

## **Chapter 9: Normalization**

### **Yes We Were**

*We were the baby boomers*

*Open to new ideas for a new age*

*Ideas that came to us with civil rights*

*Justice, learning respect, mutuality, liberation*

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*These tenets formed our common ground*

*We joined together*

*We sang the same songs*

*About unity and possibility*

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*We shared a sense of wonder*

*And pledged responsibility*

*To make this country*

*Better for us all*

### **Roots**

With the introduction of Normalization to North America in the 1960s and 1970s, the nation's adherence to traditional forms of caring for people was about to be dropped and left as a result of what leaders, workers and other stakeholders would learn to do differently. Old practices would be eclipsed due to the methods and ideas early community program developers discovered and pursued.

It was natural for institutional norms to erode as a result of larger cultural shifts and economic changes in the country during this era. The country was moving away from solutions that simply didn't respond to new expectations of citizens in a rapidly changing and more diverse world. Baby boomers were questioning everything institutional during these times, and this form of life for people with disability was no exception.

To find out about new service and support practices the country might be able to adopt, U.S. academicians and practitioners turned first to Europe. Here they found ways of support that had been flourishing in modest measure for over half a century.

One of these ways was the establishment of Camphill villages that developed after the 1<sup>st</sup> World War for the intentional purpose of welcoming people with disability as valued members in these so-called "intentional communities". Agrarian and self-sufficient, the villages spread to numerous European countries, reaching American shores in Pennsylvania and New York by the 1970s.

The Camphill concept was originated by Rudolf Steiner, a turn of the twentieth century mystic and brilliant social architect. His idea was to create communities with structures that relied on villagers to manage their lives independently of general society which he viewed as essentially corrupt and very dangerous.

The Camphill way respected the importance of people as contributing to community life. People with and without disability lived together in family households. They shared life and community responsibilities.

Villagers harvested crops, stocked root cellars, and concocted wonderful juices from their orchards for their own use and sale. They also shared responsibilities in baking, caring for livestock, and building construction.

There were no distinctions in terms of pay in the villages which didn't use money as an exchange. Leadership roles were not limited to a wealthy sector or prestigious families. Testifying to their appeal, accomplished artists and musicians found Camphill communities to be open to them.

Each village had a large hall or gathering place for worship, civic meetings, and celebrations. Gatherings were accompanied by dance and music. Conversation at events was typically vibrant, intellectual and fun.

It's no wonder that Waldorf education, which emanated from Rudolf Steiner's writing too, spread to 60 countries over the course of the 20<sup>th</sup> century, including 50 public and charter schools currently operating in the United States. Waldorf schools, like the Camphill communities that first sponsored them, stress the fulfillment of each person's unique destiny in the context of a rich community life.

Steiner's tenets under the general definition of anthroposophy, stress creative and analytical expression, respect for the earth and healthy living. While his pedagogy had limited

influence on mainstream educational theory in the United States, Steiner's emphasis on learning as a means for young people to develop into free, 'morally responsible' and 'integrated' individuals tie directly to Normalization and other modern communitarian concepts.

I remember a time at a Camphill village in Pennsylvania in the late 1970s that attests to the enduring strength of Steiner's community vision. I stopped by the village to say hello to friends in a household where I had stayed intermittently over the course of a few years.

Word got out that I was back and the village decided to host a reunion of sorts in the community hall. That evening together was marvelous, so full of genuine friendship and a sense of belonging. I never felt so welcomed anywhere, before or since.

Camphill and similar forms of community with people appeared throughout Europe during the mid- twentieth century. The trend away from institutions was so strong that they were essentially dismantled in Scandinavian countries by the time the United States began considering this idea.

France and Belgium which had been exploring community support approaches since before the industrial revolution had community living through secular and religious support approaches that immigrated to the United States as well. Even stodgy England had a sprinkling of group homes in place by the time President Eisenhower finished out his second term.

In light of these European traditions, it's significant that social scientists educated in Germany, Norway, France and Europe introduced advanced community support concepts onto American shores in the mid to late 1960s. Their outreach to colleagues in Canadian provinces and some states constitutes the first seeding of community with people in our times.

Leaders in states like Pennsylvania, Massachusetts and New York embraced the teachings of these mentors, men like Gunnar Dybwad and Bent Nirje. Home grown program developers would continue to rely on the advice of these mentors through the 1980s.

Make no mistake, these friends from other lands inspired America and helped ignite a spirit of liberation that still burns bright. Thanks to their participation in forming support structures on our shores, everyday living pursuits would be established in most of the states by the end of the 1970s, serving over 40,000 people.

### **Dr. Wolfensberger and his Brewd**

By the early 1970s, Syracuse University in upper New York State became the United States' premier center of teaching, leadership development and inspiration for the community services movement. Its faculty included Wolf Wolfensberger, Steven Taylor and Burton Blatt who authored the early institutional classic: Christmas in Purgatory with Yale University's Seymour Sarason, another pioneer.

Dr. Wolfensberger, the father of Normalization in this country, stood out among his peers. Born in Germany and educated in the United States, he worked at a large institution and developed some of the first community programs in the late 1960s.

During these early years, he also began writing which led to seminal works on Normalization and being a change agent. When he came to Syracuse in the early 1970s, he launched the National Institute on Disability and Change Agency with his colleague Steven Taylor.

Through training workshops offered by the Institute, Dr. Wolfensberger provided a means for emerging leaders to increase their understanding of Normalization as a guide in decision making. ‘Wolf’ and his training coordinator Susan Thomas, together with their brewd of change agents, took on the formidable task of introducing valued social roles, integration and developmental growth.

Colleagues who studied and worked with Dr. Wolfensberger in these times moved into leadership roles. Wolf’s brewd spearheaded dramatic change in academic circles, explored new forms of citizen advocacy, and began on paths of self-determination that were unimaginable in the past.

While a number of these pioneers have retired or passed away, their vision continues to resonate. Even with Dr. Wolfensberger’s death in 2011, there are many devotees that carry Normalization’s torch. The Institute, as well as its Canadian counterpart in Montreal, continues to develop and inspire generations to come.

Dr. Wolfensberger began grooming leaders in the late 1960s, particularly during his stint in developing community based services at ENCORE in Nebraska. Key personnel he employed there, including Linda Glenn, Brian Linsink, and Mel Knowlton, would take on significant leadership roles in Colorado, Massachusetts, and Pennsylvania.

Mel Knowlton, a close colleague of mine, began developing community living arrangements in Pennsylvania’s in 1973 after leaving Dr. Wolfensberger in Nebraska. A recipient of the Ben Censoni award for his public service in developing home and community, he continues to work with stakeholders in the Keystone state on supporting everyday lives.

I worked directly with Mel for my 30 years in the State Office of Mental Retardation (OMR) which changed its name in 2008 to the Office of Developmental Programs (ODP). My desk, cube or office was right beside his through most of this time. We were a great duo in many ways and still enjoy partnering on lifesharing and other projects we started back in the day.

Throughout our time together, Mel took the lead and cut the deals that had a profound impact on Pennsylvania’s community based service system. While there were other important players in the state throughout this time, he remained a key figure in decision making circles until his retirement from state service just a few years ago.

My role in state government was always subordinate to Mel, which was well and proper. I took on responsibilities in his Bureau as an evaluation specialist at first, moving on to policy and program development positions through the 1990s. Throughout my tenure as the Office's first and only Quality Improvement Initiatives Director, our collaboration remained as close as ever.

I wrote a slew of policies for Mel, along with manuals, white papers, waiver applications and grants. Mel relied on me to put ideas to words, research new approaches, develop training modules, organize demonstration projects, and pound the drum with him and other colleagues for change.

While my boss and mentor, Mel preserved qualities of a friend, father figure and brother to me. I'll always appreciate his patience and fortitude in the face of relentless barriers, and marvel how he kept his eye on the prize after all was said and done.

It's fair to say that the quality of our work together, like that of others who developed community services in this generation, is the subject of this generational assessment. We're all on the hook, so to speak.

Mel has no problem with this as far as I know and I don't either. I sense that Mel appreciates what Arching Tales has to say because we've never stopped talking about the issues we've faced. Mel also read an earlier draft of this work, offering me comments that are most appreciated.

### **What We Were Then and Are Now**

Recent public relations efforts in the field of human services have begun to promote the idea of program developers like Mel as revolutionaries in the history of services for people with disability in the United States. With due respect, the designation seems to be somewhat of a stretch.

While I can buy into this revolutionary quality for families who started the community movement, certain advocates, and visionaries like Wolfensberger and Blatt, change agents like us that focused on system design and development were another breed entirely. My colleagues that designed community services tended to be gradualists who approached community support and social integration incrementally. They worked through traditional channels, cognizant of the long haul nature of our endeavor.

Although program developers introduced ground breaking services as alternatives to institutions, our generation of movers and shakers didn't necessarily liberate people from institutional type systems that controlled their lives. There are also thousands of people who continue to reside in facilities, and many community service programs are still more like institutions than not.

Fundamentally, pioneers like Mel, me and our colleagues worked within established legal frameworks and organizational relationships. We became project and program workers with

titles and functions, all encased in stakeholder hierarchies, complete with civil service classifications, tables of organization and the whole nine yards.

While each of us had revolutionary ideas and tenets to inspire and guide us, the point is we didn't apply them that well or resolutely. We implemented services with funding appropriated by legislatures in an era that could no longer tolerate people being interpreted as sub-human. We weren't always leading the charge and hardly ever radical.

With tool kits that consisted of public funding, persuasion, training, evaluation, and policy papers, we did our best to work within the established parameters. It's hard to see what's so revolutionary in all that.

Apart from this distinction between being a pioneer or a revolutionary, early leaders did take control of things. They did design the approaches that came to employ workers, take in people, for better and for worse.

Defining their scope by the limits of legal authority vested through private and public agencies, leaders were focused on serving people in systems operated programs, leaving many in the community underserved and invisible in their wake. Tens of thousands of people with disability still remain on waiting lists today, or lost in prisons, mental institutions, and nursing homes.

While it's easy to see in hindsight how early leaders put too much faith in managed care systems, there was never a cook book for community support back then. Wolfensberger and his brewd in the late 1960s had good reason to believe that service systems might hold the key to everyday lives based on their Nebraska and other experiences.

Early leaders didn't have a magic ball to forecast how human qualities like autonomy and dignity are taken away from people and their communities in the creation of systems. While we all shared hope for improvement over the years, dear old colleagues that once preached the gospel of systems are as disappointed as anyone with what has become this enemy within.

Seasoned leaders have learned the hard way that there is no tried and true bridge that takes people from system control to community embrace. Like Dr. Wolfensberger and Gunnar Dybwad who disavowed formalized services in later life, those of us left from the early have come to understand what works and what doesn't too.

Even though systems that the pioneers championed have failed people in many respects, it would be too easy to blame this demise on Normalization principles, early leaders or anyone else. Normalization values are as valid today as ever, and pioneers did their best.

The fact is that the humanist qualities that Dr. Wolfensberger and his colleagues espoused and began to implement through services never had much of a chance to thrive. Systems and the ideology of the pioneers never fit together that well from the beginning.

## **Normalization Means**

Normalization doesn't mean that people with disability are made normal, or assume that anyone else is. It means that people with and without disability are supported to live valued roles in their communities with appropriate assistance, interpretations and structure.

Examples of valued roles include: working at a job that brings home a living wage, being a helpful neighbor, voting or accepting jury duty, having different friends and associates to do things with, and controlling decisions in life. Valued associations are influenced by the quality of people's routines and rhythms, personal appearance, relationships and rights.

Normalization also means that adults with disability have bank accounts and savings, along with respect and personal space on par with their peers. It means having life conditions at least as good as the average citizens.

Normalization rejects institutional living as the abomination it has always been. Normalization tenets pull no punches in contrasting support in the community to the demeaning and corrosive realities of facility based existence.

Normalization clarifies how deviant interpretations of people as objects of pity, fear and loathing are taken on by systems and society. The writings of Wolfensberger, like the illustrations of Robert and Martha Perske, show how inclusion matters in the quality of people's lives. These words and images help citizens see how lives don't need to be defined by disability.

Normalization established common understandings about the adaptability of people and about the community's potential to advance support in appropriate ways. A sense of knowledge based on values stayed strong in stakeholder hearts and minds throughout their careers.

Belief in Normalization also gave early change agents the power of their convictions. It gave those who wanted to assist people the motivation they needed to make a difference, by bringing truth and struggling on. Normalization had a unique way of rekindling optimism that people would indeed be free at last.

Normalization was liberating at its core. Those who answered the call to take on old ways did so with Normalization as a set of principles, decision making guide and call to action. Colleagues came to their work inspired with everyday outcomes to achieve.

## **Program Analysis of Service Systems (PASS)**

Wolfensberger first wrote PASS in 1969 with his associate Linda Glenn who would become the head of developmental disability services in Massachusetts in the 1970s. Both individuals would contribute to later versions of this work, ending with PASS 3 and Fundet in 1975.

PASS changed the world of decision-making in human services in North America. The dark green PASSING manual composed of funny sounding ratings and definitions became the continent's guide for emerging services focused on quality.

Initially, PASS was used almost entirely as it was intended to be, as an assessment instrument that examined the appropriateness of support structures within service systems on a state, local or agency level. Its use promoted physical and social integration, individualization and developmental growth within this system domain.

By quantifying Normalization values like 'appropriate interpretations and structures' and 'deviancy juxtaposition', PASS was able to translate otherwise vague concepts into practices that were measurable and more importantly achievable in improving people's lives. It brought common issues, tenets and values together and down to earth.

PASS also measured programs in ways that promoted dignity of risk, individualization, and cultural norms. It gave practitioners who received PASS evaluation reports and teams who composed them an invaluable understanding about how service structures influenced community outcomes and values.

PASS tested cost effectiveness of services too, along with planning structures and management practice. It embraced evaluation and renewal mechanisms to keep services honest and open to new and better ways.

PASS made it possible to hold systems accountable to achieving valued social roles with people. Its centerpiece rating called "Model Coherency" ensured that programs focused on the right workers utilizing the right methods, for the right ends, based on each person's direction at a particular time in life.

During the 1970s and early 1980s, thousands of workers in emerging service systems attended four to five day PASS workshops where they received intensive training in the assessment instrument and a familiarity with Normalization tenets. Workshop trainers and evaluation team leaders were generally certified by the Training Institute and often taught directly by Dr. Wolfensberger and his staff.

Ken Chesler was my supervisor in those days of the mid-1970s. He was trained by Wolf and he had a real gift for public speaking. Ken was a colorful and even flamboyant character. He did slide shows and led many assessment teams himself in forming Pennsylvania's full court press to adopt PASS as its official quality management too.

Ken and I had a summary of our work published in a journal with a colleague Jim Fanning from Virginia. The article was titled the PASS Sub-System which is available on my website: [dawaho.com](http://dawaho.com), as well.

Pennsylvania and Oregon were the two states most heavily invested in PASS evaluations on a system wide basis at that time. Other states took similar paths but in a more limited way due in large measure to the administrative costs involved.



In the course of these evaluation years, I personally led over 200 PASS evaluation teams and attended over 40 week long training workshops. An example of a report I completed that utilizes PASS criteria for the State of West Virginia is included in the Appendix of this book, with additional ones on my website too.

PASS evaluations required a team of trained individuals and a qualified leader to visit with individuals and providers of service, including administrators, direct support workers, and families. These visits occurred at the individual's home or place of work. Teams jotted down observations on interactions, the setting's features and neighborhood, and everything anybody said. Record reviews were done too, but not a major part of the exercise.

People were encouraged to answer questions independently. When people could not communicate verbally, answers had to be provided by workers or family members that knew the person best. Teams also talked with neighbors and shopkeepers to gauge community impressions and get a feel for the culture.

Evaluation visits took at least a day to complete, followed by another full day and evening to complete individual team member ratings, rating reconciliation into agreed upon scores and recommendations for improvement in major areas. Each evaluated program received their scores at a debriefing meeting that offered opportunities for further discussion.

A written report explaining each rating and recommendation was shared as well. In states like Pennsylvania, technical assistance in developing quality improvement actions based on the reports was available through Regional and county offices, as well as consultants.

### **PASS Constructs and Scoring**

As far as PASS was concerned, support needed to be age and culturally appropriate, individualized, and relevant. It required that experiences of life be integrated within the community, both physically and socially.

PASS also rewarded coherency between what was going on in a person's life and the structures that were available to support valued roles. For children, coherency entailed permanency in parental and family relationships, opportunity to be educated with one's peers, and to interact with friends.

For adults, model coherency dictated that people receive individualized attention to achieve valued social roles at home, work and in the community. That generally meant that people would get jobs and live in regular homes with others they chose. It meant engaging in activities that other citizens enjoyed, in the places and at the times the general public did.

Under PASS, service systems could not get away with interpreting adults with disability as eternal children, clients and patients, 'the retarded', or consumers. PASS sensitized workers and other stakeholders to how even subtle inflections and labeling can portray people as helpless, a threat, or uneducable. PASS helped us all appreciate the importance of treating people with respect and as people first.

PASS also highlighted how services could be measured reliably to determine whether valued methods were being applied and whether programs achieved their objectives in an appropriate way. PASS was all about evaluating against the highest expectations, recognizing that even when expectations are not met, aspiring to the ideal is necessary to continuously improve.

In contrast with other quality assessments that generally had a professional basis, PASS relied on community standards to measure appropriateness. PASS was unique in that it valued community and culturally valued means as much as ends.

PASS never compared community living services to institutional norms or hospital rules. It compared community living to how people without disability lived, worked and enjoyed themselves. It aspired to ideals that citizens shared.

PASS assessments were especially helpful in recognizing how everyday experiences led to people having valued roles in life. PASS scoring rewarded programs where people took advantage of social opportunities that developed ties with non-disabled peers.

The scoring system PASS applied was mainly concerned with ideologically related considerations, covering everything from a program's proximity to the local population center, to innovativeness in practice and program design. Only 5 of 50 separate PASS ratings related to operational effectiveness that was ideologically free.

On a rating scale of 800 positive points and 1000 negative points, institutions invariably scored in the minus ranges, between -300 to -600. These tallies reflected the segregated and custodial nature of facility life.

Even when people in institutions were treated fairly and maintained in a healthy state, the conditions of facility life were simply antithetical to the community values and structures that PASS adhered to. It didn't matter that facilities had certain foregone constraints or did the best with what they had.

A "0" score in a PASS team assessment meant that the program or service system being evaluated did no particular harm, with life conditions being comparable to those of an average citizen. Many community programs, like the group homes and workshops, scored in this range, averaging between -100 to +200.

Common shortcomings in this grouping included limited assimilation potential, inappropriate program structures, and a lack of relevant program and individualization. Many of these characteristics were endemic to the size of programs, their location, sheltered ways and staffing models.

While relatively few services would achieve PASS scores of 400 or better, the programs that performed at this level exposed promising practices and the highest state of the art. These programs were universally individualized, respectful, well resourced, secure in their future orientation, and intentional in taking community ways to achieve everyday living outcomes.

High scoring programs also achieved what they set out to in terms of people living valued social roles in work, home life, and the community at large. These programs appeared in most states and with both proprietary and non-profit agencies.

Programs with high PASS scores were living evidence that community services could really be done effectively. The super programs walked the talk, and administratively established themselves with strong community connections, organizational safeguards and leadership. High scoring programs were not complicated or costly either, piled high with internal control features.

People with disabilities and families provided ongoing direction within these organizations, not just advice. Person centered planning was clearly focused on utilizing valued means to achieve valued ends.

Management approaches in the super programs also touched excellence with practical community based approaches that included constructive and close relationships outside their organizations. Leaders that ran these programs understood the importance of accountability on individual, family and community levels.

Programs with high PASS scores welcomed diverse points of view and external evaluation as a source of renewal and quality improvement. They clearly recognized cost-effectiveness on the basis of achieving outcomes in people's lives.

### **Principles In Practice**

Apart from its value as a program assessment tool, PASS was used in decision making of all kinds. It helped workers, from policy wonks to family members, concentrate on steering community services and constituent relationships along a value driven path.

PASS reinforced that community ways are achieved through community means, and that interaction on a personal and organizational level are key to discovering appropriate approaches. PASS also promoted the use of people power and generic resources in the context of everyday living relationships and functions.

PASS meant developing services in ways where quality would be measured against the life conditions average Americans expect for themselves, no more or no less. Services that used PASS as a guide were not supposed to simply comply with a standard set of regulations around health and safety.

PASS meant workers would be focused on addressing negative labels and other deviant interpretations about people that the public and workers had. It also influenced programs to assist people appreciate the finer things in life like creature comforts and the beauty of their environment, close and warm relationships, and success in community terms.

PASS was good at ferreting out fact from fiction too. PASS didn't reward grand standing or assume that private institutions were somehow more humane and better run than public ones.

It reinforced structures like worker training and public education in support of appropriate life conditions with people.

It helped that PASS aspired to the same cultural values that are established for all United States citizens. It dealt with basic human and political rights, not just what a government agency wants to enforce or deem 'necessary'.

PASS expressed itself using everyday language and by applying everyday conditions, customs and beliefs. Even though some of its wording and concepts, like 'deviancy image juxtaposition,' were difficult to put together at first, PASS measures unveiled basic and necessary things. People, families and providers of service understood PASS measures and worked with them the best they could.

Tasks associated with everything service systems did had some tie in to PASS measures too. Worker training and orientation, community education, and administration all had principles to support. Our work, no matter what it was, was constantly placed before a Normalization mirror.

PASS also had a way to test workers in the course of their own careers and interactions. While it felt uncomfortable dealing with these issues on personal and even intimate levels, workers had to come to grips with tenets in their everyday lives too.

Ultimately, PASS tested workers and advocates in a good way, developing their confidence to stand up for community values, dismantle institutional practices and seek out community resources with people. PASS also helped program developers choose which struggles to take on or put off for another day.

PASS gave early program developers courage to get through the tough times and overcome the nastiest challenges too. While coming out of meetings with another stack of setbacks was no fun, workers weren't sacrificing their integrity and selling out in the face of difficulty. Our courage of conviction helped in being clear with colleagues, friends and family, and the public too.

In the final edition of PASS III, a rating section called FUNDET was introduced. This section assessed program features that had an independent bearing on financing services. Considerations like funder requirements, priorities, and various hardship factors weighed in.

FUNDET wasn't used much in these early days or since. If better linkages between service funding and ideology were made, systems might have formed differently but this never materialized.

While PASS offered truth to power, it rarely got factored into decision making around what programs were approved, continued or left behind. Failure to connect in this process underscored a deep and serious problem that continues to affect people all over the country today.

Critics rightly point to this disconnection with funding as an ongoing factor leading to the disgraceful state of systems for people today. The lack of transparency and inept management related to quality improvement remains a scandal that continues to unfold.

## **Text**

Along with PASS, Wolfensberger wrote The Principle of Normalization in Human Services, (Toronto, NIMR, 1972).

This book, short titled Normalization, explained historic and contemporary qualities of supporting people to live valued social roles. It raised consciousness around deviancy, integration, coherency and other aspects of life that applied as much to people and services, as it did to communities and society at large.

Normalization introduced forms of community support, like citizen advocacy, and community living, that were new to the American experience. It uncovered a health care establishment that conspired to keep people trapped in overprotected service domains for centuries.

Normalization exposed how popular social theories like Eugenics in the 1920s had everything to do with making people powerless and behold to system control throughout that century. It shined light on a legacy of restrictive services and professional hubris.

Normalization looked at individual autonomy and rights, as well as safety, within the context of other interpretations and structures that affected a person's life, not as the be all and end all in care giving. Normalization took the veil away from the lack of relevant programming in treatment centers and institutions.

Normalization showed how professionally managed service approaches inevitably took over peoples' lives, bringing them to a confined state of patient hood. It warned how the best of institutionally based intentions were not enough to keep people from spiraling ever downward, until they were inevitably treated like lepers, untouchables and freaks.

Normalization also recognized that community services systems, like their institutional forbearers, could falter and fail. Wolfensberger understood that community based systems would need to embrace a community spirit and identity to prevail.

Normalization understood that systems might restrict access to community resources and compromise its tenets out of convenience. As a result, it valued external evaluations, like PASS, as a means to test whether principles were being applied in practice.

Normalization was brilliant in describing how deviant worlds were created often with the best of intentions. It charted the corrosive qualities of the medical model for treating people whose basic challenges never were health related.

It also made sure deviancy was understood for its sociological meaning, and not as a perverted sex practice or anything of this sort. Deviancy from Dr. Wolfensberger's text simply meant being valued in a negative way based on a difference like disability.

Normalization also showed how modern day institutions were perilous and demeaning for people and society. Change agents relied on Dr. Wolfensberger's descriptions of institutional life patterns in translating these deleterious effects to others.

Normalization brought hope and certainty that community support was practical and workable in life. It embraced a liberation agenda for people who had been marginalized, excluded and left behind. The book also raised questions and emphasized border areas, where answers are rarely cut and dry.

For example, Normalization introduced a concept called 'separation of functions'. The idea here was that valued adults in community life have separate private and public realms. Citizens in the community do not have a supervisor at their job contact their partner or parent to report on how well they behaved at work that day.

In violation of this tenet, group home workers and families routinely communicated with sheltered workshop personnel and case managers over the course of their duties. Discussions often occurred without the person being present or knowing about what was said.

While these contacts were made in the spirit of traditional methods of agency collaboration, Normalization recognized how this practice was inherently out of character with community ways. While most programs tended to ignore the 'separation of functions' principle, others moved away from this practice and were better for doing so.

The point is that Normalization facilitated awareness and discussion in matters like this, and led workers to approaches that were appropriate with people, even when they were counterintuitive from the perspective of traditional system methods. The book is still relevant and illuminating on this basis, and a must read for understanding the principles of support that have helped define this country's enduring community spirit.

### **Guides In Decision Making**

Program developers in leading states, as well as direct support workers in the 1970s, adopted Normalization principles and PASS as guides in decision-making. Even skeptics would come to understand how esoteric concepts like 'program neighborhood harmony' actually explained the conditions of everyday life quite well.

It was obvious to those who read the Normalization text or completed a week long PASS training workshop that these tenets and measures were consistent with American humanist tradition. Jews and Christians, blacks and whites, Latinos and Muslims appreciated Normalization's relevancy to their backgrounds, too. There was always something comforting in this near universal appeal.

Program developers spent years introducing Normalization principles and PASS to colleagues, families and other interested stakeholders so they would at least have a basic understanding about community development aims. Inspired by what they learned from orientations and trainings, stakeholders became effective service workers, administrators and supervisors, advocates and policy wonks.

In their togetherness, Normalization and PASS became the base of understanding and call to action, the country's how to, and why not. The pursuit of liberation and community inclusion that Normalization explained and PASS quantified became the basic tool kit change agents carried for the rest of their careers.

While nobody liked being labeled an ideologue, many of us clearly were in these early days. Call us naïve if you want to, but program developers in the mid-1970s believed that people with disability would be valued citizens in the course of their lifetimes.

These workers took ideology as a responsibility. They saw their mission as mustering resources that would achieve everyday lives with people. Some change agents were good at hiding their everyday day underpinnings and some wore them on a sleeve, but just about everyone had them.

Thanks to the collective efforts of Dr. Wolfensberger and others, Normalization continued to be strong and vital force in service systems and academia until it turned into general disfavor in the 1980s. After that, principles morphed into splintered and less robust themes of 'self-determination,' 'people first', and 'deinstitutionalization'.

While Syracuse University and other academic institutions still operate with a Normalization impulse and conduct PASS workshops too, their ideological emphasis has been more subdued over the years, often drowned out by broader health care debates and other noise around systems going this way or that.

It was different then, as ideologues in systems today tend to identify as being leaning to the conservative right or progressive left. We were community driven in the 1970s and not into the riffs about big government vs. private enterprise that monopolize the debate today.

Our agenda was freedom with Normalization and PASS in hand. There was plenty of room in this community way for all kinds of political persuasions, and there still is.

### **Missing Its Stride**

With PASS evaluations, stakeholders got to personally assess thousands of programs across the country and learned about new ways. These evaluators were often peers and colleagues who related to the work that agency administrators and direct support professionals were doing.

Unfortunately, there weren't enough program evaluations and progressive leaders to go around by the time these early years came to a close. Normalization measures and valued based

thinking lessened as administrative demands began to monopolize leadership's attention and budgets got restrictive.

In leading states like Pennsylvania, the PASS process got wishy-washy despite systematic loop back processes that were geared to continuous quality improvement. Communities of practices that formed for quality improvement purposes faded ever so quickly too.

While PASS criteria continued to help cutting edge agencies, a general disconnect with quality improvement was turning a page as far as many state leadership circles were concerned. The new mentality would point to establishment of system rules that ensured health and safety in PASS's place.

To keep payment status secure, agencies and other stakeholders wanted something more definitive than PASS evaluations. They called for a (forgive the pun) pass-fail approach that government relied on in the past with institutions, never giving a thought that different methods might work better now that services were in a community context.

In the face of budget tightening and increased legislative scrutiny, state leaders were ready to sacrifice ideological considerations so programs could continue to serve more and more people. State leaders were feeling compelled to ensure health and safety as hundreds of people streamed into community living arrangements each year.

Advocates for licensing and accreditation also pulled out their trusty rationale of Maslow's hierarchy of needs. They assured themselves and other stakeholders that a roof over a person's head and three meals a day had to take precedence over integration, autonomy and relationships.

In the new paradigm of standards that came to be, program developers were forced into adopting practices that ensured health and safety, not as part of an overall quality framework, but as the basis for funding. Where formats like FUNDET failed to connect programs to measures of everyday lives, the system's tried and true approach to establishment of minimum standards emerged.

Quality was a vacuum that needed to be filled in the most expeditious way, and it was. The shift to minimum standards in this era was also perfectly consistent with changes in the country's attitudes. After the 1980 Presidential election of Ronald Reagan over Jimmy Carter, the free-wheeling times of the 1960s and 1970s had run their course.

Conservative approaches were being welcomed where voices of liberation and youthful enthusiasm had been having their way. These qualities would stay in place for the remainder of the 1980s and spill over to system design features that continue today.



## City On A Hill

Cutting ties with Normalization and PASS in the early 1980s was inevitable. With rapid growth in community programs under service systems, decision-making based on principles like integration and developmental growth had to end. An everyday life could no longer be expected as systems moved into congregate care approaches where people would live and be kept safely.

As Normalization values and practices eroded in the late 1970s, facility based services and deviant activities came roaring back too. Formidable principles like ‘dignity of risk’ that guided early service design and practices were gutted by regulations and system monitoring.

Approaches that sought valued social roles with people were dropped in favor of accepting programs that did puzzles and sing-alongs at work program settings just as long as these settings had the proper square footage and working sprinklers in case of fire. The notion that vocational services would prepare people for competitive community employment was turning out to be a hoax despite what the regulations said.

After the early 1980s, Wolfensberger and other early leaders were no longer being welcomed in the halls of power. It was as though some type of McCarthyism took over. Suddenly, the Normalization pioneers and their ideas could only be whispered in private conversation. Training in valued social roles and PASS stopped altogether in all but a sprinkling of states as the era of standardization settled in to stay.

Like with the puritan’s ‘City on a Hill’ that Governor John Winthrop wrote about in colonial Massachusetts, the reality of community life in the late 1970s challenged the idealistic vision of its founders. As with the puritans, realities and beliefs were diverging in the new world of community services from the beginning.

Early program efforts to forge relationships and community support became redirected by forces of commerce, power plays, and other more pressing demands. Individualized and tailored solutions with people had to be forsaken under the crucible of uncompromising policy and procedures set in stone.

The sense of discovery that came with person centered planning ceased too. Workers stopped checking against their principles in applying service practices dictated by the new realities of program size and grouping. Leaders and supervisors at all levels stopped saying yes to innovative approaches out of fear of rocking the boat.

With this changing reality, program developers began to lose touch with their ideological roots. They got cut off from value based decision making over and over again. They lost their courage too.

Ultimately, the system caught up with the fact that it couldn’t practice what it was preaching in terms of achieving community outcomes. All that workers could do was ensure health and safety of people who signed up for assistance in forming an everyday life.

Stakeholder emphasis on finding community ways through relationships and jobs were replaced once group homes and workshops became the standard bearers of this emerging regulated service enterprise. Presence of people in community without any meaningful participation was becoming all anyone familiar with the system could expect.

Once the pressures of program growth, insurance liability and funding began to take their toll in the early 1980s, system leaders became ever more risk averse to approaches that diverted from the ‘take care of me’ model that services began to fall into. Normalization and PASS had no role in this evolution except as an occasional reminder that everyday life conditions weren’t improving for people, let alone holding their own.

To help lock out Normalization methods and considerations, detractors kept up a constant albeit subdued smear campaign, twisting principles and PASS inspired practices. Normalization was suddenly portrayed as a way to make people over into something they were not, or a recipe for people feeling rejected as failures.

During this time too, both Normalization and PASS took on a reputation of being elitist and pie-in-the-sky. Program concepts like the ‘continuum of services’ that Normalization subscribed to, had no place in systems that weren’t utilizing community resources or focusing on independent living. Movement out of the system got buried under a mountain of practices designed to ensure people’s security in programs where they were placed.

From a detractor’s point of view, there was no aspect in PASS or Normalization that deserved to be preserved as long as standards were met. Accountability measures belonged to administrators, and improvement was not to be expected as long programs met their bottom line.

People and families found themselves on the sidelines in this exchange. Grass roots organizations and parent groups became marginalized as ‘interest groups’ with separate agendas from those in the system loop.

Despite obvious downsides, system advocates didn’t have much trouble selling practitioners on the benefits of minimum standards. In their meetings, leadership never bothered to compare alternative accountability approaches, and constantly brandished tactics evoking fear that people would be abused.

Leadership assured stakeholders that regulations would make accountability simpler, fairer and user friendly. They suggested that that a higher power, like the Federal government or a regulatory authority, required services to be managed in this manner too.

Almost as soon minimum standards on service were implemented, community outcomes got lost in the translation. Satisfied with a floor of acceptability as their measure for quality, practitioners lost all sense of relevant programming beyond ensuring that written plans of care were filled out correctly.

In the end, the minimum standards that systems instituted could only ensure that people were kept safely and in compliance within settings that stakeholders operated. Support outside

the boundaries of group homes and adult day programs were vague at best, with generally nothing in regulations that addressed them.

Without a common goal to support everyday lives with people under the regulations, people languished. Factors like individual and family satisfaction would become moot.

Integration and developmental growth outcomes that were supposed to be a basis of accountability dropped off the face of the earth. Devoid of heart and purpose, regulations based on people's neediness ensured they would remain in services for decades to come.

With these program standards tied to funding, system wide training in value based practices and decision lost its cache and clout. Providers became consumed with internal audits and compliance instead person centered outcomes. Interpretive guidelines that used to explore concepts of support were reduced to a 'gotcha' mentality.

Valued roles didn't have a chance in this environment, and still don't. Deviant activities and associations that were shielded by PASS and Normalization awareness returned like rats to an empty house along the river.

As the 1980s minimum standards paradigm took hold, the spirit of liberation that began the community movement also collapsed. Approaches like supported employment and citizen advocacy failed to thrive and found no place in the service schema.

Decision makers who were apt to say yes to service and support innovations just five years before could mutter no in fear of jeopardizing program certification. Hopes of people and families to achieve everyday lives in individualized ways were shattered.

Though today's residential programs are smaller and more diverse than the 10 to 20 bed behemoths that systems started with, they must still operate under the same rules that were first established in the early 1980s. This legacy has forced community living arrangements to be more like institutions than not, and caused program developers to lose touch with safeguards inherent in community ways.

While getting back to PASS and the principles of Normalization is not likely to occur any time soon, stresses on traditional regulatory methods couldn't be more obvious. Time has shown that licensing and inspection regimens are arbitrary, wasteful, and punitive. Program developers see that they have no business in regulating support in family homes, businesses and the community at large.

In light of the immense time and energy that compliance with standards requires of workers, leaders are beginning to see how alternative quality management approaches, like incident reporting and independent monitoring, have merit. Reestablishment of community centered accountability remains a major test for future leaders to address.

## Epitaph

Wolfensberger and Glenn saw the need to focus PASS measures through the lens of systems. This focus was undoubtedly influenced by the authors' 1960's and 1970's experiences in developing community programs in Nebraska as well as the work of other pioneers.

System consciousness was also inherent from the inception of community services in President Kennedy's New Frontier. While this new age design was more community directed than those that service pioneers adopted then or since, there were aspects of Kennedy's frameworks that drifted toward administrative control.

Kennedy's community center model, for example, tended to operationalize itself in the form of specialized agencies headquartered under one roof, instead of a community place with core generic resources. Community centers began to take on the culture of non-profit offices, instead of hubs where people came for and received direct support.

The question for PASS in all this is: what happens to quality and decision making outside of systems? One has to wonder why the community on its own terms and in its own right wasn't broached more with PASS. Why were programs in systems assessed and not people's lives in community ways?

While a PASS rating 'Use of Generic Services' measured how programs used community resources, it didn't garner a lot of attention in my experience or points in the scoring system. The rating examined whether people had a bank to use for their personal savings, but never considered generic usage on a higher level.

It didn't consider how financial institutions might be used to assist people and families in managing their own lives and support networks. It didn't look at resources in the big picture as part of what the community taps, including local administrative agencies, employers, personal resources, and the like.

After using PASS for a decade, I began to realize how many of its ratings applied to the quality of my life and outcomes too. It mattered, for example, that I lived and worked where and with others I valued. I realized that model coherency factors counted as heavily in my world outside of systems, as it did for people on the inside.

The system focus of PASS influenced other early program developers too, and influenced us all to relate to service development through an organization lens. In the process, PASS and those that used it failed to lead in consideration of other ways.

Analyzing program structures designed to provide long term congregate care in contrived system settings is one thing. It's quite another to support everyday life first and assess quality that bases itself on resources that the general community depends on.

PASS in a context outside of systems matters too. Systems are not the 'be-and-end- all', even if they would like to be.

While PASS is certainly applicable to agencies and larger system entities, it's critical that change agents recognize how matters of integration, appropriate interpretations, and developmental growth affect people's lives in community ways too. This orientation has gotten lost in system translations.

Assuming systems as the foundation of quality, like PASS has done, comes with heavy price tag. PASS didn't get out of its system context in the end, and there it rests, essentially a relic. What a shame.

While PASS aspired to ideal conditions, it wasn't used to assess life conditions on their own terms. It's just so ironic that the restrictiveness PASS abhorred in service systems would be its hallmark too, and certainly hasten its premature demise.

For the role it played in keeping services tied to systems, PASS did not get people to that better place Normalization seemed to promise. It made itself too much the lone voice with no one really listening.

In the end, PASS had only itself to blame for not exploring other forms of support outside system ways to make itself and Normalization more relevant. It got caught in the system trap with the rest of us.

## **Chapter 8: Early Program Character**

### **Presence**

Leaders in the mid-1970s expected that people placed in community services would avail themselves of socially integrative opportunities from their residential base, like a family residence, a group home or other congregate care setting. Program developers figured that people needed a place to live in the community first, before they got jobs and made connections.

Unfortunately, arching from the presence in a community home into meaningful community participation was too much to expect without champions and a clear commitment to community ways. Without public resources intentionally engaged to support employment and other integrative outcomes, everyday experiences wouldn't develop as they were expected to.

Believing in community just wasn't going to make connections happen. Program developers would have to work at these outcomes and be smart about it. Looking back now, focusing on serving people in special places and at separate times was never a formula for success.

Rather than steer support to community resources that would promote community ties, public funding focused on agency operated group home and facilities. With this emphasis on specialized residential and work services, disability oriented socialization followed that lead.

The more networks became dependent on congregate programs, the more programs got fed with public funding and new placements. The longer the placements lasted, the more entrenched they became. Programs didn't fade out of people's lives like they were intended to.

Insulated from the get go, people were taught to improve their skills, but not to reach out with these skills into an everyday life. Services lingered, held on, and eventually thrived in making sure that people just stayed put.

Funds didn't follow expectations that people would move from one setting to another. Systems invested in programs, not people or community resources that could have sustained them.

Service missions become a matter of keeping programs full instead of achieving outcomes in the community. Despite lip service to a continuum leading to independent and everyday living, services were clearly on a path to keeping people where they were placed.

Even though smaller and more homelike than institutions, agency operated residential settings were not places people chose to live. While some agencies matched house mates by age and similar interests, this process generally broke down for a number of reasons, including home size, bizarre waiting list policies and a myriad of expediencies.

So called 'new placements' rarely visited another residential option, and had nothing to do with the selection of their housemates or home location. While some early community agencies sited programs to support family reunification or culturally appropriate relationships, there were no guarantees.

Fundamentally, community living got to mean a system funded place that looked like a home instead of car factory, prison or castle. There was no paradigm shift in this respect, as living with family or in another life sharing arrangement could have achieved.

Except for a handful of kosher, faith based and Amish homes that started in this era, deinstitutionalization had no particular appreciation for people's cultural roots. Intentional communities were not welcomed, and faith based groups, like the Lutherans and Catholic Services were often too heavily conflicted with their institutional traditions to transform in a meaningful way.

Regardless of a person's coming to group living from their family or an institution, community agencies decided on what people would be assigned to a given home. In this exchange, institutional personnel and families misrepresented people's abilities and accommodation needs, leaving agencies to sort out personality issues after people came to live in the homes instead of before.

There were no good home studies done in those days either, though they would have been helpful to sort out relationship patterns to some extent. The problem was that the large number of people in these homes made it close to impossible to match people in ways that would be mutually beneficial and constructive. The numbers of people in the homes simply prevented this from occurring most often.

In the end, most states could do no better than plan for people's residency based on their county of origin, which was where the person or responsible relatives last lived. While serving people in their home county sometimes helped with family and community reunification, it also ignored friendships that people formed in the institutions over the years. A person centered approach to placement that took friendship factors into account never materialized.

Coupled with the lack of individual or family input into where people were placed to live, the quality of matching was never very good. As a result, people came into community living in an existential manner with little expectation of assimilation and nothing familiar.

### **Placement Factors**

Some states served thousands of people in community services by the end of the 70's decade, and some served less than 100. Each state's program composition had a lot to do with class action suits they had going, the impact of family advocacy, and funding commitments from state legislatures.

Some states began to serve people from the community right away in the early 1970s and others didn't. Some states developed programs for only adults, or assessed families to pay for part of the cost of their loved one's services.

Placement criteria were all over the map and the idea of interagency compacts and collaboration never took hold so that people might move to another state without losing their funding. Decisions ultimately depended on where funded program openings were available and a host of individual state and sometimes local variables.

In terms of similarities, group homes all over the country were quartered in neighborhoods that housed citizens perceived as disadvantaged, including adults on parole and probation, people with mental illness, and folks in homeless shelters. So-called 'group home ghettos' and 'half-way havens' were easy to spot.

Concentrating people in neighborhoods like this was supported by local ordinances that established 'institutional districts' zoned for boarding houses and nursing facilities. One state actually restricted community living to federally funded HUD (Housing and Urban Development) low-income housing.

While restricting people to institutional districts would eventually be deemed unconstitutional by the mid-1980s, early damage was already being done in the decade before. This corner of the world concept for housing people affected interpretations and placement decisions into the modern day.

Consistent with this marginalizing practice, municipal authorities, churches and civic groups were not approached to assist in community integration. The League of Women Voters wasn't contacted to teach people about their rights and voting responsibility.

Local government authorities figured that since people were living in state funded services, state agencies should take responsibility. None of the key decision makers on the community or system side thought to approach area employers to hire people who had considerable work experience in the institutions from which they came.

People from the institutions moved into a vacant bed, seat at the dining room table, and space on the agency van that would take them to their workshop or day activities. Most often, their house or apartment was controlled by the same agency that employed the person's service workers, drivers, therapists, and case manager.

Almost everything agencies arranged for people was in groups, even doctor and dentist appointments when possible. Instead of choosing aspects of life to discover and develop on their own terms, people were told where they'd be from day to day and hour to hour for years on end. Self-determination in the social spheres was especially rare.

Case managers, who were supposed to coordinate and locate community resources, didn't do these things either. Agencies were never instructed to direct people toward leaving group homes they were placed in, no matter how independent people's skills and personalities became.



Except in Maryland, Texas and a few other states that took utilization review seriously, States had no effective process for moving people into everyday living. Without this, people continued in the most restrictive settings out of respect for family choice and the system's convenience.

As more and more public funding became available for specialized services in group settings, community agencies began to help themselves in annexing new income streams through nursing, psychology and therapy departments. Large rehabilitation agencies and hospitals that already had a slew of these specialized services expanded into the group home line of business.

As community agencies became more comprehensive in scope, their capacity to respond to individual differences with new approaches seemed to decrease. While people with more complex needs could live in group community homes as result of these services, specialized services weren't contributing to people and their community life.

Placement and other decisions became a matter of what movers and shakers a family could muster on their loved one's behalf. People got swallowed up in this process. They became pawns in the game of service authorizations and still are.

People deferred to experts and went along with whatever systems, health care professionals, and their families could influence. There wasn't a stitch of self-determination to be found from the beginning of the process to the end.

I remember visiting a program in one state where the head of a multifaceted services agency that offered residential housing was the wife of a county administrative director. Other relatives ran the regional hospital, a workshop and case management agencies.

People receiving services in this area exemplified how people fit into what the players of that system arranged, and nothing else mattered. People were on a conveyor belt and in the clutches of forces that possessed minds of their own.

This was true in most other states too. When the system took over it had its own way of placement. That system way stuck, and there were plenty of handbooks and policies to attest to just how odd and overpowering their shortsighted program approaches would become.

### **Following The Money**

Instead of paying rent to a landlord, residents had benefits like Social Security Income (SSI) assessed for agency room and board costs, leaving varying amounts for personal purposes. Personal needs allowances ranged from 25 to 400 dollars a month, depending on the state.

Residential agencies pocketed room and board payments, together with service fees and other income like food stamps to cover their cost of services. These agencies were also routinely assigned responsibilities as 'representative payees' too, so residents often never saw or touched their monthly checks.

While residents in group homes generally had at least \$25 from their benefit checks to spend, a lack of integrative opportunities left people with surplus savings that could threaten their eligibility for service. Asset limits also varied considerably from state to state before consolidating under Medicaid decades later.

People living with their families had their relatives in control of their Social Security and other personal income. Family based residents might never see their \$700 - \$1400 checks either. They were also more likely to have no pocket money after clothing, food and shelter costs were accounted for.

To ensure continuous flow of Social Security income from people in residential service, agencies established 'spend down' protocols so residents didn't jeopardize their receipt of benefits from Medicaid, Food Stamps and other payment sources. To keep people from losing their program funding, providers were routinely put in positions to have people purchase a new model TV or stereo every year, or attend a slew of concerts and movies at the end of month.

The ironic thing in all this was that two or three people with full SSI benefits could often afford living independently in an apartment, even without a job or other source of income. There was a saying then that "no credit was good credit" in creating so called: 'self-determination housing'. Like other great ideas, this one never got past the pilot stage either.

Out of convenience, many service systems automatically went the course of agency purchased homes, buttressed by the rich flow of public financing available for this purpose. While costs were reduced markedly in programs that separated the support that workers offered from their employer's real estate holdings, systems were set on a course of agency ownership, much like they had been in the institutional days.

Attesting to what generally became a constant state of confusion around money management responsibilities, agencies rarely assisted people in obtaining bank accounts, preferring 'cash in the envelope' methods of accounting. Program policies also prevented people from pooling their personal funds to furnish their bedroom furnishings, or chip in on the cost of gas or staff attending events with them.

Workers didn't spend enough time on using normal financial incentives and levers either. A person's desire for certain material goods somehow didn't get factored into motivating people to secure jobs or save for down payment on an apartment. Even basic functions of saving for a rainy day or vacation could not be entertained due to a slew of restrictions on assets.

Once group home regulations became established, agencies in state after state were assigned fiduciary responsibilities that required monitoring of personal expenses. With these new rules, it became practically impossible for people to exercise autonomy when withdrawals had to be entered in a program log, approved by workers, and accompanied by a receipt.

To avoid inconveniences that came with their financial oversight roles, institutional settings issued tokens so residents could purchase candy and snacks at the agency store in exchange for personal funds taken from a person's account. Script and tokens were used in

community settings too, and community home workers routinely took orders for purchasing items for people in the community, denying them opportunities to do this themselves.

Despite lofty mission statements that promised independent living outcomes with people, group home programs didn't factor family gifting or income from a job in their plans with people. Investment strategies were hardly ever pursued apart from blind trusts for people from wealthy families.

While some savvy workers knew how to protect gift checks from being counted as personal income, this had to be done on the sly. While these side deals with workers and families benefited people, systems became more adept in creating safeguards and firewalls so that every last drop of funds went their way.

That's still the way we operate in services today. Just follow the money.

### **Backlash**

With public funding commitments to start up group homes and apartments, agencies had lines of credit to purchase or lease home settings in most neighborhoods in and around towns, suburbs and cities. In their efforts to access residences in middle class white communities, backlash became a real and present danger.

Backlash had many negative consequences, not the least of which was that it increased people's dependency on systems. It also contributed to focusing program efforts away from everyday lives, in favor of minimizing exposure to risk and keeping the lid on things.

Group home placements of people from institutions raised public concern almost from the beginning. Often confusing people with intellectual disability as having mental illness, home owners were not about to embrace residences serving eight to sixteen unrelated adults with 'mental issues' moving in across the street.

Public unease about community home placements could be witnessed at any number of the zoning hearings held during these years in just about all states involved in establishing community homes. Being the brunt of anger and frustration at these gatherings was a public relations nightmare, pure and simple.

Without the benefit of established family ties and a community education effort, people with disability were particularly vulnerable to backlash effects, as were workers. As agencies got used to managing to these vulnerabilities, they fell short in preparing communities and families for taking on new roles in support.

Programs also didn't turn neighborhood fear and misunderstanding into teachable moments, and bad blood exists in the placement of programs as a result of this neglect. While communities didn't always open their hearts to people, systems didn't take community interests and traditions into account either.

Pressured to locate group residences, agencies didn't think twice about their methods of introducing people into community life. They didn't want to admit that the size and composition of group homes were not at all similar to home life in the neighborhoods they were finding.

A group home of 8 unrelated men or women coming out of institutions was sure to be a concern in certain white middle class areas. Neighbors were outraged with the prospect of staff coming in and out of a group home at all hours of the day and night, and they feared for their children's well-being.

Neighbors also objected to group home placement in residentially zoned areas as a threat to property values. City dwellers and their building associations tried to keep apartments from anyone assigned to a human service agency.

At zoning board hearings, otherwise mannerly citizens screamed and hollered about how people were prone to behave like freaks and throwaways. The images they portrayed of inmates in institutions cast a difficult shadow to be free of.

Neighbors were also concerned that staff members would be inadequately credentialed and that agency property would not be maintained in accordance with community standards. Snap shots showing poor agency upkeep at homes swayed hearing officers from time to time. It didn't take much.

Community living opponents also trumped up problems like increased traffic and noise, and expressed absurd demands like having all adult men from institutions screened for their propensity to abuse children. The panic buttons kept being pushed once they got started.

While agency representatives did their respectful best to represent program settings as supervised homes for people who were not going to make trouble, it didn't seem that way to angry home and apartment dwellers. From their view, community residences were like little downscaled nursing home businesses that had no place in a residential area or building on the better side of town.

Neighbors didn't want to be gawking at, let alone relating to people as equals, and they had no sense of assimilation being their role too. To avoid problems, group homes constructed privacy fences to mitigate neighbor wrath that seemed to come with the territory. It got to a point where you could pick out the group homes by their high fences.

Once group homes became operational, neighbors looked askance at agency workers and often misinterpreted them as nurses, aides, and personal care workers that 'looked after' the people. Neighborliness was hard to find and there was a lot of fear playing out.

Children in the neighborhood were instructed to stay away from "those people" and report on their whereabouts to police. Some children stopped going out to play on their own out of fear that their parents had. Families moved from neighborhoods on the basis of a group home coming in.

Teenagers would be encouraged to call people names, and plan pranks especially around Halloween. Neighbors looked the other way with property damage that they may have been a part of instigating. Rumors of molestation and crime involving people ran rampant without a smidge of validity.

With all this noise and the baseless allegation, naysayers and opponents expressed a certainty that letting in one group home would lead to others. With all these rationales, zoning boards excluded people from certain areas with some success, even though public law advocates were able to address these challenges in certain states.

Neighbors were also upset about workers commuting from other parts of town. Sometimes it seemed like the race or cultural background of workers had more to do with neighborhood backlash than people with disability. Certainly the combination of shift staff and atypical groupings of people were too much for the neighbors to absorb.

Despite the merits of their cause to support people in community life, programs did not create an atmosphere of acceptance and good will during these backlash years. By taking the unequivocal stand that people had a right to live wherever they wanted to, agencies managed to piss off a lot of otherwise good natured folk.

Violence inevitably erupted. Group home burnings were not unheard of and threats to residents and staff became common in certain locales. Neighbors that resisted community homes left their mark with front lawn cross burnings, leaflets of the foulest order, broken windows, slashed tires, and slandering of program personnel. Hate groups like the KKK got involved from time to time, too.

Local editorials and news outlets took varying views of group home placement, and sometimes flamed unhealthy sentiments about property values or dangers to children. The media's lack of understanding and openness to what programs wanted to achieve came out, over and over again.

News outlets rarely interviewed a person with disability or relayed a personal story to diffuse volatility. Families who came forward generally did a good job of exposing a human side to their loved one's journey; such testimony never seemed to be enough.

Despite the best efforts of workers and agency representatives, media stories conjured up images of helplessness and vile institutional histories that made people seem more like zombies than everyday citizens. Local reporters avoided the opportunity to meet with people time and again.

While there was some excellent coverage of community services in the Philadelphia Inquirer and other national papers, local press and television affiliates generally went with the flow in interpreting people as objects of pity who needed constant supervision and care. Local as well as national television spots inevitably confused people as having mental illness and being prior inmates of asylums.

When news outlets were corrected, retractions were rarely followed by an in depth review. Through it all, the public was shortchanged from getting the 'people first' message from the fourth estate for years.

While the media had been willing to expose institutional abuses of the era, they were generally inept in handling coverage of people returning to community life. Their tendency to take the word of agency representatives prevented messages of freedom and community support from getting any play.

In response to the backlash they experienced, provider agencies felt compelled to sneak people into homes at odd hours, and locate programs on the outskirts of population areas. It was common practice to leave neighbors in the dark about what was going on. Providers also learned to avoid certain realtors and city inspectors too, and they stayed away from the press as much as possible.

While progressive agencies held open houses or “mixers” so neighbors could get to know each other in a culturally normative way, most programs didn’t care that much to engage the community out of fear. They underestimated just how important good community relations might be to their success.

It only took an ugly zoning battle or two for agencies to limit home searches to prescribed areas where backlash hassles would be minimized. While agency lawyers did win many zoning appeals to secure group homes in these years, financial and other stressors took their toll.

Despite the seriousness of backlash on the image of community services, there were rarely any system directed public education efforts to promote valued interpretations of people and the community movement. A notable exception to this was an innovative billboard campaign along major roads in the DELMARVA (Delaware-Maryland-Virginia) peninsula that expressed valued interpretations of people as citizens and good neighbors.

Politicians weren’t that helpful in dealing with backlash either. Local representatives wouldn’t weigh-in on disability issues unless forced to by some really bad situation. Constituent concerns were referred to government agencies for boilerplate responses. Hearings obviously weren’t held in a way to accentuate the valued roles people would fulfill in community life.

While some elected representatives championed individual agencies or family based associations, most politicians didn’t relate to people with disability as a voting block until the late-1990s. Politicians appreciated that community services were a step up from institutions for people, just not a foothold to valued community roles like they needed to.

In the backlash era of the 1970s, agencies and family advocacy groups were shy about extolling the abilities of people too. Those in favor of community living didn’t fashion a coherent message that promoted liberation, opportunity, and realizing the American dream.

Local news articles rarely expressed social responsibility of the general public or its resources. In the years that these zoning battles occurred, I rarely heard a speaker turn the

discussion around from standard xenophobic defense tactics to reflections on people's gifts, hospitality and positive community roles.

Fortunately, law enforcement was generally evenhanded and responsive, especially when violence occurred. District attorneys didn't discriminate in handling complaints or issuing warrants. The police didn't look the other way when threats were perpetrated on workers, people or agency property. Prosecutors and judges handled individual crimes and incidents appropriately for the most part too.

### **Opportunities Missed**

Sometimes the best advocates, providers and administrative leadership could muster during backlash times was to proclaim their support for community services and make the case for people's right to live where they wanted to. This black and white, "you're with us or against us" approach to community programs had no semblance of the tact agencies needed to win over communities at this crucial early juncture.

Now that the smoke of the backlash period has settled, it's apparent that the hide-and-go-seek practices systems used in the location of community group homes soured good will. It also left room for discrimination to flare time and again, as people and resident workers continued to experience neighborhood misgivings based on race, class and other stereotypical fears.

The fact of the matter was that people with disability were seen as *persona non-gratis* in these times, probably more than they are now since communities have had time to adjust to the group home phenomenon, and appreciate diversity more too. This negative perception continued as long as providers and other service workers underestimated the value of returning to the community fold.

While citizens appreciated Robert Frost's statement about how good fences make good neighbors, this backlash thing was something different. Citizens select their neighborhoods based on the quality of schools, safety, convenience, employment, roads, taxes and other everyday living factors. They expect to interact and develop friendships in the area where they live.

It's hard to believe that agencies have had these same decision points in mind when locating residences for people coming from institutions to live. Appreciating the differences at least would have been a step in the right direction.

Fences didn't contribute to making good neighbors for people and workers in group homes. Nothing did.

While it was unfortunate that racist and other negative qualities surfaced during the backlash years with the fervor they did, this mess could have been dealt with better. If it was seen as an opportunity to engage community support, that would have helped too.

Unfortunately, it wasn't. Advocates for community services weren't making a case for citizens taking social responsibility and demonstrating their sincere hospitality. They were back on their heels.

Without a strategy with communities, the NIMBY (Not in My Back Yard) principle underscored itself time and time again. As far as scared and intolerant citizens were concerned, group homes didn't belong on their streets and in their neighborhoods any more than flop houses did. That's still a predominant sentiment.

In hindsight, program developers should have anticipated how neighbors would be fearful that their property values would go down with a group home next door. They should have seen that community resistance required different approaches that looked to mending fences, not building them.

System leaders should have paused in their focus on group living. They should have asked themselves: What were white middle class neighbors supposed to think about "that crew of 8 to 10 'crazies' from the 'loony bin'" moving into Mary and Bob's old place on the corner?

Communities have a material side to them after all, and fears about property values and concerns for child safety shouldn't have been a big surprise. It's best to consider these matters when moving anywhere. It's also unfair to use people as a social cause that's set up to fail.

The point is that adhering to cultural norms really matters for people when they are going to live in and benefit from a being in a community context. People and neighborhoods are matched in real ways that promote permanency and belonging, after all.

If people with disability are to be treated like others in where and how they live, their sponsors can be expected to use resource finding practices that the community values too. Entering neighborhood realms means playing by those rules too.

Maybe it's time to realize that group homes don't belong in communities for all the good they do for people and the communities that host them. Maybe it would be well advised to heed the lessons from the backlash years and consider neighbors as community hosts instead of the enemy.

To avoid backlash, people with disability, like other citizens, have to be included in selecting their living arrangements and their neighborhoods too. They must have access to caregivers who are already good neighbors with secure community ties. They need to be matched by their cultural background, and not used as a social wedge.

Fortunately, most legal actions against group homes ended once the United States Supreme Court ruled that people in these settings could live in any residential neighborhood, no matter what a local ordinance permitted. The 1985 decision in *Cleburne v. Cleburne* ruled in favor of the Cleburne Living Center to establish a relatively large group home in a residential zoned Texas suburb.



The court decision ended zoning battles in most locales almost immediately and prevented new ones from ever taking shape. *Cleburne* also restrained forces inclined toward violence and left the matter of homes for people off the front page.

Unfortunately, most agencies didn't change their ways after *Cleburne*, except to make residential settings smaller over the coming decades. The Supreme Court's decision was not taken as an opportunity to develop positive community relations.

The *Cleburne* decision reinforced that living in the community was a right of people, and that rights platform was enough for system purposes yet again. Social responsibility and relationship aspects of home finding were ignored as much after *Cleburne* as before.

While neighbors learned to tolerate group homes over time, tendencies to locate residential settings in marginal or remote areas of cities and towns continued. White middle class neighborhoods found other tactics to prevent people from entering their cul-de-sacs and gated communities.

Group home placement in affluent areas continued to be a very rare occurrence indeed. Condos and neighbor association still use their bylaws to dissuade agencies from building, renting or buying on their hallowed ground.

There were a ton of teachable moments during these years and since then too that just went unfulfilled in developing positive neighborly relations. The lack of positive community engagement at an early juncture, along with a growing service arrogance that accompanied it, would continue to haunt the community movement for decades too.

Service providers never got past staying away from the media and distrusting neighbors after the backlash period. They never set themselves in a position to feel welcomed or have their message of inclusion heard by an open minded audience.

## **Growth**

The bulk of the funds and attention of the system during the 1970s went to support group and facility based residential services in the community. Eight in every ten dollars of public support went to residential programs, with the rest going to adult day programs primarily.

The investment in community services required providers to secure homes for people who could not live with their families any longer, or who would be leaving publicly funded institutions. After funding for this was used, there was little left over for supporting community ties, shared-living, and jobs.

Between 1970 and 1980, 40,000 people moved into group living arrangements. Combined state expenditures climbed from nothing to the tens of millions.

This period focused on getting residential staff and equipping home settings. It meant making sure that people had something to do outside of the home too, even if it wasn't that valued.

Expansion of non-work adult day programs became increasingly popular in this era since their programs entailed little more than activities and games. People brought their lunch or it was provided, and taking a nap after meal time was not that unusual.

Over the decade of the 70s, the reality of rapid growth in congregate care programs cast a pervasive presence of deviancy onto the community service enterprise. The great promise of community living was being taken over by a sense of powerlessness to improve upon the low expectations the system had for itself, apart from serving more and more people and keeping them safe.

The process of program development was also becoming cookie-cutter and routine. Michigan and New York encouraged agencies to use standard architectural plans that made group homes in different parts of the state appear to be exactly the same. It was easy to point the group homes out on drives through new neighborhoods.

While those involved in program development prided themselves on making living arrangements as homelike as possible, it became clear that group homes weren't that normalizing an experience, particularly as shift staff came and went, and administrative duties began to compete for the organization's attention.

Adults sharing small bedrooms and group outings were not setting the right conditions for integration and individualization to occur. Preparing and cleaning up after dinner for 12 to 15 people and workers wasn't anything close to an everyday life people might experience on their own or with a friend.

A twisted status quo of congregate living and work thus established itself in this decade. Keeping congregate settings in operation became the main focus of the service system's work.

While some states would eventually get around to developing more individualized options like lifesharing in the early to mid-1980s, commitments to group home placements needed to be satisfied first. The 1970s was this time – the time of group homes as the foundation of the community movement.

With group homes taking the giant share of funding and attention, development of respite care and other forms of family relief faltered. The paltry sums associated with family support packages, made it nearly impossible for family members to use these resources to secure valued roles with people.

The thousand dollars or so that families received over the course of a year in lieu of outside placement barely helped in making ends meet for some families, and only covered the cost of an occasional respite worker at best. While family support investments were bargain

compared to the \$60,000 to \$80,000 price tags for community home services at the time, comparisons against anything institutional care were not being made then either.

When additional state or local funds were made available, these resources went to increasing group home and apartment program capacity, raising worker salaries and covering an emerging debt that administrative intermediaries couldn't cover. Liability insurance and other residential administrative costs were escalating in these years too.

Group homes were becoming examples of the rich getting richer. Other community services related to these residences as their primary point of attention despite the fact that most people lived with their families.

Despite what program developers would have preferred, people receiving services were regularly life-wasting in settings where they were forced into segregated, age-inappropriate day program activities. People weren't headed to making it on their own or toward forming relationships outside of program circles. People were going nowhere outside the system box.

Services in group settings were stuck on first base in other ways too. Community outings of 6 to 8 people to the malls and grocery, while better than institutional approaches that involved much larger groups, weren't creating socially integrative opportunities. People didn't meet peers outside of system contexts, or develop ties with clubs, groups and associations. Workers couldn't take on roles as social ambassadors or match makers, being so predisposed to keeping groups together and out of harm's way.

Attending community activities became an exercise of bumping shoulders with the public in malls and parks, and on the streets; but not getting much further than that. Group excursions felt like a weird dance, with one-foot firmly in the old ways, and toe tapping in the new.

People weren't moving along a continuum to step out of the system and live on their own and in everyday ways. They weren't getting to experience advanced program practices because of limitations built into the programs they were forced to endure.

Outwardly hopeful in spite of what they were experiencing, program developers and other workers still wanted to believe that communities would be engaging people on a regular basis after the dust of new development settled. They expected that people would attain liberty and independence in the space and time the community offered them.

Alexis de Tocqueville, the famous 1830's social critic from France, called this process of expecting more out of life when there is freedom and opportunity "leveling". De Tocqueville viewed America as a land of unmatched promise in this respect.

Unfortunately, the leveling affect didn't materialize for people moving to group homes and other community programs. Systems and the programs they sanctioned actually kept leveling from happening by taking opportunity away from people.

People with disability in the 1970s never were free, like the citizens De Tocqueville visited. It's truly unfortunate that community living has become a realm to be cared for outside of institutions, not a land of milk and honey that has been the American way.

Until program developers come to grips with conditions of servitude in systems from these early years in the 1970s to the present, there's not much that can change. In the meantime, there are additional questions the country needs to be asking itself.

*Were the slew of failures to promote integration in the early years because of the people's disability, or was it something about the services, or community, or all that, in different ways for different individuals?*

*Is there something inherently debilitating in the size and composition of programs that community services systems create?*

*Why weren't services able to stick with their plans to secure valued social roles with people?*

### **Hiding In Reality**

In spite of serious system failures that were becoming evident during the 1970s, those in control kept reassuring workers, advocates, families and themselves that it would all turn out okay, even if not the way we planned.

It would take time, they said, for people to get accustomed to their new lives. Diverting attention from their own issues, systems claimed that the community would eventually come around.

System leaders remained outwardly confident that the presence of people in community would lead to individualized participation, jobs and strong community ties. Optimism prevailed, even as group homes replicated institutional practices and adults spent their days in social, recreational and work activities typical of what children enjoyed.

As residential arrangements of 10 or even 20 people were proving to be too big for assimilation purposes, agencies began to explore smaller apartment programs supervised by drop-in staff, and leasing smaller homes, condos, etc. In this process, leaders reassured the system that smaller homes would make conditions better for people, with more community inclusion.

Like so many other changes, smaller being better looked good on the drawing board. Unfortunately, living in these settings wasn't making life better while people remained in the system's grasp in all realms of life.

With some exceptions, system practices that kept people from engaging in community functions never changed in the downsizing process. Programs found it too hard to step back so community could grow in people's experience.

While smaller programs were more individualized the bigger ones, they also tended to be more isolating too, due to the lack of emphasis on inclusion within the system's ranks and to learned institutional behaviors that caused people to withdraw.

Apartment programs that housed two or three adults had the feel of a normalizing environment on one level, but there were issues of congregation and assimilation potential here too. Apartments with people were often clustered in one or two buildings within a larger residential complex.

It was not unusual for two or three apartments to be situated on the same floor, or for an apartment complex to house 30 people served by one or even multiple residential agencies. Having a couple of workers assigned to supervise two or three apartments over the dinner hour was also a sight to behold, with all the running around and near chaos.

People in community-based residences, both small and large, weren't making new friends or rekindling prior relationships. They were going to their separate places, or remaining isolated in their family homes. They weren't getting car rides to places with friends or learning to drive. They weren't relying on family and neighbors or making friends with their corner shop keepers.

People weren't striking out to pursue individual interests either, despite their abilities to live in community ways with a modicum of assistance. They weren't finding jobs and hardly looking for them either. They weren't supported to take advantage of opportunities to live everyday lives.

In many ways, program developers were all flat wrong about their inclusive suppositions in these early years. We were also stubborn and unwilling to discover other approaches in hopes that assimilation would eventually find a way with people.

In the end, we make-believed that neighborly relations would magically develop across side yard fences and adults with disability would be welcomed to parties, church cookouts and the like. We expected families would be reunited too without so much as policy paper, conference, grant, pilot project or research study on how that might best be facilitated.

While agencies like State Developmental Disability (DD) Councils spent large sums of public resources exploring community integration through local churches and similar resources, the disconnect between these efforts and system practices was never bridged. Even though congregation and other forms of community support were realistic and workable, state and local programs had no intention of applying inclusive practices no matter how many manuals and best practice reports DD Councils submitted for their consideration.

System leaders conjectured in those days that presence in the community would set the stage for enduring relationships even though their experience dictated otherwise. Unfortunately, life in the programs didn't have the cache or carry-over effect program developers thought it would. Community services were just too much like institutional life already, and all so shut-in.

Meanwhile, community services were becoming breeding grounds for inappropriate routines that program managers just couldn't fix. Recurring incidents of deviant behavior in activity programs and vocational facilities forecast patterns that were not pleasant to contemplate.

Negligent staff in group homes also became fixtures in the service landscape. Resident managers would make fun of people and taunt them for amusement, steal their personal funds and possessions, and even pilfer medications and the group home's food.

System stakeholders hid from these realities then, and still do to some extent. While programs have become more accountable in the ways they document and investigate abuse and neglect through incident reporting mechanisms and other means, they continue to ignore how their specialized program structures breed these troublesome patterns over time.

It would take more than weeding out a few bad apples to address this ugly side of services that refuses to go away. It would take systems relating to the reality of their existence, which they have never been inclined to do.

### **Getting Nowhere Fast**

By the early to mid-1980s, it was as clear as mud: systems were not using community resources to secure people jobs, a home of their own or personal connections. The more the system grew in terms of its paid worker networks and segregated settings, the less room the community had to contribute.

With the public's attention on the "good works" community services were doing in providing alternatives to institutional care, too many program developers started to believe their own good press. Instead of aspiring to community outcomes in their work, program developers found solace in qualities that compared their efforts favorably to institutional life.

Professional research of the times, including the famed Pennhurst State School Longitudinal Studies by Temple University in the late 1970s, reinforced such comparisons. Yes, community living was better than living in the shit-holes of public institutions, but was that enough? Was this even the right measure?

Where was the research on effective paths to achieve valued social roles? How could we ever know how to succeed in community ways while measuring quality against institutional norms? Why didn't we compare life of people in programs to Joe and Josephine Smoe's?

Services got to the point in the early 1980s where as long as money kept flowing, it was all good to go. Social Security, state-only funds that legislatures appropriated, Medicaid, vocational rehabilitation, Food Stamps, and a slew of grants became a bountiful smorgasbord to enjoy and feel entitled to.

The funds that came from these public coffers went directly to services in group homes and facilities, specialized transportation and activities, and administrative entities too. There

wasn't thought to doing things differently or channeling resources in other ways. There wasn't a sense that community resources of other types might be available to offset the public's contribution.

There wasn't room for being organic, innovative or grass roots. There wasn't a call for funds to follow people. As long as organizations held the purse strings, there were no questions asked.

Services were becoming big business by the end of the 1970s, and people 'in need' were the fuel that made these enterprises hum. Agencies that began with a couple of group homes expanded rapidly, serving hundreds of people in a matter of few years, with sizable workforces in homes and facilities all over the place.

Family groups and advocates appreciated the convenience of one-stop shopping systems offered in this respect, and felt good that community services were growing to address the waiting lists. Parents joined in the chorus for ever increasing budgets to support program expansion.

While families didn't clamor for lifesharing with relatives and friends like they did for the standard agency operated brands, nobody else did either. Group living, the reality, somehow became the horizon most stakeholders envisioned, too.

Reflecting the program's growth as much as anything, system leaders began to soften to calls for regulatory frameworks to ensure minimum standards. Pleas from stakeholders to protect their interests in the emerging system caught leadership's ear.

Those with a mentality towards taking out bad apples, also talked system leadership into taking on monitoring responsibilities akin to what government agencies had been doing for years in the institutions. Rather than taking an alternative approach that assigned monitoring as a community role, it was assumed that systems would have to take on these tasks too.

As they are prone to do in their management capacities, systems established monitoring at numerous levels, with layers of caseworkers, program auditors, and licensing inspectors doing their checking duty. While all these monitoring agents dutifully reaffirmed the presence of records and smoke detectors that beeped, they rarely uprooted anything significant in their focus on minutia.

System monitors didn't uncover abuse or agencies being non-compliant with program planning objectives. As long as individual care plans had the right date and signature, monitors could care less with being accountable to community outcomes.

Monitoring recommendations for quality improvement, while few and far between, were ignored or referred to a process that prioritized everything to the point where nothing of substance got done in a timely way. In the end, piling on monitoring did little more than focus attention on what professionals wanted to identify to cover their flank.

Making sure medical appointments were attended and drugs given correctly were two of the biggest issues for monitors to review. Nursing practices and medical forms of documentation were adopted to ensure that people were given the proper dosages. Self-medication training was done sometimes, but often ignored out of the concern that programs would be penalized for people's mistakes in the form of a provisional license or citation.

Individual satisfaction with supports and valued social roles were rarely if ever factored into the monitoring equation. Even when findings of non-compliance were counterproductive to achieving everyday lives with people, providers didn't challenge assessment findings out of fear of yet more paper work and bad blood between them and a monitoring colleague.

Despite ample evidence that community outcomes were not taken seriously in system's quality assurance processes, stakeholders stayed with the program models. On the treadmill of growth and monitoring against minimal expectations, a lot of integrity was lost.

With year after year of new funding at their disposal, decision makers easily deflected urges to step back, reflect or try another way. Funding appropriations from the legislature had to be spent, first of all.

Families in the community were clamoring for more services as well. All the pressure was to grow, grow, grow.

While systems wanted to appear responsive to changing times, new models like supported employment and lifesharing were met with skepticism. Openness to passing on system responsibilities to families and communities was nowhere to be seen. It was congregate services or the highway as far as systems were concerned.

The most that change agents at the time could expect was a new study, committee assignment, and occasional pilots to test promising practice. The likelihood of any of these tasks leading to new ways of support was slim and marginal at best.

As people, families and the community got used to congregate care alternatives, turning away from these traditional approaches became difficult and soon pretty much out of the question. What started as a liberation movement began looking more like a benign lock-down.

By the end of 1970's, system leaders were clearly on a path that ignored their founding Normalization principles in favor serving more and more people in standard congregate care ways. On a rip to make systems bigger and more comprehensive in scope, stakeholders settled for segregated homes, activity centers and sheltered workshops as their go to enterprises. Leadership let convenience and their comfort with the familiar take the lead from there.

While leaders clamored about how conditions of life in community settings were better than life in the institutions, programs struggled with everything else. While workers and provider agencies recognized the importance of coherency so that the right people could work together in the right ways to achieve outcomes, there were many diversions.



By the time the 1980s came around, doing things right was much more challenging than what program developers wanted to recognize. Although some programs assisted people move on to everyday lives, most agencies stayed with prescribed approaches just to keep up with service demand.

Fledgling state service systems were already becoming locked onto a path of congregate settings and sheltered work arrangements by the time the 1970s ended. The system's penchant to stifle new forms was becoming more evident by the day.

### **Sealing The Deal**

In the early 1980s, a series of U.S. Department of Labor interpretations of wage and hour laws it administered sealed the deal against systems moving on to community support ways. DOL rulings required that live-in group home staff receive overtime pay and benefits for periods of time they were asleep or on call.

These changes in the worker payment structure made it abundantly clear that systems would not be able to afford live-in workers that were previously paid on a salary basis or without this overtime component. Systems couldn't absorb the cost of paying house managers extra to sleep or be in an on call status and continue on their growth trajectory.

With 75 to 90% of program budgets devoted to direct support worker compensation, agencies couldn't absorb an additional wage and hour supplement without affecting other cost centers too. To salvage what they could out of the DOL decision, programs began to assign workers to group living arrangement by shifts. It was all downhill from there.

Once new wage and hour rules were imposed, long-term house parents and residence managers were released from their employment. Many seasoned workers who had been receiving decent salaries refused to accept the change and left the field in droves. Relationships that had been sustained for years ended in a matter of a pay period.

Group homes became even more like little institutions after that, with shift staff scheduled for weekdays and weekends, evenings, and the like. While leaders might have challenged Department of Labor interpretations or found other ways to ensure relationship continuity, the sentiment to adjust to whatever came along prevailed.

Since systems were not able to cough up the additional funds needed to address new staffing requirements, programs had no choice but reframe their personnel patterns that directly affected relationships and time with people. The models they ended up adopting generally assigned a shift to assist people during the day beginning when they returned from work, and a night turn that required workers to stay overnight and help with morning activities.

Part time overnight staff who were permitted to sleep on their shift put sheets and a pillow on the living couch. Bedrooms and living areas originally assigned to live-in resident managers were transformed to resident quarters, making a resident occupancy of homes larger than when they began.

Weekends were staffed by part-time workers. In contrast to the pre-wage and hour days, homes were empty except when residents were there. The home feel of these places was just lost in this translation, as they started to work like a turn-key operation.

On this shift scheduling, sitting-around became an ever present life style. People seemed to stop doing individual hobbies and stayed indoors. Necessary functions like laundry and meal preparations got done but relationships in the community were more distant than ever. Other agency workers had to be assigned to take people out to the grocery or for a walk.

Neighbors noticed how people became more isolated after these staffing changes too. Workers came to be viewed more like attendants then, and that's not what they needed to be. Neighbors couldn't remember worker names and disassociated for lack of relationship time.

People and workers stopped being friends anymore after the wage and hour rules took effect too. Frustrations grew as people found themselves dealing with 10 to 15 different resident advisors a month. Coordination between shifts became a constant nightmare.

While people and family told funny stories about these times and how they had to "train the new staff", a definite "we" the staff - "they" the residents divide became pronounced. After workers stopped living with people in everyday ways, community homes become accustomed to custodial care conditions as an intrinsic part of their character.

As it became increasingly evident that shift workers could not support people in achieving everyday lives, systems began to seriously discredit the continuum idea and cite Normalization tenets as impractical. Agencies with a developmental growth emphasis found themselves retrenching into a care-giving domain more akin to hospital or institutional settings than a home.

Systems reinforced this retrenchment, deepening their protective relationships with people as personal ties diminished. A new era of custodial care in community service began in those times.

### **Family Responses**

With systems focusing on filling 'empty slots' in agency operated homes, families related to the wage and hour crisis as further evidence that community services were reliant on agency operated sites, rather than family, friends, neighbors and other lifesharers.

As people moved into group homes after going through their intake assessments and eligibility reviews, families expected something tangible in terms of a place for their loved one to live. The process of home finding meant being assigned to a group home opening. Halleluiah say all.

Given no other options, families resigned themselves to homes with shift staff coming in and out. Permanency under these conditions became viewed as a funded slot and bench seat at the workshop, rather than security that comes in sharing a long term relationship and a job.

In the final analysis, families settled for whatever systems offered, like they did in the not so good-old institutional days. Moving through the group home and workshop system into community ways was not viewed by relatives as part of the community service deal they signed on to.

In those few states that offered alternatives to group programs, families rejected overtures for more shared and independent living as unwanted pressure. Independent living, self-determination housing, and jobs were not welcome subjects when they translated into preparing a son or daughter for less oversight by paid overseers or a move to a new place or town.

Growing family complacency with congregate care made transitions more difficult over time. Satisfaction by families on the basis that no better future existed for their loved ones gave program personnel pause to address overprotective environments and other stagnation issues.

State agencies also cowered frequently and often to family demands to leave well enough alone. System and politically savvy families were likely to be successful in making sure people who were placed in a service were able to remain where they wanted to be indefinitely.

For the most part, families remained pleased with their loved one's placement as long as their life was stable and people were satisfied. Meanwhile, leaders kept their focus on making sure their system's beds were occupied and people safe.

### **An Exception and The Rules**

Despite many challenges, a handful of institutions completely disbanded in favor of individualized living approaches during these years too. One of these agencies was called Rivercrest.

Rivercrest was located in Southeastern Pennsylvania and operated as a long term care facility operated by an arm of the Lutheran Church. In a period of five years or so, about 150 men and women who lived in this institution found lifesharing with their birth families, companions and hosts, along with group homes for people who wanted this too.

Rivercrest's closure remains an outstanding achievement that many more agencies could have replicated, but didn't. The agency's approach was in stark contrast to most institutions that held on to the people that were placed with them and to deinstitutionalization initiatives under court order that focused on group home placement as a community remedy.

The difference with this institutional closing was leadership and determination that comes with it. The difference was planning with people instead of for them. It was making community living happen without the restraint of predetermined models.

The tendency to hold pat with their facility operations applied to prestigious hospital groups, rehabilitation centers and institutes across the nation, many of which operate in the human service world today. While new agencies emerged to offset the influence of this old

guard establishment, they all set a tone of proprietary interest in people, who they constantly referred to as 'our clients'.

Both old and new agencies found an inducement to strengthen their proprietary ways with opportunities to purchase group homes and manage real estate where services were provided. Rationalized at first as an effective means to attract providers, home purchasing became a fundamental component of systems before long.

Reimbursement of private agencies for the cost of homes through mortgage allowances and return on investment formulas built into service rates made it possible for agencies to accumulate sizable assets. Supplemented by ongoing room and board payments from residents and other subsidies, real estate holdings became a substantial money maker over time.

To maximize income in this area, agencies routinely spun off their housing assets to proprietary affiliates that offered other economic advantages including boosts in executive compensation. While government agencies audited for financial irregularities in this area, the wealth producing qualities of real estate became an accepted system practice.

Even today, providers find it difficult to separate services from owning homes and buildings that serve their clientele. The trifecta of purchased service settings filled with 'clients' for an indefinite period of time is as tempting as it ever was.

While the system benefited from this return on investment approach to community living, most proprietary and non-profits agencies didn't see this practice as taking away from person centered approaches. They figured that someone had to own these homes, so why not them?

Indeed, some agencies continued to thrive in fidelity with Normalization in the group home environments for a while, stressing involvement of the community and people in decision-making roles about their life. The problem of course was that these outcomes couldn't materialize like they do with other citizens who save to buy a house or rent an apartment, or engage with a landlord, hardware store operator or the cable guy.

By promoting that agencies purchase the real estate where people lived and worked, a fundamental self-determination outcome was closed for people in the system. Except for pockets in Ohio that flirted with home ownership consortia that families and people receiving services owned, systems much preferred agencies take up the responsibility of housing along with providing residential services.

As time unfolded, it became clear that smaller agencies were often in a better position to walk the talk of everyday living. Small agencies didn't have the baggage that running a large tradition facility imposed. They also didn't have to worry about multiple lines of services that often created administrative challenges they didn't foresee and found impossible to effectively manage.

Unfortunately, the incentives toward growth in the system often contributed to small agency mergers, acquisitions and satellite offices in new catchment areas. With this growth, quality and individualization often suffered.

Once certain thresholds of program size were reached, it was difficult for programs to focus on people and community life like they had been. While there were economies of scale that helped some administrative complexities, agency heads that had been down-to-earth in their early years became fixated on managerial issues over time, demonstrating more concern with their lines of credit than anything.

Almost all the small independent agencies established in the 1970s have long since closed or merged with larger during system consolidation in the last 15 years particularly. Those few small agencies that are left know the struggle of swimming upstream all too well.

### **So Sure To Protect**

Agencies of all sizes struggled with overprotection almost from the get go. Risk avoidance reinforced safety features in homes and programs that were out of character with community aims.

Overprotective features became apparent in the social arena, preventing people from exploring their sexuality in particular, but also rudimentary utilization of social and recreational opportunities without overbearing supervision. In system and family homes alike, protections that other citizens didn't require were imposed on people, if they needed them or not.

Ramps going to group homes with all ambulatory residents became a common occurrence. Radiator covers, and regulators on the water heaters, no lock panic doors, fire exit wall maps and exit signs – all became part and parcel of group home environments across the nation. Some states even required new construction and sprinkler systems in all their funded homes.

By the 1980s, it became clear that overprotection was permeating everything from physical settings to attitudes and program practice. While workers and some agencies talked a good line about loosening necessary controls on people, even seasoned change agents found it impossible to take down the exit signs and social barriers once they were in place.

Thanks to regulations that essentially codified overprotection, the lowest common denominator of need became the standard in community living, where annual program plans tied it all together, deciding who in the system would do what and when. While community outcomes, like employment, would sometimes be included in this process, these were relegated to “long term” goals. There was already an inside joke in the 1970s that ‘long term meant never’.

Actual steps toward achievement of community outcomes like finding a home or employment didn't match what people were taught or asked to do at work. By the early 1980s, many advocates for employment or living in an everyday way gave up the ghost.

Through the 1970s, expectations on progress toward self-determination were showing themselves to be consistently low, exacerbated by planning processes that restricted people to special places where disability services were provided. Once relegated to this disability sphere, people were viewed as belonging there, like they were in the institutions.

Since all these special places were becoming risk averse in their proclivity to ensure health and safety, 'clients' of the system became interpreted as childlike, not able to handle personal relationships or responsibilities. After a while, the community could only assume that people belonged in these activities on the basis of the protections that systems offered.

Taking the adage 'you can't be too careful' to heart, systems made sure physical and social structures prevented people from risk that citizens in the community were used to. Taking away these risks chipped away at people's dignity and exposure, preventing a culture of accommodation in the community from taking hold.

### **As The World Turned**

Other lessons program developers learned were not taken to heart too. As decision-making became confined to regulated services, people had no choice but accept make work and make believe approaches that the system dished out.

If people and families wanted relief from their extraordinary responsibilities with loved ones at home, they needed to accept service delivery as it was laid out. When a job had been on their personal horizon, they'd have to settle for sheltered work or adult activities instead. They'd have to go along with professional assessments that required people to be trained indefinitely in vocational services before job finding was considered feasible.

When they wanted a home, people would have to settle for a group placement where they weren't issued a key to the front door, or rights to use the telephone except in emergencies. When they wanted to become part of their community, people would have to be satisfied with outings in disability groups to places that were not of their choosing.

As people and families became resigned to the fact that the system would be their fate, few had the where-with-all to step out or challenge the status quo. Getting something that the system didn't offer was not going to happen either. The impediments of hubris and tradition were proving too great for any one family or person to overcome.

People put up with the indignity of it all, or they reaped the consequences of sedative prescription drugs, restraints, exclusion, excessive supervision, and denial of privileges. Resistance was a no win scenario in the world controlled by the system players, and it still is.

It didn't help that professionals didn't understand what the system ways were doing to people. Oblivious to the deviant images they caste, case managers and direct service workers would have no qualms about speaking to strangers about a person's disability as if the person standing beside them was not able to understand.

Some workers even seemed to get-off on seeing people cower and interpreted as children. Program personnel would be heard making wild claims like people with disability didn't feel pain and sorrow. Information on people's diagnosis, medications regimen and daily struggles were shared indiscriminately.

While many workers still struggled to overcome negative perceptions by promoting opportunities outside of service sponsored activities, system payment structures and agency liability policies worked against meaningful social integration at every turn, prohibiting workers from taking people in their private cars, double dating, or people sharing holidays with worker friends and family. Staffing patterns weren't structured to promote interactions outside of system-operated places, and community outreach didn't materialize in people's residential or day program realms.

Making matters worse, there were no community sponsors for people like there were for the so called 'Vietnam boat' refugees who came to the country after that war ended, and no AmeriCorps to welcome people into the national volunteer fold. There were no United Way programs that supported people in getting jobs either.

It was all about giving to services for "special people" then, and that hasn't changed much either. While AmeriCorps is beginning to take an affirmative in terms recruiting young adults with disability today, funding raising like the United Way is as far behind the times as ever.

Throughout this period of rapid expansion in programs, the world became smaller for people and more confined. People began to realize that compliance with imposed routines was the first order of life in the service system where they lived, worked and even socialized.

People remained passive in the face of this shrinking world and the standardized traditions being set within it. Essentially herded from one activity to another for the course of their lives, people found their living conditions set by the routines that systems established, from the moment the alarm clocks rang in the morning to lights out.

### **Bad Faith In Planning**

At first, program developers thought person centered planning would preserve some degree of integrity so that services would support people in securing community outcomes. They expected that individualized planning processes would ensure that people found their own homes, jobs, friends and a community life.

Program developers also assumed active treatment and habilitation requirements in Medicaid ICFs/MR and later home and community based waiver programs would influence systems to apply services in the context of meaningful experiences. On almost all these counts early system planners were flat wrong.

There would be nothing active about active treatment, and habilitation became just another made up system term to justify make-work, child-like activities, and training going

nowhere. Early program developers learned the hard way they we couldn't force integrity into the system that was so tied to reinforcing itself.

They learned that teaching people skills outside the context of a community environment didn't serve to facilitate transition out of special places. System methods only made people adjust to their restrictive placements. That was it.

The system decided how much service people needed, where they needed it, and how often and where the system would be monitoring its ways. While some providers and case managers were successful in collaborating to achieve non-system outcomes, few of their best practices caught on, and no inducements could move the behemoth of the status quo ante from continuing on its regressive march.

To compensate for their failures in charting everyday ways with people, programs resorted to forms of make believe in planning and service delivery that didn't result in anything more than people getting used to the sheltered lives created for them. Goals like "Robert will learn to count to ten", would be tasked out for years on end without trying something else or accommodating to this skill in another way.

Well Robert never learned to count, and there was nothing that was going to make that happen. One, two, four, two, that was as far as he ever got after ten years of the same hour long exercise with workers after dinner using the same method of marking crayon lines on a sheet of construction paper.

Despite marvelous improvements in labor saving devices and prosthetics during this time, instructional methods remained as arcane and misappropriated as plan objectives. Program managers ignored any sense of urgency toward making community connections and finding jobs. As long as workers were attentive to some sort of active treatment or teaching module, life in group home land was good.

Disillusionment with individual planning set in early enough. While program quality still stirred in the hearts of stakeholders, practical aspects of agency operated programs, like shift staffing and restrictive planning, could not be overcome. Wanting desperately to believe that their programs were working appropriately, leaders attributed disappointing outcomes to learning the ropes and making necessary compromises.

Even with the setbacks, program developers remained poised to continue closing institutions, educating families and the public, and improving the quality of life for people living in the community. In this penchant to move forward, leadership didn't come close to appreciating how many battles for self-determination and community integration that had already been lost with people.



## **Institutional Carryover**

By the end of the 1970s, program developers at state and local levels tapped too many institutional managers to administer the community system, and not enough marketers, technicians, believers, and inspiring leaders who understood the dynamics in play. System operatives stopped listening to the philosophers, community employers, families or really anybody but stakeholders that catered to their closed minded authority.

Leaders didn't spend time with new workers, families of transitioning youth and people who wanted to live free. Instead of taking stands on behalf of people and challenging the diversionary tactics special interests were employing, program developers caved in time and time again to organizational demands with an markedly jaundiced view.

The system refused to take direction from stakeholders or appreciate the depth and scope of problems that they chose to ignore. Common problems like supporting people to live somewhere else, renewing relationships with birth families, or finding a job stayed out of the conversation.

Community living for people became a destination composed of system-controlled environments that were better, if not much different than institutions. It all became that cut and dry. If a person wasn't 'in' an institution, he or she was 'with' an agency in charge of their life. It's still that way.

With caseloads in excess of 100 service recipients, individual case managers had no real impact on facilitating movement into everyday living or insuring the system's integrity. Having to deal with so many people and programs didn't allow time and space to appreciate people's difference, gifts and aspirations.

Case manager roles became dependent on keeping the system strong and vital. Resources outside the system were 'not my job, man'.

Case management functions soon became little more than an exercise in paperwork compliance with individual planning goals divorced from everyday outcomes like finding jobs and lasting community ties. The good ideas that went undone, energy that was drained, and faith taken away by these functionaries and gatekeepers echoed for generations to come.

As serving more and more people becoming the ultimate objective, systems had no way to go but forward, like the light brigade in Tennyson' poem, regardless of the human cost. Mired in the old institutional ways or channeled into new community systems with comparable controls on people, providers muddled along as best they could.

Workers in the system got used to talking about inclusion, but managing to other tenets that were much less outcome oriented. Policy handbooks and procedures to advance program concepts were totally ignored. Even state wide conferences and well-meaning retreats weren't getting workers, families and people on the same page.

The new reality became that providers wouldn't get to do things that citizens in a community way did. Providers and their system counterparts would be caregivers like workers were in institutions. Forming community ties would take a back seat.

In this emerging state, systems began to convince themselves that services weren't necessarily meant to form everyday lives with people after all. Choice to stay in programs where people languished but found life easy prevailed.

Wondering where all this back peddling and equivocation was going, program developers and other workers kept plodding on anyway, hoping for the best while dealing with a lot of new maybes. To say that service approaches were advancing in line with program intents at this point would be a total denial of the truth.

# **Chapter 9: With People**

## **Snippets**

*People with disability are willing to do their fair share.*

*People are not afraid or incapable to sacrifice and compromise; or to try, learn and cooperate.*

*People need to be won over as individuals, and that takes time, sincerity, and more than empty promises on the wing.*

*People accept that life is give and take, stop and go, and continual too. They are not looking for handouts.*

*People have faith and patience to help them get through trying times.*

*People know they have to prove themselves, like others do.*

*People have their disability related challenges but having no sense of self-determination isn't one of them. People are actually amazingly resourceful with disability, which is neat as well as instructive.*

*Being told what to do is something people do not appreciate; even though they accept it as part of the disabled state of life they are dealt.*

*People comply to get services that they don't choose or like. They learn to accept these services never the less, like they do other shortcomings life throws their way.*

*People would prefer to enjoy life with friends, neighbors and family members. People feel frustrated when only disability avenues, without community resources, are open to them.*

*People appreciate support to secure a job, relationships, and a home of their own more than anything. While people want to be safe too, they don't expect this outside of their own making.*

*People are on the same page as communities and general public. They have a common understanding about what support should achieve and about what is fair and reasonable.*

*It takes no leap of faith for people to understand how families, friends and employers can best achieve outcomes people want in life.*

*People have faith in loved ones and one another already, despite adequate access to resources and very little community support.*

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*In supporting people within a community, pity turns to strength and ignorance to understanding.*

*As part of their community, people aren't trapped anymore. Real time support develops. Family and workers engage with the rest of the community to work out problems people can't solve by themselves.*

*When people sense their community cares about them, it feels good. It feels safe. It feels enduring.*

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*When people don't choose where and with whom they live, it shows in their appearance and how they relate.*

*It shows when the quality of life for people in group homes and institutions hasn't changed in 30 years.*

*It shows when people receiving services are looking at their life as something others create for them, a life that brands them as special.*

*It shows when people take in the community like visitors, who have no stake or valued roles apart from participating in services, without choices and no prospect for a better deal.*

*It shows when people come into a service system and never move through it.*

*It shows when people are rushed into occupying the first empty slot, stay where they are placed, and move only when someone in authority directs them.*

*It shows.*

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*We saw that great things could happen*

*When the environments were right*

*And the right people were doing the right things.*

*We knew and celebrated*

*The people who broke through*

*And the people who were trying*

*In spite of the barriers*

*To realize good lives*

*Finding jobs, homes and relationships*

*People in systems today lead overprotected lives*

*They know it too*

---

People work, live and associate in groups based on their disability, in contained environments created to keep them safe and out of the community's way. They are taken care of by shift workers people don't choose or particularly care for.

Services over the last 30 years have done little more than create a unique class of citizens, living in institutions and community service settings, with no particular responsibilities or expectations. This was never what program developers intended.

Beyond being compliant with the gracious state of care in which they find themselves, having their beds made and food prepared by others, people are pampered as a long-term care elite. People get used to this too, but it's nothing they expected either.

No deal like this goes unchecked. In return for the perks of being taken care of, people come to accept their needy state, their going nowhere services, and their unemployable status.

Accepting these conditions doesn't make them right, good, or healthy. It just makes them the way it is.

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*People want their communities, friends and family to recognize their potential.*

*People want to experience valued social roles and the opportunity to express themselves.*

*People want to get beyond being happy with services, following their plan, and letting families and professionals set their way.*

*Life outside the system is painted as an unknown and scary place to people. The message goes: 'Stay here, be happy, don't venture out, and be safe.'*

*People want that message changed now, in their lifetimes. People want to experience life without the system trappings. They want a real way today and they want in.*

### **Win-Win Scenarios**

People with disability personify win-win situations in so many ways. A community finds its more perfect union with their guidance, struggle and contributions being acknowledged.

Recognizing the qualities people bring to the community is critical, because without this appreciation, there is no way for individuals to discover and secure valued roles.

New ways of community support depend on seeing individuals with disability as people first. Communities need to develop a people first perspective, which has been difficult because of low expectations, deviant interpretations, and lack of exposure. As experience with support ways matures, communities get to recognize that people with disability have many ways to contribute, apart from being consumers of the public's charitable giving and government funded programs.

Citizens of this nation have to focus differently to imagine people with disability being part of the community's everyday life. This becomes impossible when people are grouped together and isolated under the pretext of their diagnosis or level of care.

Because of the way systems run services, communities don't see how generic resources can be applied in directly supporting people. The public understands that adults and children with disability are placed in separate classes and training programs all right. They just don't appreciate how much these groupings are for the convenience and wealth production of systems.

Facilitating individual relationships remains a key feature to creating community connections. Only by being with different people in everyday contexts, can citizens relate to one another as colleagues, work mates, classmates, friends and loved ones. This learning only happens on an individual basis, not in disabled groups. Value is as value does.

By sharing people's journey and depending on one another, we can all learn firsthand about the application of accommodations to make our relationships easier and more effective. Both presence and participation for people are demanded now. Everyday citizens need to get more involved in supporting others in the ways they can.

The point is not whether people with and without disability will get to be friends and like one another. It's whether people have opportunity to be accepted and participate on equal footing, with support to be successful. People need to be together with others outside their disability caste for this success to happen in any meaningful way.

Just like anyone, people with disability have the capacity to love and befriend. They do their best as citizens in the neighborhoods they live and at their jobs. Just like people without a negative label, each person has personality and gifts, with feelings to be included in life. Let's agree to always tap that and never forget it's there.

In their participation with everyday friends and associates, people show us all how wonderfully inclusive life is. People don't need to be managed by treatment plans in specialized systems. Let's forget those entrapments and leave them behind.

There's a lot to get done with the inclusion of people. There are roads to build, infrastructures to renew and a homeland to secure. There are vacant homes that need occupants, and stores that welcome the public's business. There is damage from flooding and tornadoes that needs to be cleared.

Figuring people with disability into community building and upkeep makes sense all around. Communities need people as much as people need them.

The human resource challenges that face this country in the next twenty years require an all hands on deck mentality. This nation can face the fact that we're all in it together, or divert our energy to system's keeping people for their own purposes.

To fulfill their roles in society, people deserve experiences that are meaningful and individualized. They warrant power and control that comes from the ever-evolving information age, the wonder of broadcast and social media, and other frontiers.

Even with a sometimes-different look, slow response or peculiar way of communicating, people with disability belong on the lines of every personal endeavor without fear of being excluded. They don't need to be the last ones to benefit from what society offers or have a different line to stand in.

People don't need to be relegated to backrooms and basements either, or forced into situations with their hand out for morsels of the American pie. They require what the rest of us do, not as consumers, but as people first, with the expectations of full citizens, good neighbors, and full time employees.

# **Chapter 11: With Families**

## **Love's Special Leaning**

Families love their sons, daughters, life-partners, and distant cousins with disability like they do their other relatives. Children with disability have the love of their parents, grandparents, sisters and brothers, as children deserve. Even into adulthood, relatives with disability get amazing support from moms and dads, and siblings too.

As people grow older and rely on their birth family members for support, brothers and sisters become more important, making decisions on the family's and person's behalf, and offering guidance and advocacy. Siblings move into long-term care support roles too, and some receive financial assistance for this support too, more and more.

Their own particular pressures and 'non-negotiables' influence families. Moms take to youngsters with disability differently from the ways dads do, which is natural. There are different types of family love in play, and different expectations.

Birth order, gender, personality, distance, economics and other factors influence family ties. Sometimes having a loved one with disability contributes to keeping families together and strong, but all too often not.

It's how family love is manifest that gets to be the critical issue. When relatives with disability are treated with respect and given reasonably high expectations, living in community gets to be a real thing, good and on the right path. When families offer permanency and continuity in life, those are wonderful features too.

When these conditions don't exist, things get off kilter. Struggles come to a head when children and adults are released from their family home, particularly during transition to adult life.

Going from an entitlement environment during the school years, families take it on the chin in facing off with yet another system, this time, in the adult service world. While letting go of youngsters is a landmark transition for any parent, its different when intellectual disability is in play.

Young adults without disability typically go off to a career, the armed services or college, while their disabled counterparts don't. Young adults also drive off in a car of their own or a friend's, and make their own decisions about how and when to leave the family nest.

Young people with disability don't step into independent living this way, if at all. They don't find a life partner or a place of their own. They don't take off with a buddy to the lake for the weekend.



Instead, young adults find themselves waiting for service or occupying a funded program slot, generally living in their childhood home with the family with no particular plans on leaving anywhere soon. Sometimes it's all very sad.

Losing the comfort of an educational entitlement umbrella at age 21, parents panic at the prospect of yet another system that controls their loved ones' adult life. While most families keep it together during this trying time, navigating the labyrinth of adult systems gets real old fast.

Having benefited from a free public education in special classes and buildings set apart from their peers, families come to expect similar routines and activities continuing into adulthood. Families rely on adult services to at least occupy their loved one for the same hours that the schools did, offer transportation on special buses, and the like.

Based on their experience in special education, families also assume that adult programs will remain in settings where their loved ones are readied for a cold, cruel world. Families get accustomed to their loved ones attending programs at different times and places from their experience in those school years too.

Exclusionary patterns come together in a profound way for families when their child's special education classmates all end at the same local programs after graduation. Separating from childhood friends and routines doesn't happen with young adults with disability like it does with their peers going on to secure valued roles like a career.

Even though families hear the talk about everyday lives and valued roles, they live in the here and now. They have their beliefs and hopes for inclusion tempered by what other families have to share too.

The message families get from professionals and other families is that there's a hard way and an easier one. The tough road for young adults is to go without the services that systems offer. This means making it on your own.

Families also hear that businesses aren't hiring and funding for supported employment is short term, requiring assessments, income reporting and other rigmarole. They are informed that home and companion finding services are not offered either.

Families hear that since systems prioritize people with the greatest needs, it's necessary to be considered in a "severe or profound" disability grouping to be considered for a day program or residential funding. They're told that once in services, it's best to take what the system offers, when you can get it.

They're told by case managers that families may be eligible for respite care funding and a slot at the day program, but that's about it. Families expect socialization opportunities to be limited to ARC Chapter dances and special vacations.

Instructed by this reality, families understand not to set their sights too high. They learn that if their loved will settle for congregate care, the system's the place to go.

When it's an everyday life they're after, families find themselves looking elsewhere for generic resources and relying on their own ingenuity. While some families do help their loved ones achieve job, relationship, and home finding outcomes, most don't take this on.

Families realize sooner or later that systems aren't interested in engaging family resources to achieve everyday outcomes either. They get it that systems are a clear and distinct choice to a valued everyday life, more often than not.

Choices come down to accepting conditions that services offer. It's a dilemma when families are faced with situations that are as good as they get, totally outside their own control.

### **Practicalities In Employment**

Studies show that parents have positive employment expectations when their loved ones are children and teenagers. While families tend to shy away from advocating curricula that promote employment outcomes in their child's Individual Education Plan (IEP), they still start off hopeful that education will lead to an everyday life in this way.

So called 'transitional planning' into adult life changes that. While some students have special education curricula that include community work assessment and job opportunity, most don't. Even through special education students enjoy an additional years in high school, they generally graduate without a career track, let alone consciousness, in mind.

According to national data, less than one in six graduating youth with multiple disabilities have a job or career path after five years. Most jobs are part time and don't pay that well.

The two or three additional years young adults with disability spend in school are often useless in preparing them for adult life. Thanks to what adult service system representatives tell them during transitional planning, parents consider finding a job extraneous to getting on a the proper system waiting list, or getting placed in a residential service.

While this 'home first' thinking has been typical with young adults with disability, it is atypical for the rest of society. Young adults without a disability who stay at home after high school typically have something going in terms of a part time job or post-secondary classes to attend.

This is not the case with young adults with disability despite ample research that shows how having job experience in high school years begins a pattern leading to adult employment. This teenage 'disconnect' with employment has a lasting effect.

In their no-job consciousness, parents settle for activity programs as an extension of their loved one's make-work and readiness training in schools. Without the experience of their son or daughter doing chores or helping out a baby-sitter, families don't associate their loved ones in a self-determined context at all.

Families don't push the employment envelope for other reasons too. Their reasoning is straightforward, if not always warranted by the facts.

Parents express that they don't want their loved ones disappointed in not finding community jobs or to fail in job assignments. They don't want their son or daughter getting in with the wrong crowd after work hours either. Transportation is common barrier too.

With due respect to the challenges families face, some parents seem to look for reasons to keep their children dependent on benefits and system offerings. They express an undertone of fear and anxiety with accommodations, social responsibility and community support.

For families with misgivings, facility-based congregate programs, however demeaning, are viewed as a sanctuary and shelter from everyday challenges that citizens face in life. Over the last 40 years, congregate settings have also been the tried-and-true option that families have relied on. Parents ask themselves: Why should our kids be any different?

System alternatives like sheltered workshops and adult activity centers remain a promise of life-long stability in an otherwise changing and sometimes threatening world. As long as system stability is present, that's enough for families to go along with the show.

While it does no good to blame parent motivations, there's nothing wrong with educating families and making sure they don't sell their loved ones short. There's nothing wrong with school counselors and adult service personnel being clear about the outcomes that are expected with people in terms of achieving valued roles either.

What's wrong is how system operatives use family protectiveness as a shield and an excuse to justify their program shortcomings and leaning toward restrictive ways. What's wrong is holding families hostage to sheltered lives that systems perpetuate for no better reason than they can.

### **The System's Role With Families**

Even the most informed parents approach adult service systems knowing to expect an uphill climb for employment. While families understand that schools and area agencies can be helpful in placing people into jobs, they also see how agencies are apt to separate so called higher and lower functioning people in selecting what training they offer.

It's not enough for a person to expect support on the basis of wanting a job in service systems. People have to fit the bill of being job-ready based on assessments offered by providers and vocational rehabilitation agencies. Most often, people stay in programs that prepare them for jobs that never come.

Parents buy into this system decision making process, for better or worse. They are also well aware that supported employment remains a scarce commodity in many areas of the country. Even in locales with lots of service options, families see how the great majority of funding goes to sheltered programs.

Families have also come to rely on disability benefits that are allocated on the basis that loved ones can't hold down a community job and bring earned income to the family. While monthly benefit checks averaging from \$700 to over \$1400 help meet family expenses, keeping this unearned benefit comes with definite trade-offs in terms of employment expectations.

Adding to their incentives to collect benefits, families are told by agencies that they will lose their slot at the sheltered workshop by stepping into a job or career. Families also don't want to jeopardize their loved one's health care benefits, food stamps, and services for a part time job that seems to be more trouble than it's worth.

Although Federal work incentives over the last fifteen years have been created to address employment barriers like this, families haven't taken them seriously. Even though financial consultants are available at no charge to navigate benefits with employment, families don't want the hassle of what this entails.

School and adult service professionals also don't guide families to these employment support resources. All major benefit programs, including Medicaid and Social Security, have specialists in their offices to help people and navigate employment in ways that are financially beneficial to recipients.

Unfortunately, case managers, sheltered work providers and school counselors don't share information about work incentives or promote employment first practices that are on the books. They don't offer assistance to families in setting up reporting schedules, offer ongoing technical assistance, or refer to agencies that can. They don't refer people and families to benefit counselors.

With a lack of support, families opt to avoid look-behind the prospects of audits that result in the loss of or refunding Medicaid and Social Security benefits based on earned income. When families are locked into protecting the financial and health resources they have from these sources, they don't embrace another way.

In many states, Medicaid funded home and community services and ICF/MR programs don't offer supported employment services at all, while those that do tend to limit them to no more than 15% of adult service recipients. While Medicaid funded residential service providers have offered transportation to sheltered day programs since the 1970s, most continue to renege on making sure people get to their job.

Families who want to pursue employment do the best they can in this environment. While training and parent to parent groups have formed so parents can learn to be better advocates and understanding complex system practices, these can only go so far.

It still comes down to what the system has to offer, and struggling with the authorities to get something other than what the facility based programs want to offer. While getting past these barriers will always be accomplished one person at a time, taking on an intransigent system on this basis is not a proven or easy path to success.

While there are inspiring tales of families securing everyday life with people that includes a job, there are many more examples of young people being isolated and holding families hostage due to deviant behaviors at home. The state of system dependency that stems from these pressures haunts families, and makes them willing to accept anything that relieves them of situations they can no longer manage at home.

In today's world, many young adults who don't transition from school into a program spend years in front of a television set before their family reluctantly agrees to pursue services at the local activity program or sheltered workshop. By this time, when a family is grateful to accept anything from systems, employment considerations have lost their meaning.

Systems readily take on people whose parents have low community expectations after trying support on their own. Programs exploit the fact that they're the only game in town, and use family sentiments to express how their traditional brands of sheltered work and activities are the best way to go.

In their interactions, system promoters encourage families to stay focused on the caring aspect of service, not on how well their programs prepare their loved one for a job or career oriented volunteer opportunity. Far too many parents are yet amenable to system pitches like this based on latent fears and uncertainty.

Knowing what buttons to push, system proponents convince families that sheltered settings are therapeutic and that sheltered work is noble, despite paltry wages and the segregated, dead-end quality of the experience. Families get used to these practices and pretenses in any event, and learn to settle for what they receive.

### **Taking On The Man**

Squeaky wheels definitely get the grease, and the system knows that stakeholders who express discontent with system approaches had best be satisfied too. The system has no problem in granting individual service exceptions for people that serve to avoid bad press, litigation, and unrest within the ranks.

If it wasn't for families who wanted something tailored to their loved one's everyday future, many innovative approaches would never have been pursued in the first place. The problem is that systems find a way of dealing with these families as outliers, instead of leaders in discovering new ways.

Winning an appeal or fair hearing with the system doesn't mean as much as families would like to believe. Resistance to fair hearing determinations is often quite palpable, showing

how administrators and direct support workers are set in their ways. While families may win appeals on paper, making systems actually respond in good faith can be next to impossible.

One thing is for sure, taking on the system means that a family member or advocate has to spend a lot of time and effort. This extra energy alone is enough to turn off most families, and the system knows it.

Due process routes also set up an antagonistic relationship with caregivers and system intermediaries, which families shy away from. Families generally want everyone to get along. They don't want severe reputations either and they're sensitive to their loved ones being targeted if too much of a fuss is made.

Without faith in something tangible related to employment and other everyday living outcomes, people and families stay clear of stepping out of the comfort zone that system representatives lay out. Unless agencies send the message that there is the assurance of support for people to get jobs, find a place of their own, and develop community ties, families revert to their pragmatic view that nothing really changes.

Only as the deal changes to one where everyday living outcomes are achieved do people and families become confident in taking advantage of opportunities that come their way. People aren't predisposed to being unemployable in support paradigms such as these.

Showing people and families that the community is behind them in achieving everyday lives adds a whole new dimension to support that families have never known. Families can and do support employment first under this basis, time and again.

Families also respond to changes in the system's tone. Expectations set and communicated clearly in terms of moving on to jobs after training would be a good first step. Establishing clear 'employment first' policies and practices would be another.

Otherwise, people and families will do what they're told whether they like it or not. They'll take the deal the system gives them, though they'd prefer something better or entirely different.

From the viewpoint of a provider or other system operative, families who become advocates for their loved one's community outcomes are generally viewed as a difficulty factor affecting the system's otherwise autonomous way of doing things. While agencies in the system cooperate with families in planning programs for their loved one, taking direction from others is not something systems enjoy or do well, especially when there are differences.

By exerting control through program funding, systems make sure families adjust to system ways and language, routines, and demands. If the family can't conform, they are prone to be ignored, lied to, and denied access. People in service get treated in a similar way and more harshly, with increases in medication, and various forms of restraint and exclusion.

If there were other options for community support, it would not be so bad for families but there still aren't. There are still only choices that involve placement into a vacant chair, workstation or bedroom in a funded service.

Choices are so system dependent that it really doesn't matter what provider a person gets most of the time. The services are the same in what they do and don't do in their licensed and regulated ways. They're the same group homes and adult facilities, and the same group functions, wherever people and families turn or go.

### **Who Needs Families Anyway**

The tendencies for families to go along with program ways and lose sight of their loved one's valued social roles are reinforced by the way services take responsibilities away from families and communities. Families aren't asked by systems to share in the responsibility of supporting their loved ones or in applying personal resources to help achieve community connections, jobs and homes.

While involved families sometimes accompany their adult loved ones in group living to medical appointments or take them home for the holidays, systems don't make serious efforts to obtain family support. Residential programs provide a place to live 24/7/365.

It's often an all-or-nothing proposition with systems and families based on funding formulas that pay providers for the days of service people receive. It becomes either the system's way or "who knows?" in the world families navigate. Only families know just how scary that "who knows?" can be.

Family advocates who want to be involved with their loved ones through system design, policy and monitoring are channeled to advisory boards and committees with no significant power base. In these capacities, families are ultimately rebuffed by funding agents who make it clear who calls the shots.

In these advisory roles, families represent organizations that get easily sidetracked into listening to what system leaders have to say. They buy into excuses like how programs must operate in a certain way to comply with state and federal requirements.

Family inability to engage at a basic outcome level with leadership is symptomatic of a widespread 'heads in the mud' to quality improvement. While most of this isn't a family's fault given the places and ways systems deal with stakeholder input, even getting talking heads for a nice walk outside the building would be a good start.

Through its control of committees and boards, systems treat family advocates as passengers along for the ride, while providers and government share the wheel and any map reading roles. Families get used to being interpreted in this way, being asked to rubber stamp what providers and government agencies wanted in the first place.

It's not that families have lost their voice or desire for person centered change. Many relatives tell the system about the issues they face. Some family advocates also have a tremendous impact on changing ways, sometimes with the support of service providers which have learned to be flexible and take direction.

While families are offered opportunities to participate in service development for their loved one, the system tends to take family input as an uncomfortable formality, reflecting a personal view that the system cannot share. Being pigeon holed in this manner gives families pause to express and follow through on their ideas.

The system, in the form of case management especially, jots down what families want all right; it just doesn't take direction from them, any more than it does from people, when community outcomes are concerned. After years of manipulation, families are saddened more than maddened with this reality.

They see that programs are not there to support a person's dreams and objectives, or capitalize on their gifts and strengths outside of system ways. Families thus lower their expectations notch by notch and face their powerlessness in the face of system norms.

Once these disappointments take hold and form a pattern, life becomes all about playing by the rules, and settling for the certainty that funded budgets will control how a loved one lives. Disappointments cause families to lose their spirit and faith in community ways.

It makes them chase the grail of more funding for traditional services as one of the only paths of support they can pursue. It makes them angry and confused.

Even when loved ones speak out for what they want in life, families find themselves filtering their demands and talking them out of perfectly reasonable changes and discovery. In fear of losing services, families see no real choice except to side with the system when it comes to keeping the lid on, or avoiding new risks.

In the final analysis, there's really nothing families believe they can do with the system except get used to it or leave it with their loved one in tow. The challenge today is to make that leaving work, ensure that decisions are person directed, and keep community in the loop.

Community ways have to rescue families too. We're all in the same the boat.

### **Family Organization Shortfalls**

A recurring question today is whether organizations that represent family interests with systems and the legislature can imagine support outside of traditional system ways. Can associations like the National ARC and UCP embrace support outside the service approaches that systems have created? How and when will family based organizations appreciate that times have changed?



While it's difficult to be hopeful that current leadership circles can make any leap into community support ways like lifesharing or employment, another generation of parents and loved ones is bound to take over. Spirited families with young adults who have come through the public education system over the last 15 years have already had some beneficial impact.

Family associations supporting children with autism are also not buying the lines that the old guard has been pandering. Their discovery of new forms of financial support through direct family subsidies and health insurance coverage has given power to the people in refreshing new ways.

The basic problem with traditional family based organizations is their acceptance of the status quo. In state after state, families representing other families aren't given the dignity of the most basic demographic information on outcomes or cost effectiveness measures.

Feeling powerless to do much else but support requests for additional funds, family organizations don't clarify their expectations for self-determination and everyday living outcomes. In becoming accustomed to being ignored, coerced and manipulated, associations have crossed over into a lazy state of service satisfaction that is not warranted.

Collectively, family organizations reflect many of the oppressive qualities individual families endure under the systems that control their loved one's lives. In a state of system dependency themselves, family groups don't get nearly as pissed off and involved in charting community ways as they need to be, and once were.

Progress toward achieving everyday living outcomes becomes even more complicated when family organizations that are supposed to be advocates first and foremost, become major players in the provision of services as they are in New York, Pennsylvania and other states. In family-operated programs, the system feeds on traditions of overprotection that allow workshops, time wasting adult programs, and congregate living to hold on virtually unchallenged.

While family based organizations that operate services generally establish administrative fire-walls to preserve the integrity of their advocacy role, board members and executive staff routinely face many conflicts of interest in the course of their decision making. It's also not unusual for local and state leadership circles to have competing missions that never get resolved.

While state and federal agencies are aware of the struggles family advocacy programs inherit in their provider network roles, officials do nothing to change the dynamic. Government agencies also rely on family groups to stand with them in their quest for additional funds and control.

While family agencies are famous for their lawsuits that created community based education and services, they still leave the room when discussions on achieving everyday lives roll around. Quality and outcomes in services are not what family organizations are talking about today.

National offices of the ARCs and UCP are notorious for being drags on independent living and employment support thanks in large measure to their stick in the mud leadership. While State and local chapters are indeed varied, many struggle in being relevant to younger families and people forming their own self-advocate groups.

Over time, family organizations have changed from their focus on loved ones to what system's do and don't, and what it takes to get into service. It's just so telling that the ARCs and UCPs of this country have not demanded closing and defunding of all institutions, workshops, or other clearly destructive service options.

The big question for these organizations is whether younger families with a different perspective will step up and change the pattern of overprotective services. Will they continue to be coerced into staying with service systems or muster the courage to develop new ways with their communities instead? Will they form new platforms and embrace leadership that looks to the future?

Based on what we've seen so far, family organizations aren't turning away from what the system offers. While they may take on some new ways over time, strategic thinking in everyday ways has not been used much.

Family organizations may be counted on to move incrementally, and that's about it. As laggards in the community movement at present, these organizations promise to be more a continuing part of the barrier in creating better futures and lives for people, than the solution, but we'll see.

These organizations, along with the systems they supported, have been content to sit back on their laurels when there is work to be done. Getting services into the community was enough for them and still is.

Community service options like group homes and special education in public schools remain the pinnacle moment that these organizations point to. They're dedicated to making these ways better, not changing them for now.

It's difficult to predict if organizations representing family interests will ever get to a point of realizing how community living isn't a brick and mortar thing like institutions were. Seeing community as ways of life that rely on resources that other citizens use will be a bridge they need to cross, like other stakeholders.

The test for these organizations now is to develop advocates for community support and end their conflicts as providers of segregated service most of all. Family advocates in these organizations also need to reach out to community resources, recognizing the surety of resistance within their ranks.

## **Beyond Organizational Impairments**

In addressing the shortfalls of family organization today, those seeking change must never forget that parent groups launched the first integrated classrooms, influenced the first class action lawsuits for deinstitutionalization, and embraced important forms of innovation when others didn't. Families have been the force behind right-to-education laws and other legislation to promote community services since the 1950's.

Family organizations also launched and supported community living in the beginning. They've taken reasonable risks and used information and resources they've needed to at times. Bringing this full circle would be great.

Despite the drag that certain key family leaders have represented, some progressive family organizations are taking on new roles. Various family institutes, like the PEAL Institute in Pittsburg, promote best practices, parent to parent education, and leadership development with consistently positive results.

Another family based provider organization in Pittsburgh, Achieva, turned away from facility-based services over the last twenty-five years to a point where most people it serves have jobs and community volunteer work. The organization takes support one person at a time, building on their successes to assist people in achieving everyday lives.

Another parent operated agency in Ohio dismantled a sheltered work and activity world it inherited making sure people found jobs and community ties instead. The director of this program speaks to other parent group chapters across the country today, urging them to make the changes his organization did. Unfortunately there have been few takers.

A director of a local chapter of the ARC in Pennsylvania also entered into a relationship with Lowes, a fortune 500 company, to obtain skilled jobs for people in a large automated warehouse operation. These jobs are there today in good number and growing.

The director is also helping the parent company expand on this approach nationally, and linking into other public and private partnerships galore. She has taken on a leadership role to ensure that government agencies are listening and following her lead. Take note that this is a family venture and a business venture being pursued, with systems and service agencies taking a distinct back seat.

These forms of family support are the essence of families letting life in and organization change. Families can certainly do what they have a mind to, individually or as part of an organized effort.

Families can also form together and prove to themselves and their communities that change is possible outside of systems, like they did when supports were first being developed in the 1950s and 1960s. They can try another way too.

## **Forging Ahead**

Community support requires that community outcomes with people come first. At some point, the community has to ask itself: So what if a person is afraid to move from the group home or facilities where she lives, unable to control a bowel movement now and again, or sometimes a little unpredictable?

So what if a family member is not willing to agree to having their loved one leave an institution, group home or sheltered workshop? Pointing to personal challenges and unwillingness doesn't negate dealing with people's challenges in another venue or way. Intransigence just makes it all too easy for systems to render people helpless.

Noting family concerns and perspectives doesn't have to mean buying into them at the expense of individual autonomy and rights. Securing jobs for people with disability is an outcome that communities can justify, even when families have their reservations.

Having a concern about safeguards at a generic job site or questions about retaining cash benefits doesn't need to close the book on jobs like it has. The same holds true with home finding and relationships people secure on their own.

The fact remains that family interests are not always shared with people, particularly as adults. While support workers have a responsibility to work with families in explaining how their loved ones can be supported, a big part of family education means focusing on the person's outcomes first.

While supported employment and home life may call on families to do their part in different ways and maybe more ways than they are used to, that's okay. Tapping family resources to ensure a loved one gets to and from their job or a home of their own is wonderful thing.

Families might be asked to contribute in other ways, such as coordinating various types of support with neighbors and friends. Families may also need to decide on including their loved one in estate planning and inheritance, too.

Some families can go this extra mile. Others won't for various reasons that are beyond a system's control.

While this generation's experience with family-directed services has been successful over the years, there are certainly families who will not be able to assume ongoing support roles. In light of this, communities must be prepared to shoulder responsibilities that families for any number of reasons are not able or willing to take.

The point is that families need to be asked to provide the support they can towards everyday outcomes. This support needs to be factored into any other resources that a person utilizes. Family resources need to be included in the planning process with people who want it, too.

Since families aren't always going to be able to be there with people, discovery of other community resources from friends to work colleagues must be accessible too. Control and influence with people doesn't automatically have to be forfeited to systems anymore.

Not having a close personal support network doesn't mean that it won't ever be that way either. People without close relationships with family members can find and be nurtured in family ways through lifesharing, reuniting with other relatives, finding new friends. Service workers and support circles can help achieve these outcomes with people too.

Ultimately, most families will go along in supporting their loved ones choices when they know that this is the way it has to be. Most will do their best, like they always have. They'll accept that services lead to independent and everyday ways of life, when that's the agenda.

Whether families join in on the community support side of living with their loved ones or not, this country must be clear that there are certain non-negotiables, beginning with the bottom line that people's outcomes in the community come first.

# **Chapter 11: WITH SYSTEM WORKERS**

## **Acknowledgements**

Archiving Tales is written with abiding respect for colleagues, many of whom have been friends and trusted associates, as well as people with disability and families I have had the privilege of meeting. There is so much to thank these people for that it cannot be put into words.

While this narrative does not hold back on critiquing our experiences together over the years, nothing is meant to imply that any worker had bad intentions. We saw things in different ways and expressed different points of view.

We had different talents and difficulties too. We had different masters and mentors. As Bob Dylan noted in his song: you got to serve somebody.

To some of my colleagues, Archiving Tales will be viewed as an act of treachery by a onetime loyalist who turned on the system that he helped develop. Critics may rightly note how I benefited from the system as a public employee who now has a good pension and opportunities for an occasional consultant gig too.

Some will impugn that I'm writing at a bad time given the challenges the system faces in maintaining its funding. They'll claim this account is right wing or much too radical a departure, or that it doesn't matter what a lone voice expresses without money and power behind it.

To these points, I say: I have no axe to grind, and am telling no tales out of class. I'm calling system ways like I see them, and as many others do too. In terms of the timing: if not now, when?

Colleagues that don't like what this book has to say may be right in suggesting that I should have been more persuasive in changing the course of services over the course of my career. They would not be off track in observing that the book is a way to make up for certain shortcomings I accept about my sometimes argumentative and pedantic style.

Indeed, I wish I had done better in getting people to outcomes, but mostly I wish we all had. I would also note that not being employed in the system anymore has nothing to do with my commitment to its departure. I wake up in the morning now, like I did throughout my career, wanting everyday lives to be real, my own included.

I don't pretend for a moment to be the person that can retire from a commitment I've come to have in the course of my life. In that respect, getting people free isn't a job at all anymore.

It's a consuming passion, and many workers have it, retired or not. For me at least it was something I grew into, and I'm glad I did.

## **Being Clear**

Arching Tales does not mean to denigrate or minimize what family and other workers have done to achieve everyday living outcomes. People are living everyday lives with valued roles thanks to these efforts.

New and innovative support approaches have been sustained for people too, thanks to the commitment of individual relatives, life sharers, workers and organizations. If only these situations were not the exception to a much larger picture of systematic oppression and under achievement, and neglect of people who receive no services or support at all.

Thanks to the commitment of workers and community advocates, a variety of support approaches continue to emerge. When taking direction from people with disability and using community resources, everyday life works. As long as these approaches survive, we can be grateful for and grounded in something good.

At least new leaders will have some examples of community to build on thanks to the support work that has been done. With lifesharing and employment support showing signs of revival, who knows? There's always that hope.

Getting community footholds for support just never should have taken this long, and we can't be strung out with these games while people languish any longer. We should be much farther along today than we are, and have a long way yet to go.

Workers have something to answer for in this respect. This pace of taking community ways is due to the condition of their clarity and energies too.

It takes more than just being a good person to get the job done sometimes. It takes heart and soul.

## **The Lifesharing Difference**

There are so many misconceptions about workers that it's hard to know where best to start unraveling. For example, workers are considered "special", doing the work that other employees couldn't. They are viewed as kind and understanding on one hand, and then again demonic, like the Nurse Ratchet in Ken Kesey's, One Flew Over the Cuckoo's Nest.

The not so surprising truth is that workers are like other citizens across this nation. They come in various colors, shapes and sizes. They have the same prejudices, fears, aspirations and desires too.

They join unions and country clubs, they play chess and other games, and they like to let off steam. They are all fundamentally human, exercising their choice and freedom in society as best they can.

Educationally speaking, direct support workers in formalized services generally do not have college degrees like they did in the 1970s. Their tenure in any one program is most often limited to a year or two, although it used to be much longer.

A number of people who enter human services come to being a direct support worker as a default based on a lousy job market, or being fired from a job. I was once one of this crew.

Supervisory personnel take on the roles of qualified mental retardation professionals with their work related degrees and experience. Their job duties consist of supervising direct support workers and programs. They see that regulations are met, policy adhered to, and people satisfied, healthy and safe.

A major difference between most workers and people in formalized service comes down to freedom. Paid workers today leave their program settings for homes and lives of their own, while people don't.

### **Lifesharing Difference**

Unrelated workers who choose to share their lives with people have rich relationships that personnel in an institution or congregate program can barely imagine. These lifesharers choose reciprocal roles with people rather than a form of oversight that so many program workers specialize in today.

Lifesharers also take people where and how they are, and work to keep their life together as everyday as can be. On the other side, there are structured programs where workers tend to keep people from pursuing community living that includes lifesharing too.

Lifesharers stay together too. Average tenure of a lifesharing arrangement in host homes in Pennsylvania service system is about eight years. Relationships that span generations have occurred and are still intact after three decades and more.

Workers in many service arrangements perform 'take care of me' jobs in agency operated environments, and that's it. Lifesharers have no special boundaries.

Workers have to be truthful about the lifesharing quality of relationships they find themselves in. They need direction and support to help their work roles and lifesharing come together.

There's plenty of precedent for taking the lifesharing way when the time is right. Sometimes workers leave the system with the people they have cared for and gotten to know. They form friendships before deciding to live together.

Sometimes 'doing right' by lifesharing has meant starting up your own agency or taking a person home. Sometimes it has meant stepping up and being a leader, or saying no, we'll have to try another way.



One way or another, this current worker state is bound to change dramatically based on the benefits only lifesharing can secure, not so much in what work functions are performed, but in how relationships and support environments are offered.

It's time for workers to know that this change is upon them so they can get on board or get out of the way. Sitting on the sidelines just won't do. The long term care approaches of the past are ending in favor of a lifesharing paradigm ready and raring to go.

### **Worker Roles**

Even in the worst program settings, workers who provide direct service for people keep order, ameliorate tensions, ensure safety, promote healthy lifestyles, and help overcome individual challenges. Despite low wages and segregated environments, workers have been devoted to the people they serve, really loving their work as a calling.

Workers in and out of the system have also been willing to engage with people with disability when others in the community have not. They have been prepared to support, mediate and convince, stand with and protect people in their care. Sometimes just listening or being a friend has a value, too, and workers have done that with empathy.

Despite the settings and responsibilities the system throws at them, workers still enjoy the opportunity of teachable moments and assisting people to develop skill sets. Even in the worst environments, workers make the best of the conditions they face, maintaining their dignity and that of the people, however they can.

Experienced workers are also critical to helping new recruits, imparting confidence and knowledge, and offering backup and advice. While community outcomes that people achieve are generally disappointing, workers do keep people with disability out of harm's way. They are generally excellent observers and communicators too.

Thanks to workers, people across the country have a home place of their own or to share with a family or friend. Some workers routinely help people get connected with a church, bird watchers, school, or other group that is not all about being disabled.

Workers who took the time and mustered the energy have also secured long lasting employment for people and worked diligently to retain jobs over time. Even overburdened case managers have helped connect people with community resources outside their closed systems in truly person centered ways.

It's not that system workers can't or won't do the community work that's called for to secure valued roles in the community. It's not that direct support professionals don't have the ability or credentials to assist people in facilities and group homes in being a good neighbor and responsible citizen. The problem is that systems don't let workers do tasks that are contradictory to keeping people in the system way of life.

Workers carry out what the systems require of them, most definitely. Workers are essentially pawns in this game. We all are.

## **Worker Tales**

System enforced environmental and program controls make providing services so much more custodial and exclusionary in nature than they need to be. Services are too much a job today, and so much less a reciprocal endeavor within a person's and the worker's everyday experience.

Individual ways leading to everyday outcomes of a home, job and community connections are the exception in the way people with disability are served. The sad truth is everyday outcomes are achieved despite what service systems do to stand in the way.

Some system workers support people in pursuit of an everyday life, helping with everything from developing communication skills to creating a social opportunities. However, many more workers are placed in a position to perpetuate what the system wants, not what people require to secure an everyday life.

Without a common understanding of what it means to have a family, a job, and community connections, workers are forced to perpetuate islands of system make believe. Unless the country can break out of this mentality, workers are destined to continue their role of maintaining a lazy and at the time pernicious status quo.

Worker time and energy are rendered ineffective in achieving everyday outcomes by program location, worker scheduling and the other fundamental elements that can't be changed without violating system requirements. Even when services are provided in the person's family home, workers are limited by a narrow spectrum of assistance focused mainly on offering relief to caregivers instead of developing the person's community presence and participation.

While workers take responsibility for what occurs within their program settings, they are not expected to engage with the community at large. They have no sense of fading out assistance responsibilities to community colleagues, generic resources, citizens, family and friends.

Program and facility rules standardize what is done with people in community and institutional programs alike, taking community ties out of the equation, except in the most superficial ways. System structures restrict worker roles to making sure people are occupied, productive and safe in their special disability settings.

System workers get used to compliance as their operational compass. Over time, their work ways become standardized and supervisory directed, negating what others, including people, friends, family and community sponsors would otherwise contribute. Workers become formulaic in their roles, making sure they can supervise groups of people, as opposed to supporting anyone individually.

Workers go along with the system show because they are not at all clear themselves on how to mobilize resources. Workers aren't compensated for doing what's right for people outside of system-sanctioned ways and places, so they don't even attempt to step out or consider how other ways exist.

Making matters worse, system workers have little influence in changing conditions from within. Even workers who have known people for years are routinely excluded from individual service planning meetings or program development sessions that are dominated by case managers and program directors.

Scanty independent research on worker satisfaction tied to everyday outcomes gathers dust on academia's shelves. Providers have traditionally resisted efforts by independent researchers to find out what workers have to say about their employment conditions.

As a direct result of their exclusion from decision-making within the system, workers remain a latent force that could certainly improve the living conditions people if properly engaged. While some workers are making inroads through professional certification, training and other avenues, most find themselves treated like attendants, aides and overseers.

Workers are also paid poorly, on par with line crew at fast food restaurants if they're lucky. More and more personnel are being recruited from temporary agencies or on a part time basis too.

Even though workers are crucial in their roles, employees are often urged to move up to supervisory and management positions after a year or two of "direct care". This is particularly true with agencies that find it difficult to hold on to workers due to low salary structures.

Rampant job turnover is epidemic across all worker sectors where average tenures for new hires in direct services is less than six months, and less than a year for case managers who are generally degreed. According to numerous studies, personnel turnover has as much to do with the segregated, routine and structured character of their work duties as it does pay.

Workers who directly support people occupy the bottom of the system's organizational tree and are treated like disposable parts, coming in and out of the lives of people being served. It's not at all surprising that temporary employment agencies have become a major source of locating new workers for system over the last decade or two.

Too many workers are no more valued in their roles than the people they serve, and are seldom heralded for helping people achieve conditions of an everyday life. Given the low status and misunderstanding of their responsibilities, it's not surprising that workers find it difficult transferring to other lines of work.

Working with and on behalf of people with disability brings out an aura of "loser" or "special" in certain quarters, despite the complex tasks workers negotiate on a routine basis. The community generally has no idea about the people and organizational skills workers develop.

From a community perspective, workers are also considered out of step. Worker jobs are viewed as positions that go to people who can't get along in 'the real world'.

Workers experience interpretations of being supremely patient, slow and less adept too. Workers are said to be 'called-on by God'.

In some quarters, workers are viewed as beneficiaries of public charity rather than agents of social responsibility. They're applauded for taking on roles others wouldn't want to. While honored for their "patience" and care giving skills, they aren't acknowledged for the community outcomes they achieve with people.

Working with people with disability is not viewed as a career path to get ahead. While unions and professional associations have gotten a foothold in some areas to improve the status of workers in community services, collective bargaining is weak and more focused on salary and benefit issues than transforming worker roles and support approaches.

No one in or out of the disability fields finds it surprising that providers of service perpetually advertise in the want ads. Even in the country's deepest economic slumps, there's any number of openings at group homes being advertised.

Aggravated by short longevity and constant turnover, workers are given little or no autonomy to pursue independent living and employment outcomes outside of program settings. They can't branch out and develop networks that other people without disability would pursue without question in achieving outcomes of a job, home or community ties.

Lack of family and community linkage hurts people's integration potential greatly since workers aren't able to perform these functions under the thumb of system constraints. Lines of communication between program supervisors and families also keep director support personnel out of the loop.

Since programs in the system have no expectation of fading out over time, workers in traditional services have come to resist ways that achieve lifesharing or independent living outcomes. Workers view efforts to move on to community ways as threats to their occupational security instead of evidence of their success.

Fear based resistance to community outcomes that has been present in institutions from the 1960's has now carried over into small intermediated care facilities, group homes, and adult day programs. Just like their social worker counterparts in institutions, case managers in community systems tend to see their occupational security in terms of keeping people from advancing into community ways.

Fundamentally, workers become accustomed to their roles as overseers in places that the system has created. Workers have gotten used to being watchers of people in their charge and interveners when things seem to be getting out of hand.

To avoid these interventions, workers get quickly to a point in their jobs where they value people being left alone to watch television, take naps, and retire to their bedroom after meals. These practices subdue complexities that come with interactions in group homes and facilities. People that are alone don't make trouble or demand personal time.

The tendency to support aloneness in service approaches also speaks to how workers are selected and matched with people. Given today's practice of accepting just about anyone who passes a criminal background check to provide direct service, workers are not expected to become friends and counselors, or trusted associates.

They're given the job to be overseers and supervisors of people, pure and simple. In the tasks they complete, workers often avoid meaningful interactions and generally have no problem being more like strangers than friends.

Making matters worse, people living in homes or their families aren't given the responsibility to choose their workers or participate in orientations of new personnel. Agencies don't establish home councils, suggestion boxes or other structures by which people and families can influence the selection process or other work aspects.

Even with ongoing training in principles and advanced program concepts, it doesn't take long for workers to understand that everyday lives are no more than words passed around in public relations material and at award dinners. Workers learn soon enough that the system is invested in what a person is funded to receive.

It's this funding of services that pays for a worker's living expenses, two week vacations and health care insurance. It comes down to the job the worker is paid to perform at program sites not the outcomes people can expect in an everyday life.

Workers see clearly that financial considerations dictate the character of services, not flowery principles or pie-in-the-sky ideals. Workers clock in and out of human services today without ever giving this process or others like it a second thought.

### **Worker Woes**

Workers hold on to a peculiar form of logic to cope with system ways. The reasoning goes like this: Since services are what people are getting, workers deduce the product to be good, effective and needed.

Following this logic, workers figure that services are reasonably high quality, respectful of people's abilities, oriented to families and the community at large, and cost effective. Having services approved and managed by health and other professionals helps to make this case.

Workers figure that community organizations, employers and family members aren't involved in the lives of people for reasons that have nothing to do with how systems run the show. They come to believe the hype about how invaluable services are without considering options or what might be done better.

While this logic feels reassuring to those who have it; none of it is valid. On one level, the logic is bad and on another it doesn't make sense.

First of all, we can't reliably be making assumptions about the quality of services without outcomes to support it. Secondly, given the history of the disability experience that people have suffered through, it's hard to have faith in what service providers are supposed to do.

Let's get this straight: systems don't follow principles or work to continuously improve everyday outcomes in the services they provide, even though they may claim to. They get work done for the system to survive.

Systems don't operate programs based on logic or science, consistency or anything else apart from their own self-interest. They don't apply professional knowledge to achieve community outcomes outside their strict program confines.

Even with public demands to change their ways, systems persist in operating under the ethos of preserving a culture of supervisory authority. Sooner or later, direct service workers understand their place in the chain of command calls for them to create billable units of authorized care.

Whether that billable unit interval is counted in minutes, days, or hours, the understanding is the same. Workers are paid to be with and not engage in community ways.

Workers put in their time at the group home or the workshop. They monitor the places they are told to, and watch over people just as they are expected.

If part of their oversight requires giving lip service to supporting valued social roles for people in their care, so be it. They can do that too.

There is a basic set of question for workers in this time that reflects the struggles they may or may not admit to. These include:

*What does believing in everyday lives really mean in your work?*

*Is everyday life a group home life or work at an activity center?*

*Is protecting people from community roles and responsibilities underlying your job duties?*

*How or why not?*

### **Gauging Satisfaction**

After a while, workers see that the system counts people as satisfied when they are compliant. They see that the system assumes how living conditions are right for people when

there are no emergencies or regulatory violations to report. They see how the system takes uneventful and routine as proof that services are meeting a person's needs.

Like inmates in prison, people in programs are apt to assert themselves as powerless and subservient to overseers. Even people receiving community services, while they are not under a virtual lock and key, have similarities with adults on parole or probation. They are also at risk of institutional care if they don't behave and live by the system's rules.

Unlike prisons that give inmates credit for good behavior that goes toward reduction of their sentence, service systems have no such dispensation. Systems generally treat people as lifers rather than service recipients that will move on to homes of their own, employment and other forms of an everyday life.

The longer workers remain compliant with services that the system offers, the longer programs endure. While some workers resist conforming to program ways, many more embrace the routines that systems set up for people, deviant though they often are.

Apart from acting out or leaving, people with disability have no choice but to stay where they are placed, and go along with the life they're brought into. As long as people are not overtly resistant to program services, the system make sure workers keep on doing what they've been doing.

### **Takes On Community**

Because of system expectations, service worker outreach to the community for support is considered too dangerous, too serendipitous and too real. There's very little consideration to trying other ways.

In the end, the system's focus on compliance to rules, routines and funding streams render everyday living outcomes, like independent living, lifesharing or a job, tertiary in importance, or something else that other agencies will need to deal with. Workers don't have a vision of how breaking out from their standards driven world might improve utilization of community resources, enhance support networks, or develop relationships and personal responsibility.

People are taught by workers to prepare meals and do laundry without a sense that they will be doing these things on their own someday, in their own place, with support from their housemate or a neighbor. People attend their sheltered workshops and work crew assignments with no sense that they are being trained for community employment.

While workers are exposed to people in ways that could be enduring and deeply personal, a professionalism distancing takes over for shift workers, especially when the going gets tough. Posturing, rank and other diversions keep people from ever getting close and understanding one another.

There aren't a lot of personal assessments made in terms of where a person wants to go or what he or she wants to achieve in life. Lots of subjects that should be broached never get started.

Workers relate as caregivers to those people in their charge. Roles that would achieve community outcomes are down played and ignored.

Workers don't adopt everyday practices to make things better and more relevant. They don't q-in to doing things differently or even outside in the back yard. There's no sense of promise with new ways. System workers are trapped in their surroundings, just like people are.

Operating within a culture passed on by overly cautious program directors, funding agents and intermediaries who are concerned with rules and getting paid, workers remain focused on people staying safe and amused. Supervisory and monitoring personnel make it abundantly clear that compliance with system norms is what counts in all this.

Methods that would be naturally in play within a community context are not due to arcane funding policy, deficit-inspired service structures, liability concerns, and practices steeped in institutional tradition. Clear demarcation lines prevent any holistic approach from being considered, let alone taking hold.

Add to these characteristics a quality-management approach that has no accountability to everyday living outcomes, and we can begin to appreciate just what workers face.

The system is a lazy monster as far as many workers are concerned. Since they know they can't change it, they go along with what they're instructed to do.

Those with the gumption to step out from the routine know the frustration of trying to change for the better, even a little bit. The additional record keeping, not to mention waiver requests, additional meetings, data entry and special monitoring visits can be maddening.

Workers that take on the challenge of different ways with or without supervisory support, find themselves in a fix. They take a chance in defying boundaries especially when exploring a person's autonomy and independence, or reducing units of paid service.

Even when workers and their supervisors find a way to pursue new paths, other entities, including case managers, are generally lurking in the shadows, ready to prevent real progress from occurring due to technical aspects of a treatment plan, or something similar.

As a result of the sheer number of people grouped in program settings today, worker decision-making becomes focused on achieving what the system can do within the limitations of group settings. Because of the size and other characteristics of client groupings, workers achieve outcomes that can only occur within the boundaries of these funded programs.

As a result of size considerations, workers don't assist people to venture out into community ways out of concern that feelings will be hurt, or the person will act out when



returning to the group life after a weekend with family or friends. Integrative opportunities are avoided and denied for no better reason than workers don't have the time to deal with the perceived affects.

In fact, workers don't have that time for social integration or relevant programs. Getting groups of individuals ready for anything, including checking that all the seat belts are buckled in the van and lunch pails closed, creates challenges and routines enough. Add to that individual factors, fickle machinery and baffling medication schedules and it's easy to see how workers in group services have a lot going on.

Time for people and their individual issues just isn't on the plate when there is a slew of daily records, health checks and other documentation to complete either. Basically, time with people is what matters, and there's already too little of that.

Even though case managers are supposedly responsible for taking a person's everyday life, work choices and independence into consideration in designing service plans, they don't. Case managers become the system's primary enforcers of the system's reality, legitimizing narrowly defined services, planning and programs as their major role.

By relegating life outside the system to a long-term goal at best, case managers sign off on the unspoken deal that makes sure people remain in their service bubble, a world apart from the community-at-large. In the final analysis, case managers avoid putting systems in a position to act on everyday living outcomes that the system can't deal with.

In the process of system-controlled living and activities, worker drive and spirit to achieve everyday outcomes get worn down, eventually collapsing from misuse, frustration and neglect. When there is little latitude or no expectation for workers to assist people in achieving community outcomes, there's no way to support everyday lives.

That's the way it is in the service system today, and that's the arching tale of far too many workers.

### **Changing Roles**

Staying true to new ways of everyday support may seem next to impossible because of the methods used by the service systems today, and the roles workers are forced to play within them. That's not necessarily the case.

While it is true that this country needs to face contradictions between system and community practices, workers can make adjustments in their tasks, but they need to be directed and supported in that way which they are not.

For too many workers now, supporting community outcomes means being subversive. While it is good that men and women have the gumption to work with people in ways that support them, forms of outcome directed action come with their risks.

Knowing where the boundaries are in the process of supporting takes time and trust and that's not what workers develop with people today. Those workers that have earned their stripes so to speak will take risks with people and that's how it should be.

It's easy to say get around system controls, be a hero, and such, but that's not really fair to workers either. Workers just expect to be workers. There's no making magic in their job descriptions.

Workers need to know what their roles are and how they are going to be evaluated according to their outcomes with people. These outcomes need to be a home, a steady job, and others to rely on.

End of story. So be it. I wish.

### **The Road Back**

Supporting people does require workers to ignore what doesn't make sense in the system and to find their own ways to escape service dependency and achieve community outcomes. Good programs accept this already.

In the playbook of community support, workers devote their time in a focused and productive manner. They begin this process by taking out the useless stuff they do to keep systems happy and by using this time constructively. They use their judgment, even when regulations are concerned.

With space, direction and encouragement, workers use their time to develop opportunities in the community, outside of institutions and congregate care sites. They stop looking over people's shoulders and lend a hand to engage with the community under each individual's direction.

Workers secure community resources for public transportation, and accompany a person in their development of friendships. They represent living that includes jobs, loving families, and good times.

They turn to community resources that already exist, and offer support to utilize these resources, whatever it takes. Workers find the funding in services, community, you name it. They're out there for people, and it shows.

Workers that make a difference in these community support venues are tapped for their expertise, and ability to get things done. They are the shakers and the movers in an otherwise dismal service existence.

Effective supported employment specialists are already able to show how success with people has nothing to do with congregate care rules and assumptions. These workers circulate in the real world where personal and task analysis skills count highly, and valued roles are the key.

Life sharers and companions enjoy one another and shake their head constantly at confining system ways and means. They flat out ignore rules and practices that don't work with people, which is good and more important necessary.

Workers in a community venue don't worry themselves with meeting physical and program standards applied to congregate care homes and facilities. They measure success in terms of a person's achievement and the community resource's stake. They work so people are competent in transacting real life situations.

Professional distancing that is so common in most system services doesn't play out in relationships born of these community ways. Neither does invisibility, negative interpretations, or moss on a stone.

### **What It Takes**

Getting beyond the system's clutches requires a whatever-it-takes attitude to spread on a much larger scale. As a country, we need to be sure workers wake up and tune into what works and what doesn't in real life, in real time. This rule book centered in agency operated places just has to end.

We need to be sure that the manner and methods workers use in supporting people are consistent with how personal assistance gets funded and community outcomes get measured. This change in direction is not about the system anymore; it's all about outcomes the community can influence, manage and sustain.

Funding in this respect becomes conditional on outcomes in community experience. Worker performance that leads to everyday lives gets compensated, nothing else.

The bitter rest is trashed and left behind. Workers who want to be accountable to new ways are retrained for demonstrated competency. There is no grandfathering in.

As new paths are taken, there is no doubt about what is extraneous to the work of supporting people and what is not. Workers in a support network would be compensated for the range of support they offer.

All parties exercise autonomy and responsibility, while taking direction from the person in achieving valued social roles that they've agreed to. They hang together and don't leave their community posts on a whim or the behest of anyone.

As compliance and organizational responsibilities are eliminated and reduced, workers are free to support outcomes and stick to that course. Workers appreciate that their pay checks are geared to achievements that the community truly respects.

With outcomes being achieved, workers become much more marketable. Their pay improves with the valued perceptions around the jobs they do. They're considered inclusion engineers.

