

# **Arching Tales**

## **A Generation's Support of People with Disability in the United States**

**Volume I:**

**The Early Years and Letting Life In**

**by  
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# Introduction

## This and Now

I didn't set out to write a critique on this generation's efforts to support people with disability, but after 40 years of working in a human service field, I had enough of pretending.

What turned me to Archiving Tales was a need to let off steam. I saw years of hard won approaches obliterated, cut or left to starve.

If our outcomes in supporting people had been different, I wouldn't have written Archiving Tales. There wouldn't ever have been a monograph or even a letter to the editor.

I would have remained loyal to the system I worked in for so many years. Shoulder to shoulder we'd stand.

The problem is we didn't get it right. Not by a long shot.

I've come to realize that society needs to take stock in what this generation achieved in addressing the peculiar life conditions of people with disability, and determine where their future is headed.

This nation has to ask itself:

*Are people finding choices and control in their lives?*

*Are they living where and with whom they want to, free from exploitation and abuse?*

*Do people have jobs, resources and relationships to rely on?*

## Summary

Archiving Tales accounts for this generation's work to support people with disability in this United States. This generation includes citizens born or living after the 1940s. The tales are taken from personal experience and relationships, reading, research, evaluation and being involved in the decisions of the day.

Archiving Tales does not draw a picture of reasonable improvement over the last 40 years, after progress registered for the first decade or so. There is no trend line showing services are getting better in everyday ways, especially in the last couple of decades.

There's no sense that this country is on track in securing community support for people, including homes, jobs and relationships of their own. The verdict of our times has to be that we had a unique opportunity to influence social change that could have worked for everyone, and started out ok, before blowing it by investing in service systems instead of everyday community resources.

The exclusionary conditions of people's lives today make it clear that service systems cannot continue to rule the roost. System intricacies and self-serving alliances are far too distant to support people in everyday life. Relying on systems also hurts people on waiting lists and in need of supports outside of the limited array of programs that systems choose to offer.

When services are irrelevant like they are, hurting people and a disservice to the national spirit that unites us all, it's time to turn away and change course. It's time for this country to free itself and let life in.

### **Beliefs and Tenets**

Arching Tales has but one absolute. It takes as truth that citizens with disability deserve to be living everyday lives. Disabled at a point in time or not, we're all enjoying this time on earth as best we can.

We all have responsibility and desires. We also have rights in this country and a culture of acceptance and opportunity that comes into play. We all have our reasons to belong.

Arching Tales is written to move communities to take different approaches that shake out the powers that be. Alerting change agents about what to expect in this process has a lot to do with why this book is written in the first place.

As to those who claim no pressing interest in improving support for people in community life, let's not kid each other. This struggle for inclusion, equality and self-determination is about all of us.

Every parent and friend, businessman and woman, sibling and grandparent, member of a union or chamber of commerce, doctor, lawyer, storekeeper, therapist, and minister has a stake. Each of us is part of what keeps people within the community fold.

Each of us also has a personal contribution to make that takes us beyond charitable giving over the holidays or after a disaster. Community engagement is more than a one shot deal.

The basic outcomes that Arching Tales subscribes to are that people secure homes of their own, employment, and others to rely on. Arching Tales finds its stride when these conditions are at least as good as those for average citizens.

Arching Tales calls out to this country's conviction of getting to a better place by bridging the divide between what is known and effectively put to use. Take it or leave it, these accounts are about discovering the country's sense of community and driving that to where this nation can and must go, for the good of us all.



## **Meanings**

### **People**

References to ‘people with disability’ or ‘people’ in this book mean individuals with significant intellectual or developmental challenges.

‘People first’ language is used to underscore that individuals have value and are not defined by their developmental challenges. The word “people” is preferred and used mostly, except where a disability modifier helps with clarity. Terms like “the disabled”, or “disabled people” are totally out.

According to the 2010 Annual Disability Statistical Compendium, there are 35 to 50 million people who profess to have some form of impairment that prevents them from taking on everyday tasks. That’s over one in every ten children and adults. 90% of these people, or in the ballpark of 20-30 million children and adults, have some sort of disability that affects their functioning and development.

As to people with a specific intellectual disability diagnosis, experts estimate that there are 4.7 million citizens with intellectual and developmental disabilities in the United States. More than 75% of these citizens live in their community without formal disability services and rely on their families for varying levels of support. Of the 25% receiving services, or some 1.2M people, over 56% live with their families.

Archiving Tales takes all these people into account to some extent, whether they are served or not. It speaks to the challenges of people on waiting lists, in institutions, and in community services, as well as those who have found other ways to survive and even prosper in this day and age.

### **Disability**

The word ‘disability’ vs. ‘disabilities’ is used in this book with ‘people’ on purpose. The term ‘disability’ is applied regardless of the number of diagnosis or clinical classifications thrown a person’s way.

A person’s disability is viewed as an overall condition of life. It is not analogous to a medical disorder that gets cured, or a mental illness, although complications like these can be part of what a disability entails. Simply put, disability manifests by not performing certain functions as well as other citizens of similar of age are expected to.

The reason for dropping the more commonly used term of ‘disabilities’ as a modifier is that people relate to the number of conditions they possess as ‘their disability’. The combined effect of blindness, hearing loss, or whatever else, not a particular impairment, becomes part of the person’s identity and interpretation in society. Piling on disability’s significance by pluralizing this term just doesn’t seem fair, in light of all this.

It's also notable that official classifications of 'developmental disability' already account for multiple impairments, including: sub-average intellectual functioning and deficits in adaptive behavior. It is also a fact that over 30% of people with intellectual disability in service systems have sensory impairments like blindness or an inability to speak in a regular way.

Over half of the people in services also take significant behavioral medications too, or have challenges with healthy living styles. Where does this pile of disabilities stop?

This book rejects reasoning that prefers to slice and dice disability in the name of science, service eligibility and health related funding. That people may have multiple issues to deal with in life is a given.

### **Bad Words**

Pejorative terms like "idiot", "retard" and "imbecile" are included in this narrative to point out language as well as perceptual changes over the generations. Using them comes at a price.

Dehumanizing slang remains a significant barrier to inclusion today. It breaks down relationships and social responsibility, and it breeds fear and stigma.

It also contributes to individuals being marginalized and exploited, even harmed and exterminated. Terms like "sped", "slow learner" and "freak" don't help in developing valued social roles one bit.

### **Workers and Employment**

The term 'worker' describes anyone with responsibility to support a person with a disability on an ongoing basis. A worker can be paid by a private or public source, or be compensated in other ways, like a self-advocate or volunteer would be. Relatives are included as workers too, based on the disability related support they offer.

The key factor to being a 'worker' is the assistance extended with the person or on the person's behalf. Workers teach, expose, and counsel. They offer aid, encouragement and stability.

Workers can also be administrators including: monitors, consultants and information or policy specialists. Workers like these are often employees hired by federal, state, and local agencies across the country, but also include academicians and independent professionals.

The term 'worker with disability' means an adult with disability who participates in any one of a number of work related activities, day programs, sheltered workshops and curricula that systems sustain under the aegis of training or education, service, therapy, treatment, habilitation or rehabilitation.

Workers with disability are differentiated from an ‘employees’ or people engaged in community employment. Employment here means a community job or occupation offering stable income and benefits where people are able to develop community ties outside their disability grouping.

A community job operates outside of system rules and is accessed through regular business channels. People are employed on the basis of their value within the employer’s general workforce, not as a long term client working in the system.

### **Community**

‘Community’ is defined according to the educator Seymour Sarason, as *"the perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what one expects from them, and the feeling that one is part of a larger dependable and stable structure"* (1974, p. 157, Psychological Sense of Community).

A community manifests itself in terms of the resources it holds, and by the opportunity, protection and support it offers. Communities bring life together for, with and through people.

### **Valued Social Roles**

‘Valued social roles’ is a term used often in this work. The expression comes from sociology and refers to the positive roles people play in community life.

Social roles are positively valued to the extent they contribute to a person being a responsible and respected individual in the eyes of the general community. Valued roles manifest with a person having social capital, or cache.

Valued social roles are determined by where people live and work, their social circles, and the like. Tax payer, law abiding citizen, family member, friend, employee, team member, good neighbor, and colleague are common examples of valued social roles people embody.

### **Systems, Services and Stakeholders**

The term ‘service system’ or ‘system’ means a network of formalized organizations, both private and public, that interrelate through the provision of services. Health care professionals, provider organizations, administrative entities, and other stakeholders populate the domain.

In systems, providers of service assure people have a place to live, work and associate, and often take care of medical and other needs. In addition to providers, systems include public agencies that administer service delivery, fund programs, coordinate and monitor too.

People placed in services, together with other stakeholders; conform to standard practices that systems embody. These same stakeholders are the main participants in councils, committees, boards and other advisory forms that influence the system’s operation and direction.

While systems can contribute to community objectives with people, systems and communities are never one in the same. Systems are distinct from communities in how they rely on resources outside those used by the general public, and by their closed administrative qualities.

### **Lifesharing**

‘Lifesharing’, a term coined in my home state of Pennsylvania after a decade-old struggle with powers that be, may be the only new word used in this book. Lifesharing is not in the dictionary, at least yet.

Lifesharing describes an arrangement where people choose to live and share their lives in mutually supportive ways. People in lifesharing live with friends, college roommates, guardians, host families, companions and relatives. Foster care and adoption constitute lifesharing, and there are other forms too.

In lifesharing, companions are intentionally matched and supported on the individual basis. There are no placements in lifesharing like there are in system operated programs. People are matched in a reciprocal way.

### **Everyday Lives**

‘Everyday Lives’ is one of those terms, like twinkling star, which magically defines itself. My recollection is that a dear colleague and one of the pioneers in this generation, Nancy Thaler, coined the phrase in conjunction with a landmark stakeholder group back in 1991.

As usual, Ms. Thaler gets it right in these two simple words that are now applied all over the country to describe the valued ways that people live with others in community ways.

There’s no separate but equal in everyday lives. The term embodies outcomes, conditions and consequences that general citizens relate to. While services that people receive can certainly factor into an everyday life, they don’t take over when people and communities can manage support themselves.

### **Format**

Archiving Tales has two parts. This first book: Early Years and Letting Life In, delves into the character of support today and reflects on this generation’s journey in the 1950s, 1960s, and 1970s.

Letting Life In also includes stories of people I’ve known and places I’ve been during this period. It also offers advice in getting past system ways to frameworks where people and communities have defining roles for good. It describes the character of program services today and advises change agents. In tales of the past and future, the volume sets the stage for Part II, titled Being There.

The second volume of Archiving Tales continues to examine the system's evolution from the 1980s to the present. It also reaches back to the Eugenics movement and disability beginnings before the Civil War. Being There also lays out a new metric of support with people and communities, before passing this torch for good to future generation leaders.

To get Archiving Tales out to readers where it belongs, I've decided to offer this narrative in portions, starting with the salad years, of course. Subsequent updates will be offered in the coming weeks and months on my website at [www.dawaho.com](http://www.dawaho.com). As the II volumes get completed, they'll be published as a set.

Until then, the works are published, there is no charge for reading or sharing this material for non-commercial purposes, noting that copyright law still applies to this work in all its forms. Commercial use of Archiving Tales is prohibited without prior written permission by me, as sole author.

Readers wishing to contribute towards supporting people in community ways are asked to consider making a donation to the Pennhurst Memorial and Preservation Alliance, Additional information the Alliance may be found at [www.preservepennhurst.org](http://www.preservepennhurst.org).

## **Bio**

Archiving Tales embodies my career in human services, and forms a sort of memoir in this respect.

In the various positions I've held over the last 40 years, I expected to make a difference with people, whether it was in direct service, policy and program development, consulting, or citizen advocacy. While I didn't seek out human services as a career, working with and on behalf of people suited my temperament, and I've stayed the course.

There have been no regrets that way. Despite feeling sick and sorry about today's service scene, I still love this work and will continue doing it for as long as necessary and the system's halfhearted outcomes persist.

This generation leaves a big mess for our children and grandchildren to not only clean up, but to completely undo before building anew. Despite its vast potential to support people in everyday ways, community might as well be a wasteland as far as people with disability are concerned.

Knowing all too well the gnawing of a change agent who should have done better in supporting people to achieve community outcomes, I offer no apologies with the tone this narrative takes. Archiving Tales calls out the arrogance of system approaches that our generation still has to answer for.

Any hurt feelings stemming from Archiving Tales are no match for the pain and suffering service systems have inflicted, whether knowingly or not, on the people of this country, and communities too.

Those that support systems and I understand one another at this point, in any event. We get it that there is no love lost.

### **Generationally Speaking**

The baby boomer generation has been fortunate to survive and learn from the 1950s and two decades that followed. As a result of what this generation has been through, contemporaries feel tied to a liberation agenda with people of color, women, non-citizens, and others.

It's axiomatic that as the love and peace children of Woodstock, this generation would also have something to say about the lousy deal people with disability in this country endure due to prejudice, misunderstanding, and economic woes. Confronting injustice is surely part of our DNA.

Let's also not forget influences like the immergence of a global village introduced by Marshall McLuhan and the social paradigms explained by Thomas Kuhn in The Structure of Scientific Revolutions. This generation witnessed pioneering pursuits beyond our wildest dreams, and become aware of social theories and practices that are unprecedented.

We were the young adults awakened by the likes of Eldridge Cleaver with his Soul on Ice and Malcolm X with his Autobiography, too. We're the generation that stopped sweeping race, sex and other isms under the rug.

In high school and college, we were the first generation influenced by everyday heroes and anti-heroes from the pens of Salinger, Hemingway, Whitman, Angelou, Frost and Bellow. We've followed great leaders, including: Reverend Dr. King; John Kennedy and his brothers; Jimmy Carter, and most certainly the Clintons and Obamas for me.

We're the age that discovered ourselves in the words of Dylan, Pete Seeger, Buffy Saint Marie; Springsteen, Mitchell, and Baez; the Doors, Monk, Hendrix and Aretha. We're Beatle mania and the Stones; rock, soul and gospel, jazz and rap. Archiving Tales joins with all these voices too.

The remarkable thing, as Alan Ginsberg's 1957 Howl appreciates so uniquely, is experience has taken a quality of 'holiness' in ways different from the past. This generation owns the energy of it all.

We celebrate it and we are humbled by it too. All of it – the good and the bad; the ugly, crooked and straight; skin, desire, foolishness, war and love - these are all the ways we thrive and relate. Our generation gets what Ginsberg is saying in spades – that community is about all of us in the precious time we share.

It's an American way we've been taking, and we love it. We're the generation that is still howling and in the flow. We appreciate the power of bringing people together, and it's something we're sure of.

In a spirit of togetherness, Archiving Tales reaches out to the wonder of the ever present, like Ginsberg did and Whitman did a century before him, all celebrating life through relationships in the here and now. We affirm this wonderful sense of belonging with our children and grandchildren too.

While Archiving Tales does not presume that everyone agrees on anything, this book does espouse values that citizens share regardless of their age, cultural ties or political persuasion. It also reaches out to any and all who would prefer to keep singing Woody Guthrie's This Land Is Your Land - all the way to the end.

# **Chapter I: Tenets and Understandings**

## **Starting Off**

So, welcome all to this pursuit of community support with people in everyday ways. Here's to a bon-voyage.

Throughout our time together in these pages, there are some basic questions that keep on coming and need to be answered. Let's take a moment in the beginning to appreciate what they are and how they matter.

Let's also know that Archiving Tales intends to explore these inquiries throughout. While the text may be diverted from time to time, achieving better understanding on the basics of community support remains the main course we're pursuing.

Our fundamental fist-full of questions are these:

*How have services and support over the years affected people's lives?*

*What difference do services and support make with people and communities?*

*How is this sense of community going?*

*Who takes responsibility for outcomes leading to an everyday life?*

*How is this sense of responsibility going?*

## **Called To Do**

The generation that entered adulthood in the late 1960s and 70s dedicated itself to supporting people with disability. We are proud of our aims and achievements in this respect.

We appreciate the sweet success of knowing that some people have had good jobs and shared their lives with others they've chosen to. We are thankful for teachers, parents, friends, and workers who took the time with people in forming healthy views and experience.

Everyday outcomes for people have been another picture entirely. Our generation's work in supporting people has been a time for sound and fury. While this generation's creation of home and community services has contributed to improving life conditions with people, we did not achieve nearly enough.

We didn't take community resources into account or engage them like we expected to. We've left future generations and our contemporaries short changed.

Although sanguine leaders like to take an optimistic view on our nation's ability to change with the times, their myriad of conflicted programs are not on track to transform.



However much we might wish systems were better, community support isn't going to emerge in this climate fixated on worlds within and apart.

Community support cannot be delegated to systems. Community is what it is: common and shared endeavors using family, neighborhood and public resources every bit of the way. Systems, on the other hand, are merely organizational constructs, relying of provider networks and administrative entities to do the work communities farm out to them.

As the system mess our generation has made reveals itself, we ponder how our lifetimes of commitment and resources failed. Going on forty years should have meant something much more than what people and communities deal with today or face in their futures. How could we have been so blind and unresponsive?

If we've learned anything over these decades, it has been that service systems stay fixed in society long after attitudes and conditions that created them change. To combat further stagnation, other forces need to weigh in.

Otherwise the system's tendency to isolate and exclude people will continue for generations to come, masked by feel-good ideas, self-congratulation, and vacuous programs de-jour. Remedies in the world of support aren't about that at all.

From now on, we'll be focusing resources in the community, not into deep pocketed systems that belong to a bygone age. We'll understand through community action that people count more than programs.

We'll engage with the community to take back roles that services and agencies snatched over time. We're ready to demonstrate how community participation supports everyday lives, like no system based services could ever hope to do.

In the pursuit of community solutions, we accept that systems can't help themselves from withholding community ways. We're giving up the ghost and moving on.

### **Beginning with Human**

Being different is integral to being human. None of us process information, obtain knowledge or communicate in the same way. Even formulations of eternity and God come with a myriad of interpretations. Why wouldn't conditions like how well we express thoughts or appear in public have a bearing on someone's perceptions and treatment?

Why wouldn't labels associated with a disabling condition, like intellectual disability, autism or mental retardation, have some relationship to a person's opportunity for a job or everyday life? Of course they would, and that's perfectly understandable, even if it isn't necessarily okay.

The point is that we need to accept difference before we can deal with it effectively. So let's start these Arching Tales by accepting that all of us are different. Nobody is just like everybody else. What fun would that be?

Being human doesn't mean running away from being different. It doesn't mean ignoring conditions, personalities, weaknesses or pain. Humanity embraces difference, and considers it the basis of strength, richness and endurance.

How a country deals with difference makes a nation unified or divided, and more or less able to manage resources effectively and fairly. A fundamental test of civilization comes down to honoring the contribution of others outside a particular clan, class or tribe.

It's when differences are ignored that the bad side takes over and exploitation takes hold. Our country's history is full of that bad side, the side where people with physical, sensory and mental differences are shut out and used for their market value as consumers of care and objects of social pity. It never had to be that way.

### **Foundations and Frames**

Fundamentally, Arching Tales is about supporting people, not serving them. This book takes the view that support is achieved through community ways, not system approaches.

When we fail in sustaining community and people together, we fail ourselves individually and as a nation. There is a community imperative at stake here, whether we want to admit it or not.

Community defines our sense of social responsibility. It's probably been this way for as long as people have been together. There isn't much that can top being supported with others who you want to live, work and be with.

Community forms the common ground in this land of liberty and freedom and in other lands across the globe. It's the passion and where-with-all behind pursuits of peace on earth. It's our cultural framework.

Community is the prize of belonging to something grander than any one of us as individuals can achieve. Community is what gives us balance and a sense of responsibility to one another as human beings. It's our wellspring of hope and promise. It's our mirror and comfort zone.

For the sense of community to reach people, citizens tap opportunities inherent in general society. It's that interaction with everyday resources that counts most highly in the area of support.

Communities open themselves to people naturally. Neighbors help-out if they are called on or not. Employers offer people jobs as part of what they do. Friends are friends, and opportunities are taken.

What our conscience and experiences are telling us is true. Communities take people from where they are, and work with them in ways that they mutually can and want to.

As citizens, workers, employers and good neighbors, we see that being inclusive in community begins and ends with all of us. We also recognize how services don't expose people with disability to community expectations or apply resources that would come naturally if systems didn't stand in the way.

While there will always be hurdles in life, what's important now is that communities deal with their support challenges constructively for a change. Systems aren't going to do that. They'll take the people off the community's hands, but that's about it.

Only communities have the where-with-all to solve community challenges and seize the opportunity to sustain everyday lives. In the scheme of things, it's the community's turn to come through and shine.

Those with a community persuasion get it about taking over for systems, letting life in, and loving it. They understand that systems have restrained people under reigns of program control outside the embrace of community ways.

Just by opening their eyes to their responsibilities, communities can finally see how breaking away from system controls is what they are called on to do. Communities are natural born liberators, and an enduring force to reckon with. It's time they let their people go.

## **Chapter 2. Deviancy and Deliverance**

### **Objectification**

Interpreted as deviant, or negatively valued, people with disability have been treated as misfits and belittled for centuries. These interpretations have resulted in neglect, exploitation and systematic abuse as bad as this world has ever known.

Beginning in the late 1930s to their defeat in World War II, Nazis arranged the extermination of a quarter million children and adults with disability to satisfy cravings for a master race. Renowned physicians and social scientists in the United States and England in the decades prior to the Nazi' rise to power pioneered a Eugenics philosophy and medical practices that incubated Hitler's racist ideals.

In today's generation, this country's systems have given people over to professionals who relate to them as clients, consumers of paid care, inmates and patients. People are passed on to service agencies charged with keeping them out of harm's way and contented. A life deferred is still the fate of far too many people.

Even with technology and modern teaching methods that compensate for disabling conditions like never before, persistent negative interpretations make dealing with disability much more difficult than it needs to be. For the hundreds of thousands of recipients consigned to service systems and millions more with not support to speak of, these interpretations combine in ways that have been impossible to overcome.

Until society values living with disability on the same basis as living without it, people and their families will continue to be cast aside and trivialized. People will remain objects of pity and labeled "poor souls", "unfortunates", "eternal children" and "lifelong burdens".

Being objectified in this manner strips people of valued roles. As long as the public assumes that people are hopeless, individuals won't have opportunity to succeed. People also can't be supported as valued members in their community while shackled to society's images of an oppressive past in systems that keep them excluded.

### **One Thing Leads To Another**

Objectifying people leads down devastating paths. This generation has learned that over the years.

We've also learned that qualified professionals including physicians, administrators, psychologists, nurses, therapists, social workers and educators have been the keepers of these paths through diagnostic tools and program practices that govern who benefits from treatment and services, and who doesn't. Today, professionals remain the keepers of the systems where these paths still lead.

These professionals decide whether people are a danger to themselves or others. They use their authority to place people in diagnostic groups, authorize benefits, and assign public funding. They make the rules people are forced to live by.

Using deficit laden assessments that ignore community supports, professionals judge people as more incompetent, sick and needy than they actually are. They also refute and ignore outcomes that valued adults in society expect to achieve - like jobs, homes and personal relationships.

After assessing neediness and eligibility for services, professionals show yet another face in controlling how services with people are rendered. These services are composed of residential, adult day, transportation, and related treatment programs. They also include case management which coordinates other services and monitors them as well.

Over all these services, local, regional, state and federal agencies create requirements through regulation, program management, funding policy, and monitoring. Providers offering services defer to these authorities, and work hard to influence how they behave.

As a prelude to these services for adults, the nation's public education system organizes itself around a combination of so called "integrated" and "non-integrated" (or "special") class offerings that cater to children with a particular set of challenges. This demarcation around inclusion sets the stage for social isolation over the rest of their lives.

Non-integrated approaches get their start in infant-toddler programs in many states and continue on to senior high school years and beyond. While special education shows signs of improvement in preparing some students for jobs and homes of their own, post-school expectations are often miserably low, and made worse by adult service systems that refuse to carry the torch for everyday lives.

Suffice it to say that people separated by their disability as children, will continue to live that way as adults. The sad truth is that even though disability specific programs are ostensibly authorized for each person's own good, services are not assisting people in fashioning life on their own terms.

Program practices that are supposed to lead to outcomes like a job or home don't jive with the adult service system aims, funding formulae and program practice. In fact the choices systems offer today are not much improved or different from the congregate residential, day and related service programs that were first adopted half a century ago.

Far too many people continue to reside in costly institutions they don't need or want. Systems still require people to live, work and socialize on the basis of their disability classification. Programs expected to serve as a gateway to independence don't operate in a people first world or a community first way.

While community based service approaches sometimes compare favorably to life in institutions, making that point doesn't have the punch it once did. People living in community

expect to be considered based on the lives of average citizens. Measuring progress against an oppressive and irrelevant past just has to end.

When measured against life conditions of an average citizen, people receiving services continue to get the short end time and again. Meanwhile, millions of people without support of any kind can be worse off yet. Isolation remains a constant sore that people across all disability spectrums have in common.

Unfortunately, once system models like group homes, sheltered workshops and institutions take hold, community acceptance, participation and capacity begin to be taken out of the loop. While people may thrive in the confinement of service environments that set them apart, that's as far as they get.

People with disability are placed in homes and programs where "folks like them" go to get training and treatment. Professionals who manage these programs reinforce interpretations of pity and incapacity with overprotective structures that just won't quit.

As the identity gap with people and their community widens, opportunities become limited to life styles conducted in service-friendly times and places where admission is closed to "the disabled". People become interpreted as less human than they were before, and forced to live in ways the community wouldn't tolerate or desire for themselves.

The more community engagement stays dormant, the worse life conditions become. The longer systems control people outside of integrated settings, the more difficult it becomes to identify with them as individuals, appreciate their value, and work toward common aims. Ultimately, the impression of people as eternal outcasts becomes transfixed.

As the popular saying "Use it or lose it" suggests, people must be part of their community or lose their social relevance. Identity is a crucial element in forming community and a terrible thing to lose or keep from people who have every right to be free.

### **Invisibility**

Ralph Ellison has come as close as any modern author in describing the effects of objectification on valued social roles. In his masterpiece The Invisible Man, the protagonist, a young man of color with all the potential in the world, receives a letter of introduction from his mentor, the school trustee.

This letter sets the stage for the invisible man's future as he proceeds into adulthood. The letter's contents are only made known to the invisible man in a dream later in the novel.

Ellison writes of this:

*That night I dreamed I was at a circus with (my grandfather), and that he refused to laugh at the clowns no matter what they did. Then later he told me to open my brief case and read what was inside and I did, finding an official envelope stamped with the state*

*seal, and inside the envelope I found another and another, endlessly, and I thought I would fall of weariness. "Them's years," he said. "Now open that one". And I did and in it I found an engraved document containing a short message in letters of gold. "Read it," my grandfather said. "Out loud."*

*"To Whom It May Concern," I intoned. "Keep This Nigger-Boy Running."*

Outside this dream in his everyday life, the invisible man accepts the trustee's envelope, pledging to share its contents with prospective employers and the like. He also promises never to read it, and is true to his word.

The invisible man shares the letter with people who form the network of his life. He endeavors for success and a positive existence throughout the rest of the novel, never once reading the poison words that the trustee penned.

Battered and alone at the end of his life journey, the invisible man retreats to an underground basement in an all-white high-rise building. Ellison depicts this cavity of a place lit by a thousand light bulbs strung all along the ceilings.

In this constantly illuminated state, the invisible man is finally able to reflect on why the everyday life he sought was allusive, and ultimately beyond his ability to achieve. In this light, the novel ends.

People with disability get their poisoned letters too. They appear in many forms: from paragraphs of diagnostic classifications peppered with behavioral anomalies, to words like 'retard' that bullies write on bathroom stalls.

Negative messages travel in whispers between schoolmates and teachers who want to know what's "wrong" with the new student who walks strangely, doesn't talk, or makes wild gestures. Infectious communications surface in service notes and by word-of-mouth. Code words for "can't do" and "stay away" abound.

Emanating from the guile of authority figures like the trustee in Ellison's novel, words like "special" stigmatize people as troublemakers, slow learners, and hopeless. In parlance of any number of systems, people with disability find their place as outcasts too.

### **No Presumptions**

While Ellison could have ended this novel in other ways, it's telling that he did not fidget with destiny. He did not have the invisible man come to some epiphany about the unseen forces that managed his life.

Ellison had the integrity not to presume the extent to which the invisible man consciously appreciated the depths of his betrayal. The author didn't romanticize oppression. The beaming of a thousand hanging lights along the ceiling was enough of a final statement.

Invisibility is a major theme in Ellison's novel and an arching one in this book too. Our common message is that it's up to others to get beyond invisibility and deal with the systems that create it.

After all, it's not that the invisible man was invisible to himself. It's not that he didn't try his best or refuse to play by the rules. The problem is that he wasn't seen in a valued way by others in authority starting out. That's the same thing people with disability have going.

In a stigmatized world of invisibility, it takes more than self-awareness to change the conditions of people's lives. People with disability are still being shuffled off to their society's cellar, like people of color are, out of sight and mind.

In this country, people get an indelible diagnosis and a devastating social label that guides their life journey. People are summoned to play along passively with dictates of their difference.

Even people with the courage to reach out and leave oppressive ways are perceived as a different caste, some mistake or anomaly. That's the pattern, path and fate for invisible people with invisible dreams, living life in traps they don't even see.

Ellison's masterpiece shows us how language penned by an agent of a system, like the school trustee, becomes the formidable tool of oppression. Under this constant cloud of authority's view, personal success and social integration are made nearly impossible.

Thus, invisibility becomes the common feature for people with lives directed by their negatively perceived difference. Built on centuries of institutional practice, invisibility prone ways are practically as common in home and community services as in large facilities and as pervasive in the nation's heartland as on the coasts.

That's the conundrum this nation faces with disability, where society relates to people in terms of their diagnosis and service needs instead of their character. What can anyone really know about a person who is perpetually described as happy and compliant with a life composed of pre-arranged activities and relationships?

Where are *arête*, understanding and triumph to be found in the stacks of diagnostic records and other documentation that encompass people's lives? Where do human aspirations fit into this scenario, or do they? Can they ever? Where do community interests stand?

### **While Banners Yet Wave**

Despite the forces that promote objectification of people, valuing its citizenry is still something the American way of life holds sacred. "Liberty and justice for all" applies to citizens with disability too.

In being a citizen, there is nothing special about the rights people with disability enjoy, or the responsibilities they have. While Congress and state governments pass laws to address



conditions of people, these statutes are based on overriding traditions that offer all citizens opportunity to live full, rich lives.

Despite the struggles people face in reaching the American dream, there is nothing in the Constitution that bars people from exercising their will based on a disability. People with disability, like everyone else in this land, are equal under law. The country's sense of liberty and justice demands no more or less.

Outside what's written in these national tenets, the United States values community as a form of its ideal state. National leaders proclaim community's virtues in a wide array of circles, just as advertisers and the public does.

The country deems citizens to be successful when they live according to community expectations, exercise civic responsibilities, interact as good neighbors, and give back in ways that they can. Citizens consider themselves enriched by their ties with varying persuasions and beliefs.

Communities are places for everyone to congregate, be political, and feel comfortable with brethren and sister alike. Children and adults view their communities as relevant to both their individual and common interests.

The community is a place to find the grocer, the baker and the candlestick maker. It is the place to find a mate and a friend. Communities are the melting pot where citizens conduct themselves with civility and affirmation. Whether in commerce, worship or love, the community is where we find what we seek.

In a practical sense, living as a valued citizen in a community relates to people when there is a collective will behind the words of the Constitution, Bill of Rights, and other statutes. People can only achieve success in life when the spirit of liberation and justice breaks through in ways that affirm their American experience.

While there is more than enough valued space for people in the American dream, only sincere invitations will result in their participation. Laws aren't going to get a person a job unless an employer is convinced that the person brings value to the workforce. A system regulation mandating that people go out into the community once a month isn't going to convince a neighbor to say "Hey Rich, let's go to a ballgame tonight".

We're all part and parcel of this American pie, nurtured from the same origin of love, and sharing the bounties of this fortunate land. What's not to like about that? What's not to share?

When it comes right down to it, this country needs people with disability as much as it does healthy neighborhoods, families and work places. Recognizing people in inclusive ways is what counts.

## **Belonging**

Citizens in this country consider communities as a common space where resources are shared and relationships developed. A bottom-line condition of community is access to others, ideas and opportunity.

People who are denied community connections become excluded from benefits that community offers. Citizens that are included in a community have both a stake in and a chance at success.

People included in their community are involved in the culture that everyday people enjoy. They participate in parades, craft fairs, yard sales, and political rallies. They take the local bus to work and share a front pew in the congregation. They relate.

Today's communities are more varied than they've ever been and increasing at an amazing rate. There are virtual communities, communities within communities, and alternative communities, all held together by their own variations of language and history, beliefs and interests.

Belonging feelings that come with community get carried in web-cams and tweets to masses of like-minded folk. On-line dating works for millions.

It's an exciting world for communities in this respect. People with disability expect to be part of this too, and they are, when attitudes and expectations about them are constructive and mutual.

People with disability belong in pioneering ventures that expand science and the application of technology, communication and teaching methods for everyone. They are called on to be ministers and ambassadors too.

Many more people would be involved in their community, but they don't have the opportunity and support to do so. In community, support brings opportunity with people or it delivers nothing at all.

The problem is that people with disability are not engaged and present in a way to show their stuff. They are viewed as constantly taking from others, but not giving back or contributing.

## **Asking One Another**

This generation has learned that community expectations about people are not prone to change under the thumb of system ways. People with disability are not expected to find jobs or contribute in a meaningful way apart from being a consumer of services.

Communities have to own and deal with these expectations to move on. They need to know that their collective support counts for something, and that it comes first and foremost as far as public investment is concerned.

While everyday citizens may think they have no interest in finding answers to questions about support, they do. Being as subject to the effects of disability as anyone, citizens have a stake in ensuring that support and services remain on a healthy path. They have social responsibility too.

Fortunately the questions we have to answer are within the capacity of communities to address. While it may sound oversimplified, solutions require participation and community embrace. They require that supports be developed in ways the community values, so the community participates too. They require togetherness.

The public has an abiding interest in making sure that people have ample opportunity to express and act on their choices whether or not they can write their name, have a severe reputation, or go to the bathroom by themselves. Citizens don't choose their disability, but they can choose their life path when community support is there for them to take it.

Decision makers representing communities have a responsibility to embrace generic resources in dealing with peoples' challenges instead of relying on specialized services, like we've been doing in this country. It's just not enough anymore for services to take care of people while ignoring them as being worthy of living an everyday life.

On behalf of our communities, let's ask one another:

- *Do living arrangements and social activities for people need to meet special codes and requirements that other citizens find superfluous?*
- *Is it necessary that people have a system-employed case manager if they have a family member or friend who can coordinate their community support?*
- *Can professionals tied to structured services be expected to make decisions critical to a person achieving valued social roles in an everyday life?*
- *Are service approaches doing any more than perpetuating custodial care that keeps systems in business?*
- *Why should systems get to limit support to an agency operated home, as opposed to living in an intentional community; with a friend in another state; an RV going across the country, or as a member of the Peace Corps living overseas? Who benefits from these restrictions?*
- *Why don't systems support people in everyday ways that offer financial and other resources to spouses, bosses, work colleagues, friends and family members?*
- *Why don't systems measure outcomes that bring value, success, and acceptance with people in everyday life?*
- *Why don't these questions end?*

## **Chapter 3: Starting Shut-In**

### **First Time On My Own**

My career in human services began after a few months of graduating from college. I took a job at a sheltered workshop called the Shut-In Society to fulfill my alternative service requirement as a conscientious objector to the Vietnam War.

The site of my employment was in Philadelphia. The year was 1971. Fresh out of college, my wife and I rented an apartment in the North East part of the city across from a nice park. We lived there for the next few years with our dog, and it's where our first son Jeremy was born.

This chapter of Archiving Tales recalls elements of this job experience at the Shut-In Society. The real names of colleagues are changed, but otherwise, the events and places are true to the best of my recollection.

This job was my first full time adult employment. I had summer work and some part time jobs at school before, but was never salaried or dependent on my employment to cover living expenses on the family plan.

### **On History's Wing**

There were a lot of beginnings in that year I received my degree. 1971 was a time of turbulence and hard times for graduates in finding jobs. It was also just a couple of years after Woodstock, so the music was great, at least.

1971 was also the year of landmark litigation involving Pennhurst State School (1908-1987) outside of Chester, Pennsylvania that served up to 3,500 people in its heyday. By the time all the Pennhurst court decisions were handed down, this and many other institutions would be on their way to closing for good.

In the summer of 1971, the Public Interest Law Center of Philadelphia filed *PARC v Commonwealth of PA* in Federal District Court, which formed the legal basis for public education of children with disability that extended throughout the nation. In 1974, which was the year the family left Philadelphia; *Haldeman v. Pennhurst State School* was filed too.

This equally significant litigation set the stage for community services in Pennsylvania and across the nation too. It took plaintiffs three tries at the Supreme Court before the deal was sealed.

Was this just a coincidence then - that my career with people and disability started in this three year period? I would say that depends on your point of view.

For me now, these dual 1971 departures into supporting people in community life seem beyond happenstance any more. My sense is that the Pennhurst litigation and I are too hand-in-glove and permanently related to be purely random in the big scheme of things.

While Pennhurst wasn't the only factor that influenced how this country or young adults like me related to people, it was a powerful event that will never be matched. After the righteous spark community living caught fire during this period, a wave of workers emerged to liberate people from their Bastilles.

Many have kept up the struggle ever since. Coincidence or not, that time from 1971 to 1974 cannot be overemphasized in these Arching Tales for anyone.

I would also say that having all these changes transpire in Philadelphia were important too. There's a definite quality in this city that garners an appreciation for history, justice and community ways that has no equal in the world. Having the rights of people with disability rooted from the same locale where the US Constitution was ratified says something indeed.

### **Location Location**

The 'L' or elevated train was only a short walk down the hill from where the Shut-In-Society was situated. I took this route to work every day, with my packed lunch of peanut butter, honey and wheat germ. There weren't any parks or high rises on this walk. The neighborhood was crammed, gritty and blue-collar.

The most common landmark of the neighborhood was Cross Brothers, a meat processing plant where the boxer, Mr. Joe Frazier, worked before he vied for the heavy weight championship of the world, and fought Muhammad Ali. The champ, as they referred to him in the neighborhood, was employed as a "stringer" whose job it was to hang heavy sides of beef on large hooks in the plant's freezer stores. It's reputed that Mr. Frazier's boxing style was greatly influenced by 'tenderizing' workouts with that beef.

Apart from employing Joe Frazier, Cross Brothers was also notorious for the stench of burned hides and entrails that emanated from its tall brick smoke stack all year long on weekdays. That reek was constant, nearly unbearable in the summer, and certainly as foul as emissions from a paper plant or garbage mound just next door.

The Shut-In Society was directly across the street from Cross Brothers, so we got the smell as bad as anyone. Being top of hill on the second floor brought us closer to the fumes on windy days and when it was foggy too.

The workshop's floor space was about the dimensions of a football field. Inside walls were unpainted cement, brick and steel. Industrial lighting was adequate, although the place was always noisy from the sound of machines, elevator doors, and material handling.

There weren't any pictures in the interior except for OSHA required safety postings and some plaques along the office walls. In the work area, bright yellow lines marked aisles for walking and transferring high piled skids by material handlers.

Offices on the north end were air conditioned too, but the workshop floor definitely was not. Two gigantic fans moved the stinking hot air in the summer, while rows of steaming radiators whistled and banged all winter long.

### **Ironese**

A company called (of all things) Ironese, owned the building and leased out its 2<sup>nd</sup> floor space to the workshop. Ironese manufactured, shipped and stored home and industrial ironing equipment for national distribution.

Ironese also contracted with the Shut-In Society to pack yellow rubber gloves into plastic bags. These gloves were one-size fits all, with no right or left handed choices. The workshop packaged and shipped them all across the country.

Here's how the assembly went: A group of workers with disability picked two gloves from a pile drawn from giant "Made in Japan" freighter boxes stored in the back. The workers neatly folded them into a plastic bag, a pair at a time. The bags were already labeled with 'sale' stickers by another crew.

After the stuffing, bags were sealed by other workers sitting at shrink wrap machines lined along the windows. After this, counts were checked and gloves boxed with US labels, and shipped.

Approximately 30 workers would be assigned to this job at one time, including 3 to 4 men and women on the shrink wrap machines. Truckloads were shipped in the weeks before major holidays and over spring cleaning season. We had this job down to a t.

The Shut-In Society found its niche in doing jobs like this. Stuffing bags, putting on sale labels, and heat-sealing were our specialty. We also did inventory control with for a big pharmaceutical company, had a part time worker who fixed wheelchairs, and operated a high volume mailing department.

### **Feel of the Place**

All told, there were 80 to 90 people with and without disability on the shop floor at the Shut-In Society, and another dozen employees in the office. We worked Mondays through Fridays, 7:30 to 4, 12 months a year.

The shop took-off major holidays and a couple of weeks in the summer. Lunch was a half hour and there were short breaks, just like in regular industry.

The workshop was an easygoing place with a lot of acceptance. People got along. Supervisors, front office staff, and workers took breaks and lunch in the cafeteria together. There weren't parties, but the annual picnic that the Society sponsored Fairmont Park, near the zoo, was nice.

While some workers may have hung out after work hours, people's private and work lives were generally separate, or so it seemed to me. We all came from different places in and around the city.

The variety of workers at the workshop, based on their cultural ties and economic conditions alone, was impressive enough. Disability just took it all to a different level.

On any given day, a young man with sickle cell anemia would be going through one of those unbelievable painful attacks he had, beside a person with brain injury and a lung ailment whispering and spitting politely in a paper cup beside her. Across the aisle, a new employee with an attention disorder would be walking around nervously, trying to get his bearings.

Somehow it all worked out. We never had fights or physical conflict. We did the work we were assigned to on deadline. As we used to say in those days: it was "all cool." It was.

As far as the neighborhood was concerned, workers with disability were treated like everyone else. It didn't matter whether a person wheeled or walked into the Shut-In-Society or Cross Bother's plant across the street. We were all in that city flow - doing our best to arrive on time, complete work assignments, and get back to our families and home places at night.

The routine we experienced at the workshop felt real normal. Except for those times that United Fund tour groups came around and gawked at us on the work floor, it would have been easy to forget that there were features about the Shut-In-Society that set us apart.

### **Supervising**

In the shipping and receiving department where my stint at the Shut-In Society started, I supervised Jim, my assistant, who lived at the state hospital and took their oversized blue bus to work. Jim and I wrapped packages of every size and description, filled and emptied trucks, and loaded skids of merchandize bound for warehouses, trains, and shipping centers.

Cold days, wet days, hot days, it was a constant stream of physical and demanding work. We knew each other's moves, moods, and propensities. We got it right because we had to.

We moved freight, stayed safe, and watched each other's back. Jim and I survived a tough winter and two summer sweats together. I'll never forget a couple of weeks of high wind and ice on the docks. It was no picnic. We worked our butts off too.

In all our months together, Jim smiled at me twice if you count the day we said goodbye. While Jim took directions real well and had good memory for finding things, his verbal world was very limited.

One of the few words he used around me was his version of my name. He called me Dano, with a short a. That was close enough, and we actually communicated quite well.

I don't know what happened to Jim. We shook hands, or tried to, that day I left. I suppose he continued to work there on dock for a while.

I do know that the state hospital where he lived closed less than 10 years later. If Jim was part of that court ordered dispersal, I imagine he found some community opportunities after that. He was certainly a capable man, and very healthy although, all those cigarettes he smoked might have taken their toll.

After a year or so on the docks with Jim, I was promoted to floor supervisor. In this role, I organized jobs that workers with disability performed, ensuring quality and efficiency as my primary duties.

I made sure workers did their shrink-wrapping, labeling, and sorting at various assembly lines and tables. I was responsible for ensuring that their raw materials were set up properly.

I also counted production on an individual worker basis, since that's the way everyone got paid. I was not a social worker in any shape or form doing any of this.

One of my ongoing responsibilities was to ensure accommodations were an everyday occurrence. Installing modifications like portable ramps at work stations along with personalized adaptive devices we called 'jigs' became routine. I also had to make other adjustments when workers were sick or indisposed due to various conditions.

Regardless of their handicap or condition, all Shut-In workers, including supervisors like me, were expected to perform at the best rate we could, while keeping to zero defect quality standards.

Everyone at the workshop knew to avoid errors and use standard practices too. Quality was our motto. It really was.

### **Sub-Minimum Ways**

Most workers with disability earned sub-minimum wage. I know this because one of my other floor duties was to prepare reports from which pay checks were issued. I did this every day, with every worker I supervised, on every job.

Wage levels varied depending on rates established by time studies done by our production chief, Mr. Hankery. My favorite Mr. Hankery quote related to his method of doing these time studies.

The quote was, "There's the right way, the wrong way and the Roy Hankery way. Guess which one we're taking?"

The time studies Mr. Hankery completed were a big deal, as they established what income people were paid in doing their piece rate work, factoring in supervisory salaries and other expenses. The time studies also dictated steps for getting work done.



Mr. Hankery did his best to make all this as simple and efficient as possible. Most of the time, his methods worked well, even if the wages people received were unbelievably low.

As a result of sub-minimum wage allowances granted to workshops like the Shut-In Society, workers didn't take home nearly the amount of pay non-disabled workers outside the workshop did. Checks varied from a few dollars a week to minimum wage for those lucky enough to work in the mail room or pharmaceutical storage.

Sub-minimum wage provisions were initiated by Congress after the 1st World War to transition wounded soldiers as they returned from the front to the general workforce. By the 1930s, employers were required to request special permission from the U.S. Department of Labor to pay people less than the federal minimum wage.

Though few returning war veterans took advantage of this option, sub-minimum wage caught on with programs for people with disability, beginning in the 1950s. About 420,000 Americans are now employed under a sub-minimum wage certificate, according to the Government Accountability Office.

The justification for this wage differential has been that people with disability who work at a slower pace than prevailing wage dictates should receive proportionally lower pay. For example, a person who performs at half the rate of an average worker would receive ½ the wage.

Few workers with disability performed at or near 50% of the prevailing wage at the workshop. Most men and women cleared no more than \$15 or \$20 a week.

Workers with disability who tolerated their job assignments and sub minimum wage paychecks would stay on at the workshop for years, even decades. Since a decent pay check didn't keep them from leaving, other factors had to.

### **That Poster With May**

A United Fund (UF) poster was distributed in the city over late summer of 1972. The poster includes a prominent photo of me supervising a young woman; May.

May is pictured in her wheelchair; the type the Shut-In Society repaired and rented, with a label that reads REHAB written boldly on the shiny side panel. She is putting together a hand-held fan on a worktable, with me peering over her shoulder.

Above this photo, there is a by-line that reads:

*The United Fund*

*That quiet sense of satisfaction from proving that you can*

At the poster's footer, in smaller type set, there is another statement, that's misspelled, stating:

*The shut-in society is a shelter (sic) workshop, a UF service*

The photo session that led to the poster occurred within the first eight weeks of May arriving at the workshop. I was pretty new to the floor supervisor scene at the time, too.

I remember being surprised that May agreed to participate, even at this early point in her Shut-In Society stay, given some of the issues she expressed about her work. I didn't have much choice myself in taking this assignment, as Mr. Hankery was in charge of this selection process and my supervisor.

The morning of the photo shoot, Mr. Hankery plucked me off another job, walked me to his office and said, "Wait here." I waited, as he brought in the camera crew and May.

A crewman informed May and me that they had been walking around the shop and noticed the work May was doing. He said he and his camera man wanted to take some pictures of us together.

The crewman also noted that the pictures they wanted to take might be used for publicity tied to a fund raising campaign. There was nothing said about a poster specifically. It all seemed a little vague.

After this explanation, Mr. Hankery blurted out something like, "Good, let's do it." Dutifully and without another word, May and I signed our names to the release form, and returned to work.

We all got together for the photo-shoot about an hour later, over lunch to boot. It took about 15 minutes, maybe twenty, with the set up and lighting.

### **Learning the Ropes**

From the first couple of weeks of supervising May, it was clear that she was smart, a good dresser, nice to others, and able to apply herself to work tasks. She had a lot going for her.

May had a strong personality and will. She made it clear from the first few days on the job that she didn't like the workshop that much.

She expressed frustration with the solitary nature of the fan job most especially, along with the short hours of work she was permitted to do under her Social Security benefits. She scoffed how her pay rate was 'piss poor'.

Learning that most workers earned sub-minimum wage just aggravated these concerns. While she liked staying busy, May didn't appreciate the prospect of being grouped with others on the basis of disability.

May would state her reservations and concerns to anyone in earshot, but she wasn't a complainer. A proud and true daughter of brazen South Philadelphia, she was not by nature

patient about her future, and wasn't going to pretend. She was also crystal clear about wanting to get back on career track that was interrupted by the accident.

After a few weeks of May's comments, I felt I should drop-in to talk with the agency social worker, Jennifer. I'd never been in Jennifer's office before, or dealt with some of the issues that May was expressing. I thought I needed some guidance.

Jennifer assured me that she was aware of May's objections, and that contact had already been with the trade school May attended before the accident. Jennifer also made it clear that she couldn't help in changing May's job assignment. I'd have to go back with Mr. Hankery about that.

When I went to see Mr. Hankery about this later that day, he insisted that the fan job was the 'best thing we had to give her'. He patiently pointed out that May was needed there because of her accuracy and speed. He also inferred that the job offered stability that should help in her recovery, which I doubted, but didn't dispute.

Mr. Hankery curtly closed the conversation then with another one of his sayings: "This is a business, Olsen, not a democracy. Now get out of here." I did, and quickly.

Thinking then that this floor supervisor thing might not be working out, I made a mental note not to question Mr. Hankery's assignments ever again. I got it then too, that this 'lack of democracy' he referred to was a principle that Mr. Hankery held in some esteem.

When I reported back to May, I said she would have to stay on the fan job for a while longer. I won't relay what she said to me then, but it wasn't that nice.

After that, May went back to the fan assembly, all the time listening to a pocket radio in her purse. It didn't take her long to adjust to Mr. Hankery's undemocratic ways, I thought.

Indeed, May mastered that fan job without a hitch. By the time the United Fund photo crew arrived, her skill level was surely better than I would have been able to muster. Over 20 tiny gears and screws it took other workers an hour to take apart and reassemble, May would complete in 12 to 18 minutes.

The job kept on growing too. As I figured it, the original manufacturer screwed up big time and May was correcting their initial errors. She'd take each fan apart, replace and reposition parts in the gear assembly, put it back together and test. If a refurbished fan smoked or made a grinding noise, she put it aside. Few were.

Over the next year, May completed hundreds of these repairs and checked out over a thousand fans. No wonder she hated it. It was definitely a drag.

## **Changing Views**

My impression of the poster with May has changed dramatically over the years. At first, it seemed flattering to have our images plastered on the side of city busses and in store windows.

As I advanced into policy and program development positions at Pennsylvania's State Office of Mental Retardation, I framed the poster and hung it prominently so colleagues would see it. It hung in each cube and office I occupied over my 30 years there.

If visitors asked about it, I'd recall something about the workshop. I'd gaze at the poster from time to time too, wondering about how life worked out for May and other things. That poster was a comfort to me, a window to my past where thoughts of all kinds found a place to wander.

That poster, somewhat the worse for wear, was also in the final arm-full of personal items I packed to take home when I retired from state service a few years ago. Apart from its release as the cover of this book, the poster has been rolled into a cardboard core with no particular plans for resurrection.

## **The Quiet Sense**

While the poster with May was meant to evoke something positive about the Shut-In Society and opportunities in general, I question now whether it was making this point. Where was the back-story after all?

Where in this image and wording was a kernel of the truth about May in pursuit of a career, doing the type of job she had been schooled for? Where was a message that conveyed May's skill, personality and independence? Why was the poster so much about the workshop, and not her?

These questions have come back again and again as I prepared this book. I've asked repeatedly whether the poster's words of "quiet sense of satisfaction from proving that you can" are something I can buy into anymore.

Is the "quiet sense" any more than code for keeping the community disconnected from people's aspirations, or a sweeping generalization meant to excuse the general public, and employers in particular, from taking on roles where people are listened to, offered jobs and lifted up in respect? Is the "quiet sense" just another route to keep people invisible?

What if May didn't prove whatever it was she was "quietly" supposed to in the work she was doing? Would that make her less human, less qualified to pursue the career path she chose, or less worthy to be supported in the life she wanted and was able to take on?

What makes organizations like the United Fund convey people's achievements in this way? What is it about places like the Shut-In Society that find themselves link with charitable causes like the United Fund instead of businesses that could employ people like May?

Further:

*What truths are communities being shielded from by putting their faith in sheltered service settings?*

*Is this lack of inclusion a problem with people or communities that don't relate in an everyday way?*

*Is it any wonder that we are all still living in a shut in society today, and leaving it for future generations?*

### **United We Fund**

As I see this poster presently, no supervisor needed to be looking over May's work like I was. Making my presence so prominent in that image has gotten to me more and more. May was doing this job just fine without me.

In retrospect, it's obvious that this combination of image and a phrase confirmed already popular impressions. The United Fund, like charitable fund raising organizations today, catered to people being shut in.

'Helping the handicapped' through sheltered work was viewed and is still seen as progressive, inevitable and heart felt. The problem was, and still is, that "giving to the handicapped" through some programs detracts from people's valued roles and employment outcomes.

People with disability don't choose charity and paltry pay in a sheltered work site. They take this deal because that's what they are instructed to do, with no or little choice. That's the deal people make for obtaining health care and other benefits they rely on to survive.

People want support to live everyday lives through jobs and careers, not compensation that keeps them dependent and shut-in. Seeing the poster and its charitable message in this light changed everything for me.

Under the United Fund approach to supporting people, a citizen's social contribution has meant putting up personal earned income through area business and industry so specialized services like this workshop could continue to operate.

Employees all over the city gave to the United Fund in these days. Their annual campaign brought in millions, even back then. My guess is that 20% of The Shut-In Society's budget was obtained through charitable gifts of this nature, and it might well have been more.

All I knew then was Shut-In Society workers on salary, like myself, were expected to contribute 10% of our take home pay to this United Fund. I never liked giving in this way, and won't plant a dime on these charitable drives today.

I don't recall if workers with disability were expected to donate at the same rate, or if they were canvased at all. I wouldn't doubt it.

For me, it wasn't just the amount of the donation, although \$600 a year was a chunk at that point in my life. It was the expectation that I didn't like. There I was: contributing to a fund that was used to support my miserly salary along with the 'piss poor' wages that workers with disability took home.

Further, it appeared like area businesses were using this United Fund appeal to ensure that people remained at the workshop and places like it. By the time I left in 1974, the whole situation seemed weird and punitive, not that I sensed anyone outside the workshop probably cared one way or the other.

As far as general citizens seemed to be concerned, the Shut-In Society was the kind of disability-only place where people belonged. Workers had best get used to this perception, from their point of view. They should thank the community for their giving nature.

This donation thing got to be a love it or leave it situation, for sure. In this heyday of Queen for a Day and television telethons, making a point about how workers like me give at the office in other ways, would not be appreciated at all.

To gin up interest in their annual funding campaigns, United Fund business representatives from throughout the city walked through the workshop on tours. We'd have a couple of tours a month usually, and weekly visits during the annual fund drive.

As I understood the drill, the representatives went back to their job sites to drum up donations from their colleagues. Each business was expected to reach 80% participation levels, and usually did.

After the drive was done, there was a big dinner in a swank center city hotel that the mayor and business leaders attended to unveil the jackpot each year, applaud teary testimonials, and stammer through awards for 'best worker' and 'employer of the year'.

A line of United Fund plaques hung in the Shut-In Society office area and meeting room honoring our director, and some long time workers. A posthumous plaque with the image of a thin man affixing labels to popcorn bags was in this gallery too.

The touring visitors, usually dressed to the '9's, would walk down the yellow lined aisles at the workshop, huddled in groupings of 10 to 20 people. We joked about them 'on parade', walking through quickly, nodding sometimes or waiving, communicating that it all looked 'ok' to them.

Despite their smiles and waves, it was easy to see that certain visitors were uncomfortable with the tours, for one reason or the other. We didn't take it personally.

There was too much work to do in manufacturing to care about that, and the tours brought income which was viewed as a good thing. As long as the charitable money kept coming, nobody asked questions about the benefits to the people or the community at large. Those donations still piss me off.

### **Should-Ofs and Did She**

As I see it now, the image of May on the poster shouldn't have been about her overseen by a supervisor, doing a piece rate job in a shut in world. It shouldn't have been displaying her in that wheelchair with the "Rehab" label so prominently displayed. It shouldn't have said what it did about a "quiet sense" of achievement.

The poster should have shown May working somewhere else, demonstrating her ability in a chosen career that paid a true living wage. It should have portrayed May in a valued way. It needed to shout out her pursuit of an everyday life full of confidence and a sense of determination she definitely had.

Though she never admitted it to me, May was probably the perpetrator that tore down the poster in the workshop entranceway. Now that was a 'quiet' act of defiance that I could see May doing.

I could see her ripping the poster onto the floor and rolling her chair over it for good measure. I could see this as May's protest to being displayed as a disabled poster 'girl' for the city, which was essentially her world too. I could see this as her demonstration against the fan job and her benefit restrictions, too.

Even if she didn't tear it down, the fact that a replacement was never rehung in the poster's place says something. Another poster was removed in the meeting room shortly after the incident too.

That image of us was also totally 'non-gratis' on the workshop floor. Nobody talked about it or ever told who pulled it down. People knew, they just were telling the supervisors. There were no slaps on the back as the messengers of our little workplace.

That poster rubbed some workers the wrong way. While the greater community would have this United Fund image and these words as an affirmation of 'the handicapped' at work, it appeared that workers had to let all that go.

The image of our daily grind as charity just wasn't sitting well with people coming from the production side of the equation, doing the tasks of everyday workers even if we weren't paid like them. While Shut-In workers absorbed this indignity, posters probably remained as an ongoing humiliation in their lives, for as long as the United Fund kept going, at least.

In the final analysis, that United Fund approach to supporting programs like the Shut-In Society underscored how charitable statements reap perverse consequences, not so much on the

organization that benefits from funding, but on people themselves. In any event, the real damage was already done by the time the poster got torn down.

Thousands were placarded all around the city by then. Thinking back on that episode now, all I can say is sorry.

### **Frustration**

Jennifer, the agency social worker, called me in for another meeting a couple of months after the photo shoot. In this final work talk we had, Jennifer expressed concern that May's case manager had not returned phone calls in weeks.

Added to this, an admissions officer at the trade school was faced with a contractor delay in modifying a doorway and bathroom stall that May needed. The contractor required more money to finish the job, which would take additional time to locate and authorize.

Jennifer also confirmed what May had told me concerning payments on her student loans. While May was being assured by her attorney that a monetary settlement from the accident would be forthcoming, the judge kept granting delays and continuances. May didn't like collection agents bothering her family. They worried her.

It got to be one thing after another like that. Even intervention by the program director and an influential board member weren't moving things along. Jennifer wasn't expecting a breakthrough for a while.

Jennifer then asked what I thought about May continuing her education somewhere else, and getting another job or training program. Maybe the workshop was not the right place for her now.

After thinking about this for a while, my sense was that May would be hurt not getting back to her old school to finish out the degree. The school was close to her neighborhood and seemed to be in May's vision of her own recovery.

I also reminded Jennifer that any job 'on the outside' wouldn't take kindly to May's work limits under Social Security. Even so, I thought that other opportunities would be worth checking out. Options were good.

In either event, I reminded Jennifer that I would prefer not to approach Mr. Hankery again about changing her job assignment, after the last incident. Jennifer assured me she understood my hesitation with this, and wasn't asking me do anything like this.

Then I shared some frustration of my own. I reinforced with Jennifer that we were not alone in our concerns with May's progress. Delays and false starts were getting to others at the workshop too.



While we all wanted to believe in the workshop's mission, May's situation was giving us doubts. She still disliked the fan job and was kept on it. What kind of place was this? I felt bad for not sticking up for May too.

As I left the office, I wondered whether Jennifer lived through some of the same challenges May faced. I wondered what Jennifer knew from the perspective of a person with disability herself.

Jennifer had polio or something like it. She used a wheel chair and braces to get around.

I asked myself then: Was Jennifer held back because of those braces and her disability, like May was? I thought probably, yes. Did she overcome all this? Yea, she seemed to judging from her job as a qualified professional, doing what she wanted in her career.

But what about that frustration she expressed? It was a dimension of social work that I didn't get on the workshop floor, but something I was beginning to appreciate for the first time through my discussions with both May and Jennifer.

I was seeing firsthand how this service world of disability was different from putting labels on bags and assembling fan motors. After that meeting with Jennifer, I recognized that supporting people was not a job for the faint of heart.

I realized then too that supporting people meant more than moving a paralyzed leg that got out of position, or setting down production numbers in a log book. Support meant dealing with people in a total sense, taking into account the will of others, personality, job titles, prejudices, resource rules, delays, family pressures and such.

I also took away something else from that meeting with Jennifer. I grasped that people with disability are at constant risk of being trivialized and having barriers thrown in their way for no better reason than they can be by those in charge.

I even sensed that the life goals of May didn't seem to matter like they did before she had her accident. I also felt like all of us at the workshop were being bounced around by school and service decision makers, lawyers and concerned parents in ways that denied May reasonable access to a future she deserved.

I felt real bad about these roadblocks and the lack of urgency that was so apparent in finding solutions or another way. I wanted the barriers gone not just for May, but for me too, and for the Shut-In Society where we worked.

### **Same Old Same Old**

As I see the situation that May faced today, we all should have done better as a community and system dedicated to so-called rehabilitation. The accident that severed May's physical ability had been exacerbated by services that weren't doing their job to get her back into community ways.

From what May said, services at the workshop weren't helping her family life either. Her mom and dad expressed doubt about May's prospects after the accident. The family questioned her ability to get back on a career track.

These doubts spilled over to other matters, like May's plans to rent an apartment, and get together with a guy she met in rehab. They were making plans but these seemed on hold too, and getting more complicated by the day with problems around benefits and service delays.

May, like other people at the workshop at some point, didn't appreciate her time being wasted and her career track trivialized. She knew she didn't need to be grouped in a handicapped environment among peers who had become accustomed to sub-minimum wage compensation in a shut in world.

She didn't want to be restricted to three days of work a week instead of five because of her Social Security benefits either. She shouldn't have had to worry about her lawyer's suggestion that 'not working' could result in a more lucrative settlement down the road.

As time passed, May discussed this stuff with me when we were together. I'd come by and sit with her as she put together the fans, and others did too after a while. Co-workers filled in to make her feel better and not so alone, at least.

My sense from these conversations was that May was still focused on getting on with her life like she wanted to, just as soon as she possibly could, and she was ready. She retained a sense of urgency about her future for sure.

I wanted to believe that this feisty spirit would help May recover from this time of being bored, kept broke and misinterpreted. I also never gave up hope that she'd get past that sheltered image of herself on the poster, and get on with life despite the barriers standing in her way.

### **Good-byes**

The situation with May didn't improve by the time I left the workshop months later. She was still doing the fan job the day I came in to say good-bye.

While we kept up appearances that morning, I sensed that her confidence and good spirits were shaken. There were some problems with sores on her legs too, and new medications.

We chatted of plans for an inventory control position in the office area that opened. It could lead to a full time job here at the workshop, who knew? She reassured me that she applied and had an interview on the calendar.

Half-heartedly, I offered to talk with Mr. Hankery again about getting off the fan job if she wanted me to, just in case the inventory position fell through. She said forget it, and I felt relieved. I didn't want to confront him again, even on the day I was leaving.

Finally, we affirmed that Jennifer was still meeting with trade schools and the area vocational rehabilitation agency, so there was hope there too. We acknowledged that nobody at the workshop had given up, at least, then hugged goodbye.

Even though there was a ring of hopefulness and solidarity in our brief embrace, there was hollowness too, and a whole lot left unsaid. I felt good to be leaving, but bitter and deeply disappointed that May wasn't headed out the door too.

### **Over the Years**

Over the years, this hollowness struck again and again in similar situations where I witnessed support that could have been addressed in the right ways, but wasn't. Sheltered workshops everywhere displayed it, and it never went away.

The amazing thing is that these conditions have continued as a norm in society. Today, the same frustrations that May experienced are playing out with hundreds of thousands of young adults in workshops, day programs and activity centers, with no career track in sight.

Young adults still routinely transition from high school to the sheltered shops and remain there till they retire, held hostage by convoluted benefits and sub minimum wage laws that stubbornly persist. Despite the dismal results of workshops finding people real jobs, our country still supports the same status-quo brand without question.

Modern charities like the United Way also continue raising funds for the workshops too, and their tour groups still walk and gawk their way down workshop aisles, like they did back in 1970s. Charitable poster drives and funding campaigns have not progressed to a point where people are portrayed any differently either. Their content and imagery are basically as bad now as they were in the poster with May and me.

Over the course of my career, I've been part of many workshop tours myself. What I witnessed on them hasn't changed much either: people underpaid and devalued, not being trained or prepared for any type of community employment, and trapped.

While I still wish saying sorry for all this would help, I know now that it won't. Getting beyond society's comfort zone of exclusion is going to take more than that, a lot more.

### **From Shut In to Sheltered**

The Shut-In Society name had been handed down from the late 19<sup>th</sup> century, when city patrons decided to assist people with disability find work. This was part of nationwide efforts to take people out of asylums and protect them from abuse in jails and work gangs.

This Society was dedicated to bring the dignity of work to people who were shut out from regular jobs. Early papers of the agency's founding express the clear and optimistic view of civic minded individuals and families marshaling resources on behalf of their communities.

During the early decades when Shut-In Society operated, people with disability had no means to get out of their homes and institutions. As transportation and treatment options improved, the shut-in contingent diminished. There weren't more than a dozen so called 'homebound workers' contracting with the workshop when I was there.

Those workers hand stitched tiny finger mittens used by machine operators who put together electronic parts. I remember the work being tough on the eyes, and that people with arthritis couldn't do it.

The workshop director, Mr. Floury, began to discuss changing the agency's name in response to a growing awareness that the Shut-In Society name was not conveying a positive interpretation to the public. Advanced program concepts like Normalization were just being introduced to human service agencies at this time and Mr. Floury was probably influenced by these new ways as well.

The director called a general meeting. All workers on the floor and office staff attended. The assembly lines stopped for an hour or so, which was unprecedented.

Standing on a makeshift platform constructed from wooden pallets; Mr. Floury discussed reasons for the name change and presented options that he had cleared with the board of directors. These options included naming the workshop after an obscure creek that ran behind the building, or an Indian chief that signed a treaty brokered with Benjamin Franklin in colonial times. Another choice was Sheltered Employment Services, or SES.

After a lively discussion that raised misgivings about changing the agency name at all, it was decided that a group of workers would meet again to present a final recommendation to the board. Sheltered Employment Services, or SES, became the group's recommendation and the board approved it unanimously. The general body accepted the change without any fanfare, the group of workers that met with the board disbanded, and the workshop went on like it did before.

As the new name settled in, workers and customers may have noticed the new Sheltered Employment Services signs hanging over the dock area and front door, with a freshly painted United Fund logo of hands holding hands. The neighborhood didn't have much to say about the sign, and probably never noticed the change. The same workers kept coming to the building, passing on the streets, and stopping in at the corner stores.

As Mr. Floury promised, there wasn't any noticeable change in the character of the workplace after the new name was adopted. That workers would now be associated with a name that interpreted them as sheltered instead of shut-in seemed to be no big deal.

The succession from Shut-In to Sheltered Employment had been quite clean and uneventful, and the acronym SES was innocuous enough for business and public relations purposes. The place sure felt, looked and smelled like it did before.

## **A Step Not Enough**

As I see it now, that step of changing a name was as far as a place like the Shut-In Society could go in straddling competing demands of a social service and business, as it tried to do over the years.

The shut-in character of services didn't change at Sheltered Employment Services or SES. Workers with disability didn't get to experience a work life beyond how it was set up by those with a mission to serve.

Neither the 'shut-in' nor 'sheltered' moniker would help people find careers and jobs of their choice. The workshop was still a place specifically for people with disability, where they could be watched over, used for their production, and put on display. Except for the fact that people had a place to work, the enterprise was still a rip off to people who would never be able to escape their trap of sub minimum wage and benefit restrictions.

The name change to Sheltered Employment Services, though it followed an open and predictable path, didn't improve conditions for people who worked in this sheltered space. Nobody got raises or better hours by the change. No great sub-contracts came in the door. Workers with disability were not suddenly supported to find community employment under this new banner. It was the same old, same old, all the way.

Looking back, it's obvious that going from 'Shut-In' to 'Sheltered' over the course of forty years is nothing to crow about. When so many people remain isolated and diverted from their communities because of what programs in systems continue to perpetuate, we have to ask ourselves why there aren't more and better ways, than these shut in and sheltered paths people are given.

Workshops, regardless of their name or sponsor they represent, are still based on an overarching premise that people with disability, intellectual and otherwise, belong grouped together in sheltered ways. Sheltering degrades people's work, has no relevancy in a modern economy, and ignores the talents people have to share in the general workforce.

These workshops operate under the assumption that disability is reason enough to be quarantined in settings set apart. As facilities continue to promote conditions that are more institutional than job-like, they can still make a meal out of protecting people from imaginary risks while perpetuating their 'do-gooder' ethic and a sweet bottom line.

Changing program names like the Shut-In Society without changing attitudes, practices and how resources are channeled means nothing but cheap ink on agency letterhead, paltry paychecks for workers, and another agency logo built upon pity.

The lesson is: don't buy these words or piecemeal changes for a backwards minute. They'll only make you sick and sorry. Believe me. They do.

## Postscript

I decided to return to the workshop site while finishing up this book. I went there with my son Jeremy born there in Philadelphia in 1973. This was the first time I came back to the workshop site in 40 years, and I liked the idea of sharing it this way.

As Jeremy and I arrived, I noticed the half-collapsed smoke stack, with all of the letters C-R-O-S-S, as in Cross Brothers, still visible. All that remained of the plant that used to surround the stack were piles of bricks circled by chain-link fence.

After parking, Jeremy headed to what remained of the collapsed building to explore, as he is prone to. I felt relieved that the smoke stack stench was gone and wished him good luck getting through the fence.

I then headed to see what the Shut-In Society had become, now that it had been transformed into a mattress outlet according to the name painted out front. Judging from brightly colored balloons and banners that danced in the breeze along the entrance way, it certainly looked to be open.

As I walked toward the entranceway, I was taken by the old workshop's drab brick exterior now freshly painted bright white, shimmering in the late summer sun. When I walked in, the interior had a lot more natural light than I remembered, too.

This lightness seemed to be a result of large plate glass windows installed across the entrance way walls, and added fluorescents along the ceiling. The interior space was also much cleaner and the air conditioning a definite comfort we lacked back in the old days with those big floor fans.

All the Shut-In Society walls between the offices, pharmaceutical cages, and storage areas were gone too. The outlet was basically one big open space with shelving here and there. The space was taken up with fresh and clean bedding, furnishings and related accessories.

Only a slight faded strip of yellow used to designate aisle space remained from the old floor plan. The strip reminded me of the United Fund tours. "Always stay between the yellow lines", we told the visitors. They did.

The outlet personnel were nice and not at all high pressure. One saleswoman listened to my story of the building's history, as legitimate shoppers looked over the merchandise and talked among themselves. I thought about buying something, but didn't.

Leaving the outlet, I introduced myself to the manager who was taking a smoke break with a colleague at the entrance steps outside. I told him my abbreviated SES story too. He remarked somewhat gravely that "Times do change".

He also said that he had not been familiar with this history. "Yea, it's sure changed," I responded. "I'm happy to see what you've done with the place."

As I turned to leave then, I had a flash memory of May. I had a sense there would be a recollection like this when we were driving up to the place. I even talked to Jeremy about it, wondering about what I'd recall.

In this fleeting image, May and I were face to face, in one of our easy afternoon talking modes. She was smiling and I was too, and she was not working on the fans.

It felt good not to be overseeing her like I was in the poster at long last. I hope that image is done for good. It's not as indelible now, at least.

## **Chapter 4: Letting Life In**

### **Being Open**

Community outcomes of an everyday life won't come from a system. These results require community ways that are negotiated, nurtured and applied within an everyday context. The effects of community life can't be required or controlled by forces that systems represent.

The truth is that systems don't operate in a community way. They operate outside of everyday norms and take over functions that family and other community resources would otherwise fulfill. They have lost touch with the community, becoming irrelevant and inept in the very ways communities and people need to be competent.

While systems have evolved to create mangled truths in deviant worlds of their own, their relationships with community are still distinct. Systems have members that join in association within the physical space of community, but that's about it.

Where systems thrive, there's always money involved and rule bound decision making. There are hierarchical controls and checkers who aren't supposed to be arbitrary and out of touch, but are. There's a lot of lazy behavior too, with workers not making decisions because of the work and bother they create.

Some of these systems work for people, but most are not that healthy to say the least. Systems watch out for themselves and take care of their members first. They stretch and manipulate the truth to look good, while hiding deep decay within.

While communities are not pure and problem free, their everyday qualities come through in the end. They are considerate of cultural norms and traditions that systems tend to suppress. They sustain healthy realities and acknowledge their accountability to everyone.

Communities, through citizens and other resources, support people in achieving outcomes associated with an everyday life. They prefer it when people have jobs and social value.

Communities tap into specialized resources, from doctors to plumbers, but don't rely on them exclusively or let them intrude into areas of life they have no reason to be. Communities rely on resources like realtors to find people homes and visiting nurses to teach family members to administer medication. They don't task functions out just on the basis of a person's difference. They accommodate.

Communities rely on city inspectors, health departments and the police. They have citizens, the press and other resources to monitor life conditions, advocate for cost effective ways, and manage aspects of life that become too difficult for people to do alone.

In community ways, people have support related to the extraordinary difficulties their disability imposes in the context of home life, employment, and community ties. They possess



financial and other power to manage decisions that are currently usurped by systems, families, agencies, workers, guardians, case managers. The list goes on.

In community, resources rely on people to contribute to their own success and well-being. Individuals with and without disability assume responsibility to the best of their abilities, just like everyone else.

Expectations of people in community are reasonable and tend to drift to the high side for sure. Communities don't thwart everyday achievements. That just wouldn't make sense.

### **Realizing What Is**

People first principles and practice don't mean system interests first. Supports focused on living and working can no longer be parceled out by programs that devote themselves to impeding pursuits to live full and satisfying lives.

Systems should never have the power to pick and choose which people will be living in the community ways or getting jobs. Choice of support should never have been restricted by service definitions and irrelevant provider qualifications. Expectations with people and resources just have to change in this respect.

Responsible citizens cannot continue to allow agencies and system intermediaries to divert funds from the everyday tasks at hand. Our communities can't in good conscience let a professional's diagnosis trump anyone's access to get a job, relationships or home of their own.

No one should tolerate a parent's protective love dictating what everyday risks adults can reasonably take in life. We all need to be able to mediate better, and stay involved in improving living conditions through ways apart from inspections, talking-head conferences, and trainings that don't contribute toward everyday lives.

As responsible citizens, neighbors and friends, we also need to stay focused on the outcomes people want and communities expect. We can't let people still living in institutions rot there any longer while we debate what to do with worker jobs and systems that should have ended decades ago.

People with disability don't need to be readied for community life or trained in disability settings as a prelude to community living and getting a job. Instead, they require support to live in the context of everyday structures that are already available in the communities where they want to live.

As community resources reach out, people get to demonstrate how they want to live and contribute in everyday ways. Without support people don't get on this path, ever.

In community, people with disability are able to grow up, take on adult responsibilities, and show their stuff. Without people being self-determined, none of this is doable either.

People rise to the occasion, with support and autonomy. It's worked for everyone else, why not people with disability too?

While people in today's systems have not been informed about any change of expectations, they'll get the news soon enough. When they do, people will welcome support that takes them into valued lives they want to pursue. That's what they've been asking for from the beginning.

This life taking everyday ways won't be about their mom and dad's agenda anymore, or the system's solutions for that matter. People won't be placed 'in' services or 'with' an agency, like they are pinned to today.

The future that awaits people isn't vague at all. This community support is focused on securing jobs, a home and community ties. It's all about accommodating, not creating something new. It's developmental and relationship driven too.

Anyone and everyone are eligible for support if they want it, and it's got to be available without charge. Objectives have got to be clear and solutions straightforward. Incentives established would build on success, and failure would be left like a hot potato.

While health and related needs would be looked after in the achievement of home, employment and community outcomes, that all goes along without question. Health care, rights and safety assurances are already in the pursuit of happiness mix.

The only personal requirement in support would be that people who receive it agree to take responsibility for their participation. Though it all, the community will be behind the person, all the way.

That's where we're headed now: into a culture of success and out of the restraints of being needy. We're headed down a responsibility path with the community.

Valued roles emerge in this context as people become confident and secure about their future. People become self-determined by calling their own shots. Communities gain confidence and competence too.

In this process, community structures accept that people with disability make mistakes and fail as others do. Learning from these situations and taking new ways is what matters then, for all of us.

Getting up and dusting ourselves off is the course we're all pursuing in one way or the other. People with disability get to do this, too.

In the final analysis, community support puts the interests of people above systems that provide and administer assistance. Community lets life in.

## **Staying Clear**

It's gotten to the point where if people and their families don't get the responsibility to exercise real choices in their lives, they won't find a way to real dignity or life on everyday community terms.

When it comes right down to it, systems don't give real choice that includes community support and will not be able to do this any better in the future. Only communities can offer the choices people want in terms of living a full and satisfying life. Having conflicted intermediaries in this respect is no longer justified, any more than it ever was.

While system workers and organizations can provide personal care, housing and other forms of assistance, their functions will continue to ring as hollow as they ever did without dramatic changes in perspective, participation, focus and control. That familiar dull thud of custodial care and life wasting resonates across the nation's programs and facilities where people with disability live and work today.

Only the public can change this dead tone into something grounded in the experiences we all have in common. No system will do this. Changing services from the inside out is out of the question at this point.

People with disability deserve respect for the contribution they make to our community life, and honored for doing their best, just like the rest of us. All people expect is to be treated in ways that reflect their value as contributing members of society.

By discovering ways that bring out the value in people, we'll have better communities with less violence, rivalry and frustration. Discovering value in others is the basis for building communities we want for ourselves.

If people with disability aren't involved in this community building as equals who enjoy life conditions on par with the general public, communities become weaker. We can't afford that any longer. Strong communities contribute towards everyone's security and well-being.

Our common task now is to build direct connections with individuals and their community that have nothing to do with oppressive system controls. This country can't achieve the outcomes we need by keeping the system in charge.

Redundancies, arrogance and contradictions in systems will give way in this community framework. Superfluous structures will disappear. It's time to move out from system controls, so community resources can develop and flourish in people's lives again.

## **Finding Nexus**

Jean Vanier, an unassuming Catholic priest who supported community living with people in the 1960s and 1970s, describes a healthy community. It's good to reflect on this.

*When a community is healthy, it acts like a magnet. Young people commit themselves; visitors are happy to come there.*

*When a community starts to be frightened of welcoming new people and visitors, when it starts to lay down so many restrictions and ask for so many guarantees that practically no one qualifies to come, when it starts to reject its own weakest and most difficult members, - the old and the sick – these are bad signs. Then it is no longer a community. It is becoming an efficient place of work. (Page 82, Community and Growth, 1973)*

After a generation of trying system ways, it's evident that this country's challenge in supporting people is more than being person centered. Its community centered, too. Our generation calls out for communities that draw in everyone.

We have a nexus today that is waiting to rise up in support of people with intellectual and other disabilities in securing everyday experiences. It's about us all helping each other now. We can all start improving from there.

Communities, including citizens and visitors, can embrace their welcoming roles, or continue along their road of blissful ignorance and social decay. It's not healthy for communities to shun people who really can, want and need to contribute to society and the common good. Continuing to disregard people with a contribution to make can only keep coming back to haunt the health and spirit of us all.

In pursuing both social and personal responsibility, it bears repeating that systems aren't going to be able to support community outcomes when their programs are all wrapped up in themselves. Systems have no understanding about how to deal in a community way even though they profess to be experts in this all the time.

Support for people to live an everyday life can only be achieved when people and the resources they require are pointed in the right direction and staying the course. That course is taken when a person is achieving valued social roles, like working, paying taxes, contributing to the family, and making choices about his or her life.

That is not the course that people with disabilities take today in service worlds and in programs that systems offer. Only when support ways are based on valued outcomes in the real world, will people with disability have a better go at life and opportunity to build for the future.

### **Keeping Conscious**

For the community to get its act together, it must be conscious of a responsibility in supporting people to achieve everyday living outcomes. Workers, families and volunteers need to accept their role as social responsive representatives and delegates willing to apply themselves in new ways that have relevance and community standing.

Everyday living cannot be achieved without people with disability doing their part in connecting with community resources. Support cannot be left to health care professionals, and held hostage by congregate care interests, whether private or public. People must be supported to be themselves.

The work of supporting people also cannot be done by overseeing group at congregate care facilities or by concocting program requirements that have no effective way to improve people's everyday living outcomes. For these conditions to change, the country, and its communities cannot afford to sit on the sidelines.

Rather than accept the half-truths of conflicted agencies that make their living by restricting opportunity, the public needs to see for itself what works and what doesn't, and make sure its resources are going to secure effective intervention and support. Citizens need to be involved and invested.

Community leaders need to understand and deal with the fact that systems can't get it done with outcomes we require. Employers, shop keepers, and neighbors must be part of the move of people from being viewed as 'them' to 'us'. Community building thus becomes a unifying theme.

Community is what we begin with, nurture and enhance. While it's perfectly reasonable to seek other outcomes -- like organizational stability, an increase in worker pay, and family satisfaction -- we must all be clear that the character of support matters most, not billable units of service or making life easy for system operatives and guardians.

Real life is an outcome that communities create with people, not keep from them. Care laden services don't have to define life's ways.

### **Using Social Capital**

The surest ticket to everyday life comes by holding social capital. Fundamentally, social capital means that people have community standing based on the resources they bring to the table. Social capital is scored by the valued roles people play.

While not immune from negative interpretations, social capital gives another perspective based on how people live. It is achievement oriented. People with disability, like anyone else, acquire social capital by gaining respect and standing in their communities.

Social capital is often taken for granted in this society, where a lot of people claim to have it, and anybody can sue anybody for anything, strike it rich, or gain notoriety. While there are race and class distinctions that play out in the process of acquiring social capital, leading valued roles trumps prejudice like this time and again.

If a person happens to be black or white, gay or straight, this doesn't matter so much in the arena of social capital as long as the roles a person fulfills have value, with resources to back that value up. People with disability can hold social capital on this basis, just like anybody else.

The problem has been that systems have held social capital from people and manipulated it for years. By controlling people's lives, systems seize the capital people should have for themselves. Systems turn that value into programs that end up rewarding system stakeholders, workers and caregivers at the expense of people they serve.

System inspired programs take value away from people by virtue of the control workers exert as administrators, program developers, supervisors and direct support personnel. Direct support workers become valued for the doing work others wouldn't want to do. People are left holding the bag.

In contrast to people in the clutches of service, men and women with advanced degrees have social capital in academic circles, as individuals with wealth have entree to those with political power. Individuals who are physically fit and attractive have social capital in their good looking/healthy sets.

Students who join the band, a ball team, or an after-school club have social capital with their classmates with similar interests. Adults have social capital when they succeed as a life partner, spouse, and loyal employee.

Social capital also applies to people who can be counted on as friendly neighbors. People that direct and are able to take care of their own lives, with however much support they require, have capital too.

People, who don't have these qualities, lose value. Their social account is diminished, like it is when workers forfeit their jobs or married people divorce. That's how the value thing goes. It adjusts with the conditions of life.

A person in this country raises social capital with the support of others, like family and other relationships. In the realm of social capital, no person is an island; and everyone has potential value.

Within a community framework that engenders social capital, artifices like system based guardianship and case managers, human rights committees and categorical funding rules often stand in the way. These system controls take the power of self-determination away from people, and mask the social contribution people and communities would otherwise make.

Community approaches that generate social capital leave behind the rash of rigmarole that systems rely on. Cookie-cutter rules and tradition essentially disappear in a social capital universe.

In a paradigm that values people's capital, there are no prescribed monitoring requirements by system operatives. Practices that did no more than perpetuate system ways are scrapped. People don't live or work in places they don't choose or want to continue.

While public resources tied to a person with social capital can help locate and coordinate support, people share in the control of the assistance they use. People decide who does work on

their behalf, without being predisposed to certain professionals or restrictive service definitions. Personal decision making becomes the currency of social capital, above all else.

Social capital takes direction from people first, followed by their family, employers, neighbors, friends and other community connections. In this state, there is no need for case managers determining what and when, how and where programs develop. People with value often have that covered.

In a socially capitalized environment, people choose whether a case manager or any other provider of services would even be invited to a planning circle, or merely informed of decisions. They'll be no other parties, agency heads, and sponsoring organizations taking all the credit or the resources either.

Social capital rests on a foundation that supports people who manage their own lives to the extent they can. This responsibility makes people or breaks them in a social capital context. It's not a matter of choice in this respect.

People can't secure social capital with one foot in system approaches any more. It's time for leaders, families, workers and people to walk away from what hasn't worked, buy into what does, and make others have this opportunity too.

Social capital demands that the right workers provide effective support in the right ways. For this to be achieved, workers need to stop taking care of people in groups and start supporting them individually.

Social capital dictates that people be supported in ways that do more than keep them safe, clean and out of the community's way. It means more than managing a plan of care that scraps valued outcomes from the start.

Social capital has to be people driven, not system enabled. It requires language, routines and practices that the public values and expectations that the community shares.

### **Taking Responsibility**

Historically, communities in this country have not engaged with people placed in institutions or other congregate care settings. Over time, citizens and community resources were told in a myriad of ways to stay away from institutions, inevitably located in the outskirts of population centers, and to mind their own business.

Even before modern times, communities agreed to separate themselves from the institutions in return for a promise of benefiting from that particular brand of prosperity. Like they did in courting other area industries and business, communities honored institutions on the basis of the jobs they brought and professionalism.

From the beginning, communities learned to respect institutional space as private, where the highest medical and professional standards were upheld and order maintained. Even

neighbors to the facilities viewed residents like patients in a hospital setting and not at all like citizens. No one was surprised that these people were absent in voting, worship, and everyday activities around town.

Communities paid a price for their hands off demeanor. We all did. No institutional walls should ever prevent a community from taking responsibility for a citizen's quality of life like they have done over our nation's history.

No place that serves people should be beyond the community's eyes, ears and responsibility ever again either. People who reside in institutions have every right to vote and participate in community ways. They have every right to be considered like everyone else.

Our history shows the need to be ever watchful when congregating people under professionally sanctioned supervision and public sponsorship. Whether a group's defining difference is poverty, a disadvantaged neighborhood, race, or disability, the affect is the same.

People congregated by their difference get segregated and exploited, pure and simple. Some have even gotten killed and slaughtered en masse. Communities make or break this cycle by staying involved with people or not. It's really up to them more than any fact finding commission or arm of the law.

Remedies to address community neglect begin with the awareness of social responsibility. Social responsibility is developed in family, civic and friendship circles. It's imparted by teachers in classrooms, and parents to their children around the dining room table. Business and industry take on social responsibility too. It's a big thing.

For social responsibility to happen for people with disability, communities need to open up themselves, and let people and their individual ways of life in. They need to appreciate that being human means living in ways we share and value together.

Social responsibility means understanding that inappropriate and degrading ways of life like institutions belong to the past. It means appreciating that a secluded life should never be imposed in a society that is able to accommodate itself.

The tasks along these ways of accommodation require opportunities for people to live successfully in towns and neighborhoods, without the entrapments and costs associated with redundant services and professionals, among other things. They require sharing the valued domains.

While this generation has reduced its reliance on institutions over the last 40 years to a point where a state like Vermont is institution free, tens of thousands of people in other states have no plans to move into community life. Thousands more are trapped in community services systems which exert the same barriers to self-determination that facilities do.



People deserve support to leave these restrictive conditions behind. Indeed, we all do. We're not just rescuing people with disability from institutions any more. We're rescuing each other too.

## **Believing**

The future of community support appears promising in some areas, but totally lost in so many other parts of the country. While new ways bring change, the nation's history clearly demonstrates that support for people with disability doesn't follow a cost-effective trajectory. Herein is the rub.

The inertia of systems to sustain programs that protect and segregate people is unmistakable, constant and vicious, even when accomplished with subtlety and tact. The effectiveness of change agents to win over these traditional approaches and engage community resources remains a tremendous challenge that is not going away any time soon.

Despite impediments thrown in their path, people with faith in community ways believe everyday lives will materialize. They know support works and subscribe to historic tipping points and paradigm shifts that affect the consciousness and practices of the country at large. I'm one of those people, and there are many, many others.

We believers have faith that power, now used to keep people dependent, shifts with knowledge, new social ties, self-interest, persistence, and experience in doing what is right. We see history as our call to learn from mistakes and discover alternatives. We appreciate the importance of timing and value each other in the roles and responsibilities we share.

Believers in community ways have a peculiar power. We have the power that comes with doing what we believe is right, and in persevering to bring people together through common understanding.

Believers know in their hearts and minds that the future finds its way despite daunting ambiguity in human behavior, greed and indifference. We view our times as fascinating and enriching, and still see opportunity at every turn.

Because of its failure to secure community ways with people, we also know that this generation will not live to see aspiring practices take hold in the future. Despite our best efforts, we'll never know how community approaches wins in the end.

The best many of us can do now is testify about what we're brought to bear on American society, support contemporary efforts that make sense with people, and get out of the way as new leadership emerges.

We can also be honest about our shortcomings and respectfully pass on the truth about what we did and didn't do. Above all, we must still keep the faith.

The future has a different view of people with disability in store, along with a new sense of community roles and governance. We can share in the faith of this.

So let's face it: these old ways suck. Let's get on with the future and believe.

# **Chapter 5: The Kennedy Thread**

## **When Boomers Were Kids**

Senior citizens would be the last segment of this generation that might recall documentaries on their black and white TV news, exposing institutional abuse and neglect in places like Willowbrook in Queens, and Pennhurst in the suburbs of Philadelphia. Baby-boomers, now in their 60s, were barely teenagers at the time.

After Bobby Kennedy witnessed Willowbrook's conditions in 1965, he put it this way:

*"We have a situation (there at Willowbrook) that borders on a snake pit...Children live in filth....Many of our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, lack of adequate manpower. There is very little future for these children, for those who are in these institutions..."*

Before these types of institutional revelations, isolated facilities for the 'insane' and 'mentally deficient' were accepted features of community life, and respected for their good works. State and privately operated schools and hospitals, often housing over a thousand residents each, were admired as the best examples of America's caring ways.

It was noble in these times to protect people with disabilities from the public and the public from them. It was accepted that doctors, nurses and medical professionals would control the realms where people with disability lived and worked.

The institutions in the 1960s represented traditions of specialized care going back hundreds of years in this country alone. Benjamin Franklin and other founding fathers proudly constructed separate hospital areas, schools and almshouses for people with handicaps to keep them from being exploited in jails and all kinds of other facilities. These special places operated with the unquestionable support of the well to do, business sectors, academia, clergy, and professional circles.

Over the years, the same institutions that began with the best of intentions regressed. Resident quarters began to look more like warehouses, jails, factories and barns than any home place by the turn of the twentieth century.

By the time the 1950s rolled in, it cost more to keep an animal in the zoo than support a person in institutions. The individual rate for Pennhurst was less than \$6 a day in 1969.

In vast day rooms and wards that became their existence, inmates would strip naked or be strapped to prevent their arms from moving. People in the day rooms masturbated, hurt one another, threw their shit on the walls and ate it, before being showered with a fire hose and mops.

Even in so called “better institutions”, residents had no clothing of their own, privacy or personal space.

People had no rights in these places or way to communicate with the outside world. They had no identification, no wallet or purse, no radio, no pocket change, no family picture, no book, not even a bible.

By the 1950s, people in institutions were herded from one activity to another down long tiled hallways, under the constant blaze of industrial lights. Every single door to every room and outside area was locked. Only ward supervisors and nursing staff had keys and they had many.

There were 125,000 people in state operated facilities for the “the mentally retarded” in 1950, reaching a high of 195,000 by 1967. There were over three hundred large state operated facilities in the country in 1950 too, each housing an average of 800 people a day. Before Willowbrook began shutting down in the mid-1970s, there were over 5,400 residents on grounds, making it the biggest institution of modern times.

In addition to these state institutions, there were hundreds of private facilities too. Some like Elwyn, Vineland and Woods School had sterling reputations back then, and some were as bad as or worse than the snake pits that Robert Kennedy decried. Some of the so called good ones also became real bad, too.

Before the right to education in the 1980s, only private schools that catered to relatively well to do families offered education and comfortable living quarters. Arts and culture were included in the program in these facilities to maintain a refined element that the public institutions lacked. While food quality, medical attention, and other features varied based on location and socio-economic factors, private facilities often had families who took ongoing interest in their loved ones lives. Adults didn’t usually work on the farms and as unpaid labor at these facilities, at least.

Some private facilities became specialized as nursing care establishments for medically complex children and adults who would not be accepted to regular hospitals and nursing homes. Residents in these places lived in cribs that were crammed together in long rows, attended to by matrons and their assistants. Usually private facilities that served people with severe medical needs did not accept able bodied people as residents.

Specialized institutions were also established for other groups, like women with disability of child bearing age, and adults with tuberculosis, blindness, and other conditions. Young adults with criminal background and no family to speak-of often ended up in institutions too, along with youngsters with speech impediments, mobility problems, and physical abnormalities. Vulnerability factors were varied.

Violence, child abuse, and exploitation were common in many of these settings. Rape and sexual exploitation were rampant according to stories of people who have survived.

As awareness of substandard conditions in the facilities began to leak out in the 1950s, early change agents and the media got involved. The National Mental Health Foundation, formed in 1950 to raise awareness of disability related issues, began to expose subhuman conditions right away.

Photos by Albert Q. Maisel's in Life Magazine and his 1946 Bedlam article set the stage for muckraking institutions, particular public ones. Maisel called these places a "shame and disgrace". Life Magazine also published a similar article about the horror in mental health facilities in the 1930s too.

Later in this decade, Frank L. Wright Jr. wrote about deplorable conditions in mental hospitals that were at the peak in this era, serving some 559,000 people, including over 50,000 people with intellectual disability.

The Association for Retarded Citizens (ARC), formed in 1950, began to mobilize grass roots and political efforts to improve on these conditions too. Along with other family based groups like the United Cerebral Palsy (UCP) Association, the ARC formed local and state chapters, setting the stage for advocacy, litigation, public education and community service changes yet to come.

### **With No Place To Go**

In the face of a growing awareness regarding subhuman conditions that institutions offered, the country had no options to fall back on. There was no emergency plan and few therapeutic alternatives for people who couldn't be cared for by their families.

While facilities that served people with mental illness were prepared to take in some people, these institutions were already busting at the seams and being scathed in the press for their overcrowding. Some foster care and small residential care programs utilized to ease institutional overcrowding from the 1930s were available too.

Pockets of community based alternatives were limited and often temporary given changes in institutional demand and new construction schedules. Institutions basically continued to grow from the turn of the 20<sup>th</sup> century to the 1960s, with growth spurts in the 1930s particularly, and to a small extent, the 1950s too.

General hospitals, rest homes, and boarding houses were equipped to offer care too, but there was no public entity to organize or link them with supporting people with intellectual impairments. These types of resources also excluded people with any form of intellectual impairment requiring accommodation or extra assistance.

While county homes would accept people with disability to work on the facility's farms and in the stables, people with intellectual impairments tended to stay in institutions for the 'mentally disabled' until the end of their lives.

Bodily remains of residents were returned to the families and home districts, or buried on grounds. Institutional visitors can still see grave stones lined up on a distant hill like beds on a ward, with resident numbers chiseled onto the headstone, but no names.

People with disability were also accounted for in the records of itinerant work crews and chain gangs of the time. They were long term residents of jails and prisons too. Even today, estimates suggest that 10 to 20% of inmates in state and local prisons test in a mild to severe disability range.

Though there will never be a good number on this, most people then, like today, were taken care of through private arrangements that families made and sometimes passed on to friends and guardians. People with mild forms of disability also worked in many family business and ventures, including farming, retail and manufacturing.

Along with a dearth of institutional alternatives for adults, agencies of that era did not have "special needs" foster care and adoption like they do now. Child care organizations only offered orphan homes and youth farms designed for wayward boys and girls.

Adding to the dearth of options, community doctors didn't provide medical care to children with disability then and dentists wouldn't either. There were no community resources interested in taking on this group of human unknowns even as youngsters.

Hospitals didn't take children as patients for the same reasons religious congregations didn't welcome them to Sunday service. The Eugenics moment of the 1920s and 1930s labeled people with disability as dangerous, immoral and diseased. There would be no tenets to break that deviant mindset until the 1960s.

Without education available in normal schools of the day, children with disability of the aspiring middle class often found themselves in special private schools. As long as funding for their care in these settings held out, youngsters would remain institutionalized through their adult years. Espousing missions to make institutions as much "like a community" as possible, private facilities could be reasonably accommodating to people's individual interests.

There weren't specialized training programs or activities for people in the 1950s either; at least till they began later in the decade with fledgling family based organizations like the ARC. There were no State and Federal programs with funding to serve people in the community until President Kennedy and a few states began such initiatives in the 1960s.

Other organizations in this era like the March of Dimes focused on childhood health and disease manifestations, not on developing new forms of support. The halls of social science and

educational pedagogy wouldn't deal with advanced program concepts for at least another decade either.

For the first half of the twentieth century, pediatricians routinely made institutional referrals from the delivery room based on a newborn's abnormality however minor or correctable it might be. Medical and popular journals of the era warned parents to avoid becoming attached to children who could "never live a normal life".

Fortunately, never was about to change, as it inevitably does.

### **Institutional Communities**

While it might be nice to believe that citizens and local officials would stand up against barbaric institutional conditions, the truth is that communities were silent and took no social responsibility during the 1950s and 1960s. The towns, cities, districts and counties that hosted institutions within their borders removed themselves from what was going on.

Since most institutions were located in remote areas, the separation of people and community went beyond physical distance from population centers. The fact was that communities didn't consider people in the institutions as being part of their communities at all. They didn't see these people as fully human.

Local political and civic leaders vied to host these facilities, like they would court an auto plant or other big industrial concern today. They saw their roles to protect the institutions after that, so jobs would be secured.

Even home towns that expressed a flurry of dismay when institutional abominations were exposed in the 1950s and 1960s didn't change their behavior. Local leaders didn't reflect on their complicity with institutional practices, or move to bring people into the fold.

A psychological link between communities and institutionalized residents never developed over the decades. Institutions kept people out of local halls of justice, just like they did churches and social groups as a matter of unwavering policy and practice. Their worlds were as separate as separate could be, which was just how the institutional professionals wanted it.

During this era, as in subsequent decades, local citizens and contractors who benefited financially from institutional life had no qualms about shielding the facilities from social responsibility, no matter what abominations people endured. Employees stayed true to the institutional oaths that pledged fidelity to institutional norms.

Since workers kept information about the lives of people to themselves, abuse, violence, food poisoning, maltreatment and neglect, while rampant, were not discussed in or outside those gated walls. Institutions with their own security force, doctors and clergy made sure that violations of civil and human rights were not referred to local law enforcement or the courts.

Since institutions were often the largest employer in a rural county, it was easy for bad stuff to be swept under the rug. Workers who represented families employed in the same institution for generations weren't going to bite the hand that fed them, in any event.

Local media channels focused on keeping the institutions viable too. Editorials took the side of institutional leaders time and again. They stressed how the facilities provided jobs, and had the interests of their 'unfortunates' in mind.

The press didn't even use their knowledge about the deplorable conditions of institutions in other places to spark monitoring or changes in their own locales. Local ministers were silent too, despite inhumanity in their midst.

### **A First Family Connection**

The Kennedy experience with John's sister, Rosemary, resulted in an appreciation of how people with intellectual disability were treated, how families are affected by disability, and how support and services might be constructed to preserve a loved one's dignity and other human qualities, above all else.

Rosemary Kennedy, on the advice of a family physician, was lobotomized to correct escalating behavioral outbursts in her young adult years. Rosemary never recovered from this operation to the point where the family was able to support her in community life.

After the lobotomy, Rosemary was placed into a private institution in Wisconsin where she stayed for the rest of her life. Her attendants were dedicated and capable by all accounts and Rosemary was considered happy living there.

Some family members maintained contact with Rosemary after her move to Wisconsin and visited her in the institution. About all the family seemed to agree on was that Rosemary's operation was unfortunate, and not at all what anyone expected.

From this experience, the Kennedy's began to consider how services and support for people with disability in general might be improved. Beginning with Eunice Shriver, family members began to promote awareness about the conditions and struggles people faced, and to explore ways to address stigma they viewed and felt personally.

### **The Kennedy Way**

Early Kennedy family initiatives were focused on community-based approaches like Special Olympics and Foster Grandparents. These led to other social forms that supported inclusion in school, and eventually community employment through Best Buddies, a program that matches people in various realms of community life.

Fast forward to today and it's hard to over-emphasize the impact the Kennedy family has had in raising consciousness and community expectations. Just recently in the news, Maria



Shriver credited a friend with disability in helping Ms. Shriver get through a messy divorce from actor and then governor Arnold Schwarzenegger.

This statement of gratitude by Ms. Shriver was the type of expression that emanated from the Kennedy's for years. The family made the most of opportunities to share the valued roles of people in their lives. Now 50 years after John Kennedy's inauguration, yet another generation of Kennedy family leaders are working to support people who are "differently abled". They get it.

The Kennedy ways have sought full-fledged participation of people in community life, using available community resources as the heart of each and every endeavor. While critics challenge the "special" nature of Special Olympics, the driving force to value people in a community context continues.

Kennedy family actions underscore beliefs, attitudes and citizenship that hinge on community participation. They promote social responsibility, not system control and structures. They translate beliefs into outcomes geared to people securing jobs, friendships and family ties, not just a life time of care.

In line with these outcomes, Kennedy approaches emphasize matching people with community mentors, champions, and sponsors. Kennedy ways have consistently relied on opportunities created by naturally occurring relationships such as these, and the power of relationships to better life in reciprocal ways.

### **The President's Vision**

Having combed Europe and academic circles for promising practices by the time of his inauguration, President Kennedy's domestic team speedily introduced comprehensive community approaches on a national scale. Led by Sergeant Shriver and others in the famed "think -tank", Kennedy's administration launched the nation's first community mental health programs, along with programs to protect the rights of people with disability and advance program concepts.

Community centers were the centerpiece of the administration's domestic agenda. Under its New Frontier banner, a comprehensive array of accessible health and human services would be developed like never before in the nation's history.

The community center approach considered co-workers, community operatives, family and friends as the centerpiece to operational success and continuity. Locally based administrative structures were established to ensure community participation and oversight.

There was no inkling from the Kennedy record that people with disability would be directed to access restricted specialized systems outside the social mainstream under this plan. Salvaging outmoded institutions was never part of the Kennedy agenda that stressed inclusion and protection of rights.

The President's approach was all about empowering the community do its thing and find its ways to secure valued community outcomes and connections for people. The New Frontier was not about carving out services for people as a protected class. It was about working out challenges within community frameworks, using valued community ways and means.

Bridging class and caste, the New Frontier was a blending of humanist tradition and practical interventions for promoting life, liberty and the pursuit of happiness in ever changing times. It was about enabling communities most of all, and a paradigm changer in every sense of the term.

### **Changing Patterns**

The Kennedy team assigned to develop community services for people with disability soon realized that the gap between what was known in the United States and effectively put to use was not going to close overnight.

The New Frontier pioneers knew they had to deal with a public, practitioners, and political establishment that had no tradition with community support and services. There was no precedent to what they began to undertake in terms of developing the community's capacity to coordinate and sustain health care and social services.

They knew that children and adults with disability were not going to instantly receive public education or live outside of institutions at the flick of a switch. They realized that they would need to proceed carefully, and not get too much ahead of themselves in rolling out their vision and new programs. The Kennedy approach was to bring community along at natural and deliberate pace, focusing on education of the public and development of frameworks and good practice.

In rolling out support for people with disability, the Kennedy team began a campaign under the New Frontier banner to educate human service professionals and decision makers, as well as the public, about advanced program concepts. They called this initiative Changing Patterns.

Through Changing Patterns, the country was introduced to concepts like Normalization, dignity of risk, and social integration. Similar awareness building occurred with other New Frontier initiatives like VISTA, the Peace Corps, and Head Start.

Well before the first manual, titled: Changing Patterns in Residential Services for the Mentally Retarded was compiled by the President's Committee on Mental Retardation in 1969; its contributors had already had a marked impact on service understanding and new tenets. Changing Patterns contributors, who were all big hitters, included: N.E Bank-Mikkelsen from Holland, Burton Blatt from Massachusetts, Gunnar Dybwad from Brandeis University, Bengt Nirje from Sweden, Seymour B. Sarason from Yale, and Wolf Wolfensberger from the University of Nebraska. All these leaders continued to have a profound impact on the development of supports for people over the ensuing decades.

The initial Changing Patterns edition was followed by subsequent printings and contributors through the next decade, when the National Committee reformed into a Presidential Commission. Each edition kept on the course of identifying promising practices, a tribute to President Kennedy and his team once again.

Changing Patterns publications remain must reading for anyone interested in the sheer power of new ideas in this country's discovery and early struggles to support people in everyday ways. The books' contributors were our generation's first community teachers, and their insights are as relevant today as ever.

## **LBJ**

After the Kennedy's 1963 assassination in Dallas, President Johnson (LBJ) made a point to retain Sargent Shriver and the team to follow through with what they had started. Historians rightly credit President Johnson for staying true to Kennedy's policy initiatives throughout his term. Despite his dislike for elements of the Kennedy style and hard feelings about how then Attorney General Robert Kennedy treated him as Vice President, President Johnson did what he could to stay true to the Kennedy vision during his years in office.

While President Johnson wanted to make it possible for Kennedy programs to be carried out, his wishes weren't the only factor deciding on how support for people with disability would develop at this juncture. The country's struggle for civil rights and economic strains, not to mention the escalating war in Vietnam, had their impacts too.

Though efforts to address racial discrimination flared in the Kennedy years with protest marches, freedom riders, and National Guard deployments, the civil rights movement found its stride in Johnson's tenure. During this era, the national civil rights agenda moved to front-and-center. It would be the time of Dr. King's and Bobby Kennedy's assassinations too.

Taking a stalled civil rights bill that President Kennedy couldn't get out of committee, President Johnson masterfully worked this legislation through Congress, obtaining bipartisan passage in his first term. LBJ cut similar deals again to bring the Voting Rights Act into fruition, too.

With overwhelming pressures brought about by stubborn Jim Crow practices and urban struggles, it was only natural that social responsibility themes began to take a back seat to justice for oppressed and disadvantaged groups. Civil rights thus took on an identity that overshadowed fledgling efforts to develop community support.

While social responsibility tenets diminished in importance during this era, Johnson's civil and voting rights legislative efforts were significant. Under these laws people with disability, due to their 'minority' status, would have expressed rights as citizens underscored for the first time in our country's history

That civil rights brand that LBJ became known for has come to be a mixed blessing too. Having so called 'minority rights' asserted that people should already have had by virtue of the

Constitution makes a peculiar and fundamentally uncomfortable statement after all. There was also the problem that bills were seen as a way to address racism primarily.

While it's important that the Voting Rights and Civil Rights laws were able to correct overt discrimination and overturn racist practices, their relevancy to social integration for people with disability has never been that clear cut. People and families were seeking community services more than equal protection and rights, and really still are.

### **That Old One - Two**

While Kennedy's social responsibility theme and the LBJ approach to civil rights and justice had the potential of an effective one-two punch, the country got shortchanged on the social responsibility side of things. Communities and the public didn't get to experience the effect of the Kennedy magic like they needed to.

With a continuing emphasis on rights and due process, support tied to social responsibility languished in the LBJ era, and has never resurrected. A sad example of this today is how laws and community responsibility play out for thousands of people forced to live in institutions over the years.

Even though the nation's highest courts have asserted the right to a least restrictive environment in services through legislation in the 1990s, people are still forced to remain in facilities, whether they want to or not. There are still no court orders powerful enough to free over a thousand people in the public institutions in Pennsylvania where I live, and it's that way in many other states too.

It's not that law and social responsibility are inherently conflicted in supporting people. The problem has been how leaders tend to favor one way over the other, and play the two off. In these exchanges, rights approaches generally win, as they are more conservative and system oriented than the outcome qualities inherent in social responsibility approaches.

Ever since President Johnson, national and state leaders drifted to law based solutions that focus on preventing discrimination and keeping government agencies out of class action lawsuits. Bucking the tide of legal mediocrity and standardization has not been a popular cause, suffice it to say.

As we look back, early program developers may have been better off crawling in their discovery of community ways under a New Frontier tradition, than trying to force fit integration on the basis of due process rights expressed in the Civil Rights Act, or subsequent health care entitlements and services funded Medicaid waivers.

Prospects for a good marriage between law and the achievement of community outcomes got stymied time and again over the years to the point where it's time to drop this big legal stick

that national leaders prefer to carry. We've got to look at our community play books again, and try another way.

With all the laws we've created to assure people with disability are free of institutions, it's time to assure that people are welcomed in community life. It's not about what's legal game anymore. It's the rest that comes after law making that is demanding attention today.

Its time this nation sees that support has more to do with awareness, attitudes and relationships than behavior under the force of law. Laws and programs stemming from litigation like Pennhurst aren't going to achieve community outcomes on the basis of living free of an institution.

It's evident that court orders under the banner of civil rights, like established legal frameworks for systems, aren't on a course to nurture healthy relationships and everyday lives. The work of changing minds and community behavior never got emphasized like it needed to then, and it's still that way.

Inevitably, the country never regained the community first spirit it had during President Kennedy's leadership. Since his death, the nation has become more and more bound to different paths than to those Changing Patterns would have taken.

Since communities didn't 'get it' about support being their responsibility first and foremost over the decades, leaders got diverted to building controls based on due process and legal standards, specialized provider issues and government convenience. They got hung up in outmoded precedents and organizational relationships, instead of investing in community ways.

Leaders also focused on putting system safeguards and controls in place, instead of taking direction from people. Without a socially responsibility banner leading their efforts, leaders opted for what was safe, civilly just, and minimally acceptable.

Under the cover of law, those responsible for people in systems also found it easy to wield their policy wands in order to control the course programs and services followed. When those wands didn't work, leaving thousands upon thousands underserved and misdirected, leaders cried: "Our hands are tied. It's the law."

When the wands of law and order achieved what systems wanted, people survived. Indeed, it's been that way ever since. Life under regulations and law is what systems relate to. Outside of that, they haven't a clue.

### **Spillover**

Taking its lead from Kennedy's New Frontier and civil rights in the Johnson era, national leadership beginning with President Nixon continued to condone and sometimes develop community-based services, while making sure existing institutions remained safe and humane.

While some administrations, notably that of the elder President Bush, with his “A Thousand Points of Light” address, refreshed social responsibility as a national theme, efforts to develop support outside of systems never took hold in the way Kennedy’s vision had formed it. None of the later Presidents had a message that soared or had the punch to succeed like Kennedy did.

President Carter’s commitment to address poverty, while it materialized with Habitat for Humanity and other work in his later years, didn’t fully emerge in his one year term. While Roslyn Carter tried to address a dearth of mental illness support at the beginning of his term, that flopped too. So did efforts of the Clintons, including Hilary’s It Takes a Village which never translated into a national affirmation of social responsibility like it was intended to.

While all the presidents in our generation applauded community services as an institutional alternative or cost effective idea, none of them has yet to declare anything close to a community imperative, or a commitment to close institutions for good. No president has seen his way to take on the institutions and other human service establishments that people find themselves trapped in.

In their hesitance to embrace community resources first and foremost, each administration since JFK’s has fallen short in engaging community resources to support people as a social responsibility of family, friends, business owners, and community organizations. Each has gone along with people with disability as a responsibility of agencies and professionals, not communities first.

For example, instead of investing in community support with businesses and generic services, public programs that emerged under Medicaid and Social Security beginning in the 1960s have repeatedly tied themselves to restrictive service approaches that result in congregating people in specialized settings. In relying on private and public agencies, they’ve left community resources high and dry.

Presidents after LBJ also didn’t take a stand on liberating people in institutions or using the American with Disabilities Act to chart a new course away from the legal constraints of the past. Their follow-up on the right of people with disability to vote and receive services in the least restrictive environment have lacked gusto and resources alike.

While people with disability are considered more of a voting block today thanks to the foundation set by the Voting Rights Act, office holders have traditionally responded to family constituents above the aspirations of people themselves. Federal and state agencies like the US Department of Labor, while they acknowledge people with disability as an untapped resource, haven’t done squat to develop job opportunities on the magnitude that is required.

While Medicaid home and community based service waivers that began in the 1980s along with right to education and other programs have chartered new ground, there has never been a national party platform that promised to ensure that institutions and service systems let their people go. After 40 years of trying, the prospect of community imperative seems as far from a political reality as it ever did.

The silence of national and state senators and representatives to articulate community roles outside of system controls has also been deafening in its own right. The lack of a political will to get beyond the self-interest of systems and local provider direction continues to astound, given the common sense community solutions that are right before our eyes.

Choosing silence to action, politicians and other leaders still don't express how valued outcomes are dependent on community ways. Out of convenience, ignorance and constituent influence, national as well as local leaders have continued to focus on programs, not people.

## **Legacy**

In many ways, the challenges we face in developing community support today reflect the barriers President Kennedy first encountered in the early 1960s. Kennedy recognized the need to change the pattern of services for people with disability. Today we need to be about changing these patterns again.

Pursuit of valued social roles was the way the Kennedy's pointed to in the beginning of this generation, and this pursuit is as valid today as it ever was. The tests of our time continue to be those requiring community metal, and character of the nation's people. These are not attributes a law can enforce or lay down. These are fundamentally a 'community thing' built on developing social awareness and responsibility.

While laws intended to benefit people with disability have made it possible for stores, public buildings, restaurants and hotels to be accessible in their doorways and use of the rest room; physical accessibility isn't enough. Accommodation practices established by the ADA need to be built on so people have opportunity to really participate as valued members of society, hold good jobs, and have lasting relationships.

Instead of tweaking existing rules established in law, we need to be about addressing barriers vested in oppressive attitudes, systems and social practice. We need to be about closing the gaps between laws and practice, and starting over from the mess we've made.

We need to be focused on increasing community awareness and exposure to what's going on in our everyday lives. We need to be letting life in.

These undertakings require a different set of tools than law spun regulation and enforcement. They rely instead on people working with and on behalf of their communities. They require trust and mutuality.

Closing the gap to achieve everyday lives takes support workers speaking the language of their communities. It takes people helping each other, and a continuous focus to engage leaders and organizations outside of service systems.

President Kennedy's call for all Americans to: "Ask what you can do for your country"... captures what the community's stake is in all this. A support ethic isn't about what

the government can manage in finding placements and service solutions for people. It's about what citizens do with each other and their community resources.

Everyday lives don't materialize where people are kept away from the challenges of an everyday life. Support is about citizens engaging with one another with the resources they already have in hand to address common problems in mutually beneficial ways.

Unfortunately, the country never got connected with its community spirit like it needed to after John Kennedy and his brother Bob passed. Their assassinations robbed us of a history that would have been different. It would have had to be.

Even though some aspects of community responsibility have advanced since the 1960s, we've carried on as a nation with the sense of something missing. The United States is still sorting through the ashes of this era; this Camelot of community and personal awareness that was so short lived.

It remains for us now to acknowledge this loss and urge younger people to move on with the country's ideals, so later generations can recover from what we've endured, and bring to light new champions, awareness and awakening. We call again for that magical spirit to be renewed.

We call on youth today, like Kennedy did in 1960, to lead this country out of the doldrums and make the magic of believing in ourselves come alive. We call on good sense and the spirit of common interest to prevail.

The arch of time comes into play with the Kennedy tale, as elements of the New Frontier need to be revisited, too. The country must look again at the community impulse that transformed citizens and leaders out of centuries old institutional mindsets. It must look at the benefits of community centers and tapping personal responsibility.

The nation needs to understand what went right and wrong in supporting people under service system in our lifetimes. It needs to appreciate how and why we diverted from our initial path to assist people in achieving valued roles, for better and for worse.

The Kennedy way stressed acceptance of people with difference, inclusion and opportunity, not handouts or even government programs necessarily. It stood for civil and human rights too. It designed community services that would be accessible to all citizens and developed programs on a local scale, with community control.

President Kennedy and his team represented a touchstone of generational change in this country that eclipsed support and services to any particular group or class of people. The unique Kennedy spirit carried many in this generation into the decades that followed with a sense that change agents can win the struggle for liberation with these people too.

While this nation can be thankful for the impact of civil rights that followed Kennedy's call to take social responsibility, we must also appreciate that community belonging goes beyond



law and justice. John Fitzgerald Kennedy along with his sister Rosemary and other family members touched these ways and continue to bring about healthy community consciousness.

The Kennedy's inclusive way is our generation's heritage. We claim that and thank this marvelous family for sharing their journey and making it our own.

# **Chapter 6. Taking Sides and Turf**

## **Takes and Tactics**

As community programs inspired by the New Frontier and the struggle for civil rights began to emerge in full form during the 1960s into the mid-1970s, service practitioners became increasingly leery about the messages coming from the White House and certain academic quarters in response to institutional atrocities. Providers representing centuries of tradition took to community overtures with a large dose of trepidation.

As the awareness of community support options took hold in the Johnson years, professionals and families vested in institutional ways began to feel more and more threatened. This introduction of new community based approaches was not politely asking institutional leaders to try another way. It was demanding wide spread change.

Normalization and community service advocates that the Kennedy team introduced in their Changing Patterns campaigns talked of institutional approaches as violations of basic human and civil rights. They posed questions that challenged the appropriateness of public funding.

To address what they perceived to be thinly veiled attacks on their traditional ways, public and private institutional leaders made adjustments where they could. Institutional superintendents conformed to demands for health and safety inspections, professional certification, and other forms of oversight and quality improvement.

With the influx of tax dollars, filthy and unsafe buildings got cleaned up, and partitions went up to provide adults privacy for the first time in a century. When new funding became widely available under Medicaid coffers in the late 1970s, institutions even constructed swimming pools and gymnasiums to make institutions better and more 'home and community like' than ever before.

While physical improvements and some new programs created during this cleanup phase were ameliorative, efforts never addressed the roots of social exclusion that remained. The combination of new laws and exposure of institutional malfeasance led to institutional reform, but nobody leaving facilities necessarily.

As the pressure to close institutions continued and new outrages of dehumanizing conditions like drug experimentation on residents came to light, traditionalists found themselves taking on an increasingly defensive posture. In the face of these challenges, community service advocates, academicians and social scientists kept calling for these places to end, not get a face lift.

The struggle to free people with disability from their institutional chains was on.

## **Game Plans**

Traditionalists who favored institutional approaches met challenges posed by community living in assorted ways. A favored tactic was to engage families to speak on the institution's behalf and protect their common interests. Institutional advocates even engaged with community leaning family associations too, to keep the wolves at bay.

In this campaign, facilities went to great pains to separate "bad" institutions from 'good' ones, knowing that the horrible conditions in places like Pennhurst and Willowbrook would not be tolerated. Comparing life conditions of 'good' institutions to deplorable places was to become an arching theme that facility advocates have continued into the current day.

Institutional advocates also began to interface with policy wonks and lawmakers during this 1960s-1970s era. Their main unvarnished objective was to preserve choice of institutional living in the lexicon of long term care for people and families. This battle over the choice of institutional living has continued in the courts and in the lives of people ever since too.

In this pursuit to retain their institutional domains, provider organizations became adept at challenging the legitimacy of community ways, stooping to xenophobic tactics and citing modern concepts like Normalization as a radical idea. Loyalists claimed that if their institutions were just given more money to clean up and modernize, everything would be fine and dandy.

Harping on this theme to modernize, institutional advocates were successful in convincing states and ultimately the US Congress to invest public funding to help ensure facilities were safe and meeting basic expectations. Beginning in the early 1970s, Intermediate Care Facilities (ICF's) subject to Medicaid entitlement funding became a god send that would continue to grow and serve as the major bailout of facilities for decades to come.

By the end of this era, facilities that had been hell-holes would clean up their act. With the assurance of continued Medicaid funding firmly in place by the early 1980s, both private and public facilities were able to renovate aging buildings, construct completely new campuses on grounds if they wanted to, and salvage some of the most inhumane conditions citizens of this country have ever experienced.

While ICF/MR regulations eventually brought about a semblance of quality assurance in the form of "active treatment" and a new service term called "habilitation", none of these words or practices changed basic conditions. People were still tucked away, out of sight and mind, and continued to be for decades to come.

## **Guardianship**

Families accepted life conditions and practices at the institution on the basis of what doctors and social workers told them. There were no publications of independent agencies to refer to, or alternatives to choose. Bringing loved ones home wasn't discussed as long as people got along as facility residents, and state and local funding kept up with demand.

Most families who maintained contact with their loved ones in the public institutions had very limited exposure, averaging less than once a year. Often living far away from where their loved ones were placed, families tended to limit visits to large gatherings like summer picnics and other events that the institution sponsored.

During these occasions that included parades with resident marching bands, baseball teams, and other community like features, there would be plenty of complimentary food and activities. Attendees were dressed nicely, restraints were put away, and everyone seemed to be on their best behavior.

On their visits, parents would never see the crowded dorms or sample the bland food, meet stressed-out matrons and aides, or spend a miserable a day in their loved one's shoes. They left feeling good about their loved one's circumstances without know how they lived.

Facilities considered institutionalization a family decision then, much like they do now. Even efforts to protect the rights of people in institutions with agencies like State Protection and Advocacy agencies formed in the Kennedy era could not crack the perverse consequences of families keeping their loved ones institutionalized.

While family-based organizations take rightful credit for influencing the development of community services in these early days, they also helped make sure institutions were made safer and more respectable. It wasn't all that cut and dry with the families then, and providers of institutional care used this uncertainty to their advantage.

Where no families were involved, public and private agencies also took over decision making in a guardian type manner, which also contributed to keeping people where they were placed. Through decisions made by institutional trustees and legal guardians, people were remained powerless to access community life long after their immediate family had passed on.

While changes in guardianship statute over the last couple of decades were supposed to make it more difficult for unilateral long term care decisions to be made by guardians, new laws haven't really helped that much. Since family decisions count most with systems and so called 'orphan courts' still, people in both community and institutional services continue to have no autonomy to make decisions about their placement status and futures.

To make matters worse, certain states including Pennsylvania have separate offices operated by government officials to protect the rights of people in public facilities who do not have family guardians. These state guardian offices have done little more than ensure that people remain in the facilities.

State guardianship practices are also notorious for their tendencies to prevent people from acquiring income, finding jobs, and making decisions while in the institutions. They have even managed to ensure that people remain as destitute as possible after they leave the facilities, depriving them of court ordered financial compensation and damages.

The string of tragic endings emanating from guardianship lives on with tens of thousands of people who still have no choice about where they live or work based on this legal muzzle. There's no sign of this ending any time soon.

### **Tricks of The Trade**

To keep families on the side of institutional living, program personnel trumped up their mission to keep people safe and protected from the hazards of community life. Medical staff exaggerated the necessity of facility placement, stressing anything from foot ailments to a lack of interest in community living as a reason to keep people from leaving.

I wish I had a nickel for every time an institutional advocate said to me over the years that people who lived in institutions could not make it in the community. How could people be expected to adjust to an everyday life, they reasoned, after living in facilities all these years? Who are they kidding?

Institutional social workers also made a special point to portray their colleagues as unified behind family interests. They extolled the caring nature of aides who kept people clean and orderly, and heralded institutions as the one and only place family members would be cared for until death. They cast people's prospects in the community as pitiful and limited, problematic and dangerous.

One of the more abhorrent tricks that institutions used was to draw a definitive line between so-called 'higher and lower functioning' people. To ensure people were classified as lower functioning, medical employees diagnosed people with extreme deficits that exaggerated their functional level and adaptability. People in institutions and community services have been subject to trumped-up diagnosis to this day.

Just before retiring, I introduced myself to a long-term resident of a public institution after concluding a work meeting on grounds. The man was delivering mail on a four-wheel gas powered vehicle. He was very social, describing his favorite ball teams and their standings in the pennant race.

The man's program record that I later reviewed would state that he had been living in the institution ever since his teen age years. There were family problems and a break up that caused him to be placed in the first place. The family was poor and lived a day's drive from the facility. They had no contact for over fifteen years. The record repeatedly stated how much the man enjoyed living on grounds.

The man's psychological assessment signified severe deficits in adaptive behavior and an IQ in the low 30s, which was in the severe mental retardation range. There was no mention of mail deliveries or driving a four wheeler, let alone his knowledge of baseball.

Above all these shenanigans, institutions sold themselves to families on the basis of providing all the basics of life, free from the stressors of community. Institutional workers prepared and served every meal; cleaned all the linens, mopped the halls and made the beds.

Attendants showered all the residents and chaperoned every outing people attended in and outside the gates. If their loved one's needed therapies, that could be arranged through whirlpool paths to calm the nerves, sedatives and shock therapy if things got really bad. Unpaid work and other responsibilities on grounds were also touted for their therapeutic value.

By keeping their eyes on people every minute of the day and seeing to a specific set of basic needs, institutions made themselves into family saviors. That's what a lot of families wanted or wanted to believe they wanted. In either event, that's what they were reminded about, again and again.

In being the objects of this take over quality, residents were never recognized for their competence and human qualities. In those rare instances where people were allowed to assume responsibility, like the man who delivered the mail, there are no records of such achievement.

Residents who brought in the crops, fixed machines, and took care of babies in the nurseries never got their recognition either. They got work to do but not the value that others would have received from doing it.

By setting people up to remain incompetent and totally dependent, institutional practices sentenced people to nothing more. That was the basic scam in the institutions, after all –this myth that people in are as helpless as they are stated to be. It was always that way in America since the 1880s, and it was certainly so in this generation's experience too.

### **Early Compromises**

Despite their primary interest in keeping people in facilities, the private sector was careful not to be overly resistance to advanced program concepts. Some providers even welcomed new ways in light of the problems they could not address.

Unlike their public facility counterparts who were increasingly under siege, private facilities in the 1960s and early 1970s wanted to be considered differently. They wanted to be part of developing community based services and to disassociate themselves with public institutions too.

Through inference and association, private providers set up the public institutions as evil doers, and themselves as being flexible and open minded. They offered up their best examples of academic and scientific research to make their case for continuation and increasing investment of public funds. They made sure they got money to improve their physical conditions, too.

When push came to shove, many private agencies were open to adapting themselves to this new generation of people who had a different community orientation, as long as their investment in the institutional way of life was not threatened. All was well and dandy as long as people placed in private facilities weren't forced into leaving the places they were already residing.

While government representatives were not ignorant to the dynamics being played out at this time, they looked the other way for mainly practical reasons. Instead of cutting the private institutions off as they probably should have, state and national leaders turned a blind eye to rescuing their programs while they focused on cleaning out the state schools and hospitals, where troubles were most apparent.

Instead of demanding that all public and private institutions let their people go, state and federal agencies invited private institutions to join in the community movement, hoping their involvement would lead to institutional closings down the road. Sanguine leadership predicted that it would only be a matter of time before the private institutions saw the light and closed facilities on their own.

With funding in place through Medicaid and state coffers to salvage their facility operations by the end of the Nixon era, private providers went along with developing community services in a measured way, as part of a larger pool of agencies that emerged over the next couple of decades. While institutionally oriented providers didn't necessarily buy into advance program concepts like Normalization in this process, they played along and opened up their operations, at least.

Apart from their being champions of choice, private agencies didn't want their business of caring for people from going elsewhere. As far as many of these legacy providers were concerned, community living was still taking care of people, just in smaller facilities that were a little more dispersed.

Although some agencies used the introduction of community funding that came about in the 1970s to deconstruct institutional structures, most didn't. The majority of institutions held on to their old domain for the next couple of decades at least.

In this era, serving people in the community services became a new form of management for institutionally prone administrators, and nothing more. Ultimately, a sense of institutional carryover and entitlement took hold in state after state.

Community services that operated by agencies with an institutional anchor kept behaving like institutional services do. They used the same workers in the same ways they were used in the institutions. People got moved to a group home selected for them, often on properties adjacent or near the old main buildings.

Group homes of 8 to 20 people become these providers' bread and butter, with cramped living space and regimented routines under the oversight of old school professionals. Community day programs offered off grounds used the same program plans that were employed in the institutional day rooms and wards. People living "off campus" would return to the institutions to work on the farms and liveries, too.

In the end, traditionalist strategies of passive resistance and sitting on the fence prevailed. Private facilities somehow survived the onslaught of modern ways by dummifying down the enterprise and curbing unwanted enthusiasm.

With victory for its mediocrity in hand, the facilities, soon to be transformed into comprehensive service agencies accessing plentiful Federal and state funding, would still be holding the keys. They'd reassert control that families and communities were used to them having too. They'd keep running the show under systems that were all about stakeholders that didn't include the community.

### **Blurring Lines**

To cement their standing in newly formed decision-making hierarchies, institutionally schooled administrators established footholds in emerging state and national leadership circles.

Executive personnel from the institutional sector moved into the community services arena as program directors and department heads, consultants and policy analysts. Institutional aides and supervisors moved into the community world too, as direct service workers and administrative assistants as institutions down sized or closed.

With a strong status quo presence, program developers in this era would be confronted with significant institutional biases in every new way they discovered. Despite retraining facility aides and supervisors in advanced program concepts, horror stories about sabotaged community based initiatives began to surface.

Workers with proprietary interests in the status quo kept barring the door from taking new ways. Patterns of treachery attributed to personnel employed by institutions and community agencies became difficult to dislodge.

Internal agency struggles between change agents and traditionalists would continue in the decades to come. Fresh ideas from community stakeholders would be watered or taken down through time honored obfuscation and administrative tricks that the traditionalists used.

Adding to this drag, emerging state and national provider associations representing traditional interests made a meal of convincing legislators and public officials to align on the side of institutional choice. These alliances blocked and stalled efforts to close institutions and restrictive services ever since.

Ultimately, the country was left with two service camps of service that continue into today. Systems composed of institutional and community based domains set their own sets of rules and expectations from this era on. In these separately administered and controlled realms, each sub-system set itself apart from everyday living in their inimical way.

### **Footholds**

Thankfully, traditionalist opposition to community ways was not entirely successful during these early decades. Life, liberty and the pursuit of happiness continued to resonate, especially in states with class action litigation to address and in board rooms of progressive agencies committed to everyday lives.



Continuing institutional atrocities, like putting people in cages, kept coming out through the press, too. That's been one thing that we could be assured of at least, in keeping public awareness. The stories, as they got out, were not getting better about the conditions in the institutions, even after ICF/MR certifications took hold.

While many institutions were allowed to remain operating in the 1970's, certain facilities did close and many reduced their census significantly. Families, at first shy about the safety of their loved ones in group homes and other community services, became their staunchest allies.

This early era was the time of promise, if not big change, and everyone involved in supporting people with disability sensed it. The fundamental questions by the time the Kennedy/Johnson, Nixon/Ford, and Carter eras ended became a matter of how much impact these changes in thinking and resource allocation would have.

By the end of the 1970s, it was abundantly clear that early change agents in government and service programs were making inroads, but there was a tremendous amount of development work to do and many issues still in play.

Scientific advancements, new program concepts and innovative ways to assist people in their pursuit of everyday lives were just getting started then. Advanced practices like community based assessment, person center planning, 'backward changing' and 'task analyses' were being applied for the first time.

Medications to address psychological and behavioral challenges were still to be discovered or coming to market then too. There were just so many things that professionals and other workers didn't know at this point, or even know to ask about.

In the midst of developing group homes and similar services in that era, communities were adapting, too. General practitioners were accepting referrals of people who had once resided in institutions for the first time. Dentists were too, along with speech therapists, and psychologists. Movements to create and sustain community relationship building were promoted within government circles, including state developmental disability councils, funded through Federal auspices.

Landlords offered use of their property as apartments and homes to agencies serving people who had never lived in the community before. Banks accepted agency lines of credit for opening new homes and facilities. Newly created supported employment services began to link into community employers, inspired by the amazing success of Mark Gold and others.

New leadership with bright and hopeful ideas was emerging and taking charge in state after state. Idealistic program directors took the reins of emerging agencies and people entered the field for the right reasons from a perspective of liberation and social justice.

Workers fortified with new behavior management tools delivered on the promise of community living for people who never would have been accepted into community life just a decade before. Speech augmentations and other technological engagements began too, fortified

by Federal and state subsidies that created lending libraries for a wide variety of accommodations.

Following this expansion into community ways, taxpayers became invested in community service networks. Even though it would take another three decades to serve more people in community programs than in institutions across the country, community advocates had a foothold by the end of the 1970s, and fertile ground from which to grow.

There was a definite feeling that community services were going to be the answer for people. Politicians and practitioners of all stripes expressed support of new ways. Providers were off to the races in starting up group homes, day programs and administrative frameworks to make community service system dreams come true.

By the time President Reagan took office in 1981, a stakeholder didn't need to be clairvoyant to see that a hundred and fifty year tradition of institutionally based care was about to loosen its grip on people and their futures. The basic questions remaining about the movement's impacts were:

*How much affect would these new community initiatives have?*

*How far could traditional programs and practices be stretched in adjusting to new ways?*

*How could the institutions even survive in a culture of change like this?*

### **Family Takes**

When community service options came into being during the early 1970s, families had various reactions. Relatives with an institutionalized loved one often sided with existing providers and made sure the institutional placements continued for their loved ones.

Others stayed neutral, maintaining their bottom line that state agencies continue to take financial responsibility for their loved one wherever that happened to be. A definite minority of families expressed support for their relative to be let free.

As long as their relatives were safe and not viewed as "guinea pigs" in a starry eyed social experiment, families got used to having little say on where their loved one ended up. All many families knew was that they couldn't provide care at home without financial and other support.

Despite numerous misgivings and fear, some relatives took the plunge into community living from the get-go, when it was first introduced in this era, supporting their loved one moving to an early group home or apartment program. Many of these family members became leaders for community support in this era too.

Those families that took a leap of faith found that services in the community met their test for keeping their loved ones safe. It was also easy enough for families to see that community

service workers were able to preserve health and well-being, and that people enjoyed being free from institutional stigma and restraints.

With rare exception, people placed into the community from public and private institutions never returned out of their choice to remain in community life. Involved families supported this choice as often as not, while keeping a watchful eye on the programs as they developed.

The families that supported community living did so for various reasons. Some were in a rescue mode, motivated by the deterioration of their loved ones behind facility walls. Others believed in the abilities of their son or daughter, and welcomed the opportunity posed by the new paradigm. Some relatives felt guilty and remorse for their decision to place a loved one in the first place. Some took on the liberation cause.

Whatever their motivation, family members commiserated with the struggle of other families during this time. They listened to their loved ones too. In this process they began to see that community services worked with their involvement, and if not, that was okay too.

Those who engaged with their loved one in services, confirmed that community based ways were much better than the facilities. They shared their experiences with other families, relatives and political leaders too. Families with loved one at homes got interested too.

From this point, community services took off with nearly a thousand local family organizations all over the country. Under the banners of the Association for Retarded Citizens and the United Cerebral Palsy Association in particular, local organizations advocated for new funds and programs, and often received contracts to operate services themselves. The organizations reached out to schools and business also in efforts to forge collaborative agreements in principle and practice.

Locally, families were especially influential in organizing agencies to ensure community programs continued to meet their loved one's needs. Many of the earliest initiatives to support people in the community trace their origin to concerned families sitting in a living room, over coffee and cake, figuring it out.

In setting up programs, families set a certain tone and brought their share of baggage, too. Motivated to ensure loved ones would be taken care of after the parent's death, family run agencies were established in state after state in the first wave of the new community provider community.

The family run agencies set out to offer a wide range of residential and other long term programs. In their quest for continuity and permanence, families sought for brick and mortar qualities of congregate group homes instead of the security of lifesharing relationships, and tended to value sheltered forms of adult work services, too.

By developing the comprehensive service systems they sought, families directed their loved ones to be agency bound, as users of the big three: group homes, activity programs, and

workshops. Taking it to the point where specialized events and sports, dances and camps would be added to this mix: nothing much in community outreach was getting done.

In this development process, siblings and parents became executive directors, agency heads, and influential board members, tending towards service missions that entailed perpetual protection and safety as much as anything else. As program after program rolled out, family ties to services were becoming eerily reminiscent of institutions in the totality of the service experience.

Motivated to ensure that their other children weren't burdened with responsibilities of care, parents often made doubly sure that disability funding continued to support the group living and sheltered models long after their passing. Relatives appreciated the benefits of paid staff, professional supervision and on-going resources on a number of levels.

Parents valued programs that promised permanence into perpetuity. Programs became like family saviors whether institutional or not. Services made life easier and more manageable for families. Difficulty of care and relationship strains could be eased or eliminated with services taking charge. Moms and dads could have their lives back, with peace of mind.

That take over piece was a service indeed, and families welcomed it even when the cost in terms of a person's inclusion, individualization, and valued social roles was high. Given their institutional traditions, it was not that surprising that sharing of support roles was never considered back then.

While some families remained involved with their loved ones after their return to the community, many didn't change their interaction patterns one bit. For a variety reasons, the first waves of people returning to communities were composed of folks with no family ties to speak of.

Lacking these ties didn't help integration potential one bit and fostered definite system dependencies too. While the men and women who first left the institutions were arguably among the greatest pioneers of our time, their movement into community ways was made all but invisible too, in many ways.

Moving from ward life to agency operated homes and facilities didn't prompt reunions, a Welcome Wagon representative ringing the door bell, or a neighborly get together. There were no parades, ticker take or otherwise.

Since service systems weren't focused on reunions with kinfolk, friends and associates, people were placed in towns and districts where they had no roots. They returned to community life without the sense that they belonged to anyone or anything.

Even those individuals that had family ties didn't have relatives who were poised to help in getting jobs, homes and relationships. Such application of family support was not in the cards. Community outreach like this was all considered the purview of systems, not families or community bodies. Case managers would handle all that, or so it was assured.

For this and other reasons embedded in system approaches to service, the special things that families traditionally contribute didn't materialize. Without family and friends to support social integration in particular, people had no choice but to rely on workers in program settings where they were placed.

On a personal level, agency workers filled in where family and friends didn't come through. Workers became the only friends people had, agency operated settings their only homes, and workshops their only "jobs".

Before long, systems took over where community resources were not invited or explored. No clear message that systems and families would work in sharing responsibility ever arose. People stayed kept in the shadows.

### **Law Abiding Dilemmas**

As we reflect on the benefits of taking a rights or social responsibility path during these early years in this era, we see how people with disability, like people of color, are still segregated, poverty stricken, oppressed, under employed, marginalized and poorly educated. Regional differences, cultural rifts, and economic disparity continue to exert deep strains of oppression throughout all parts of the country.

While society often romanticizes the benefits of a dual approach that combines rights with social responsibility, living examples are often hard to find. The truth is that social policy directed to improving community outcomes often backs off once new laws are promulgated, or new services created by a court order or executive decree.

Foundations in civil rights and voting rights legislation were important for people with disability, but not as important as some legal champions might like to believe. Securing valued social roles requires something more than law, namely cooperation and support from community resources and openness to trusting and relying on people in new ways. It demands that the community step up, vacate their cozy sidelines, and participate in taking on new roles for good.

That's the world beyond law that change agents and advocates are called on to develop, as much now as at any other time in our generation. Change agents have the responsibility to get the public's attention one community at a time, taking direction from people every step of the way. As a healthy country, we can't achieve inclusion of people and be tied to systems like we've been.

We can't be successful by accepting the system as the fiduciary middleman who ends up calling all the shots. We can't assume that the system will be a fair arbitrator under laws and controls that keep people from having a community life. With all the rigmarole and inaction that has become their brand; we can't even trust that systems will care enough to get off their petards.

Litigation and legal parameters that seek to address this country's failures has its place, but can no longer be the underlining impetus for people to secure valued social roles, especially when systems end up using even the most progressive laws to control where or how people live.

As laws designed to protect people with disability as a distinct class continue to be placed on the books, so do more devils appear in the details.

When law and regulation loose the capacity to secure valued social outcomes, it's not time to write something else like an amendment or heaven forbid new law. It's time to try something else: namely, community.

It's time to ensure that people have a positive standing and respect where they live, and until they do: we all have to wonder about just what is going on. We have to ask ourselves honestly how well we've balanced our community roles with the demands of a modern world. How much do we as citizens outsource the good graces and common sense of civil society?

We've learned from our experiences that service systems are adept at 'gaming' all sorts of legal requirements that would lead to community outcomes for people. It's no wonder systems get around least restrictive environment rulings of the ADA by re-branding large residential facilities as community residences.

It's no wonder that systems create vacancy and other policies that strangle program movement into states of inertia. When service worlds get the point, like they have, where people begin to be placed back in state and private institutions under the charade of "active treatment", there's no more room for delay or excuses.

We've learned that no edict or court master is going to ensure placements in least restrictive environments, as litigation and many regulations have required. No legal constructs have been effective in holding systems accountable beyond paper compliance with half-baked standards around health and safety, and '(cya) cover your ass' plans of care.

We've come to realize that no law can substitute for the resources the community has to offer. Life doesn't work in the ways laws do and people's behavior is shaped by more fundamental everyday influences and demands. Laws aren't going to make integration and everyday lives happen. It takes much more than paper to provide effective support. Yes, it takes a village, and we know that too.

If anything, law made solutions have tended to take community resources out of the support equation. For example, employers know that it is against the law to discriminate on the basis of disability in jobs, but have no sense that each of us has a key role of support in this way.

Under the regulatory frameworks created for services, people with disability are too often viewed as the responsibility of specialists, caregivers, and anyone the system deems to be in charge. Getting jobs for people with disability is something disability professionals are supposed to facilitate, but generally won't or can't do for a variety of reasons.

The point is that law predisposed to empowering systems doesn't present positive and valued roles for people and the communities to fulfill. People are still pitied, protected and misrepresented by the interests of those in charge.

Law can be punitive too, in their predilection towards verdicts and precedent, black and white decisions, and other dos and don'ts. But after the rulings are done and written, then what? There's still no recognition for employers who accommodate their workplaces, no acclaim to people and families who find a way themselves, and no sense of a community imperative.

Communities understand support differently than systems and courts do. There are no verdicts in community support. There are no restrictions beyond those applied to everybody else. There's belonging in community, being an outcast, and a lot in between.

Communities take responsibility for one another out of a sense of their own common interest. They apply situation ethics and common sense measures in responsible ways. They don't need to be told what they can and can't do, and know what to do with interlopers and fraud.

# **Chapter 7: Program Development Paths**

## **Expectations**

*We, as program developers, expected that the services would focus on assisting people in everyday life.*

*In building these services, we rejected debilitating images, specialized programs, and deviant interpretations that kept people from being respected citizens.*

*We insisted on 'people first' language and pointed out conflicts and inconsistencies to colleagues so they might improve their expression and deviant imagery.*

*We avoided terms and approaches with age inappropriate traps, and pity mongering that diminished people in the view of others.*

*We knew healthy community environments would change the world for people so we tried to create them and nurture them along.*

*Some agencies took the opportunity they had to discover new ways that led to jobs and homes people chose, but most agencies didn't.*

*Most agencies just did what they were expected to in keeping people safe. They saw success in terms of program growth, more than anything.*

*When service ways kept missing their mark, we ignored that people weren't tied to community resources like they would need to be in everyday life.*

*We might have done better in bringing people into the fold if institutional ways and system approaches weren't so strong.*

*We were deluded into taking community services on faith, as if a step in the right direction would lead to another step, and then another.*

*Caught up as we were with finding places and keeping people in them, we didn't appreciate just how much services kept people outside of community ways.*

*We hurt the character of our work by ignoring what our outcomes looked like, felt like and told us in terms of the everyday lives people were leading.*

*We disappointed people who trusted us to get it right. It's not been a pretty sight this system we've created and grown to call our own.*

*It hurts still that our sense of achievement began to die away so soon.*



## **A Program Developer's View**

Through tolerance, sharing, and not a little bit of good luck, emerging systems actually had the feel of fitting together in the beginning years, at least a good deal of the time. Those of us involved in program development at a state and local level during the 1970s especially seemed to be headed in the right direction.

We imagined people with disability, of color, and of different ways of life, being part of an ever-expanding community, living in peace with itself, and letting life in. It seemed for a while then that we found our stride and ever fertile ground.

Normalization helped those of us who focused on supporting people with disability engage in a form of freedom train. Our emphasis on age and cultural rights, along with parallels to supporting other disenfranchised groups, made our work seem part of something bigger.

Though there was naivety in this era, our motives were good at least. In any event, it felt great to be a part of something that mattered, and something to believe in. We went about realizing what was doable and right for people in the best ways we could.

The world we wanted to sustain with people then was one where children with and without disability were together in friendship circles, clubs, classrooms, events and on fields of play. It was like John Lennon's song "Imagine".

Our world was the place where people with all forms of differences worked and associated with other citizens, neighbors, family and friends on a regular basis, relying on one another, doing their own thing in their own ways. It was an open opportunity world, if you will.

In this spirit, program growth became our mantra. We assumed that more services meant more people on their paths to better life. In some cases this was certainly true, in others not so much.

In too many ways even then, we forgot the community. Oops.

## **Our Roles**

Early program developers were change agents then, more than they are today. We took on traditional government and other status quo ways as a matter of course. Keeping the old guard quiet, while not pissing-off authority, became routine. We were trailblazers for sure, but not necessarily looking for a fight.

In our roles, program developers weren't just training, developing, operating and teaching to compliance or some system script. It was still a matter of changing patterns of application and attitude in those days. We devoted a lot of energy to orientating others to the "why" and "how" of community ways.

While program developers had certain limits imposed by a lack of sophistication and system maturity, our intentions weren't that much affected by these deficits. We'd still reach out and assist stakeholders develop new ways.

In this one-another mode, we ended up becoming architects of the very service systems that haunt us today. While we didn't intend to create formalized and external structures at the expense of community outcomes, we did.

We didn't see until later, if then, how roles and responsibilities delegated to providers, case management and administrative entities would limit the space in which community support was able to function in people's lives. We didn't see how empowering systems, turned off other resources that the public relied on.

With indomitable spirit and optimism anyway, program developers established thousands of new programs across the country in the 1970s. We created administrative entities, arranged for monitoring and evaluation too all across this land and in Hawaii and Alaska too. We devised allocation methods that gave programs what they needed year after year to increase their capacity.

As program developers succeeded in these growth endeavors, legislators and the public became to believe in what we were doing. It was apparent that our service designs would accommodate significant numbers of people, at a good clip. Key constituencies on both sides of the aisle concurred that development of community services was the right way to go, and the "future".

So we kept launching provider networks into a brave new world. These were the early days of group homes with room for 6 to 12 people each and live-in house parents/resident advisors who shared their home life with people.

To keep services organized, program developers relied on state and regional/county administrators to keep funding and programs on the right path. Legal frameworks relying on state administrative entities were established so community services systems would allocate available resources equitably, setting the stage for more complex funding systems to follow.

Analysts and policy makers also composed every kind of position paper, memorandum of understanding (MOU), application form and procedure imaginable during those days too. They also individual program planning tools that got folded in to regulations down the road, too.

During this era, administrators also set down guidelines on program practice that became the precursor to formalized system approaches related to program standards, assessments, planning tools, and vacancy management. We set up assessment formats, service definitions, provider qualifications and eligibility tests to secure standard operating procedures.

Despite this development of policy and procedures, program developers in this era maintained a general sense that administrative structure had definite limits. Decision points often came down to trying new ways while keeping the allure of establishing minimum standards

at bay. While program developers liked offering resources to develop community services, setting down rules and new policy was something else.

In the program development process that ensued in the 1970s, prudent leadership consciously held pat in developing new regulations in areas where community norms would take hold. States held back issuing regulations on program character, size, site identification and such, assuming key entities would take these matters on in an appropriate manner. Decision makers also used their power to control budgets to set parameters and limits, or to give out warnings and penalties, when needed.

The point is that program developers didn't seek to formalize approaches that were just being discovered. While no one knew precisely what to expect in such an empowering state, program developers were definitely more inclined to take up issues on an individual basis at this early juncture based on relationships that developed with stakeholders.

Program developers took some pride in this freewheeling and interactive approach. They'd handle issues in a phone call instead of by a letter or issuance of a policy interpretation.

Program developers considered this lack of system sophistication a strength that promised the potential of improved community connections. We didn't want to mess with a good community thing or the cooperative working relationships that were becoming established.

Reinforcing this position to hold pat on regulations, nothing was showing up broken in this community inspired approach. There was no abuse or malfeasance to speak of. We didn't see the need to fix communities or change them, say no to stakeholders on the basis of legal precedent, or restrict anything else that promised to achieve the outcomes we sought.

Although we continued to leave community resources out of our program development efforts more often than not back then, we took a liking to community ways with systems in charge. Even if people were going out in little packs to the movie and park, they were out in the community in some form at least. These were the times the times when service outcomes were generally 'good enough for now'.

While leaders developed a sense that standards of care might be required after a while, defining a floor of minimum acceptability was not on our radar screens back then. The consciousness we had aspired to ideals of social integration and valued roles that were still our guides in decision making of all kinds.

To ensure the valued role messages were getting through to stakeholders, early program developers often met with institutional administrators, direct service workers and families during the early years. We tried to obtain support from these stakeholders to develop community services mostly, and were also interested in their points of view about tactics and strategy.

While these interactions were helpful, program developers went the ways their systems made them. Family, provider and other groups came to accept this approach as inevitable before long, while staying committed to finding other solutions when they needed to.

Unfortunately, certain old ways were not up to debate in the beginning any more than they are today. For example, legal terms and relationships in Pennsylvania going back to Welfare Code in the 19<sup>th</sup> century would come to classify community homes and shared living as ‘mental health establishments’ setting the stage for serious missteps to follow.

While adopting existing verbiage may seem trivial and was certainly not considered seriously in those days, interpretations and ways that came with these definitions became increasingly problematic. Old ways in government, we learned, meant taking up with established entities. These ties resulted in such eventualities as licensing by government agencies, state inspections of homes, and other bureaucratic activity.

Program developers could feel it coming, for sure, this sentiment to make services a standard commodity, wrapped up in a neat set of regulations and policy, funding structures and information management that government agencies were traditionally comfortable dealing with. We couldn’t stay hidden ‘under the radar’ forever, as we used to say.

Such was the unraveling of the dream that began to be developed back then. We took paths marked by institutional rescue efforts. We measured progress by the number of new homes we opened. While there was nothing inherently wrong with these paths, other more standardized kept knocking at the door.

Increasing reactionary and growing more cautious, program developers began to lose their optimistic in views on how community integration would succeed. We reasoned there would always be the good, the bad, and the ugly to get us through the doubts we had.

We had the group homes sure, but getting people to a life beyond them was not happening. What were we to do with the sheltered workshops and day wasting activity programs that kept people busy during the day at best? What about the large facilities that remained and the too-big group homes?

Who knew these answers? No one knew, and that was the biggest challenge of all, especially when leadership wasn’t looking for answers and just wanted everything to be okay.

It was like there was no one to go to, no authority but ourselves. There was no manual or expert to ask. We were the experts, scary as that was at times.

Quality in service systems started to get away from program developers then, and have been on divergent paths ever since. Today systems are set, the rules are in place and the people are staying, staying, staying. Today’s systems take up most of their energy with paper work, leaving little room for creativity and action toward achieving everyday lives.

Not seeing this development was on program developers, probably more than any other stakeholder group. They had the power to make the rules and the funding. While troubling signs were visible, there were always seemed to excuses and other priorities to divert attention from what mattered with people.

It was only natural that some approaches would work out better than others, we reasoned. Community participation would take time, we told ourselves.

*What accounted for this inability to see the state of the art?*

*What was it about the services that kept us from appreciating their contours, limitations and trends?*

*What keeps us so powerless to deal with what matters still?*

## **Achievements**

With all the turmoil during these early years, program developers were doing some things right. Although we didn't have a lot of data to support it, we sensed at least that some community outcomes were being achieved.

By staying in touch with what was going on in the programs, we were aware of how people and their programs interacted. Records kept by direct support professionals informed us of the day to day lives people led. Frequent program evaluations were also conducted to ensure Normalization and other tenets were being adhered to.

Through training and technical support, and by being with the people and their service providers, program developers stayed in touch. State and local administrators, along with private agency personnel often spent days and weeks living in group homes to experience that life. Case managers visited people often to monitor their progress toward everyday lives.

In this process, program developers knew that we weren't where we needed to be, and recognized ways to improve. They tried to stay on top of their game by sharing the load and communicating within the system at large.

Important new methods emerged during these times, including practices like Marc Gold's 'try another way', and various forms of lifesharing approaches in numerous states, particularly Colorado, Ohio and West Virginia. A bunch of citizen advocacy programs were created during the 1970s too, to assist people secure community resources and ensure health and safety outside of systems altogether.

These were the times of the first intentional communities like L'arch, and Camphill villages in Pennsylvania and New York. This was also the era of everyday leaders like Jack Pealer in Ohio, and the O'Briens in Georgia, along with teachers and practitioners across many states who shared their knowledge and experiences with others in the field. Of course there was Dr. Wolfensberger and his brewd too, who, along with other academicians, who stayed connected with program developers and continued to educate emerging leaders.

New medicine and interventions had a big impact in these times too. Prescriptions for behavioral and medical conditions made it possible for people to live in their communities like never before. Early intervention with infants and toddlers was introduced based on Piaget's

work and others, demonstrating wonderful achievements in early childhood development and inclusion.

In their work to develop consumer and family participation, program developers assisted people with disability advise programs on how best to proceed. People with disability were named to advisory and governing boards of many organizations in this era. Family handbooks and other user friendly structures helped stakeholders understand what to expect about service delivery.

As program developers realized that family and friends could embrace community ways, they began to authorize health care professionals to teach families and other direct caregivers in providing specialized services. In this way, the country moved away from direct intervention by medical professionals like therapists, nurses, physicians, and psychiatrists to the professional training of workers who had everyday relationships with people, including families.

With the assistance of qualified professionals, families and other workers learned to give medications, clean a tracheotomy and draw blood. Families with medically fragile children were empowered with resources and instruction to live together for the first time in the country's history.

Initiatives to pass on professional skills to service workers and families culminated in allowing workers in community homes to pass medications. Program developers worked closely with their state Nurse Practice Boards to ensure that these competency based courses were adequate in safeguarding individual health and safety.

Efforts to promote independent living bore fruit too. Individuals that learned community skills in the group homes moved into a home of their own or with friends and family.

People began using regular community resources once in a while too, interacting with the public at times and places that non-disabled people did. People who were institutionalized for forty years became volunteers at the local fire department, and members of the Moose or similar community group. Bingo and bowling were popular pastimes for some reason. People were getting connected with friends, shopkeepers, and family members.

To address institutional stigma of people living in newly created group homes, program developers also made a conscious effort to include people coming from the community into the placement pool. This action was especially effective in procuring the support of families with youngsters and adults still living at home, and giving people a way to take on adult roles and responsibilities.

In this process of community living, some people found jobs, mostly part time in low paying trades like janitorial work and cleaning services, but it was a start. Program developers in the State of Washington stood out for the success in job finding during these early years.

People voted, volunteered and contributed to neighborhood projects and charitable affairs as well. Individuals who had been institutionalized or hidden away gave back to their community as volunteers and by sharing their wonderful personalities with others.

Men and women dated. Some married and had children of their own. Innovative programs specialized in supporting these parents with children emerged without much fuss.

While there were mishaps and even tragedies during these times, it became evident that community based services worked well when the right dynamics were in play. People became valued members of families and neighborhoods with support from programs as well as community resources.

### **Voices First Heard**

People emerged from the rubble of institutional life to discover their voice in taking on the struggle for equal rights and inclusion. People became what we call today “self-advocates”.

People let system leaders know in no uncertain terms that there would be “nothing done to us, without us”. Acknowledging a responsibility to support people in deciding about their lives, systems facilitated self-advocate forums and offered other opportunities for people to speak out.

During this era, people with disability were persuasive in their stand for community services, education, respect, opportunity, and relationships. They were brave too, willing to walk in a protest line or attend a rally as anyone.

People were also becoming unified in their objection to tokenism. Individuals dedicated their lives to helping others speak out, even when they had never before expressed a word on their own behalf.

Organizations like “Speaking for Ourselves” were born in this era too, along with state and area consumer boards and committees. Academic institutions, including the Institute on Disability at Temple University, took a lead in supporting people and their families express themselves and learn the system’s ropes.

As their advocacy skills developed with experience, people would continue demanding what they deserved, and working with the powers that be. People became comfortable in the roles of liberator, arbitrator, and counselor.

Some individuals became the best intermediaries I ever witnessed in relating to people in institutions and a wide array of service settings. I remember Roland Johnson, a famous self-advocate in these days, telling me how workers needed to take more time in communicating with people.

Roland took time in a manner that was totally respectful and suited for the occasion. He wasn't about waiting lists or bothered if all the issues on a case worker's task sheet weren't addressed.

Roland Johnson wasn't directed by paid service units or hurried by another appointment. His only deadline was what it took for others to understand. He was real with people, amazingly in some ways.

Roland's autobiography was conveyed in the book Lost in a Dessert World, written with Karl Williams, his friend. This is one of those must reads for understanding how community life presents itself for people with family, friends and dedicated workers. Thanks to publications like this, people were finding their voice and being listened to by an ever widening audience.

Like Roland Johnson did in his book, people shared stories about the struggles in institutional and community life. They decried life wasting in sheltered workshops as well, along with the abuse they witnessed and endured in institutions. Their memories were fresh and others were eager to listen.

Based on the time spent with people like Roland Johnson, program developers had no doubt that people would realize valued social roles. We knew first hand that people with disability made good neighbors, parents, classmates, co-workers and citizens, club members, comic geniuses, life partners, bosses, and comrades in arms.

People affirmed their value in a thousand different ways, and communities responded to the people with respect and appreciation. People came through time and again in their everyday lives.

As we look back on these early achievements, our strength was that we all worked at this community building together. The house parents, program managers and directors; job coaches, families and the case managers, all did their piece.

We had a common vision and we sensed from our own everyday experience what ways to follow. We were enterprising and resourceful, confident and committed. We relied on people to take responsibility too.

We worked with people, too. There wasn't a cookie cutter approach to developing plans of care. It wasn't so much a matter of fitting people into a pre-conceived life script. It wasn't about corporate mergers, service units and payment restrictions.

When we got it right in those days, we supported companionship and permanency. We listened to people and took direction from what they wanted in life and the process they wanted to follow in getting to a better future. We matched people's wants with what their community offered.



We respected what people had to contribute too. We recognized that great things happen when the environments are right and workers are doing the right things within them. We were committed to letting life in.

## **Chapter 8: Miguel and Christina's**

### **A Place In Time**

The 1970s included time with my friend Miguel and his wife Christina. They lived with their children and six unrelated men in a home in the Mt. Airy section of Philadelphia, near Germantown.

Each of the six men had been a resident of Pennhurst State School and Hospital, placed under Federal Court Order issued by Judge Broderick in 1977. The judge's order required the Pennsylvania State Department of Public Welfare to disperse all people living at Pennhurst into their counties of origin, providing home like community services, along with other support and services. By 1987 the institution closed its doors, never to reopen.

Homes like Miguel and Christina's were opened to accommodate people in the community for the first time thanks to this decision. Of the thousand or so people placed from Pennhurst in Philadelphia alone, over 400 prior residents are living in the city today, some in the same settings there were first placed in the 1970s.

Miguel and Christina had been house parents with their family for a couple of years when I met them. Over the course of the next five or six years, we became close. I was a familiar enough face around the place, for sure.

After Christina died unexpectedly, Miguel stayed on at the group home for a while. Miguel then remarried and changed jobs, joining the ranks of academia, where he taught statistics and social work subjects at the college level for years.

A non-profit neighborhood association owned the group home and employed Miguel and Christina as the primary house parents or resident managers. This agency had a couple of other group homes in the area too, and did other community service as well.

The agency had after school programs and pre-schools, even a literacy project. I remember that it sponsored a neighborhood cleanup campaign when I first visited. I joined the men in picking up trash and leaves in the park across the street one Sunday afternoon.

The really special thing about this organization was that it wasn't only disability focused. It was first and foremost community based. It took its social responsibility to support people seriously, inclusive of everyone who lived in the Mt. Airy locale.

A multi-county proprietary agency bought-out the organization a few years ago now. The sale, like so many others, was brought on by tough budget times and a need for agencies to consolidate in order to prevent budgetary collapse.

## **Part of A Continuum**

Miguel and Christina's place was a warm and vibrant home where these six institutionalized men had their first opportunity to live as part of a community. This was a time when systems hadn't developed complex regulatory and service frameworks with a myriad of rules and policy expectations. This was when programs operated on the assumption that people would learn to be self-sufficient and move on to more independent living.

Those in the field of human services called this emphasis on people moving into community life, the "continuum of services". The continuum concept assumed that people would embrace less restrictive settings as they became accustomed to community life and learned everyday living skills.

The continuum called for services to assist people in developing skills and securing relationships so they could live as self-sufficiently as possible. People were expected to move once they felt comfortable.

Like other group home programs of the era, Miguel and Christina's place operated under its agency policy handbook, common sense funding approaches, and workers taking social responsibility for one another in the home and community. Training consisted of learning from program experts and a lot of on the job experience.

I remember too that Miguel had a log, which he used to jot down the events of the day. That was the only form of written record the home used, and it was Miguel's idea. Program monitoring by case managers, while present, was not overly burdened with extensive documentation like it is now. Therapies and other specialized services were at a minimum too, as service approaches stayed with the basics.

Public funding through the state was adequate to pay Miguel and Christina a respectable salary and benefits then, along with free housing, health care and meals for their family. Like many workers in these days, both house managers were college graduates who selected human services as their career path for one reason or another.

Christina was also a nurse, and had a part time position at a nearby health center. Miguel had a Bachelors of Arts degree in American history from Dartmouth at the time.

## **Decisions**

Life at Miguel and Christina's place was a no-nonsense, family first enterprise, where people with and without disability truly shared their lives together and engaged with their community like other households did. Miguel and Christina represented the centerpiece of this experience, along with members of Miguel's extended family and their friends who lived in the area, too. Their combined energy, contributions and good sense were critical to the quality of life the men would lead, not to mention the life of the children and neighborhood too.

Miguel and Christina had their own unwritten policies about home life. They tolerated no inkling of impropriety in dealing with the men. Christina held the men's personal funds in envelopes, locked in metal box in the family's living quarters.

The men and the family ate meals together, saw the same doctors, and celebrated holidays and each other's birthdays together. There was never a hint of physical abuse or aversive programming.

Decisions relating to support and supervision reflected on the community objectives the men had, as well as the good reputation of the home and the agency. What was right was right, as far as Miguel and Christina were concerned. The situation ethics of the place were really quite amazing.

As an example, one of Miguel's brothers did part-time worker duty at the home. He accompanied a couple of men to church too. After a while, the men and Miguel's brother began attending the same Sunday services together on a regular basis.

I remember being at the house the day Miguel decided with his brother that the time spent together at church wasn't going to be billed to the agency, as it could have been. It just wouldn't be right, they felt. That was that. Going to church with the men wasn't going to be billable unit.

### **References and Roles**

At the group home, everyone in the household was called by their first name. The men who could speak knew not to refer to Miguel or Christina as their family. This was different than institutions where female aides were routinely referred to as 'mum' or 'mom'.

I remember one man who took on the role of a fun-uncle figure with the kids, which was nice. He relished the kid's play times and tumbled carefully on the rug with Miguel's oldest boy before dinner.

This man would pretend to read stories to the kids too, though no one understand what he said. He pointed to the pictures and mimicked. He was very expressive and funny, brimming with personality.

Christina and Miguel accepted this relationship as it developed, helping it along and giving it parameters like they needed to from time to time. That was how they handled family relationships with all the men.

In light of this fun-uncle's family orientation with the children, it was sad to learn about his struggle in reconnecting with his own parents and siblings since his return to community life. The man had been trying to establish contact for over a year without much success.

He would send cards on holidays; and he would telephone his mom, too. The cards didn't get answered though, and the talks were brief, with no commitments made for getting reconnected any time soon.

Not one to be easily dissuaded, the man arranged to have another one of Miguel's brothers take him to a memorial service of an older family member. The man found out about the uncle's death through a caseworker who knew the family too.

The service was a 20-minute subway ride from the group home, and another 10-minute walk. The man bought a dark suit with tie and black shiny shoes for the occasion.

Apparently, the mom broke into tears when she saw her son at the viewing. After that outburst, the rest of family consoled the mom, and whisked her off after the service was concluded. The man wasn't invited to the family dinner that followed and relations didn't improve after that either.

Relationships were not something many of the other men at Miguel and Christina's place seemed to seek out. They were said to avoid interactions as result of their many years in the institution, where inmates were encouraged to be compliant around authority figures. As people with virtually no opportunity to develop close personal relationships in the institution, the men couldn't be expected to develop social ties that quickly in the community either.

While I developed some closeness with a couple of men over the years, the pace of getting to know one another and appreciating personality differences was gradual. Personal ties weren't voided on this basis, just different.

One of the good things I learned with the men was an appreciation of time without conversation. Just sharing space in the living room together, without doing a common task, or even saying a word, was the best it got to be sometimes.

### **Expectations**

Despite differences, shyness, and general lack of social skills, each man took his turn in shopping for groceries, clothes and personal items with Miguel or home staff he assigned. The men also frequented the park across the street and experienced conditions that approached those of an average citizen in certain aspects of their lives.

Sometimes the men went out alone, crossing the street themselves. Mostly they went with a buddy. They also used public transportation or got rides in the agency van or station wagon to medical appointments. The men took a public bus or van to their workshop sites too.

The men helped in preparing the family meals and in cleaning up after dinner too. They shared in the yard work, raking leaves and clearing snow. Each kept his side of their bedroom neat and took turns in cleaning common spaces. Some rooms were messier than others, which didn't matter too much as long as no one was hoarding food or taking over another's space.

The men received instruction in daily living skills on a regular basis so they could master such tasks as their laundry, taking baths, and cutting toenails. On any given day, there was some instruction going on, using only non-aversive and supportive methods.

Learning community living in this way didn't seem to be a frustrating experience. All the men had their basic community living skills down pretty well by the time I met them. Lapses from time to time occurred, but the men understood their roles in the home, and completed their tasks on time without a problem.

The men did individual things on weekends too, like traveling cross town to visit family or a friend, or going to a nearby tavern on Friday night. Some men went to church services on Sunday, while others slept in.

Dances at the local association for retarded citizens, Special Olympics, and sports were events a couple of the men really enjoyed. Free tickets to professional and college sports were common forms of donation from the local fire department and civic groups that the men enjoyed too.

Christina would say the men developed social skills from these experiences, sometimes quickly, and sometimes not so fast. A number of men preferred dancing, camping, and bowling. I joined them on a couple of their camping adventures, which were great stories in themselves.

### **Challenges**

Life wasn't always rosy at Miguel and Christina's place. Individual issues around hoarding and other institutionally born behaviors had to be addressed, sometimes repeatedly for stretches of time. Some men were on token reward systems, or had a time out arranged for short periods of time. Personality clashes with six unrelated men and a corps of family, friends and relief staff flared from time to time as well.

Behaviors of some of the men got them in trouble, even with the police. I heard from Miguel that one man had to leave the home for exposing himself in the park. This was before I came to know the family, so I never met this man. Apparently, the exposure was done innocently enough. The man needed to relieve himself.

A neighbor complained about his child seeing the man with his pants down, and the man was removed to another group home the next day. No other incidents like this happened again over the time I knew the men at least.

From Miguel and Christina's viewpoint, the situation came down to crossing lines that the community wouldn't tolerate. The community was setting boundaries with incidents like this, and that was okay as far as they were concerned.

There would also be problems with the men's family or workshop that carried over into home life. Appropriate sexual expression was a difficult issue with some of the men. Masturbation in privacy was stressed, and dating involving overnights was not permitted in the home.

Issues related to money management and personal hygiene would be the subject of a number of sit down discussions over the course of a week. Miguel and Christina did all this counseling, or managed it in some way. It was all done discretely.

Rarely did Miguel and Christina actually have to directly intervene in difficult personal situations. Instead they would offer a little reminder, and that would be enough. A number of personal matters never got recorded in the daily log out of respect for the men's privacy and trust. Nobody in the family raised their voice to the men, let alone threatened anyone with any force of violence or retribution.

Some men had health issues that were pretty serious too, and just about everyone had horrible tooth decay after years of neglect in the institution, exacerbated by psychotropic medications that ate away at the gums. Imagine not learning to brush your own teeth from the time you were a little boy, like these men weren't. That's what institutions were like then.

Dealing with various forms of institutional neglect was part of what community living was trying to address. It was taking people to dentists for the first time and then routinely, and weaning them the men off medications that kept them docile and generally out of it for years on end.

Getting the guys to wear their dentures was a constant struggle. False teeth hurt and were messy, and a couple of men didn't wear them at home except at meals.

Medication reductions proved to be much more successful. Long-term dependency on psychotropic drugs had taken a heavy toll on some of the men by the time they returned to community life. Personality traits blossomed, and phobic behaviors disappeared with medications being reduced, or changes in script.

Miguel and Christina didn't shy away from elephants in the room. They knew the men's strengths and challenges on a personal everyday basis. They recognized even subtle clouds forming and problems brewing, whether it was a full moon or a certain blank look before a seizure. They knew about each man's issues.

Because of this awareness, Miguel and Christina were able to address behavioral challenges in a natural way, often preventing episodes that could have been far worse. One or two men were unpredictable at times. I remember certain interactions getting tense at moments, but situations got defused pretty well.

Unlike the institution, nobody at the group home was hitting the men or herding them, or keeping them from doing things they enjoyed. That seemed to make all the difference. People were communicating in human and supportive ways.

## **Coming Through**

Miguel and Christina had been coming through for the men with consistency and warmth for years by the time I knew them. That quality of support was just so evident. It was a dynamic relationship to be a part of and witness when I could.

Looking back now, I see how Miguel and Christina's place was a good start for people coming out of institutions. The men's health care needs were attended to and they had access to community and specialized resources they needed. They got respect and the support to live in community ways.

While it is easy to see now that six men from an institution were too many to make the most of community opportunities and individualized pursuits, Miguel and Christina's place seemed at least like the right place to begin. It seemed right too, that the men would eventually move on to more individualized living arrangements once they learned what they needed to, and made the necessary connections.

Despite adults being shortchanged in terms of their job opportunities, the men and other community home residents of the time enjoyed a fairly good standard of living. Even though they couldn't begin to achieve self-determination due to benefit restrictions on income and resources, most of the men had modest savings, and likely a burial account too.

The major challenge I saw then, like now, was to move with the men into more independent living. The men seemed very comfortable with their surroundings and group home 'digs'. They were used to having home life set up for them like it had been in the institution.

When I discussed the men's future opportunities with Christina, she was quite adamant that she didn't want the men used to justify some ideology or continuum idea. While she agreed that people should move on to their everyday lives, she didn't want her home being likened to a training program.

It was their home place too, she'd say. Arbitrary timetables shouldn't be applied on the men's tenure. Miguel seemed to feel the same way, although his take was somewhat different too.

Miguel loved to say, "The fix is in" and indeed it seemed to be with placements and community life. Miguel pointed out that the State and County administrative units wouldn't push for moving people into everyday living arrangements as long as institutional cost comparisons continued to be applied.

He was probably right about that, too. Compared to the \$100,000 per-diem rates institutions began to charge in the later 1970s, community services were only about a third of this cost. Even though rates have increased and come much closer together over the years, the system's fixation on community services being "better and less costly than institutions" continues to take its toll on aspiring to everyday outcomes.



One of the biggest barriers to independent living we all agreed with was the men not finding jobs and relationships. The emphasis on securing a group home slot far outweighed these outcomes then, like now. Miguel and Christina's take was that people wouldn't be employed as long as the workshops held sway.

### **Sheltered States**

The support that Miguel and Christina managed to offer, together with other services in the community, didn't translate into changing the men's sheltered state of living or work, at least in the time I knew them. While the men learned to do their wash and prepare meals, the continuum of services was not playing out as planned.

Whether this was a matter of people needing more time or not at the group home, the condition of people staying put continued to be a matter of discussion. Regardless of the time factor, it was apparent that certain barriers to independent living were not going away.

Some of these barriers were associated with people feeling satisfied with where they were placed, but there were system factors too. It was not until later years that it became more obvious how people were poorly prepared for living in everyday ways

Case managers, who were supposed to be locating increasingly independent support, weren't fulfilling this function at all. Families were also not interested in their loved one's moving, and moving for moving's sake didn't make any sense.

As far as most case managers and other system operatives were concerned, people who found a 'slot' at a community living arrangement like Miguel and Christina's place could just as well stay where they were placed. That first place for community living would be as far as systems would take people, unless agencies wanted to move them to other homes for their own purposes.

From a system perspective, making residential placements work was just about all that got done in those days. These homes became each person's base for finding health care along with sheltered work and social outlets. The effects of keeping people occupied and healthy in these settings eventually formed a protective web with group homes in the center of a system fed network that continued to grow and grow.

As living in the community became a function of residency in agency owned and operated homes, the probability of people moving into an apartment with a friend got to be more and more distant. There was also plenty of money to build new homes, so why rush it with folks? Leaving well enough alone was definitely the overriding sentiment of the times.

The focus on securing a place to live occurred despite the skills and desires of people to live on their own or outside of the system's domain. In these early days, holistic approaches that stressed social ties and employment were just second tier in importance, if that.

People, like the men at Miguel and Christina's place, were successful in making adjustments to community life in a relatively short period of time, but went nowhere after that, at least for the years I knew I them. The men got good at conforming to the ways of a life in group home, like they conformed to life in the institution they came from.

It seemed to me then, like it does now, that some of the men would have moved on into more independent living if the opportunities were there. They could have been coached and supported in that way and families too. Sadly, they weren't. The system was not ready to move on with people then, and never has gotten to that point since.

## **Lessons**

Miguel and Christina's place was among the first group homes in this country to provide community living and it succeeded on numerous levels. The men made the best of the limited socially integrative opportunities presented to them during these times. They offered their neighbors and others like me a living example of people with and without disability being accepted within a broad community context.

The quality of life sharing at Miguel and Christina's place was a highlight of this living experience. The home felt, at least to me, like living in a big family. I appreciated the comfort and hospitality the men received, and the sense of belonging they developed in the neighborhood.

Life in group homes like Miguel and Christina's place meant talking with neighbors and crossing busy avenues, taking the streetcar down to City Hall, and managing everyday dangers common to city life. It meant having regular household routines around eating and going to sleep, having an opportunity to worship, and taking on a dignity that came with hanging in there with the challenges of community life.

It meant lending a hand to housemates as part of a common endeavor to live well. It meant being clean and tidy. It meant trying to learn new things and be more self-sufficient. It meant keeping up on current events, and voting.

While the men would be called degrading names once in a while by youngsters that didn't know them, or get involved in difficult situations, they got over these hurdles. So did the community. Neighborhoods learned a thing or two from these early days of community living.

Program developers at the time, like me, liked what we saw, experienced and felt about being able to support people in community life like this. We saw in places like Miguel's and Christina's how community living worked and how it could be improved.

Paths to improvement seemed clearly doable, too. Staying focused on the men's well-being and development seemed to be the way to proceed. While some improvements in home living required additional funding, most adjustments seemed to be a matter of how work time got delegated and helping people get adjusted to new expectations.

Doing better with the work of supporting the men wasn't viewed then as a means to do more, as much as doing things differently. Often improvements in behavior or motivation would evolve from backing off, and letting people find their own way. Aversive methods were always out of the question, thank goodness.

Knowing the men and Miguel and Christina's family helped me appreciate the realities of living in a group home. The spirit of possibility was so alive then, it was easy to feel it every day. Despite the challenges, it felt like life worked for people then.

It felt like community living was destined to turn out all right in those days. I'll always value these times we shared in Mt. Airy for how they helped me appreciate how great the basics of community living could be. How good it was, letting life in.

I learned from Miguel and Christina especially, that living with and supporting people was not much different because of disability. While some teaching tasks took longer with a certain individual or required different approaches, a lot of the challenge came with learning each man's learning style.

Support at Miguel and Christina's started with discovering how people learned. It meant trying another way when one approach didn't work. It meant not giving up or getting upset about slips and mishaps. It meant keeping home life secure and positive.

In these ways, the men at Miguel and Christina's place, along with thousands of other adults in the early group homes across the country, first learned to adapt to community worlds that were completely new to them. People with disability like them, who had been exiled to institutions for 150 years, were taking the first courageous steps into community life, and sharing this with resident advisors, their families and friends.

The deepest impression from Miguel and Christina's place, for me, was that people who shared lives got to live reasonably well. I came to appreciate the creativity and energy around this lifesharing process.

Teaching and lifesharing were natural partners in this respect. While each of the men had their share of challenges and demanded time from Christina, Miguel and other personnel, having these issues unfold in a supportive family atmosphere was amazing.

In view of the roles they played, Miguel and Christina, along with their family reflected well on all of us, and as a generation too. The work of community living that the nation came to appreciate was grounded in their achievements with the men adjusting to community ways. This was something important and lasting.

So we, as a generation, thank Miguel and Christina, and their family, along with other workers that started the community movement in this country. We acknowledge these pioneers who worked together and the people from the institutions who said yes to community ways, imperfect as they were.

These people and the support workers made the best of it and showed the way for the rest of us. Nobody could have asked for more back then.

### **Postscript**

Miguel and I got back together recently, after 30 years or so. He was still living in the city, doing different things, and as vibrant as ever.

Although we had lost touch, I always counted Miguel as one of my few very best friends and mentors. Our greeting was warm, and we didn't skip a beat.

Over drinks and dinner with my son Jeremy, Miguel updated us on the men and their lives. Last he heard, two or three of the men settled with family, or were living on their own. One of the men got married, and others passed away. A couple of the men found jobs.

It was great to hear from Miguel that community living support worked in these ways with the men, and it surprised me somewhat. I assumed that the men would be still living would be living in group homes or even facilities, like other people I've known.

Perhaps, Christina was right after all. It would just take more time with the men, like she had said. I'll have to hear more about this, now that Miguel and I are talking again. I look forward to this time again immensely.