

## **True North: The NAMI Provider Education Program Comes of Age**

By Joyce Burland, PhD

The final report of the President's New Freedom Commission on Mental Health concluded that the nation's mental health system was "in shambles", and proposed a set of guidelines designed to fundamentally re-invent mental health care. The urgent tone of the report has inspired an outpouring of commentary calling for innovation and "seismic" change. In part, this shift in direction reflects the influence of leaders within the system whose progressive views on mental health reform have gained ground once the ailing system was officially declared beyond resuscitation. But the real credit for advocating radical transformation in the way people with mental illness are served in America belongs to the foot soldiers in the family and consumer movement.

This is another way of saying that our unwavering insistence on inclusion, validation, and respect over the last generation has not been in vain. A review of the recent system-change literature reveals that our ideas, and our ideals, inform many of the papers and proposals currently in circulation. Chief among these is a concept, staggering in its potential to revolutionize mental health care service delivery, called "True North."

In navigation, true north defines an ordinal point determined with reference to the earth's axis, rather than its magnetic poles. Synonymous with "accurate", "legitimate", "trustworthy", this term signifies an absolute reality rather than something which is manifest or assumed. A craft navigating by true north will unfailingly find its intended destination. In health reform, True North stands for an unerring guidance point in system transformation. Donald Berwick, the originator of this metaphor, proposes that in planning for reform, "the experience of consumers and families and communities" must serve as True North. This means the ordinal point for system quality derives from the *recipients' reality* – our lived experience, our needs, our beliefs and strengths as well as our reactions to services extended in our behalf. In the *Quality Vision for Behavioral Health*, authors Allen Daniels and Neal Adams advance this concept, state that in reinventing mental health care, "nothing is more important in the end than maintaining focus on the experience of recipients of care and their families. This commitment must set the compass and serve as 'True North' on the roadmap to change."

Rarely do we get a more telling correction, or subliminal analysis, suggesting why the mental health system veered so far off course. If the truth be told about our perceptions right now, the most significant feature of our reality is that so few people know anything about it. How many times have we heard families and consumers say that no one can possibly fathom the excruciating dislocation of mental illness, until it has actually happened to them or to someone they love? The late Senator Paul Wellstone observed that most Americans learn about mental illness only through "intense involuntary immersion in it." Most others are oblivious to the enormous pain and trauma of this passage, and remain totally unaware of the tragic insufficiencies of our nation's response to it.

Many observers have attributed this cluelessness to the social distance (actually social isolation) imposed on those stigmatized by brain disorders. However, relatively few cite the drastic impact of professional and academic misdirection affirmed throughout most of the 20<sup>th</sup> century. The claim that mental illnesses derive from poor parenting and/or weak character suggests that the source of our trouble is more a private failing than a legitimate national concern; such a view from authorities in the mental health field deeply anesthetized the moral awareness of civic responsibility in the public mind. Furthermore, this same mistaken certainty supported the clinical premise that since the experts already “knew” the causative personal details of our reality, there was little left of any importance to learn from us. Inevitably this assumptive error jarred the compass of True North; a mental health system evolved to assist people stricken with serious mental illness without an accurate or sufficient understanding of the true nature of this human experience.

In 1995, NAMI-Vermont developed and piloted the Provider Education Program in each of the state’s ten public mental health agencies. This training model specifically targeted agency line staff, the yeoman workers who provide most of the day-to-day services to consumers and their families. Many of these direct care providers have no prior education or training in clinical interventions of any kind; they comprise a segment of the mental health workforce estimated at 40% of public agency clinic staff, and 60% of patient care staff in county and state psychiatric hospitals. We invited this group to undergo intense *voluntary* immersion into the private universe of families and consumers, promising that this experience would help them to offer what we needed most: an understanding, empathic, well-informed partner to work with us toward recovery.

Setting our compass squarely on True North, we trained NAMI family members, consumers and providers to teach the course in teams of five. They vowed to come to class prepared to reveal every raw emotion, personal truth and unedited response to mental illness, relating to the course content, as a core part of the curriculum. Operating from our no-fault educational mantra that “You Can’t Know What No One Has Told You”, we opened the door to our subjective, often chaotic world. We trusted that in ten weeks of working through the course together, the cumulative accounts of our lived experience with mental illness would tap into a common humanity and compassion more powerful than any socially or professionally conditioned belief system. And it worked. By the end of each course in the pilot project, the participants had witnessed the immense challenges involved in coping with mental illnesses, and acknowledged the elemental value of learning how to collaborate with supportive family caregivers.

Since 1997, NAMI organizations in 28 states and the Province of Ontario, Canada, have joined in to offer the program. Over 500 consumers have been trained as teachers, and over 6,000 staff members have taken the course. From every quarter we hear from providers that our commitment to “True North” has opened their eyes to suffering and heroism they had not seen, warmed their hearts to consumers and family members they had not understood, and made the Commission’s call for a “consumer-and-family centered system” a tangible reality. Recounting our lived experience has demonstrated that recovery and resiliency can be achieved; it has reinforced the principle that our shared humanity must govern every domain of mental health care. Most radically, the

program has called into question the claim that authority accrues only to an “all-knowing” professional elite. This model of training is a potent catalyst of transformative *empowerment* – of advocacy-through-education – enabling consumers and family members to take their rightful place as frontline experts and legitimate instructors on the subject of living with mental illness.

In 2004, the NAMI Provider Education Program was selected as an outstanding innovative training program by the Annapolis Coalition on Behavioral Workforce Education. This coalition of progressive mental health administrators and clinicians argues that “without conscious, concerted and urgent attention to improve workforce education”, meeting the goals of the President’s Commission may elude us altogether. To speak of system transformation without insisting on cutting-edge training programs for the workforce at all levels, defeats the purpose and spirit of reform. If we ignore this “elephant in the room,” the workforce will retain the old attitudes and habits which blind them to the competencies required for compassionate and collaborative practice. We must join together, as system reformers and advocates, to train and re-train the workforce, and to make True North the ordinal point for change in mental health care in America.