists in the 90s: Who will want us, who will need us," *The Canadian Journal of Psychiatry / La Revue canadienne de psychiatrie* (1986) 31(6): p. 493-498.

On the Nature of Neglect of Persons with Developmental Disabilities

BRUCE D. MCCREARY

Introduction

Having been involved in the care of persons with developmental disabilities for half a century, I find it difficult, sadly, to avoid Jean Vanier's conclusion that these individuals are "among the most oppressed and excluded people in the world".[1]

The neglect of persons with developmental disabilities is pervasive – medical, educational, social – and often appears to resist the efforts of advocates to reduce it. Neglect of an individual or of a group of individuals with shared characteristics like intellectual and adaptive impairments reflects both passive inattention to their special needs and a more active kind of discrimination called "stigmatization" in contemporary parlance. Inattention and stigmatization are distinguished here to suggest that, while simply informing others about their needs might reduce neglect, it is more likely that additional efforts to prevent or modify problematic attitudes and to teach relevant communication skills are necessary for success.

This essay endeavours to explore neglect and to investigate why sincere efforts at advocacy have often failed to have a significant impact on improving the care provided.

Medical Neglect

Prior to and during World War II, persons with developmental disabilities were not only neglected medically, but also euthanized as persons seen as having "lives not worth living" by the Nazi regime in Germany.[2] While this era illustrates an extreme that goes far beyond what most would now conceive as neglect, it merits consideration in terms of identifying the nature of neglect and the failure of advocacy, although feeble at that time, to reduce it. It also serves to illustrate that simple inattention to the special needs of persons with developmental disabilities can be entirely submerged by attitudes that outright deny their dignity as fellow human beings.

But what evidence do we have for neglect in contemporary medical practice and what kind of advocacy has been mobilized to reduce it? When Mencap, a UK advocacy organization, published *Death by Indifference* in 2007,[3] many were shocked to learn that individuals with developmental disabilities were dying unnecessarily in circumstances characterized by inadequate training of health care professionals, faulty arrangements for coordinated health care delivery, and a failure of those responsible for quality assurance to correct obvious systemic problems. In spite of an outcry in the UK media and a major investigation by the National Health Service, there is worrisome evidence that improvements in training, service delivery, and monitoring of health care provision have yet to adequately resolve the UK challenges.[4]

Ontario researchers,[5] having demonstrated worrisome disparities in health care provision for persons with developmental disabilities, have suggested the following:

- Improving quality of primary care based on best evidence and care standards,
- Modifying broader health care structures and processes, and
- Strengthening partnerships with patients, their families, and their paid caregivers.

It is sobering to consider these suggestions in relation to Wolfensberger's 1991 retirement essay where he reviewed advances in care: "One important thing that we should note about the positive changes is that a remarkably small proportion were the result of significant research, scientific or technological developments. The overwhelming bulk of the improvements all derived from two states of mind that are available anytime, anywhere, to anybody: imagination and a humane attitude."[6]

One is left to conclude that, while medical neglect is significantly less than in Nazi Germany, it continues in the developed world. There is clearly room for improvements, some to be based on scientific attention, but more based on recognition that stigmatic attitudes can significantly hinder progress.[7]

Educational Neglect

For the purpose of reviewing educational neglect, this section considers both the education of persons with a developmental disability and of non-disabled youth who can usefully learn about empathy for disabled persons and how to express it; the aim of the latter is to explore the possibilities of reducing stigmatic attitudes increasingly seen to represent a burden for disabled persons beyond the direct burden of their intellectual and adaptive impairments.

There is ample evidence that neglect of the educational needs of children and youth with developmental disabilities reduced significantly over the 20th century. One can detect a sequence of improvements from total neglect, to segregated instruction, to "mainstreaming," now the norm in most of the developed world at the start of the 21st century. And early in the present century there is growing recognition of the role of post-secondary and adult education programs, so that older individuals can function optimally in self-care and employment. In most jurisdictions, institutions, originally called "hospital-schools," have been replaced by community-based public education. Advocacy for these improvements can be described fundamentally as "parent-driven"; parents grouped together to develop local classes and schools and then, having demonstrated their benefits, demanded that governments assume financial responsibility for their operation. In contrast to the inconsistent and patchy training of healthcare professionals about the special needs of persons with developmental disabilities, teacher training in "special education" is well established. Indeed, it is likely that Colleges of Education could assist those responsible for training healthcare professionals in correcting their current deficiencies.

I confess a particular interest in the possibilities of preventing the development of stigmatic attitudes, an interest shared with UK autism expert Simon Baron-Cohen[8] who recommends that we teach empathy along with the 3 R's. My own interest in these issues has grown since I observed how non-disabled students interacted over time with mainstreamed disabled peers. In junior grades, disabled students were fully accepted and supported with little guidance from teachers or teacher assistants. However, by grade 6 or 7, non-disabled individuals became preoccupied with their own issues (e.g. appearance,

continued ⮟

continued from page 13

dress, gender identity, fads) and, unfortunately, awareness and concern for their disabled classmates fell by the wayside. As part of my consulting practice in southeastern Ontario, I had the privilege of visiting local schools to review the progress of some of my patients. I can report that they were puzzled by the changes in their fellow students and, while some appeared indifferent to them, others reacted with mood and behavioural disruptions – their first experience of stigmatization. I believed then, and believe more strongly now, that teachers and teacher assistants could turn this troubling scenario to advantage by providing guidance and instruction about empathy. All students, disabled and non-disabled, would benefit.

So we can conclude that improvements in the education of youth with developmental disabilities occurred over the 20th century, and to a considerable degree these improvements represent the hard work of dedicated parent advocates. We are also challenged to consider the desirability of educating non-disabled students about empathy since indifference and stigmatic attitudes appear to have their roots early in life.

Social Neglect

Social neglect includes failure to support the families of disabled persons and to provide direct supports (residential, employment, recreational, etc.) for disabled adults themselves, particularly when parents are no longer available to assist them because of infirmity or death.

Early in the 20th century, public policy was focused on the provision of life-long institutional care; such arrangements were seen as optimal for disabled individuals while simultaneously taking up the burden of care from families. Particularly after World War II, partly because institutions had become seriously overcrowded and poorly funded, and partly because innovative approaches to community-based care provided another option, a policy of deinstitutionalization was established. Exposés of neglect and abuse in institutions and strong advocacy from families based on the normalization principle promoted the shift in public policy. Here in Ontario all of the regional institutions were closed by April 2009 and "social inclusion" legislation replaced the Developmental Services Act, which had been in place since 1974.

Five years into the "new" era we can ask if longstanding social neglect is being reversed – are families receiving adequate support, and are disabled persons being successfully "included" in local communities? Previously, I expressed concern about the vulnerability of persons with developmental disabilities, the challenges faced by local service providers in successfully integrating them in their offices and clinics, and the absence of arrangements to recognize and respond to evidence of abuse or neglect.[9] More recent developments suggest my concerns were warranted. Ontario's Select Committee on Developmental Services, created in October 2013 and reporting in July 2014, noted "that individuals and families who need developmental services and supports are in crisis" and set out 45 recommendations for improvements to be implemented by a new Interministerial Committee.[10] Although the Ministry of Community and Social Services immediately announced "new" funding, particularly to enhance individualized direct funding for persons with developmental disabilities, the recommendation to establish the Interministerial Committee to oversee implementation of the other recommendations was rejected. In

November 2012 the Ontario Ombudsman established a formal investigation of increasing complaints that adults with developmental disabilities were unable to access needed assistance; a report on this investigation is pending.[11]

Accordingly, we can conclude that, while there has been success in closing traditional institutions that had become demonstrably unable to provide optimal care for persons with developmental disabilities, there is ample evidence that "social inclusion" has yet to be shown to be a viable alternative. Contemporary planners are either unmoved by concerns expressed by advocates or are simply incapable of implementing approaches that will successfully resolve current levels of social neglect.

Conclusion

As we examine the evolution of public policy concerning persons with developmental disabilities through the lens of neglect, clear evidence of "from the frying pan into the fire" emerges. The now-abandoned institutional approach represents the frying pan and the current crisis in implementing social inclusion is the fire. What is needed now is a close examination of our successes in reversing neglect and the courage to apply what we can learn from them in revisiting our failures.

In contrasting medical, educational, and social neglect we have observed some success in providing public education for persons with developmental disabilities at the primary and secondary levels. What factors appear to have contributed to this success? The list would include the following:

- Establishment of pilot schools or classes to demonstrate their effectiveness,
- Strongly committed parent advocates,
- Responsive political and government officials, and
- Effective training programs for "special education" professionals.

This list can serve as a checklist for those who are responsible for addressing our continuing challenges in reversing medical and social neglect.

I will conclude with a final comment on the suggestion to provide instruction on empathy and the possibilities for preventing stigmatization. That stigmatization reached a disastrous level in Nazi Germany and that advocacy to resist it was almost non-existent has already been noted. However, we also need to consider that the UK's *Death by Indifference* report and the current crisis in implementing social inclusion represent diluted evidence – considerably diluted, but evidence nonetheless – of "lives not worth living". Should this be so, it is clear that we need to actively immunize our children and youth during their formative years against the development of such stigmatizing attitudes. Indeed, modeling and teaching empathy, especially how to communicate with persons with developmental disabilities to signal their worth as fellow human beings, may be what social inclusion is all about.

The challenges involved in making a place for the disabled in the broader community are longstanding. Biblical scholars may identify with these challenges: "As He passed along He saw a man who had been blind since birth; and his disciples asked Him, 'Rabbi, for whose sin – his own or his parents – was he born blind?' Jesus replied, 'Neither for his own sin nor his parents – it was to let the work of God be illustrated in him.'" (John 9:1-3)

Bruce D. McCreary, MD, FRCPC, joined the Queen's Department of Psychiatry in 1968 and established the Division of Developmental Disabilities in 1977. Since retiring from clinical practice in 2010, he has continued scholarship in topics related to dual diagnosis and contributes to the Division's teaching programs. He also serves on the Board of Ongwanada.

REFERENCES

1 J Vanier, *Becoming Human*. Toronto: House of Anansi; 1998.

2 R J Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide*. New York: Basic Books; 1986.

3 *Death by* indifference*: Following up the* Treat me right! *report*. London: MENCAP; 2007.

4 I Tuffrey-Wijne and S Hollins, "Preventing 'deaths by indifference': identification of reasonable adjustments is key," *Brit J Psychiat* (2014) 205: 86-87.

5 Y Lunsky, J E Klein-Geltink, and E A Yates (eds.), *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*. Toronto: Institute for Clinical Evaluative Sciences; 2013.

6 W Wolfensberger, "Reflections on a Lifetime in Human Services and Mental Retardation." *Ment Retard* (1991) 29: 1 1-15.

7 B D McCreary and A Rischke, "Intellectual Disability and Stigma: an Ontario perspective." *Clinical Bulletin of the Developmental Disabilities Division,* Schulich School of Medicine and Dentistry (2013) 24(3): 1-5.

8 S Baron-Cohen, *The Science of Evil: On empathy and the Origins of Cruelty*. New York: Basic Books; 2011.

9 B D McCreary, "Welcome to our community! Social inclusion for persons with Intellectual and Developmental Disabilities." *Clinical Bulletin of the Developmental Disabilities Division,* Schulich School of Medicine and Dentistry (2012) 23(1): 1-6.

10 "Inclusion and Opportunity: a new path for Developmental Services in Ontario," Final Report of the Select Committee on Developmental Services, July 2014.

11 "Ontario Ombudsman to investigate province's services for adults with developmental disabilities in crisis," Press release, Ombudsman Ontario, 29 Nov 2012.

Glosa

BY BETHMARIE MICHALSKA

Teach me half the gladness
That thy brain must know;
Such harmonious madness
From my lips would flow,
The world should listen then, as I am listening now.
— from Percy Bysshe Shelley's, "To A Skylark"

Did you know that each year
birds sing different anthems?
BrdU science shows these
creatures make fresh neurons,
growing sound inventions–
everlasting newness!
From their raw experience,
setting down connections,
chirping voluptuousness!
Teach me half the gladness.

Human brains advance
neuroplastic growth.
Stem cells produce new
forms to specialize.
This was not the thought
most had *ab ovo.*
Such exciting finds
of the last few years,
inner cosmic show –
that thy brain must know

Mental health providers
work to combat stigma,
see the fear – that "different"
triggers violence. When
people still blame victims,
nothing's learned. Stale radness
systemizes hatred.
Geel presents one kindness
that transforms much sadness –
such harmonious madness!

Poet as I am,
psychotherapist,
making metaphor
take its active role,
lifting hearts again,
after they've dropped low.
"New paths still exist,
find support out there,
choose now how to go!"
From my lips would flow

We still have ears to hear, a chance to comprehend
the ways that might bring light to spirits crushed or bent.
Sometimes to be a witness is a role to take.
Bring stories forward to a power – advocate.
Or like the bird's new tune, the skylark warbling high,
share something radical; express your voice. Ask how
the suffering people think that one could benefit
from sources known to you; seek peers for their thoughts too.
Delight might still come through a deeply-furrowed brow,
The world should listen then, as I am listening now.

A **glosa** is an early Renaissance form that was developed by poets of the Spanish court in the 14th and 15th centuries. In a glosa, tribute is paid to another poet. The opening stanza, called a *cabeza* (Spanish for "head"), is by another poet, and each of their —usually four (but in this case five)— lines are embedded elsewhere in the glosa.

The opening stanza is followed by usually four, but in this case five, stanzas (it's five here because Shelley's poem had five-line stanzas), each of which is generally ten lines long, that elaborate or are "glosses" on the *cabeza* chosen. Each ending line (the tenth or last line) of the following five stanzas is taken from the *cabeza*. The usual rhyme scheme of a glosa is final word rhyming of the 6th, 9th, and the borrowed 10th line.

Source: paraphrased slightly and adapted for a 5-line stanza "situation," from the following site: http://poetic-forms.deviantart.com/art/The-Glosa-8932612

North Superior Bardo, Bethmarie Michalska's first poetry chapbook, was launched at Novel Idea bookstore in 2014. An Assistant Professor (Adjunct) in the Department of Psychiatry, Queen's University, she maintains an active private practice in clinical counselling and health psychology in Kingston, ON.

15-0204 Queen's Univrsity Marketing