Michigan Association of Community Mental Health Boards

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Connections

for communities that care

ON YOUR OWN WITH NO DIRECTION HOME

The Threat Narrow Health Reform Strategies Pose for Consumers and Communities

Patrick C. Barrie

In the eulogy he delivered at Patrick Barrie's memorial service, James Haveman remarked, "He shaped many of today's current programs, for many he was the primary architect." Patrick's most recent thinking was focused on the changes precipitated by the Affordable Care Act. It was circulated in a document containing nearly 10,000 words he titled "The Sisyphus Project," an analogy borrowed from Greek Mythology in which Sisyphus is condemned by the gods to a life of hard labor pushing a heavy boulder up a hill only to have it roll back down just before reaching the top.

Most people believe this to be a tragic tale of a life lived without meaning. But there is much more to the myth. First, Sisyphus was acknowledged as a very cunning individual, tricking even Hades, the god of the underworld, and escaping death. But perhaps most significant, as the existentialist writer Albert Camus intimates in The Myth of Sisyphus, *"One must imagine Sisyphus to be happy." Why? Sisyphus knew no task is ever complete or perfected. It is enough to know you are fully engaged with all your cunning.*

Although this article has been carved down by nearly two thirds, it is still a substantial rock. To read the entire unedited version, which includes references, go to: www.macmhb.org and click on the Connections link.

— Clint Galloway, Editor

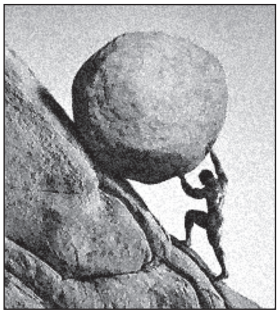
This paper registers alarm regarding the direction and emphasis of health integration plans and/or proposed changes in the configuration of public programs (including, but not limited to, the state's evolving plan for dual eligible beneficiaries). Pushed by federal agencies, and buoyed by financial incentives, the pursuit of such health alignment strategies may seriously destabilize local governance arrangements and social care delivery systems that have been specifically established to address the more extensive care parameters of special need populations and the least well-off.

Much of the impetus for integration or realignment comes from the passage of health reform (the Affordable Care Act) and various inducements being offered by the Centers for Medicare and Medicaid Services (CMS) primarily related to Medicare Part A and B expenditures. The models and approaches incentivized by CMS are shoving social care arrangements (underwritten in part by Medicaid) in directions that subsume social care delivery (currently managed by specialized local governance systems) into large health systems or other private health plan arrangements. There seems to be little appreciation in the CMS health centric world that such social care arrangements are inextricably linked to other community social and community services that are vital complements to the specialized supports covered by Medicaid.

Many in the health sector welcome the medicalization of social care and supports, and the shift in the governance of these services from public structures to health systems and private entities. Administration of these services by professionals or through private "managerialism" is preferred to the presumed "messiness" of public governance structures and democratic procedural requirements.

Furthermore, some advocates and consumers of social care/community support arrangements applaud any change that reduces what they regard as the petty bureaucratic "mandarins" in locally governed systems, who pose unnecessary obstacles to participant direction and control.

However, what may be welcomed (professional oversight of social care) by health sector professionals, or lauded (demise of local structures) by advocates, is considered in this paper as threats to



individual and community well-being, to democratic governance and to the broader concept of a common good (in other words be careful what you ask for!).

In drawing a distinction between medical and social care, and in disputing the direction of integration and/or alignment, this paper explores the "democratic deficit" in emerging models, and tries to make a case for public governance and collective action.

Social Care is Different from Medical Care

Medical care is defined as evaluation, treatment, intervention and/or management of any emergent, acute, and/or enduring injury, infection, illness, disease state, or condition; provided by (or under the supervision of) qualified medical practitioners in a home, office, outpatient clinic, ambulatory care setting, inpatient hospital centers and/or nursing facility.

Social/community care is defined as a broad set of enabling services, such as personal assistance for activities of daily living; supervision and supports for instrumental activities of daily living; skills acquisition and/or retention training; habilitative or reablement services; various accommodations to enhance functional capacities and/or to promote community participation; transitional assistance for transfers into a community based home or residence, and back-up response systems. These services/supports are arranged/obtained through a case manager or supports coordinators, and facilitate the least restrictive, most integrated setting for the individual.

The public mental health system was established as a priority population, severity-based, resource constrained, queuing (wait list), and rationed care system for the "least well off" seriously mentally ill or developmentally disabled individuals. Over time, funding arrangements became more diversified and community support options expanded.

However, then and now, very few of the services and supports provided through the public mental health system for persons with serious mental illnesses, substance use disorders and/or developmental disabilities could properly be termed "medical care" as described above.

The overwhelming volume of mental health encounters involve case management, supports coordination, community living supports, skills training, attendant services, supervised monitoring, supportive employment, habilitation and rehabilitation services, caregiver respite, psychosocial rehabilitation, crisis stabilization, residential (in-home) assistance, peer specialist services, and other non-medical forms of care.

Medical care is a well-financed enterprise—dominated by insurers, hospitals, and physicians—providing insured individuals with a universal claim to policy/plan covered benefits, consistent with medical need, as determined by physicians and practitioners, and subject to payer authorization and utilization management.

On the other hand, social care and community support systems for the mentally or developmentally disabled (and for the physically disabled, the traumatic brain injury patient, and for seniors) are underfunded, frequently means-tested, rationed, and generally locally organized with significant user/family participation in care system governance, policies and service practices.

Most social care and community support systems are also inextricably linked to other local agencies, non-profits and charitable organizations that offer complementary components necessary for community living (e.g., housing, vocational rehabilitation, income supports, etc.). Moreover, social/community care provision arrangements are actually comprised of many overlapping social care systems, each with slightly different target populations, distinct missions and legislative mandates, multiple funding sources, and a gradually assembled core of provider networks. This patchwork configuration of overlapping systems reflects historical developments, hard-won delineation of population and service priorities, piecemeal accretion of necessary resources, and use of means-tested or ability-to-pay criteria to manage overwhelming demand (frequently accompanied by waiting lists).

Social care and community support systems have slowly and incrementally devised a hodgepodge of resource streams to underwrite the cost of social/community care for designated populations and recipients. In the mental health arena, creative design of optional benefits and waiver programs—targeted for beneficiaries with serious mental and/or developmental disorders—along with redeployment of existing state and local mental health resources (to provide the non-federal match share required to draw down federal financial participation), expanded the resource pool underwriting social care and community supports for mentally/developmentally disabled individuals. The creative benefit design and funding strategies played a key role in facilitating the state closure of 33 psychiatric hospitals, developmental centers, and other specialized facilities over the past 30 years (saving the state billions of dollars).

However, devising and co-funding these targeted and tailored Medicaid optional benefits and waiver programs (without new state general funds to match federal contributions) did not mysteriously convert these social care and community support benefits into "medical care" services to be administered through health plans or integrated medical care systems. These expanded community support services were, and remain, variants of social care arrangements, and should remain under public governance and management structures.

Medicaid is the largest but not the only funding source underwriting community support and social care arrangements for persons with serious mental illnesses, developmental disabilities and/or substance use disorders. Regardless of funding source, the public mental health system retains its primary identity and character as a social/community care system, not a medical care system.

Medical care insurers, health systems, and managed care organizations have vigilantly guarded the border between medical care and social care/community supports. These medically oriented systems have only a rudimentary understanding of the underfunded, resource constrained, and rationed social/community care systems that lie beyond the border of medical care; neither do they have the requisite, tacit knowledge of the linkages between social care systems and other local agencies/assistance networks. One managed care organization that has explicitly grappled with the differences and gaps between medical care and community support/social care is Kaiser Permanente. KP was interested in health-social care integration for its commercial plan members, and boldly attempted to examine the gaps between medical care and social care/community support system. KP put its money where its mouth was, funding 32 projects to investigate the medical care-community service interface. The results of many projects were intriguing and interesting (but also sobering), leading KP to conclude that better linkage, communication, and coordination—not integration with underfunded social care/community support systems—was the most practical path to foster understanding and engagement between medical care and social care systems.

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A recent study reported in the journal *BMJ Quality and Safety*, suggests that more spending on social care and social services rather than subsuming social care resources and services into the medical care system could significantly modify medical care cost trends. Realization of such results implies somewhat less stringent criteria for social care and supports, as well as safeguarding these resources for their intended purpose.

The existence of multiple social care/community support systems is not an accidental phenomenon; these systems have different mandates and distinctive objectives. Illness, like disability, is a part of life. We all occupy a common world with shared vulnerabilities and universal experiences of ill health, disease and (over time) declining functional capabilities and disability. Everyone needs and relies to some extent upon medical practitioners, hospitals, technologies, devices, drugs and delivery systems.

Medical care is no less important to working age individuals with mental/developmental disabilities than to the rest of the population. However, medical treatment is not the sole concern of working aged disabled individuals. They need personal assistance, skill building, community living supports, income supports, affordable housing, transportation, meaningful activities and/or employment, opportunities to participate, to be recognized, and to have their voices heard. Hence, while it is silly and naïve to deny the importance of medical care, it is also foolish to negate or ignore the significance of social care and community supports arrangements.

Despite the critique of health plan and managed care organizations, one cannot dismiss the impressive capabilities and infrastructure of these systems. Rather, the point is to suggest that these capabilities are minimally transferable to social care and community support systems. One publication suggests that using health plans or commercial managed care organizations in social care was akin to "...pulling in a tank battalion in pursuit of small game."

Furthermore, the hegemony of medical care within a plan that includes both health services and social care/community supports runs the risk of social care resources being slowly siphoned off to address rising costs in medical care. This is an avoidable tragedy, since other arrangements in which medical care is not the dominant "partner" may offer better medical cost-containment potential without reducing social care resources.

Certain characteristics of social care/community support systems, the intended (and prioritized) recipients and purposes of such care, and the role of government in allocating funds among various diverse populations in need, strongly imply that social care systems should fall under the ambit of public governance. These systems are naturally closer —and subject to—political authority, rather than market mechanisms or non-governmental private administrative/managerial control. Democracy requires political and policy choices, and government has the recognized (and necessary) legitimacy for making difficult rationing or resource decisions.

GLANCING BACK

It has been less than a generation since caregivers, often mothers, stood up and insisted that the needs of the developmentally disabled be recognized and addressed in educational settings, and in the broader community. In that same period, families with practical and experiential awareness of gaping holes in community support systems for individuals with serious mental illnesses insisted that these problems be brought "out of the shadows" and confronted by government and society. Finally, denial and avoidance of an "invisible" epidemic of substance abuse (and later co-occurring mental illness and substance use) could no longer be maintained, although societal response continues to lag.

Those who have advocated for, and have achieved improved social and community care for persons with these disabilities and/or impairments, recognize that there are things that should be defended and conserved. Past breakthroughs must be protected, care arrangements must be honored, and networks and linkages must be maintained during volatile and transitional times. One author describes these activities as "social safekeeping" and notes that:

"Safekeepers do more than defend the past; they also repair the damage from complacency and counterattacks, expand the reach of promising ideas, create new innovation, and remind society of the great potential for the future."

Community mental health is the flip side of the localism coin...

BEYOND SAFEKEEPING: BUILDING A NEW PLATFORM

While safekeeping focuses upon preservation of past breakthroughs, it is not enough. Disruptions in the economic and societal equilibrium and the instability in current political, civic and social institutions suggest that a tipping point has been reached. New pattern-breaking configurations, organizational arrangements, and modes of operation are struggling to emerge. The community mental health system cannot simply defend; it must proactively propose credible and sustainable innovations in system structure and operations.

As previously indicated, wholesale assimilation into medical care plans and systems offer little for consumers and communities served by locally governed entities. The least well off—raisons d'état of the public system—will likely "disappear" in large health systems, their opportunity for voice and recognition dispersed among the large constituencies of health systems.

Nor does the notion that community mental health programs should "forward integrate" into healthcare provision appear to be a viable path. While better access to primary care would benefit mental health consumers, the idea of "owning" clinics or practice sites seems duplicative and unnecessary. Local community health systems have distinctive competencies in social care and community support arrangements, in local linkages with other institutions (e.g., schools, law enforcement, and social services), and in collaboration with other assistance networks. The mental health system lacks the requisite capabilities, capital, infrastructure, and expertise to operate medical services and facilities.

Local mental health entities have more in common with the concerns and perspectives of county government and municipalities, economic and community development, public health, affordable housing, transportation, accessible facilities, public recreational space, etc. than they do with the emerging medical/health colossus. Community mental health is the flip side of the localism coin, focused upon residents with developmental disabilities, mental illnesses and/or substance use disorders, interfacing with other local institutions and agencies that assist persons with disabilities or individuals in distress, advocating for accommodations in housing and transportation networks, promoting diverse and inclusive communities, and equitable treatment of all community residents.

Thinking along these lines distinguishes the proper space and role of community mental health: it is in the public sphere with a local role in improving individual and community well-being. Economic and community development requires incentives, workforce skills, distribution channels, and other amenities. It also depends upon community cohesiveness, social care and community support systems, and alignment of local institutions that assist or encounter those with special needs or social difficulties.

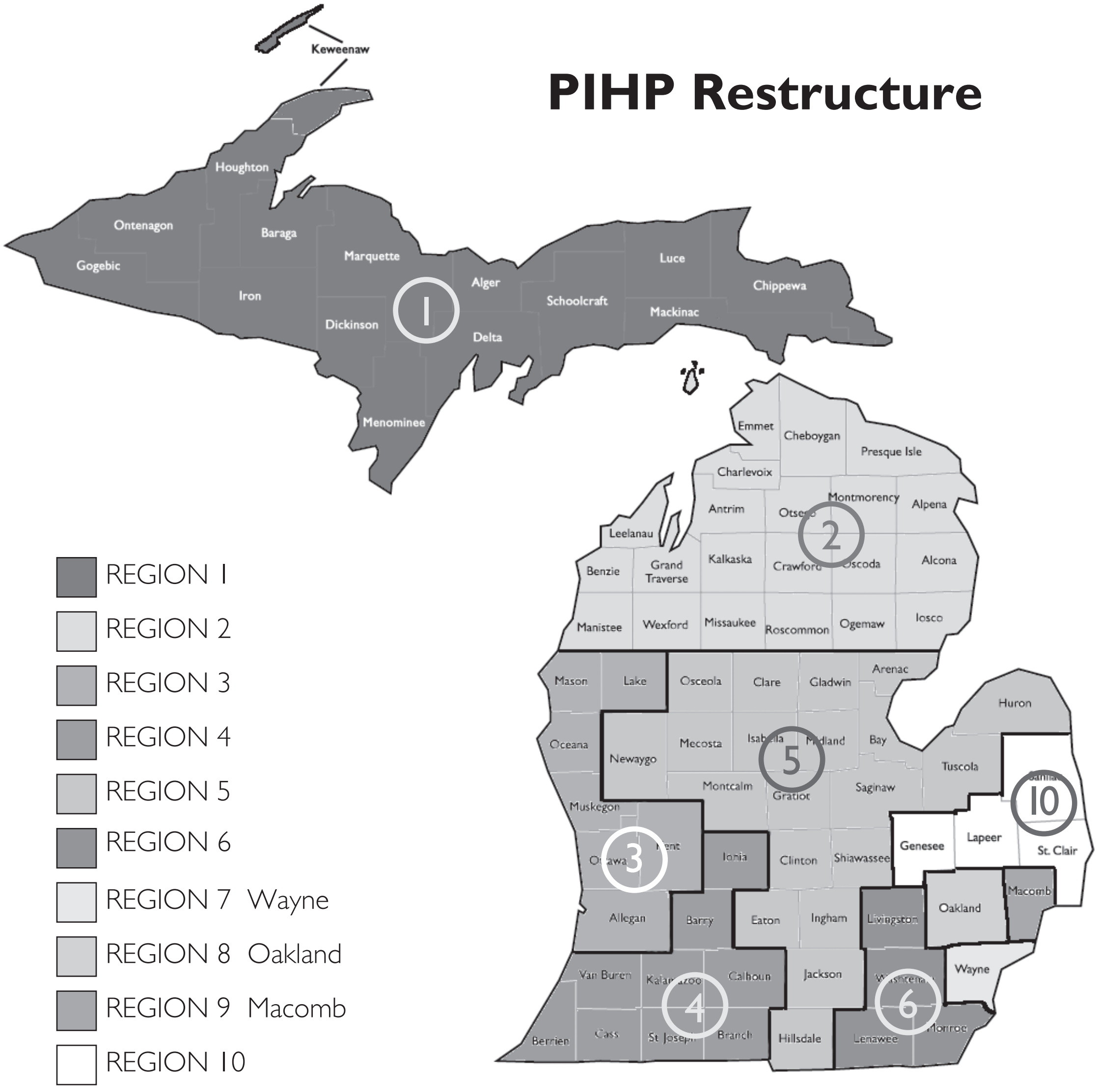
Social explorers often combine discordant, clashing or paradoxical concepts/models to generate new social or institutional composites. This is the case below, which paradoxically combines greater regionalization and more intensive localism. The new composite or social compound and their dynamic mixture provide the platform for further developments.

First Ingredient: Expanded and Renovated Regionalism

Carrying out administrative functions consistent with federal managed care requirements involves certain capabilities, overhead, and transaction costs. By substantially expanding regional boundaries and/or by significantly increasing covered lives criteria, considerable economies of scale (declining average cost of administrative functions, activities, and outputs as these are spread over a larger user or population base) lower aggregate administrative costs with fewer administrative bodies.

It is critical that the mental health system cut the Gordian knot that strangles both regionalism and localism. Current arrangements are not sustainable, leaving the system vulnerable to charges of redundant administrative costs while simultaneously obscuring public appreciation of what local community mental health programs do best—serving the least well off in their communities and county.

This paper proposes resolving the paradox by splitting the designation of PIHP from single county community mental health programs and assigning the PIHP role and responsibilities to a larger PIHP region that is jointly governed by its creating entities. Under the proposed configuration, a single community mental health program could not be the designated Prepaid Inpatient Health Plan for a region with multiple CMHSPs. The PIHP designation would move to the Regional Planning and Operations Council, retaining governance and functions under public auspices and support the localism concept as described below.



Second Ingredient: More Intensive Localism

One of the benefits of organizing regionally is that it lifts various burdens off the shoulders of local community mental health programs by managing regulatory complexity, reconciling funding streams, streamlining arrangements with provider organizations that operate in multiple counties, standardizing reporting, etc., thereby unleashing new possibilities for local innovation and partnerships.

The power of localism lies in its keen appreciation of the unique features and its tacit grasp of "how things work" in communities. These are details of an acquired familiarity with the local "terrain" that the state, a large insurer, a health plan, or geographically dispersed health system could never readily decipher. Various social scientists and anthropologists have described this phenomenon. John Elster, in his book, *Local Justice*,

(continued on page 11)

A Celebration of the Life of Patrick Barrie

Memorial Service Eulogy – December 8, 2012

James K. Haveman, Director, Michigan Department of Community Health

Welcome to each of you and thank you for coming. For those who visited with the Barrie family last night and your being here this morning is deeply appreciated. Your stories and remembrances will be cherished forever.

Let's face it folks, none of us expected to be here today. I talked with Patrick this past Sunday from 4:00 to 4:45 p.m. on a variety of matters. His death is part of the great mystery in the journey of life.

I want you, Mary, Philip and Ally, and Cullen to know how often your husband, father, and father-in-law talked about you. In fact, Patrick made it a point to learn as much about your interests as possible. From music, to theology, sports, information technology, education, digital sound mixing... you name it. He wanted to be able to relate to you and your passions, and my, did he talk about you with us. We all felt as though we knew your family, and we watched you grow up through him. Patrick was committed to providing for you and made sure you had opportunities and life experiences he didn't have growing up. You were his pride and joy.

But he also worried about you; prayed for you, Mary: the accident you were in, your teaching experiences, your retirement; the wonderful way you raised your sons. And Phil and Cullen, the excitement he felt as you grew up and stepped out in life on new adventures. And you even got him so involved in music, I remember when he warned us of the pending problems hip hop music would bring the world! Patrick vicariously lived your experiences with you, and my, did you do him proud.

> *"He was like the biblical Joseph: a scholar and a dreamer of dreams, and always full of compassion."*

Philip, the sound mixing skills you free-lance in film production in California. Cullen, your attending divinity school and now working for a city councilwoman from a large New York neighborhood.

Additionally, our sympathy today also extends to his brothers, Michael, Philip, Timothy, and Paul—your family as a whole. The death of your mother and brother, Brian, in 2005 was a very difficult time for Patrick. We often heard family stories of the good times, and the challenging times of growing up in Detroit. But he was fiercely proud of his family and grateful for the bond you all had together.

To colleagues from the mental health community who worked so closely with Patrick, we offer our sympathy. To Eric Kurtz from Washtenaw CMH, we know how close the two of you were and our thoughts are with you and the Washtenaw CMH family and the University of Michigan at this time as well.

It should come as no surprise to you that Patrick was the class valedictorian in his political science class at MSU in 1971, and subsequently got two masters degrees: one in history and another in psychology. Pat was a brilliant mind and trusted colleague and friend to many of us in this room.

I, like many in this room, worked with Patrick at the Michigan Department of Community Health for a number of years. When I first met him, I knew even then that there was something very special about this clinical services director from Lenawee County Mental Health Authority. I invited him to join our team in 1995. Even after we no longer worked together on a daily basis, Pat and I kept in close contact with each other, and like many of you, our friendship has stood the test of time.

Earlier this week I was in Texas talking about Michigan and many of our innovative initiatives and programs. It struck me that much of what I was describing, was directly influenced by Patrick. He shaped many of today's current programs; for many he was the primary architect. Patrick was our democratic political strategist, David Axelrod; and republican political strategist, Karl Rove. I was still in Texas when I learned of Patrick's passing, and even the commissioner of health in Alaska was stunned, for he also knew Patrick.

Patrick was known by many across the country because he never failed to think outside the box and find solutions to complex issues in ways that people had never dreamed of before. He was like the biblical Joseph: a scholar and a dreamer of dreams, and always full of compassion.

In his professional life, Patrick approached a project by focusing on what was best for the consumer. And in his personal life, he continued to show that care and attention to those who were most important to him.

His intuition and loyalty to those close to him never wavered. He was often the first one to know about a new theory or idea. And if any of us read about a new health idea in a review or article, and we mentioned it to Patrick, within two days he knew more about it than anyone. He was always eager to gain new knowledge, figure it out, and then find four more books and articles to review. Amazon was his Library of Congress.

In every aspect of his life, Patrick was a keen observer and listener. Winston Churchill said, "Courage is what it takes to stand up and speak; but courage is also what it takes to sit down and listen." Patrick listened well—a trait that too few have today.

He was one of the very few I knew who actually enjoyed reading Medicaid rules and regulations for relaxation and enjoyment. I told some folks this week he was the Michelangelo of how to shape Medicaid policy.

We all knew that Patrick had health issues, but he struggled with them more than what he let anyone know. He wasn't the type of person who wanted others fussing over him. As endearing as that may seem, the sadness we all feel today should serve as a wake-up call. Our health is critical, not only to our own lives but to those we love; those we cherish. And I'm so deeply sorry that we are all here today because we have lost our dear friend to a health complication.

The Barrie family: Patrick, Mary, Cullen, and Philip

Patrick was humble and unassuming. He put others first and the small details in life were important to him as he wanted things done right. Patrick never had a bad word for anyone, though he was wise in that he held little respect for those who attempted to bully him or others.

He retained knowledge when many of us forgot things over time. And if I needed a paper or article from the past, he would say, "OK, chief. I can get it." Then he would dive into his massive computer files and find it. I never figured out how he did that.

Patrick could take complicated issues, give you eight key points, and if you only used three of them, he was happy. I could call him at 10 p.m., ask him for some help, and he would say "OK chief, I'll get right on it." Then by morning I would have it.

I am well aware that he often worked all-nighters. He could advise many of us that the alligators were going to bite us before they did. He could plot the path on how to complete the mission and always rose up to the challenges of the legislature and politicians.

He enjoyed working alone on projects, as the big group processes frustrated him. He would rather work it out with just himself and that brilliant mind. When he presented his findings to MDCH or the Governor's office, he would focus on the message, not the messenger.

Seclusion offered him tranquility, peace, and space to think up the wonderful things he always did. Patrick really didn't like conflict, and I worry that at times suffered physically and mentally more than any of us knew. But we would give him his space, and when he was ready, he would talk about it. At times he would remove himself for days, but we always knew that when he was ready, he would surface. He was resilient.

His writings were works of art, science, and health policy. You had to read them twice, three times and then you would begin to get it. He often quoted Tillich, Kierkegaard, Leon, Calvin Kuipers, and Aquinas.

Patrick was often way too critical of his thinking and writing. It was hard for him to just say, "OK, this is good as is." Because of his humility, he found it hard to take credit for all he did, and would rather give the person who only helped with 20 percent all of the credit. Pride of authorship was not important to him, but I promise you that even today, it's widely known his brilliant thinking continues to be embraced and cherished by all of us at MDCH.

One person told me this week that Patrick worked hard at not letting his extraordinarily high intellect come between him and some of his less intellectually gifted friends—then he added, "like me." He was a walking encyclopedia. Patrick truly was the CMH and DCH historian. I simply don't know how he remembered all of the things that he did, but believe me, I am eternally grateful.

He was the wise owl of policy. We all knew that his wheels were always turning. He could pull out an old file he hadn't looked at in years, and just by reading the file title, he instantly recalled all of its contents. Don't you wish you had that gift?

He didn't like vegetables and he always ate way too much candy. According to Carol Danieli, there was always a ready supply of M&Ms and Twizzlers at his desk. I recall that he always drank too much coffee. He would order hamburgers and didn't want lettuce on a hamburger because it was a veggie. Once he was visiting Philip at the Warner Brothers Commissary – it was a lovely buffet—and all present had an enjoyable meal. When Patrick sat down he only had two plain hot dogs and buns. Again, this is our wake-up call. We need to take care of ourselves.

Pat was a workaholic, and this, too, is a lesson for us today: pace yourself. He set a high bar for himself. He often felt the situation or his product might not be good enough, but other people were! He had a low tolerance for injustice and discrimination, and he didn't like gamesmanship. He expected better of people: something that is truly respectable.

As the prophet Amos said, "Let Justice roll on like a river, in an endless river of righteous living." I honestly don't think Patrick realized just how much he influenced and mentored people. They loved him. And this is a lesson learned for me. When someone has a great impact on you, tell them.

At DCH he often would sit with consumers and diverse staff members and ask questions just so that he could better understand their journey in life. Everyone felt his genuineness.

He had a great wit—a bit of a dry sense of humor. He would write things in a policy paper, and I would later find myself laughing at a section wondering what he was thinking when he wrote it, or whose goat he was trying to get. I know full well he wrote those clever sections on purpose.

Titles didn't impress him and I found myself having to pick one for him. He would say, "Chief, just pick one. I just want to get the job done!" He got anxious when secretaries brought him coffee: "No, no! I can do that!"

Patrick had a spiritual and practical, almost mystical approach to *duty*. We often talked about our responsibilities in reforming our communities, state, nation and the world. We often talked about God's grace in our lives and our responsibilities. He felt that he had a duty to serve his constituents, especially those who were developmentally disabled, the medically fragile, and those with mental illness. As one person wrote to me this week, persons with disabilities and their families were able to rest better at night because of Patrick.

Patrick:

> You fought the good fight.
>
> You blessed so many of us with your 63 years on earth.
>
> You truly did leave it a better place.
>
> You can and should be proud of your accomplishments.
>
> Your family, we your friends, and your colleagues love you.
>
> You shared your passion, grace and resilience with those who count, and for everything you gave us, we thank you.

When Patrick and I talked Sunday, we covered the waterfront. The last thing he said to me was, "I want to do what is best for the poor and disabled in Ann Arbor and Ypsilanti."

Jesus, when he was speaking in the Book of Matthew, said to the disciples…

> Blessed are the poor for theirs is the kingdom of heaven.
>
> Blessed are the meek for they shall inherit the earth.
>
> Blessed are they which do hunger and thirst after righteousness, for they shall be filled.
>
> Blessed are the merciful for they shall obtain mercy.
>
> Blessed are the pure in heart for they shall see God.
>
> Blessed are the peacemakers for they shall be called the children of God.
>
> Blessed are they which are persecuted for righteousness sake, for theirs is the kingdom of heaven.
>
> Blessed are ye when men shall revile you, and persecute you and shall say all manner of evil against you.

Patrick, may you rest in peace. ■

Uncle John Reuniting a Family: Past and Present

Julie Moran, Associate Director for Support Services for Persons with Developmental Disabilities, North Country CMH

John, front and center, is enjoying the day near the Old Presque Isle Lighthouse surrounded by his nieces.

They have so many emotions—sadness, anger, guilt, disbelief—and so many questions all beginning with, "Why?" But you cannot be in the same room with John's nieces and doubt the overwhelming love and devotion they have for their Uncle John. Uncle John sits at the head of the table concentrating on the chocolate cake and the variety of puzzles they have brought him, clearly basking in this glow as the smiles, laughter, tears, and family stories tumble out non-stop. "It is bittersweet," they say. When they first met him they cried because he looks so much like their mother and they miss her so much.

These are grown women with families of their own and it wasn't always so. For the greatest part of their lives they did not know that Uncle John existed. They found out when their grandmother's obituary listed him as "surviving." They asked their mother, "Who is John Garrity?" She said he was her twin brother, institutionalized when they were 15. Their mother found out about his disappearance in as alarming a manner as they learned of his existence: she came home one day and he was gone. She tucked John and her sadness away and did not speak of it, not even to her husband.

John's life was spent in various institutions for the next 46 years. With Michigan's efforts toward deinstitutionalization, John moved from Mt. Pleasant Center to a new AIS home in Kalkaska in the spring of 1985, and into the services of what is now North Country CMH; both continue to the present. Meanwhile, at the 2009 funeral of John's younger brother, Tommy, the family decided to begin their search for Uncle John. They had heard of a move to Kalkaska many years prior. A conversation with Ed LaFramboise, director of developmental disabilities services at Northeast CMH, brought John's niece, Cindy, one step closer with his suggestion to call the Bellaire office of North Country Community Mental Health and ask for Julie Moran. The journey back and forward began with Cindy's call to John's home, where they call him "Peaches," because "he is such a peach."

His family feels as though they have been robbed of all the years they could have known their uncle, but they are making the most of the time they have—visiting, taking him to Big Boy Restaurant for lunch and hot fudge brownie cake (which they say, in wonderment, was also their mother's favorite); bringing him to family landmarks and celebrations, and lavishing love and gifts on him. They are planning a whopper of a 90th birthday party for next November.

John was always considered a loner, but enveloped by his family, he appears happier, more content and to have a feeling of "belongingness." When family members began visiting on a regular basis, John would get up very early to wait expectantly by the window. When asked what he would be doing that day, John—never a talker—would say, "My family is coming." The local Big Boy knows John is part of a family and the table is set for Uncle John when they see him coming. There is no doubt that being part of a family has changed John's life. As his niece so aptly stated, "I believe he knows we are family and perhaps he no longer feels forgotten."

Along with the extraordinary power of family bonds, we learned something else from John's family that we had not known. John is a bit of a celebrity. His family has a 75 year rich and distinguished history serving as Michigan lighthouse keepers—coming straight from Ireland with an appointment by the British when they held Mackinac Island. John's grandfather, Patrick Garrity, was appointed by President Lincoln as the last lighthouse keeper of the Old Presque Isle Lighthouse, and he lit the lamp for the first time on the new station in 1871. His wife Mary and their children all served as light keepers in the area, helping to guide mariners safely into

*(see **Uncle John**, page 12)*

Recovering from Schizophrenia by Zach Edgerton

I was diagnosed with schizophrenia in 1996. My road to recovery has been turbulent, but I have overcome many obstacles and met many goals. When I was diagnosed, I never would have thought that it was possible to conquer all the hurdles that the illness would put in my path and accomplish what I had never thought that I could do.

The first symptoms of my schizophrenia were my holding meaning to things that happened around me that no one else noticed. I thought that people were sending me messages by making things happen around me that would make me paranoid and flare my anxiety. I couldn't explain why I would react in this way, I only knew that it was real to me.

Reacting to everything around me in this way made it difficult to concentrate on even the simplest things. I was a high school student at the time, and eventually I could not cope with the demands of an education or the demands of other things in my life.

This paranoia resulted in me becoming an angry and often depressed person. I reacted to the paranoia violently, often striking out at other people, somewhat of a way to defend myself from their perceived ill will towards me. These violent actions were very unlike my basic nature. I was very confused and in a great deal of pain. I lived in fear of everything that occurred around me.

I had two psychotic episodes which led to two hospitalizations, each over a month long. The meds that they had me on at the hospital made me so tired, to the point where I could barely function and hold my head up.

At the end of my two hospitalizations, I was placed on other antipsychotic meds. They stabilized me enough to where I was eventually discharged. When I was discharged from the hospital the second time, I was immediately placed into counseling and outpatient psychiatric care. I was placed on another antipsychotic medication, which was currently the most state-of-the-art medication for treating schizophrenia.

In this period of time, my support system and my own will to get well were also important. Eventually, I was able to cognitively replace paranoid thinking with thinking that was more based in reality. I was able to alleviate my anxiety, and accomplish and achieve things that I couldn't have without the proper mental health care.

I was later able to complete my high school education, have many different jobs, and even graduate from college. I am also involved in NAMI, (National Alliance on Mental Illness) where I have been able to meet people in my situation and help them on their road to recovery. In NAMI, I have been active in facilitating support groups and speaking in public about mental illness, in addition to writing about mental illness issues.

My road to recovery has been littered with obstacles and adversity, but all can be overcome once someone receives the right treatment and therapy, works hard, and believes in themselves.

EDITOR'S NOTE;

Late last fall I was very pleasantly surprised to receive an email with this simple message:

"Please consider publishing the attached file. It is a writing that I composed on my recovering from Schizophrenia."

What made this so special was that this was how I envisioned our Connections *working. Without any editorial prompting, someone with a story to tell was inspired to share it and had discovered the venue* Connections *provides to do so. And I still didn't know his full name. So I wrote Zach, thanking him and asked if he could send a photo. He replied, "I am Zach Edgerton. I submitted writings about my experiences with schizophrenia and obsessive compulsive disorder. Here is a picture of me. The hat that I am wearing represents the Omega House. The Omega House is a local hospice facility and program for caring for dying persons. I chose this picture, because I love to make positive contributions to the lives of people and to help them as much as I can."*

Later I was able to contact Vicki Mikkola, Executive Director of Copper Country Mental Health Services, where Zach lives. Vicki shared, "I do not know Zach well, personally, but do know that he is a strong advocate for people with mental illness. He works tirelessly with numerous groups, locally and at the state and national levels, in advocacy and educational activities; I look forward to seeing his articles published."

Thank you Zach!

On Your Own *(from page 5)*

examines how local institutions often achieve better and more equitable allocation of scarce resources and a more balanced distribution of burdens and responsibilities than other mechanisms or approaches. James Scott, in the book, *Seeing Like a State: How Certain Schemes to Improve the Human Condition Have Failed*, recounts various situations where some centralizing authority introduced seemingly reasonable "improvements" into deprived areas, only to experience miserable failure, because the centralized authority could not "see" certain conditions/obstacles readily known by the supposedly less sophisticated local inhabitants.

If the medicalization of social care arrangements expands, and if the Medicaid program continues to pursue models that subsume such benefits/resources under health plans or medical system auspices, local communities will be left holding the bag. Insurers, health plans and medical systems will draw a bright line between social care benefits included in the policy or plan, and any residual social care and assistance needs (housing, jail diversion, civil commitment, state hospital placements, etc.) of the disabled—or for that matter of any community resident whose distress or social need does not fit within the parameters of insurer or health plan benefit obligations.

Regionalization and alignment of major social care and/or health and well-being systems (mental health, public health, services to seniors, substance abuse, etc.) asserts and strengthens the claim that such social care, public health, and well-being services are governmental concerns, not arrangements or resources that can simply be shifted into health plans that lack community connections (roots) and public accountabilities.

Localism, Partnerships, New Networks and Joint Commissioning

Under expanded regionalism (utilizing Regional Councils or similar arrangements) local entities would still receive allocations (from the Region) to fulfill core service obligations and traditional missions/mandates. But local entities are also aware of situations, circumstances, and/or "wicked" problems that can only be properly addressed through joint action or new network configurations.

If health plans or medical systems could incorporate considerations of community development and well being into their perspective, and if these systems (or the local component owned by a larger enterprise) accepted the premise that all integration is ultimately local, the possibility of local health system/community mental health system partnerships (focused on community health and well being considerations) re-emerges as a feasible option. The Regional Councils and the health plan/medical systems leadership could assist local entities and local components of large health plans/systems in devising legal structures and/or coordination agreements that would facilitate some form of shared governance (e.g., a Medicaid Accountable Care Organization) and shared saving arrangement.

Further, locally governed entities could identify other community issues and endeavors that necessitate extensive coordinated actions by multiple public and private entities to ensure success. Such situations demand what is now referred to as network governance: a multi-agency, public-private alignment, jointly governed, and chartered to solve seemingly intractable problems or to coordinate community development efforts (e.g., housing and supports for individuals with disabilities).

Regionalism (alignment of public health and social care systems, the reassertion of public interest considerations and authority for social care resources and community support systems, the ability to commission special local partnerships and networks, etc.) works in tandem with localism (better ability to perceive particular circumstances, allocate scare resources, distribute responsibilities and identify boundary spanning problems, etc.) to establish a more robust, expansive, and democratic platform for change than narrow health reform strategies, which lack an understanding or appreciation of the broader community considerations.

One might anticipate a number of reactions or questions related to this proposal.

- Some might regard Regional Councils as simply another "layer" of government and overhead. While it would overlay local community mental health programs, the Regional Council would not add costs, since funding for the operation and functions for Councils would migrate upward from existing community mental health programs currently designated as PIHPs. Given the larger regions, the proposal anticipates that the Regional Council could perform these functions more efficiently, and with greater standardization.
- Another question might be: why multiple regional councils? Wouldn't it be simpler and more efficient to enlist a single statewide administrative services entity? The answer to this logical inquiry is that Regional Councils are envisioned as a platform for other innovations and/or reconfigurations. ■

MACMHB
426 S WALNUT
LANSING MI 48933
Telephone: 517-374-6848
www.macmhb.org

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Uncle John *(from page 9*

harbor. Historical markers at the lighthouses depict this history and John's family is mentioned throughout a three-volume set of books by local historian, Janet Young, titled *A Place Called Presque Isle,* most prominently in Volume I, *Presque Isle Harbor*. Uncle John was a part of this important legacy, spending most of his first fifteen years with his family at the Harsen's Island St. Clair Flats Range Light Station.

On June 23, 2012, John helped unveil a statue of his grandfather Patrick at the Old Presque Isle Lighthouse. At the base of the statue was a picture of Patrick. The resemblance between the two men was extraordinary. The statue is intended to honor all lighthouse keepers for their dedication to the safety of the mariners sailing in and out of our harbors. Four generations of the Garrity family were there to celebrate the occasion. John was patient and generous with his smile for the multitude of pictures taken with all the family and well-wishers. We all had a glimpse of a small part of Uncle John's history where his grandfather kept the light and his father was born.

John's family continues to unite him with his past and present, right where he belongs. When the time comes, he will be buried in the family plot, reunited with the rest of the family. "His life will be like bookends: the first 15 years with his family and now the last however many." The tears well up as they say, "We don't even know if he has a middle name."

There are undoubtedly many stories of families and lives interrupted, and people disappearing from their rightful places. It's just how it was. We have learned so much since then. It is fun to know the man who sits with his nieces, who say about John, "What's not to love!" ■

Left: the statue of Patrick Garrity, John's grandfather, located at the Old Presque Isle Lighthouse. John was present for the unveiling on June 23, 2012.