Chapter 12: System Ways

Collapse

Service systems have the feel of being trapped in a vast deteriorating building. Conditions have come to the point where persistent water damage from a leaking roof has led to dripping walls, blistered ceilings, and sagging joists.

Problems are serious, with wide cracks and bulges in the basement's foundation. Vermin roam freely. Nightshade and poison ivy grow wild around the place. Thick strings of wild morning glory cover what might have been a garden, and there's still no place to park.

We know this collapsing world all too well as advocates, policy makers, program supervisors, workers, families and people receiving services. We know about the dangers imposed by being where the system makes us be. We can see the need for getting out.

We keep telling ourselves that something new is coming but remain in this domain that we're used to. We even keep coming back here for any number of reasons, some of which we don't pretend to understand.

When pressed, we realize we're here because it's pretty much what we know. We think maybe this is as good as it gets.

We've even convinced ourselves that communities are powerless to imagine or act responsibly like service workers and their systems do. As system workers, we're not sure about what supporting people in jobs and homes of their own might really mean to our life styles.

While those who live and work systems have a vague sense that we'll be moving out somehow someday with people, no one voices a clear way to proceed. Leaders vacillate on how or even whether to adopt new approaches, buying into a sentiment that community alternatives are cold, unreliable and scary places for 'vulnerable' people used to something sheltered.

For whatever reasons, those in charge of the decaying building want to keep a lid on things. They don't want to piss off their tenants that call this place their home or work place.

 They also don't want to alarm the community, lenders or their sponsors that their current existence cannot be sustained. It's been clear for a long time that these owners are resigned to wait till the whole place falls down, after bleeding it for all its worth.

 It's no surprise that the current building superintendent has a jaundiced way about him, like the last one did. His fall back never changes in terms of staying away from publicity and having no more money to make what he refers to as 'improvements.'

While nobody admits to liking the superintendent for the infuriating remarks he makes about people, his assessments are at least consistent. I for one have never met a man or woman more ignorant of others. He's all about himself.

Having been down so long, those of us living and working in the building are not at all that confident that new places will be any more welcoming and secure. We've lost confidence in relating to community resources that surround us, and we don't know where to go for the change we know must happen.

We don't have the energy we once had either. We're afraid we can't do the work that we'll be called on to do in taking new ways. We're disbelieving that checks and balances can be sustained outside of these walls.

We've even come to a point of admitting that good intentions, promises and pretending won't make things better or correct the hazards we face. At least we've stopped pretending that a new invention or surfactant, or more resources are going to save the day here.

As window panes crack and floors buckle, we see all our current ways coming together into a kind of uselessness. There is also a sense of immediate danger and wastefulness that washes over us all now and again.

As another section of gutter and some bricks fall to the ground, we finally decide to let the chips fall where they may. Whatever happens outside our collapsing state, we'll be saving ourselves and future generations.

We finally refuse to be self-imposed victims of exile and invisibility any longer. We don't want to be buried here, so we pick up our belongings and go.

In stepping out to engage in community ways together, we sense the wonder of all that awaits us. We walk through a pasture, along a busy avenue and up and down rolling hills, saying hello to passersby and admiring the sites.

We realize the openness of possibility and space that the community shares. We feel renewed and a sense of belonging. We feel safe too, as we realize this world works for those living in it.

We're surprised about these feelings and pleased too. We like that there are all these doors and windows in life now, places to explore and interesting people to meet.

With every step away from the crumbling building that defined us, we feel less burdened. This lightness that comes over us and stays feels good, and so does the sense of strength in being together.

As we let life in then, we know we can never move back to the building. In the community at last, we relish the arching promise of new ways.

A Vonnegut Take

As the struggle to adopt new ways takes form, a stubborn status quo stands against people leaving the system's control. Executives and their boards claim that living in a group home or facility, or working in a day program comes as close as possible to everyday ways.

They claim that people are satisfied in service environments that they don't choose to be in or attend. The truth is that without any opportunity to sample lifesharing, jobs and other forms everyday life, people are essentially told what to like and what to fear.

While conventional wisdom says that that keeping people safe and happy are fundamental outcomes too, there's more to life than that. Positive aspects of a secure environment aren't legitimate outside the broader context that achieves valued social roles with people.

Within the confines of group homes and sheltered workshops, practices and routines are very much like those in institutions. People attending these programs get up in the morning together and go to sleep early, have few outside friends, take loads of medication, and spend most days in demeaning life-wasting situations.

People in community services, like their institutional counterparts, also get transported to make-believe adult work and social events supervised by paid program personnel and families. People learn to accept these conditions and their primary role to be cared for by others.

Kurt Vonnegut, speaking to this role in his novel <u>Slapstick</u>, wrote:

"My dearest Tish- Our children will be very happy here. We can be proud. Our architect can be proud. The workmen can be proud. However short our children's lives may be, we will have given them the gifts of dignity and happiness. We have created a delightful asteroid for them, a little world with only one mansion on it, and otherwise covered with apple trees."

A little later in the novel, Vonnegut continues:

Consider: "We were at the center of the lives of those who cared for us. They could be heroically Christian in their own eyes only if Eliza (the protagonist's sister) and I remained helpless and vile. If we became openly wise and self-reliant, they would become our drab and inferior assistants. If we became capable of going out into the world, they might lose their apartment, their color televisions, their illusions of being sort of doctors and nurses, and their high-paying jobs.

So, from the very first, and without quite knowing what they were doing, I am sure, they begged us a thousand times a day to go on being helpless and vile. There was only one small advancement they wished us to make up the ladder of human achievements. They hoped with all their hearts that we would become toilet trained.

Again: We were glad to comply."

Like Vonnegut's passages convey, people living in service systems are not supported to assume responsibility outside their most basic personal care. This applies in community as well as institutional programs today as much as in the past.

People are taught to get along within the formalized programs to let the system take over and make their decisions. Given the alternative of being taken care of, they become, in Vonnegut terms, "glad to comply."

Vonnegut's passages in <u>Slapstick</u> also touch on how daily living functions, like what and when people eat, are taken over by systems. The longer programs are involved in this way, the more functions they come to control until they manage every corner of a person's existence.

The idea that program structures would fade-out, as people become more self-reliant through community engagement and learning new things, is not taken seriously. Substituting community resources for institutional ways just doesn't get done due to the structures systems have created.

Vonnegut knew, from working in institution as a young adult after college, that inmates are watched over by workers. He experienced how nurses and aides relate to people and how rock bottom expectations pervade their relationships.

In the year or so that he worked in a facility, Vonnegut figured out what was going on. For workers, he saw how taking care of people became the job. For professionals, he saw the same thing with more perks and organizational duties.

Vonnegut realized that it took resources to maintain that 'mansion surrounded by apple trees'. Following the money helped him explain the behavior and interpretations of workers, families, and people alike.

In deference to the author's observations in <u>Slapstick</u>, this country doesn't want 'mansions' for people anymore. There are certainly better ways.

<u>Money Flows</u>

Public funding is what systems are all about. Money which agencies get allocated from state and federal coffers explains why certain types of programs remain entrenched in certain places, and why others never get started or fade away.

The almighty dollar sets the stage for worker sentiments and its why families and people feel leery about taking new ways. Decisions about how funding flows become paramount on any given day in almost every service related action. Entities that receive funding call the shots with those pass this funding on.

The behavior that funding evokes makes it all too clear that there is nothing in systems that comes close in systems to the satisfaction of having fully funded programs. In contrast to money flowing, good ideas don't count and futures elsewhere don't either.

The work in today's systems is about making services run with resources allocated by Medicaid and other funding streams passed on through state legislators. Tens of billions of these dollars flow annually to ensure that as many people as possible are served.

Budget formulas and service definition requirements established in Medicaid create strong incentives to superimpose 'half-way' and institutional conditions on everyday life. Funding to secure community ties with people isn't even on the radar in most areas, and accountability to community outcomes is bantered about at best.

In Medicaid and other state and federal programs today, community support outcomes like lifesharing and employment emerge in fits and starts without any clear path to being first and foremost. When funding get tights or cut, models like group homes and facilities are left holding the money, while cost effective alternatives get the proverbial bag.

Even in times when funding is not a problem, agencies that would like to transform archaic methods are dissuaded by restrictive service definitions and funding formulae, not to mention what systems are used to doing. Cost effectiveness considerations are gamed to the point where a clear picture on what services actually cost stays perpetually murky.

Rather than be straight about the feasibility of supporting what works with people in securing everyday living, systems ignore continuous quality improvement processes that would lead to the adoption of new ways. Systems don't value independent assessments and other renewal mechanisms as a means to improve cost effectiveness like normal business and other organizations do.

Systems ignore all that. They've been immune from consideration of market forces and even elemental forms of customer satisfaction for generations. It's been much too easy for funders to avoid key decisions by leaving what they perceive to be well enough alone.

Economically, systems operate like a monopoly or fiefdom. Instead of comparing the true costs of system services to community support approaches, systems establish their own metrics that selectively compare community and institutional expenses. They use averaging and other means to hide outrageous outliers, and dissuade agencies without deep pockets form entering the provider ranks.

It is easy for community services to be considered cost effective when a public institution in New York State costs a quarter million dollars per person a year. It's a lot harder to be honest about comparisons with lifesharing, employment and volunteer work support fees that utilize generic resources, and cost a whole lot less.

Using their peculiar style of justification with legislators, systems get away with continuing outmoded approaches. They get to interpret waiting lists as an indicator of service demand, never confronting the feasibility of alternative cost effective roles that untapped community resources would otherwise fulfill.

Efforts to locate community support options with people are strangled, shortchanged and bypassed time and time again by system operatives who keep their cost effective message on point. As long as legislators and the public continue to buy comparisons to institutional ways and other deviant indicators, there is no room for changing ways to take hold.

Money Matters

It's time to call this monopoly of agency controlled and operated services what it is: a hoax, a waste, and a violation of the public trust. Ensuring the continuation of public funding for their array of expensive and restrictive programs leaves no room for cost effective community support resources to develop.

The average annual per-capita cost of a group homes in the 21st century has eclipsed $80,000, compared to $20,000 to $30,000 for a lifesharing package. Public and private institutions under the entitlement protections of Medicaid ICF/MR cost about $200,000 a person in many parts of the country.

On average, individual system recipients with disability utilize about $60,000 annually in Medicaid home and community based waiver funding outside of medical expenses, social security income benefits, food stamps in group homes, and the like.

Services in Medicaid waivers as well as ICF/MR funding in institutions, are expected to be indefinite, compounding costs year upon year. At today's rates, twenty five years of community services can be expected to cost the public a cool million dollars a person over a lifetime. Triple that for institutional care.

While supported employment costs more than sheltered work and day activities for a couple of years, individuals who spend their adult lives in congregate training programs cost taxpayers over $300,000, at the current clip of about $17,000 a year. Long term supported employment costs are no more than a quarter of this and often quite a bit less when ongoing support is taken over by employers, work colleagues and others.

Despite the cost effectiveness of lifesharing and other forms of everyday living, people with behavioral and medical challenges are routinely placed in multimillion dollar a year residential programs with shift workers, restraints and social isolation. So called 'one-person homes' for behaviorally and medically challenged individuals have cost $3 million dollars a year thanks to 3 staff on 1 person staffing models they have utilized.

Lifesharing and other creative support alternatives could be available at a tenth of the cost of these high end programs, but can't be accessed due to funding and attitudinal restrictions associated with living approaches that are not agency operated. When considering how many people are still forced to leave their family homes due to lack of family resources, it's easy to see how systems could have been much from cost effective than they were over the years.

Tales of relationships torn apart by the lure of high cost community homes are all too common today, and among the saddest tales imaginable. Too many wonderful and inspired

lifesharing relationships that had been together for decades have been torn asunder by conniving case managers and residential provider agencies putting pressure on frightened families to conform.

As system ways like this give way to community support, agencies will have to give up their specialized settings and programs. There won't be legacy services sneaking in through the back door and institutional or group home services for people to live.

If agencies that operate congregate services want to reinvent themselves and participate in new ways, that would be well and good, but it won't be on the old terms anymore. This nation can no longer afford to allow the old ways to continue while new forms gradually evolve.

With formalized services cut off, congregate care approaches will not have the power they did to suck energy out of workers and people's spirit. They'll be no more fixation on pleasing the system once its responsibilities to place, define, control, and structure have been turned over.

Standard bearers will need to give up the special resources they've used to keep systems going. They'll have to sell or find other uses for those group homes and center based programs they've been able to procure.

Those agencies that operated in the old ways will also have to begin anew and be a lot more humble in the process. They'll need to accept that communities and people are their main customers now.

Ways and Means

The ways of the service system are not those that people rely on in the community. People receiving services get closeted into a disability world.

People in service don't congregate or organize outside their restricted program circles. Disability focused relationships become the closest people get to a family, friends and community life.

In this world of service, systems decide what gets done and what doesn't. Systems don't offer services that lead to everyday lives like they pretend to, and they aren't accountable to achieving meaningful community participation in any way, shape or form.

Thanks to the spin that systems put on the neediness of people, the public gets tricked into assuming that people must be living in a special world of programs and benefits, herded in groups both big and small, and kept safe and excluded from the experiences of community life. What else could the community think but that people are helpless, even though they are not?

While system's give lip service to employment or lifesharing as something they strive to achieve, the chances of developing community ties with people is no better than the odds of

snatching the gold ring on a merry-go- round. Community is just a bit player in the system's high stakes game.

No wonder so much of human service work is disconnected from the mainstream of community life. No wonder community stakeholders shy away from support roles as family, employers and coworkers, neighbors and friends.

For far too long, the deck has been stacked so the system could take over people's lives. It's time to change that now.

Binds and Critters

What we've created in systems today is something workers and advocates stopped admiring decades ago. Although diehards continue to assert that their structured programs are doing just fine 'for' people, they do so without considering everyday outcomes or how their work might be done 'with' people for a change.

Though system advocates will not admit it, the basic problem is that programs have become disconnected to community ways and the motivations and relationships that fuel them. What people and this country expect is becoming more and more distant from what systems can offer.

People want opportunity and community embrace. They want support that achieves everyday living outcomes, and not services that don't. While some service providers would gladly give over control to people and communities, they can't make this call under system funding and policy constraints. Support without legislated frameworks never gets considered.

It's time to be honest: service approaches that might have worked as a half way measure thirty to forty years ago when deinstitutionalization was beginning and in a rescue mode don't work like they were intended to any more. A system that ensures that people remain in overly restrictive programs doesn't deserve to be calling the shots.

This country has been duped by systems into believing that programs are flexible and leading to everyday lives for people, when they are not. The truth is that people in services hoover about the community, never rooted, drifting and out of touch.

As a country, we've become so used to this distancing of people that we're unable see a way to welcome them home. We've become a nation unable to reach out to one another and apply community ways to the social challenges we face.

While systems maintain sophisticated data bases on almost every aspect of people's health and daily lives, what good is this information if the community can't use it to support people on the personal journeys that they choose? What good is having this information if it can't be shared?

While service operators talk a good a line about advancing promising practice, there are sheep in wolf's clothing. Here's a warning to community leaders about that: these system critters stay focused; travel in packs, and flash sharp teeth without a moment's notice.

What's new in this generation is that the rapacious appetite of monster systems has caused them to become sluggish, no longer able to maneuver in a world that expects tailored and individualized solutions. The systems of today simply can't keep up with society with its rapid pace of change.

They don't have the customer ethic and other qualities that have become part of this me-generation either. Systems suffer by costing too much for the meager achievements they have been able to realize with people.

The gap between the system's constraints and community alternatives is too great for leaders to bridge anymore. Like they say in a building about to collapse, it's time to get out while the getting is good.

Collaboration (Not)

Collaboration between the various agencies that work in system ways is done poorly at best, rarely reaching people in the manner intended. Collusion to sputter and fail, incoherent practices and rigid lines of demarcation stall progress and undermine possibilities, time after time.

Agencies representing different funding streams typically can't find common ground or won't hold themselves accountable to achieving what they can do in the best interests of people. Collaborative bodies, from advisory boards to task forces and coalitions, aren't dedicated to improving outcomes beyond leaving well enough alone.

Collaborative bodies also keep out important community players by determining who is invited to their functions and events. Remarkable as this may seem, system players have not reached out to business leaders in talks about improving employment outcomes or to community groups to enhance use of generic housing and volunteer resources.

Meetings occur in system agency offices and at times that suit professionals. Program managers are so busy that legitimate collaboration tasks get rushed through and brushed over.

The cooperation debacle between systems affects state and local entities in education, adult services, and vocational programs. Child welfare and health related services are also included in the mess. No agency or stakeholder is immune from the ills of this ruse.

In Pennsylvania, local interagency coordination councils that have been in place for decades haven't contributed an iota to improving post school employment and community outcomes for students transitioning into adult life. The talking head culture of these and similar bodies is widely known.

Meanwhile, federal agencies responsible for funding legislation through education and adult services stay out of state and other coalitions, avoiding accountability to community outcomes as much as they can. While the Centers for Medicaid and Medicare Services (CMMS), and the Department of Labor have provided incentives and many grants to States so they can improve infrastructure integrity, no amount of resources have improved outcomes or a change in the straightjacketed cultures that persist.

A basic problem with all this is that workers in collaborative bodies talk to their counterparts in other systems. Program developers talk within their circle, as department heads do, and none take direction from people and communities outside their domains. That which is considered important by one agency is trivialized by another.

People receiving service, families and community stakeholders are often included in collaboration activities as tokens while the real power rests with funding entities. While State developmental disability planning councils (first established in the Kennedy era) have had some positive affects in fostering community ties, council ties to system operations are generally tenuous at best.

Because of divides like this, collaboration between systems remains pretty much a lateral game played within the bounds of systems play. There's always lot of talk at meetings about getting things done at certain 'levels' without a sense that program improvements will affect people and their lives in sustained community ways.

Decisions about program practice are not being made in these collaborative bodies either. They're limited span of control results in suggestions being run up chains of command, a tried and true recipe for getting nothing done or unconscionable delays.

There's generally nothing looping back or reaching out in the process of collaboration either. For each program change that a collaborative body champions, there's any number of operational barriers standing in the way. Follow-up to determine effectiveness of new practices is generally out of the question.

While access to community resources is a topic that is talked about in task forces and such, the confines of public funding prevent action being taken outside of strict program domains. Systems are not using one another to make their rules and practices people and community friendly, or any more accountable to outcomes.

The net result of collaborative failures is that foster children and young adults with disability are dropped off at the door step of adult service systems when they turn 21 with no funding to support their transition to adult life. Adults who have worked in sheltered workshops for years still can't get referred to vocational rehabilitation agencies for evaluation and employment support. People with multiple diagnoses can't access mental health services due to policies that prevent Medicaid waiver and other funding streams from combining in reasonable ways.

Because collaboration has failed and given up, older Americans with disability are not welcomed at senior centers, and people can't access shared rides to work. The ills go on and on in the use of generic resources too, since probation and parole, municipal authorities, transportation companies, and other agencies are left out of these discussions.

Memoranda of understanding and other administrative tools that are supposed to promote seamless access to resources from different system have no influence on local entities and providers that march to different drums. In those rare instances where constructive practices involving multiple systems are issued, stakeholders game them and delay implementation.

Monitoring and follow-up practices to measure progress of joint system initiatives are almost impossible to find, let alone track. Once a project's pilot funding dries up, so do the good ideas and momentum that developed.

Linking pilots to actual statewide or national practice is an art systems have refused to nurture. After initial enthusiasm that comes with beginning to test new forms of support, nothing endures to affect people and systems in general.

In Pennsylvania, collaborative work involving the Office I worked in and others within the Department and outside dropped the ball in expanding pilot experiences in supporting people with dual diagnosis, on probation and parole, in school to work transition, and in foster care transition to adult residential service. While some collaborative activities worked too, the percentage of successful endeavors was never that high.

A major reason for these failures is that local communities of practice, which everyone agrees to as being a necessary core to improving outcomes with people, aren't given the autonomy they need. Contradictory laws and program practices in place within sister agencies hold up their progress in all sorts of ways, from getting jobs, to home finding and securing community ties. Before long, turf issues, and malaise contribute to nothing of substance getting done in these forums either.

Systems relate to one another as silos and won't have it any other way. Individually, each network is so caught up in its own special protocols that workers are unable to focus on combining resources to advance cost effectiveness.

Instead of passing people's support to an appropriate agency in another system, case workers and other professionals get caught up in doing it their way or no way. They become proprietary and stuck in their silos.

The brain dump and misappropriation of resources that occur in collaborative interactions also remain unmatched. Falling back to a state of contradictions and separate cultures, instead of finding new and better ways, becomes inevitable.

Committees and work groups formed to bring resources together become mired in turf battles, and a parade of prestige-laden, show-and-tell exercises. Higher-ups assign their staff to work groups to forestall decision making, expecting nothing to get done.

While agencies claim that collaboration is their strong suit and a sure fire way of addressing system woes, nothing could be farther from the proof. Systems dance together for the image their togetherness creates, but not much more.

In this way, systems that specialize in community and institutional services treat other agencies like they do community resources. They deal with the other agencies, especially on a state level in a surface way, attending functions together, but never getting down to much that makes a difference in people's lives.

The code word for collaboration today, like it has been for decades, is wishful thinking. Nothing gets done with interagency collaboration; nothing changes and nothing improves.

Talking heads are what collaborative bodies end up being, focused on their next big conference where dazed and hurried stakeholders receive a flood of redundant information and feel good tales of promising practice they will never be expected to implement.

In the end, collaboration operates the way it feels: like a colossal waste of time and money. Such is another arching tale of system woes, where there is always another trap along the way.

Dependent Norms

People with disability and families become pawns in this game too. They cater to system practices to obtain paid and unpaid disability benefits and relief from responsibilities they can no longer manage.

People who use system resources generally rely on systems to receive grants for the basics of life: housing, food and health care. They also receive monthly Social Security Income checks for room and board and everyday expenses, too.

Given what people are allotted through government and charitable funding sources, it becomes unnecessary, and sometimes nearly impossible, to find space and time for other resources and unpaid relationships to take hold. People are totally given over to their system whether that's institutional of community based.

Some families stay in close touch with their loved ones during the process of system take over and others don't. There's not much going on in the systems to influence family ongoing relationships, one way or the other.

Systems don't encourage families to recruit support workers from their work and friendship circles, take on quality improvement roles with programs, or take on substitute care responsibilities. The system's tendency to keep families, like other community resources, away from their operations affects millions of people across the country, and costs plenty in more ways than anyone admits.

Meanwhile, the AARP (American Association of Retired Persons) reports that more than 40 million Americans cared for adults with disabilities and aging individuals in 2011, voluntarily for the most part. The value of volunteer services family members provide was estimated at $450 billion annually.

An author of this study notes:

"A key theme to emerge from systematic reviews of family caregiving studies over the past 30 years, is that family care can have negative effects on the caregiver's own financial situation, retirement security, physical and emotional health, social networks, careers and ability to keep their loved ones at home."

Service systems funded under Medicaid and Social Security have become more than an umbrella that takes care of people when they need it. People who use these resources are expected to stay pat and go along with the program, while the public unquestionably pays.

These publicly funded worlds that systems create for people are not healthy when they close off other resources like they do. Their misplaced entitlement structures are not a formula for success in real life, but people and families have to settle for them anyway.

People and families who rely on disability services do what their benefits require of them. Because of the limited array of choices systems authorize, systems control the way of life for these hundreds of thousands of individuals, even millions of people when families and loved ones are considered.

Scariest of all is the prospect of formalized systems taking over support for baby boomers experiencing disability in the next 20 to 30 years. What will the system look like under the structures that operate now?

What will happen to the independence and relationships of older people when systems begin to cut out access to their community resources too? How many case managers will it take to police the lives of older people to keep them under a system's control?

How many more monitoring resources will be wasted doing the wrong things in wrong places for the same closed minded results?

Crooked Tongues

While stakeholders apply nice sounding words to describe what they do and strive to achieve, their systems work against community ways and keep people from using resources they deserve. Hiding behind lofty principles and mission statements, leadership disregards what matters with people and the community alike.

 Systems know the power of feel-good words in their use of concepts like community, choice, personal control, success, and self-determination. Leaders toy with these words, but can't apply them.

While advocates of program control will readily admit to difficulties that systems face, their bland acceptance of inertia doesn't change. They talk about doing things, but don't bring home the bacon.

Systems manipulate feelings, like they do words, like they do people. For example, the term "community homes" in system-speak encompasses medium-sized institutions as well as group living homes of any size in certain states from Pennsylvania to California.

Calling a place where people live a home is a stretch when residents don't chose to be there in the first place, and would just as soon be living anywhere else. Calling a sheltered workshop a job for people ignores similar inconsistencies with cultural norms and living conditions that the general public understands.

Studies over the last ten years show that half of the people in residential services don't even participate in deciding where they live, whom they live with, or where they find work. A house or work place is not a home or job in the system. It's a placement.

Similarly, the commonly used term "vocational training" has nothing to do with people choosing their career or line of work. The only training people in these programs get is work that allows them to stay in their sheltered living state.

To make matters more confusing, systems frequently update their lingo in describing people, procedures and programs, resulting in an endless parade of acronyms and politically correct phraseology. Some wording changes, like people first language have been good, and others have not been helpful at all.

For example, so called "person-centered planning," is not at all centered on achieving an everyday life with people. While person centered wording speaks to how planning should be about people first, application and methods mask the ugly truth that there is really nothing person centered going on beyond system confines.

To keep current with the state of the art in theory at least, disability services constantly change the names and labels of people they support, and services too. Systems love to play with words in deference to respect for people that their services rarely achieve.

Today's preferential term: "people with intellectual disabilities" will be eclipsed too, just as words like consumer, client, resident, imbecile and inmate have come into disfavor over time. Who knows, maybe people will just be people.

An ever evolving pursuit of the right name for people underscores how much systems want to do right, but can't. While decisions about what people are called in institutions might be expected to be deviant considering how hundreds of people are congregated there, the lack of people first wording in community services is a little more curious.

Regardless of their institutional or community status, workers routinely disregard person-first options in referring to individuals, preferring terms like 'the retarded', 'our kids', 'the

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residents', 'clients' and " the high-functioning ones". It doesn't say a lot about respecting others when workers refer to people in the third person, like "these people" or "the residents here."

Calling people by their disability reflects distance and invisibility most of all. Substituting clinical terms for real names is a measure of how far workers remain from having close and warm interactions with people and utilizing community ways.

Avoiding real names also is a symptom of all the clinical and group contexts where systems place people. System terminology reflects that people live in worlds apart.

The saying self-advocates use: "label jars, not people" makes it clear that people with disability recognize the detachment that's being reinforced by the names systems use. Rarely do people in service get introduced in public by their first and last names, as would be expected in the general community.

First names for adults like James become 'Jimmy', or even 'Jimmy, my boy'. Workers who are barely out of high school ignore respect to their elders on the basis of their client status.

System-speak also manifests in other specialized terminology, acronyms, and jargon. Residential service abbreviations like PLF for private licensed facility, ICF for intermediate care facility and NF for nursing home form a verbal short-hand that is only used in system parlance.

These acronyms have no root in community life and nothing relationship oriented or valued about them. While program abbreviations like CLAs for community living arrangements have a 'c' in their favor, these initials also stand for program funding streams, too.

So called 'waiver homes' named for Medicaid Home and Community Based Services (HCBS) are another example of how people become associated with funding streams responsible for their residential and other programs. Referring to residences by their capacity, like a '4 bed home', just makes deviancy finger pointing worse.

Another aspect of system language is how it continues to affirm stakeholders who are in-the-know about how services operate. Knowing the lingo definitely helps those who want to communicate about funding, policy and procedures within system circles.

System speak is also great example of how human services have become like other industries and business that specialize in a particular line of work, in this case caring for people. The acronyms and other code words wouldn't be a problem if they didn't serve to dislocate people further from community life.

The community doesn't relate positively to these terms and phrases. The words aren't born in the relationships and valued roles people with and without disability have.

Language of the system, like its other aspects, is all about the system and not the people or the communities they live in. To change that, communication needs to begin with people and take direction from them in framing messages that support valued roles.

Terms need to reflect generic usage and meanings like home, job, and community ties. Nobody benefits from deviant wording anymore.

In the big picture, clinical terms and abbreviations do little more than amplify how language separates people and workers in everyday life. Social responsibility emerges when the community speaks the language of people within it.

Neighbors and congregations support people, not clients or residents or 'them". Employment means a job and career, not a sheltered workshop paying subminimum wage.

Using words to Objectify people also underscores the "we-they" divide that is common throughout systems today. Systems can't get their workforce past labeling people as "them", not "us" since people in the system live and work in such different ways than their workers and the community at large.

We-they distinctions cascade into other realms as well, demonstrating how language mirrors experience. For example, workers don't usually live in neighborhoods that include a group home, facility or other form of service. Workers also don't socialize with people they serve either, even though this would be quite helpful as part of their everyday support roles.

Until these separate conditions change, the language of separation and distancing can only stay in place.

Counterfeit Need

Systems justify their programs on the basis of 'consumer need', another curious phenomenon.

Needing a service as a consumer, while it sounds like a reasonable benchmark, plays out in a number of ways. Generally speaking, needs get confused with the system's authorization to place people in programs.

The needs orientation opens the door to standard approaches provided in special places and different times. Needing is also viewed in terms of what specialized systems offer, not communities.

When it comes down to opportunity to achieve community outcomes, people served in programs on the basis of neediness aren't going to the chance and support they deserve to live in everyday ways. As consumers, people will be viewed as soaking up resources from the system, instead of citizens who utilize support to achieve valued social roles.

As far systems are concerned, people in service will always have to be treated in ways to address their needs first, not their aspirations to be valued members of society. A basic problem with this orientation is that programs don't see the other side of neediness, or everyday living outside its confines.

From the system's viewpoint, neediness requires no more of a community response than for the public to fund their special programs. Using system resources to support people in community ways doesn't get considered in this universe focused on living with the handicap - not the outcome.

In the name of neediness, people are denied access to job possibilities and lifesharing options as a matter of course. Thanks to neediness, opportunities to use social capital and secure valued roles are wasted.

When people are deemed needy, even seasoned support workers and loving families get fooled into advocating for specialized services, instead of empowering people and their communities to work their challenges out together. As consumers, people don't get to be citizens, contributors, self-determined adults due the same respect as others.

People served as needy get loaded with medications and other health related remedies. They also get oversight when freedom would do them better, along with new diagnosis and classifications instead of new ways.

Programs don't want to let on that people are, in fact, less needy than they are portrayed. Practitioners don't want to admit that the needy sides of people get addressed when community outcomes, like having a loving relationship or a job, are achieved.

Overwhelmingly, neediness perceptions sever employment opportunities, as much as residential or community ones. Service and government agencies that could "walk the talk" by employing people can't get over their needy stereotypes.

Neediness and consumer identity fits like a hand in glove. In contrast, accommodation with people sets a much different tone and relationships.

As consumer neediness interpretations continue to prevent community businesses from employing people, people find themselves deprived in other ways, such as being left out of family businesses and estate planning. Thanks to neediness, people don't have access to a personal debit card or the support they need to manage a checking account.

Neediness prevents people from seeing their benefit checks or having any control on how it's spent. It puts workers into roles that they don't have to fulfill.

Systems get trapped in an all or nothing mentality so that people become assisted in totally needy ways. In this approach, those in need get needier, and the element of support gets lost.

Being needy, a person who requires minimum assistance to get a job gets the same costly array of training services, case management, and monitoring that a person with the most severe impairments in an institution. One needy size fits all.

Until resource flow and support relationships change, systems will continue to keep people in a perpetually needy status, using service constraints as their point of control and excuse from finding common sense solutions. Without opportunity being a real part of their lives, people will continue to be dealt only needy cards.

Once resource allocation methods are individualized, people can assume valued roles and responsibilities within families and the community at large. They can put their neediness away and begin working with their abilities and resourcefulness for a change.

In an achievement directed paradigm, the only need going on is the one to ensure that support achieves the community outcomes people expect. Beyond that, support takes care of itself.

The thing is: even people who are almost totally disabled aren't totally needy. Dalton Trumbo's 1939 novel Johnny Got His Gun said this most eloquently in this tale of a man returning from war with only his mind still able to function. The WH0, made a similar statement in their rock-opera "Tommy", with a "deaf, dumb and blind kid who sure played a mean pinball."

There is a lot to life between the extremes of being totally functioning or not having any apparent ability at all. Life between these extremes requires support, from assistive technology to human intervention, whether you're a person with a disability or not.

People are always more than their needs imply, and cannot be viewed as consumers first, even in systems that would want it this way. People rise above need when supported in ways that honor them and help them demonstrate that they are a part of the world with the rest of their community.

There's nothing particularly needy about all that, or consumer driven even.

White Middle Class Matters

Systems have not embraced cultural diversity. They have been particularly unwelcoming to groups representing people of color that have tried to establish and maintain service agencies.

Crackdowns by systems through licensing and case management have hit black and Latino owned agencies especially hard over the years, even in cities and areas where large constituencies are non-white. Already behind the eight ball as a small contingent of providers with sub-par rates and a raft of other inequities, organizations of color have faced extreme challenges in accessing the non-profit provider ranks and public agency leadership.

In the last thirty years, grass roots organizations have been particularly hurt by being denied lines of credit and entre to power. Affirmative action standards applicable in grant and provider selection processes are totally ignored by government agencies that prefer to keep their funding within white oriented agency networks.

Systems have also been unreceptive to approaches like intentional communities that utilize methods that do not correspond to standard practices within a business dominated culture. While some community homes have been established for people representing the blind and deaf communities, cultural competence along these lines has been sorely lacking too.

Representation of people of color as both staff and service recipients has been unconscionably slim in many rural and suburban areas. Institutions in many parts of the country still reserve low paying jobs for non-white workers, particularly in kitchens and personal care.

Asian, African and European enclaves that embody a strong sense of cultural identity have been left out of provider recruitment too. While funds have been channeled for decades to mainstream religious groups like predominantly white Lutheran and Catholic social services, small faith based congregations have been noticeably absent in the provider ranks.

Agencies associated with the Mennonites and Amish, or kosher homes, have been funded in some states like Pennsylvania, but are not nearly commensurate with their overall social impact.

Cultural indifference of systems is reinforced by leadership styles that have little contact with non-white community experiences and no sense of taking direction from people and communities regardless of color or cultural ties. The system's whiteness comes into play in everyday decisions of governing boards and collaborators all across the land.

In defense of their methods, systems claim to be 'color blind' and 'equal opportunity', as well as compliant with applicable civil rights law. Looking behind these assertions, it's easy to see that there is a severe the lack of cultural competence in systems as well as obvious transgressions with the law.

While middle class families have had proportionately high participation rates over the last 30 years, people of low-income families and communities of color remain stubbornly underrepresented in almost all ways. For numerous reasons, the leading middle class attitude has been to take what the system offers, and not pressure the community to take on social responsibilities or support roles.

This response derives from white middle class families holding down multiple jobs and making ends meet, leaving them unable to care for their loved ones at home or to develop community supports. Their daily grind, combined with the lack of resources, has given parents and siblings in the middle class little choice but to go along with what systems offer.

Although reorientation to cultural competence might help the system get past class and race barriers, there's a lot more to be done than this. Relationships across color and class lines must be restored in everyday life for any significant progress to occur.

Resources need to flow into many different communities and culturally centered sponsors to establish roles of support with extended family, fraternal and faith groups, and other organizations. While it's convenient to assert color blindness by using service agencies that are

predominantly a-cultural in their vision, translating this into the community support paradigm doesn't work with people or communities either.

In beginning to bridge the divide of cultural competence, it's important to remember how diverse neighborhoods of mixed working class families have been tolerant and accepting of people in community group homes over the years. Mixed communities, in contrast to middle class white ones, have given people a chance.

Over this generation, diverse working neighborhoods could be counted on to stand with people, respect their space, and appreciate the value of their differentness. Just as city neighborhoods first opened the first community houses for 'the indigent' in the 19th century, so do they continue show the way for assimilation of people in today's world.

Diverse neighborhoods in towns, mobile home parks and cities receive newcomers as people first, regardless of the issues they present. There is nothing 'community like' about them; there's is the real thing.

In my city neighborhood, there was an "Association for the Blind' at the corner until recently and throughout the last 20 years an amazing array of people with all types of challenges who have been neighbors and friends. We have always had block parties and get-togethers that people of color, Latinos, and neighbors from SE Asia enjoy as much as anyone.

The neighbors in my area also use the same resources including the barber shop, dry cleaner and corner store, the Vietnamese corner store, the yuppie coffee house and best little Italian bakery in the city. Proprietors of these stores live here too.

 Those of us living here are called "porch people" since our row homes have covered porches where we sit and chat, read the paper and keep in touch. Our world is structured to be integrated and welcoming.

We welcome new people, decorate for the holidays, talk about the quality of our schools and safety of our streets, and pass out candy on Halloween to the swarms of kids and young parents that walk-bye. We help each other out with chores, personal challenges, and the like.

Considering the persistent challenges that race and class persist in neighborhoods like mine, it's notable that we remain as hospitable and open as we are. Perhaps porch people in my city are more interdependent too, given the poor educational opportunities for children here, drugs and violence too.

Whatever the reasons, mixed neighbors are already inclusive. While some wealthy and gated white neighborhoods have hospitable qualities too, there's a general feeling across the country that the white classes would just as soon leave the country's "poor dear souls" to live and work in poorer areas like mine, regardless of a person's roots.

<u>Reasons to Leave</u>

In the world of systems, personal relationships and opportunities are restricted by practices that control what workers are able to do with people. While some workers find ways to break out of the rut of system control, program personnel generally do what their supervisors tell them and not much more.

Taking care of people in restrictive settings rather than supporting them to get a life becomes the work in the system, and there lies the rub. Ultimately, systems could care less that people living for years in group homes and facilities could apply their skills in a home or job of their own.

As far as systems are concerned, there is no particular value to people living outside of their program operated domain. People who move on to live and work independently are lost as payable units of service, and they generally don't return. Moreover, funders don't commend agencies that achieve these outcomes with people.

Even though there are thousands of people on waiting lists that would move into community homes as a beginning step to their everyday lives journey, systems would rather keep the people they have than let new people in. They would rather continue to satisfy the demand for a place to live than raise expectations that services would enable people to live and work on their own.

After all is said and done, systems value programs that are filled to capacity. They point to long waiting lists as evidence of need for their outmoded programs, instead of proof positive that movement out of formalized services is totally constipated.

This system's disconnect with a developmental approach to life is rampant at every turn. Case management and administration, along with direct service delivery and program evaluation, all buy into the idea that people are in the system to stay.

The answers to this conundrum aren't a matter of readjustment. They are a matter of taking support to many different community places and out of the system's hands. Until this departure is achieved, systems will continue to gobble up resources and divert workers from providing outcome directed support.

Even as system proponents admit that their programs aren't working as well as they would like them to, no one takes responsibility to get the situation back on track. The incapacity of systems to self-correct is monumental and everywhere, underscoring how leaders are powerless and hand-cuffed.

The effects of leadership's incapacity are bred into stakeholders who plead "Just tell us what you want us to do". Stakeholders know they can't fight city hall or make a dent in methods they must abide by without leadership giving the okay.

Ironically, these same stakeholders really expect no changes from their appeals for developing more coherent approaches and practice. While they bemoan muddled payment processes they have no control over, they have no faith that anything constructive will ever be done by leaders who will be here today and gone tomorrow.

Just about everyone in the system knows that they can't unclog administrative bottlenecks that prevent people from moving from place to place, or influence cost-effective, common sense solutions. All they can do is what they're told, and that they do in spades.

Something more relevant than system leadership needs to emerge for these pernicious ways to end. Outside powers need to cut to the chase, declare themselves as primary stakeholders, and take the system's power away.

When power is taken back, the system's top down, neediness inspired business model crumbles. Opening up financial eligibility to everyday resources makes the world a better place for people and communities alike.

While apologists disagree that the system's departure is eminent or problems are that dire, their arguments get weaker all the time. It's certainly more difficult today for program advocates to tout services that continually ignore and waste opportunities for people to achieve independent living, jobs and community ways.

It's also harder for systems to justify piling redundant monitoring practices on top of one another, so people remain safe, needy, and occupied ad nausea. Systems have made a meal of authorizing checkers checking checkers in homes and facilities long enough.

In the course of a few months, it's not unusual for people I know in Pennsylvania to undergo home visits by a utilization review team, court monitor, licensing inspector, supervisors, independent monitoring team, case-managers and accreditation agency representatives. Systems must stop piling authority of this nature onto systems that communities can fulfill more effectively and efficiently.

They need to drop their cover your ass (CYA) mentality and get to a place where people and the community is vested in reporting themselves. Until this nation accepts its community role seriously, system checkers will continue to ignore service qualities they should be evaluating and working to improve. Without a 'people and community first' consciousness, systems will just get bigger and more complex, all the time avoiding the promise of everyday lives.

Systems allowed to exist as they are will continue to erode the quality of relationships between workers and people in services too. As agencies continue to furlough, transfer and promote direct service workers in rapid fashion, interactions have nowhere to go but badly.

Continuing in the vein they're in, workers will assist people in tasks like cooking, laundry and taking medication. They'll interact like a teller at the bank or store keepers would with their best customers.

They will get their business done, but the balance and understanding with people won't be there. Without that, there's not much to salvage and no room for letting life in.

We're in this era of distancing with people now, and it can't improve in system ways. As long as programs continue to operate in the frenetic fashion that they do, from crisis to crisis, and payday to payday, there's no chance for systems being any better than they are.

Human qualities have left services before our eyes in this generation. It's gotten worse, not better of late. Programs can no longer be trusted to work in the best interests of people being served.

There's no place else to go but out if people and communities are expected to thrive.

Certainties

Under the surface, system advocates are terrified with the implications of taking community ways. They feel ever more vulnerable as their soft spots are exposed.

To avoid these feelings, leaders remain steadfast in resisting new ways from taking over. They insist that people have a right to choose a service they don't want or need and that takes away their self-determination.

In a state that approaches paranoia more often than we'd like to admit, system advocates can be counted on to blame others when pressed about why community outcomes don't change with people. They'll resort to assertions of being attacked, and claiming it would be more "helpful" if the "good news" came out.

Rather than address the sad state of their services, leaders deep-six the facts about cost and utilization trends. They refuse to share that community outcomes with people are falling while system costs are rising across the board.

Beneath all this, administrative entities, workers in outmoded service and case management agencies are terrified that their jobs and reputations are being threatened too. They go nuts at being viewed as "middle-men" who have lost their relevance and value.

Ignoring the fact that community resources work better and more effectively with people, defenders of the system do their damnedest to prevent win-win scenarios in every shape and form. Between putting their heads in the sand and listening to what they want to hear, system advocates have no shortage of tricks to keep their demons at bay.

All pity aside, it's time to draw some lines and be that worse nightmare returning for good. The country can no longer settle for preserving whatever programs systems offer, or agreeing to develop new approaches at a pace over patient stakeholders are comfortable in pursuing.

It's time to say no to people who want the choice of program settings that have restrictions that they don't need. It's time to resist people, families and providers who insist on preserving ways that impede everyday life because it more than about them.

There's no getting around confrontation and bad blood with those who represent a culture which was supposed to be dead and gone decades ago. The only surety now is that this restrictive culture must come to an end and taking this down isn't going to be a push over.

The reasons that systems are collapsing are that their interests are not as powerful as face of community interests that are emerging, the employers, the civic organizations and the people most of all. The paradigm shift that David Schwartz writes about in <u>Crossing the River</u> is getting closer all the time.

While community approaches like employment and lifesharing will have their share of problems in the community paradigm, stuff happens. The difference is that in frameworks where people and community resources come first, stuff can be managed without all the rigmarole of systems.

The community frameworks that come with paradigm change won't have to deal with a case manager's file note, or a plan of care. Resources that empower communities and people together don't have any use for systems that can only take over again.

The system's rationales for keeping people apart and perpetually planned for are falling apart. Tales of lifesharing and employment being out of people's reach are being discredited by those who are living on their own and staying with jobs they want all across the country.

The fact is: community resources are already doing this work of support without systems. New ways are alive, kicking and raring to go.

What remains now is for communities and their leadership to realize how everyday lives with people work, and how social roles in this support network achieve successful outcomes together. That's what lies ahead, starting with support that's here and now.

Charitable Giving

As long as the community is kept in the dark about the separate places where people with disabilities are held by systems, the struggle for community support cannot be advanced. The public's misinformation must end.

Ignorance and bliss have come at a high price in masking the benefits of community support roles and responsibilities, and overestimating system value. Change agents have a primary role in taking on the ignorance-making machine systems have devised.

While addressing this challenge would be easy enough based on the dearth of everyday living outcomes in systems, the public is shielded from the truth. Service systems are still revered as primary agents of caring for the needy.

On this basis, government and provider spokespersons are trusted with unfettered access to media channels to broadcast their public message. By projecting people in the embrace of special programs, systems find their common theme.

Agency flyers and public relations material extol the virtues of differentness from horseback therapy to petting zoos for the disabled. Advertisements in the daily newspapers underscore how people love to live work and play in disabled ways, as if they would not be able to enjoy these pursuits with the rest of society.

Along with media campaigns, system-sponsored events latch on to popular public figures willing to lend their reputations to keeping people with disability happy and content. Charitable funding drives, a la the Jerry Lewis' telethon, have exemplified public appeals since the 1960s.

Thanks to these events with the public, citizens perceive that programs are on the right path when they keep people occupied and out of harm's way, as well as out of sight and mind. Teary testimonials by family members still tout how programs have 'done miracles".

The sad thing about this country's charitable giving is that their funding drives benefit organizations, not so much people directly or community objectives. The country's goodwill goes to capitalize building improvements or sustain endowments, as opposed to achieving outcomes with people outside the system's domain.

As United Way contributions get channeled to a new wing, program staff bonuses and office upgrades, hardly a trickle finds its way to unambiguous community objectives. Charitable funding doesn't get used to cover the cost of people who need roof repairs on their home, a new washer-dryer, or a fumigator to get bed bugs out of their apartment.

Nor does community giving defray the cost of post-secondary education or career oriented trade school, or other support that systems don't cover. Meanwhile, colleges, trade schools and universities that pride themselves in obtaining million dollar grants for developmental disability studies have no scholarships or career tracks for these young adults.

In today's charitable climate, the community has been left in the dark about what systems cost and what they deliver. The public doesn't get the truth about the benefits of community resources, or how everyday citizens have key roles in achieving a better life with people.

As far as agency public relations personnel tell it, the system is going well and there is really nothing to consider apart from increasing charitable funding levels from last year. That's the message on highway billboards, advertisements, bus and taxi ads, brochures, television spots and newspaper features.

Notice however, the undertow of deviancy in these 'give to me' public messages. See how service agencies punctuate their advertisements to elicit a public sigh or mention or 'poor dear souls'.

Notice the logos in these advertisements too: the images of hands together, ubiquitous rainbows, and cartoon like figures. The system clearly has no interest to move away from broadcasting paternalism and make believe.

Throughout this generation, agencies have consistently played the neediness card to maximize financial gain. While it's evident that this missive must be substituted for variations on the theme of "I can" with people, there is little chance of this happening with the culture that prevails.

As long as services continue to represent themselves as being as disadvantaged as the people they represent, their appeal to charitable giving will be hard for compassionate individuals to resist. And why mess with a good thing, systems figure.

Symptoms of Gone To Far

As changing ways continue to threaten the status quo, families, staff and people can expect to be co-opted like they have been in the past.

Just like in the old days, people needing support will be bought off with promises of life long service funding if they will just hold firm with the programs they receive. Agencies will find ways to cut their side deals and private understandings.

On the flip side, people and families that do not go along with the current program can expect continued threats to withhold resources if a person pursues a job or home place of their own. There's no reason to expect this behavior to change as long as program personnel make up rules and barriers as they go.

While punitive and covert actions by systems are inevitable with care dependent systems focused on maintaining their market share, barriers are not insurmountable. Just because systems do certain things, doesn't mean they can't be challenged.

First of all, holding people back in congregate care settings under any context violates rights people have under the Olmstead decision and the ADA. While states are very used to being sued to deinstitutionalize, they don't like these actions for any number of reasons, not the least of which is the bad pr.

Institutionalization, sheltered workshops and other congregate forms of care are also an abomination of a person's basic guarantees of life, liberty and the pursuit of happiness under the Constitution. It's not okay that people are being denied self-determination through actions by provider agencies, families, case management agencies and administrative entities.

If a case manager claims that she doesn't have the time to help people find a home of their own due to other priorities, families have every right to insist that those priorities change. Advocates for everyday lives with people should not hesitate to demand changes in service to achieve life conditions at least as good as the average citizen's.

While those who see themselves beholding to services don't see it this way, there is nothing inherently coherent or sacred about systems or their practitioners. Those agencies that offer support shouldn't be viewed as saviors. Resources that offer support can flow responsibly without them being in charge.

Let's be real clear about this: as long as systems have control over service delivery, people and communities will be manipulated. As long as services continue without accountability to real life community outcomes, custodial care will remain unabated in group homes, institutions, workshops, centers, home based services and adult activities across the nation.

As long as keeping people safe and happy remains the fundamental expectation of programs, the public will continue to be fed myths about how well systems and their people are doing. As long as the public accepts what little the system shares, it will deem living outside of an everyday life acceptable for 'people like them'.

As long as systems are allowed to keep their focus on people within their services domain, hundreds of thousands of people who would benefit from support won't find it. As long as services are allowed to cost as much as they do, there will be no money left for taking new ways.

It's time to realize that accountability to everyday outcomes presents systems with a reality that they will avoid facing at all costs. Things have gone too far to be corrected by a public relations angle or policy adjustment.

Today's systems are tomorrow's dead end. We can't get to where we want to be from here anymore.

Vanilla Skies and Self-Interest

To keep things going smoothly, there is an overwhelming tendency for life in the system to become more and more vanilla. Allowances for variations, waivers and exceptions in the face of predisposed plans and practice become harder and harder to find.

With pressure to follow a life script organized by a disposable and constantly changing work force, individualized ways get trashed. It becomes more important to keep other agencies from getting upset, avoid riling parents, and prevent hassles with program monitors, than to do what's right and reasonable.

There are just so many interested parties to please and keep in the loop of service delivery that accountability for an everyday life gets lost. It's no wonder that the system looks the other way when there are obvious areas of trouble.

Programs learn to keep quiet about other provider agencies and professionals out of fear of retaliation. To avoid the danger of a severe reputation within system confines, service providers, direct support personnel and case managers toe the line.

Fear of retaliation from funding agents and monitoring agencies is a clear and present danger when programs are beholding to public funding. Programs that step out of the fold of custodial care methods are easy targets for auditors, administrators and the regulatory police.

What goes on in the system stays there. Exposing so-called "internal" problems to a wider arena is viewed as a threat rather than an opportunity to broaden community involvement.

When situations do get out, scapegoats are easily found to defer serious challenges to the system's control. Reporting to the community about deaths, injuries and malfeasance has become less accessible since HIPPAA, the national health care privacy act issued in 1996, has evolved.

It also bears remembering that when stakeholders engage community resources, they do so with the system's status quo in mind. Vocational service providers, for example, routinely participate in local Chambers of Commerce to obtain work contracts and sponsorships for charitable fund raising efforts.

This approach sits well with employers and other civic leaders, making it possible for them to remain supportive of workshops in their midst. Meanwhile, those in the business community who directly benefit from the subminimum wage labor source the workshops rely on, take their bows.

There is unfortunately no discussion at the Chamber or Rotary luncheon that would promote employment for people at the workshops. There isn't mention of a campaign to host community work experience with students and adults either.

Self-determination barriers like subminimum wage restrictions don't get raised in this mix. Workshop representatives are too busy marketing themselves as subcontractors to step out on a limb in terms of presenting a different social responsibility theme.

In selling their company, workshop and vocational service reps do little to calm the waters about the Americans with Disabilities Act (ADA) or promote Federal and state work incentives. Instead, they point out that workshops are the community's best way to avoid dealing with the complexities of employing people who they serve.

Workshop directors push the right buttons about 'quality added' manufacturing, too. They speak employer lingo and know the back-slapping drills real well.

While there is nothing unusual about a business wanting to show its best side to suppliers and their customer base, systems take selling to new levels. Developing a proprietary interest in people on the basis of an intellectual and other disability is a very slippery slope.

Promoting a service is one thing, but marketing a niche that exploits generic worker protections on the basis of disability is something else entirely. Making money on the backs of subminimum wage workers can't keep happening and being swept under the rug.

No workshop, affirmative industry, job creator or activity program has a right to limit choice on the basis of disability. No community should be obliged to pay for this either.

Chapter 13: Accountability

A Stool With Many Legs

Behind it's entitlement mentality; systems hide a deep seeded fear that if one leg of their operation is broken or taken away, the whole thing collapses.

Systems cannot see themselves as whole without their major players, contributors, collaborators, networks and boards huddled together in neatly organized ways. This congregation of system-dependent entities becomes a community within itself, held together by mutual interest and a common sense to remain the controlling force in people's live.

A collegial quality develops within these parameters, sustaining a sense of safety in numbers and comfort in partisanship. While there is active and sometimes fierce competition among agencies for 'clients', a semblance of professionalism and comradeship also remains strong.

Picture this togetherness in the form of a four legged stepping stool that rests on a hard wood surface that represents the community at large. Administrative controls and structures are the legs of the stool, while the stool's top is where the programs happen and the people settle in.

Envision too how the stool glides along this surface where the community engages in everyday life. Imagine how workers and people busy themselves on and around the stool like ants.

Petitioners, interest groups and provider networks run up and down the legs of the stool in orderly ways, bringing resources for people and programs to use on their behalf. Life on, off and around the stool is bustling in all directions.

Now imagine that someone on the stool calls out over a scratchy loud speaker this riddle: "How many legs does a service system need to stand tall ?"

In response, all the creatures in and around the stool call out in unison, "As many as it can buy, burrow and steal", everyone screams back, laughing uproariously as they do.

From the system's view, there are the programs it runs, confined to the stool with many legs, and then there's the rest of life, on the floor where everyday lives play out. On the stool, it's different as community outcomes of a job, home and relationships become irrelevant.

The stool has different boundaries and dimensions too, particularly since access is controlled by these many legs that hold the system up and all together. The closest life on the stool can bring people to an everyday existence is literally a step away and a notch removed.

However satisfying the experiences on the stool, people above the ground are just not at the level that rest of the community enjoys. People on the stool are also shielded from ground view.

Within the limited area of the stool, people learn to tie their shoes and do their laundry, without the expectation of getting down to the level of community life. There are few resources available to assist people in leaving their perch that their handlers insist is 'as close as possible', to an everyday life.

Enough Is Enough

Enough is enough with this tidy and confined domain. People with disability don't need to be removed from satisfying lives and possibility. They don't need legs which are not their own or those of citizens that support them in the community along with everyone else.

To achieve new roles with communities, the public must get beyond comparing the quality of services for people in community systems to the deplorable conditions of institutions of the past or the present.

They must invite people from the stool to mingle more and secure their valued roles with everyone else. The public must welcome workers offering support too, and honor their contribution in achieving outcomes with people.

The public's self-interest in community living is high, and there's not much of a learning curve for the public in this. It's more of an exposure thing, at least at first.

From there, it's a matter of understanding how accommodations and social responsibility play out to benefit everyone. Getting to support solutions is nothing magical when there's a will of the community behind it.

To get things going, the public must be open to new roles for itself.   In discovering these roles, they must realize their social responsibility with people first, and not get hung up in ideological and turf battles, or deferring to 'trained professionals'.

Citizens can only make room for people with a consciousness to let life in. The public comes through when they understand what's right for everyone.

Let's Not Be Fooled

Service systems can no longer be permitted to just assure health and safety of people outside community outcomes.

Without being held accountable to securing jobs, homes and community connections with people, systems won't change what they do. Without resources tied to fundamental everyday life achievements, there's nothing to discuss.

Today's systems that should be measuring program performance to improve outcomes, don't count, let alone report, on people moving from the system to everyday living situations and

jobs. Afraid to deal with the implications of this rut they've dug for themselves, agencies have no will left to bring everyday living measures to the public's attention.

When's the last time a state or the Federal government broadcast how many more people were living in community thanks to the multi-billion dollar programs they fund to provide home and community based services? When's the last time systems announced how many people have moved out of facilities and group homes into everyday homes and jobs?

While the inevitable examples of progressive programs will be lauded for their innovation, the same old programs also thrive with no expectation for improvement or change. Indeed, most agencies that offer community support with people also provide a much larger array of institutional and congregate services in their portfolios.

There's not a lot of quality improvement going in systems today beyond talk and occasional pilots to test promising practice. Systems stay focused on their continued funding, preferring to let change take its sweet time through protracted regulation modifications and funding adjustments.

Dramatic shifts from system to community ways are not even on the horizon in all but a few home and community service programs across the country. Even in those areas of the country where quality of life indicators are beginning to be measured through the National Core Indicators Project and other promising formats, state and local systems that utilize these tools feign powerlessness to improve services based on this information and the clear trends that they see.

Regardless of the source, data and research pointing to new community support approaches aren't accompanied by adjustments to policy and standard practices. With rare exceptions, states that engage in quality of life reviews file away the knowledge they obtain or utilize it in a very restrained and circumscribed manner.

Sharing information on community outcome indicators that are available is on a need to know basis that continues to exclude the general public and most legislators as well. Systems figure that what these parties don't know won't hurt them.

My home state of Pennsylvania, for example, has been unable to report on the number of people in services who are employed for over 5 years, despite a multi-million dollar management information system upgrade that was developed to do just that. It's not that data isn't there either, or the expertise unavailable to extract the information.

It's all a priorities game, and frankly no one cares about quality of life and outcome indicators in today's funding climate. They're also half scared to see what's happening in these areas. Meanwhile, data management's obsession on reporting service units, filling immediate vacancies, and monitoring abuse and neglect allegations not gets old.

In the hierarchy of information management, data that can be horded by decision makers is. Since accountability to quality outcomes is not required by state and federal funders or even

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included in provider participation monitoring, everyday outcomes remain a don't ask-don't tell phenomena.

In light of the system's misuse of quality management data, it's not at all surprising that there are so view promising practices based on studies and the applied research. Linkages between quality measures and service change are not made by system leadership,pure and simple.

One of the system's tricks in avoiding accountability to everyday life outcomes is to neatly separate quality considerations into two parts. The so-called "quality assurance" portion requires adherence to standards and rules, while everyday outcome measures like choice, social integration and developmental growth get remanded to a lower priority tier called "quality improvement."

Systems claim responsibility to address quality assurance measures first, reasoning that it is more important to deal with matters of compliance before anything else. In this Malthus approach, the vast majority of programs stuck in compliance mode don't appreciate how community support approaches embrace quality assurance parameters when given half a chance.

The system's insistence to apply quality assurance measures ignores the fact that everyday life is better, greater and more real than segregated worlds of disability. They ignore that life includes being safe but also being challenged and respected, loved and content. Intransigence to embrace quality improvement measures reflects why services remain lodged in 'safety nets', and not on roads to success, integration and self-determination with people.

Ask citizens in the community if being with a loved one who shares their life counts more towards keeping them safe and secure than any rule or requirement. Despite the power of lifesharing safeguards in everyday people's lives, the vast majority of systems completely discredit this line of thinking.

In the system's understanding of quality, lifesharing safeguards created through relationships get ignored or down played. Programs are monitored for brick and mortar, square footage allowances, health care practices, planning, policy and procedure.

The result is that programs haven't figured out how to improve opportunity, social integration, community outcomes and satisfaction outside of the system's scope of control. Apart from compliance to physical standards at program sites, worthwhile approaches like 'home studies' which match people in supportive relationships have been totally ignored.

There's no need to match people or consider relationships in systems and they've always been that way. Whether there is a residence manager that's not going to be living with people, or an institutional attendant, people are related to as part of the job, and not much more than that.

Instead of developing safeguards with people on an individual accommodation basis, programs focus on obtaining compliance with regulations that allow privacy fences that block out their neighbors, class III fire extinguishers on every floor, water temperatures regulated to

not get too hot, and doors to bedrooms that don't lock. Instead of expecting vocational programs to secure community employment, agencies embrace hospital accreditation bodies that monitor their adherence to professional standards of care that are often totally irrelevant to community living.

As part of this framework, record keeping requirements become patterned after medical procedures that nurse practice. Health and safety safeguards are applied without any sense of their developmental growth orientation or appropriateness.

In the mix of system accountability, case managers have no place at a person's job, but they go there anyway to monitor supported employment services, as though they were no different from an adult day care program. Like other operatives, case managers haven't gotten the word that supporting community outcomes has nothing to do with checking off a box on a monitoring form or treating community resources like a another facility.

From an accountability point of view, systems measure the time that agency personnel are involved in their work, but not what their interventions achieve. As long as workers can ascribe their time to an eligible beneficiary on an approved and authorized s plan, there are no other questions asked.

For example, a typical system activity requires workers to accompany residents of a group home on a weekend shopping trip to satisfy a goal of community integration. This outing would normally require program workers to document that the outing occurred, who attended and maybe how people behaved and enjoyed their time together.

The worker's note might also recall where people ate lunch and what items they purchased. Beyond this, there would be no sense that people were being supported to make decisions and choices on their own, or begin to spend time in public without the rest of gang.

It wouldn't matter how long the people were at the group home either, or whether they had a desire to go out on their own. In the pass-fail universe that quality assurance considerations dominate, there's no sense that meaningful quality measures used in everyday life matter.

While progressive agencies have adopted appropriate and balanced measures on their own from time to time, quality measures that have not been counted by systems have led to the worst of all worlds. It's just not enough that some agencies and workers adopt advanced program concepts or test themselves against what the community values.

Planning To Stay

Systems could theoretically be held accountable to measures of community support through state and federally required planning processes, but that's not going to happen either. Government agencies don't have the will to improve program integrity, even though they have the authority and funds.

Nowhere does this lack of program integrity show up more than in the type of individual planning processes used to guide workers in the provision of service. Without a commitment to change this planning and the service settings that drive them, systems will never be able to get away from keeping needing people safe and busy.

The basic problem with system prescribed planning is that it doesn't reach into community ways where people secure a job, home place, and community connections. Planning also makes it possible to adjust programs to meet the needs of the system and people trapped within it.

Despite claims of being individualized, planning with people in congregate settings is everything but that. The plans people have written for them by workers and case managers mostly serve to keep individuals behaving in ways the system wants them to.

Without the expectation of achieving outcomes outside of programs, learning home and community skills becomes an exercise in living without the community coming into play. Community resources from jobs to lifesharers are viewed in the abstract, if at all.

The service plans of today, like they've been for decades, document how little outreach to community resources goes on. So called 'habilitation plans' for home and community based services, are carbon copies of plans of care in certified ICF/MR institutions and group homes.

Holding anyone in these settings accountable to everyday living outcomes using the planning processes in place is thus not really possible. Safeguards to preserve integrity are a bad joke at best as state and local monitoring entities play along with making sure programs follow plans for people that show even a spark of life or individuality.

With individual planning managed within system parameters, there is no room for designing life beyond program activities. Without funds being linked to achieving community outcomes in individual plans, there is no hope of accountability beyond adherence to minimum health and safety standards.

Beyond this, the scams and even fraudulent activity that routinely occur around service planning must be exposed and end. Case managers must be prevented from signing off on plans for people and families who didn't attend meetings or know what the plans say. They must also be stopped from pressuring families and people, and delivering services that have no bearing to long and short term goals that have been agreed to.

Program planning methods have sustained lands of make-believe for people with disability at the expense of the national trust. It's time that those with power outside of systems take a hard look at the mess services have made.

When it comes to quality, it's time to consider that:

> Life in the system is organizationally driven, with restrictions and boundaries that protect and sustain program operations regardless of cost.

It becomes more important that each 'i' is dotted in a planning record, than to ensure that people are supported to achieve everyday living outcomes, like a job or home of their own.

Staff and program functions are beholding to system demands and routines at the expense of people becoming more self-reliant and connected with community ways.

The system gives its full attention to what is measured, and that's safety for people being tucked away, out of sight and out of mind.

When it comes to quality, it's also time to ask some questions too.

How can people be integrated in society when they don't have opportunity to get out of their segregated service settings?

What good is it to the community if the skills acquired in the group home can't be applied to a home of her own?

Why aren't there system funded services to find people homes of their own and shared living opportunities, jobs and community ties?

Too Much To Manage

The size and number of interest groups created within the system create challenges too. The system's constituencies, including people, families, government and the provider networks, are quite substantial.

Due to increasing levels of complexity that come with size, system constituents have been unable to act responsibly without stepping on one another. There are just so many administrative hurdles to jump through that people get lost along the way.

On the program side alone, we're dealing with hundreds of thousands of full- and part-time workers along with minions that train and supervise them, including administrative checkers and policy makers too. We're dealing with all the people and families as well, along with many thousands on waiting lists in state after state.

There are also the Fortune 500 firms, consultants and academic interests that assist systems in many critical ways. There are hoards of information specialists, so called "experts", fiscal agents and medical professionals who are tied in too.

In their pursuits to manage these constituencies to work together efficiently, there are few deals that the system will not take. Rather than divert existing resources to continuously improve outcomes or address the myriad of obstacles they face, systems find excuses and other priorities so key players are not miffed.

To address these system tendencies, the country has to find other avenues of independent monitoring that are not vested in keeping programs operating. It has to be open to other ways that tap into advocates, people receiving service, families and other resources.

The Riot, an irreverent periodical published by and for people through the Human Services Research Institution in Boston, expressed the accountability gap in achieving outcomes with people quite well in a poster it's been passing out at national conventions. The poster reads: STOP FEEDING THE DINOSAUR: We Want Real Jobs.

The image on this poster is of an open mouthed alligator-looking creature swallowing people on a conveyor belt. I'm afraid that captures systems perfectly and the accountability surrounding them too.

As long as people keep going into the system and not out, nobody really looks at the character of the enterprise itself. Like the Riot image reminds us: there's really no way out of this thing once you're swallowed.

Same Walls, Different Places

Continuous quality improvement is kept out of the decision-making process in systems. This is a conscious thing.

There is no sense of improvement, just more of the same. While occasional bad apples get identified in fraudulent schemes and Medicaid fraud, providers and administrative entities don't get penalized for keeping people from achieving valued social roles.

While some states have applied system wide program evaluation for a decade or more, quality improvement has not materialized as a result of these endeavors. Information that is readily available to improve everyday living outcomes just sits.

There is plenty of resistance to developing quality measures too. Provider associations lobby to preserve limited measures that keep people safe and occupied, and that keep outcomes out of the discussion.

State departments of education and adult service avoid quality measures too, and fail to review the extent to which people transition from services to community life. These agencies have also been particularly negligent in tapping third party and independent assessors which aren't already conflicted with the status quo.

Over time, the resistance to quality improvement has led to a pervasive pessimism about the power of knowledge to change systems for the better. After decades of evaluation having no tangible results in policy and practice, stakeholders settle in to letting providers do their thing.

As more and more people come to rely on community-based services in lieu of institutional care, the country needs to get beyond making sure services remain sturdy for their own sake. The country needs to accept that services are functions of people securing everyday

lives, and give up the notion that systems are entitled to serve people or immune from the measures of quality that communities adopt for the general public.

Stanley Myers, one of the first mental retardation service directors in Pennsylvania pictured the ideal community living arrangements in the early 1970s as "souped-up homes" where people would get additional support that would help them get a life. His vision, like that of other early program developers, was that that these arrangements would be homes first.

We've lost that home first quality in the accountability of services, along with a lot of other reference points that could have kept services grounded in community ways, but didn't. While it's too late to reclaim these qualities in the services we've created over the last 40 years, it's never too late to call a spade a spade, and that's just what we're doing.

Health and Safety

Those that defend service systems do so with rule-bound decision-making in mind. Despite decades of physical and program requirements installed to protect people in services, there is not a stich of evidence that system rules make people any safer or healthier than community standards do.

While community standards have their issues, its best to remind ourselves that general physical site and health standards are good enough for 'the rest of us'. Truth be told, people with disability are generally living in homes that are safe due to generic standards around home improvements, construction, and universal design, more than any specific requirements established for disability.

Having a system required "EXIT" sign, radiator cover, or regulated water temperature at the group home doesn't improve safety for people. These features also let workers and people not pay attention to everyday environments in everyday ways.

In the long run, disability inspired requirements apart from wheelchair accessibility in homes also cause people to be less adaptive to their environment, which carries over to additional overprotective and custodial safeguards over time. Special places don't save lives or promote developmental growth as much as they make places safe, sanitized, and institutional.

As system defenders stake out safety and health outcomes to crow about, standards based on the lowest common denominators of need become established. These standards inevitably brand people when they really don't deserve to be.

While community homes for people with disability are not supposed to be institutional, community home physical safety requirements are often just a notch removed from standards established in asylums during the Eugenics period in the 1920s. Community worker responsibilities in terms of keeping people from harm also aren't that much different from those that attendants fulfilled at the old state schools and hospitals.

If this country expects people and communities to relate in a positive and valued manner, people and their networks need to function according to community norms and in ways that suit their personal styles. It's time to step out of settings with environmental safeguards based on people's disability unless modifications are required as an individual accommodation.

If a home for average citizens doesn't have an exit sign, a community home for people with disability should not be assumed to need one either. Instead of the lighted red sign over doorways, people would be supported to learn how to evacuate without these atypical appointments using developmental approaches.

In a community framework, people's residences wouldn't be operated like boarding homes, foster homes, group homes or facilities. There wouldn't be resident rules on using telephones and snacking from the refrigerator, or 10:00 lights out.

There would simply be home places: condos and apartments, houseboats, dorm rooms or even shelters where people choose to live in mutually supportive ways. There would also be efforts made to ensure that the agencies that operated homes didn't own or lease them too.

These homes would be chosen by people and then adapted and accommodated according to what individuals and their sponsors required. These places wouldn't be inherently deviant, special or overprotective, and people without a disability would be pleased to live there without feeling special.

Service rules should not encroach on the generic character of homes of people and other private places, except when an aspect imposed a clear and present danger to a resident. If people are going to learn to manage risks, everyday hazards like scalding need to be addressed in other ways than regulating the water to lukewarm for everyone.

Building specialized support structures based on keeping bad things from happening just isn't enough and it's often counterproductive too. As adaptations are needed, they can be discovered through the home finding process and fade out as individuals become competent in taking community ways.

Social risks in and outside homes, can be handled in a similar way. There is already any number of community contacts to call, from the police to child protective services. Unusual incident reports frameworks are already installed in system too to ensure that workers follow through based on the severity of each situation.

In weighing what works with accountability mechanisms like this, the public has to pursue some basic questions to test assumptions that service systems have perpetuated around their so-called safety nets.

Would people be just as safe without the system's oversight? Why couldn't people be just as secure living by community standards and norms?

Why wouldn't a family member or neighbor looking in on someone at home be just as effective in monitoring a person's well-being as a system case manager?

Why can't people and families self- report incidents and issues they have?

Do life sharing relationships offer better ways of ensuring against harm than case management and licensing visits?

Why can't community resources take over program evaluation and monitoring that systems have cherry-picked?

Why won't systems be accountable to everyday living outcomes like they are supposed to?

Why do so many people with disability get caught in restrictive practices and environments that they don't need or want, with overseers checking the places where their programs are provided, instead of the outcomes people in service achieve?

Why are community living and activity programs so reminiscent of institutional life?

Why doesn't the system get out of the way so communities can figure this out?

No Count Leaders

Accountability to community outcomes is nowhere on a federal or state hit parade. Apart from a lone cry of a handful of representatives, elected officials are not ruffling any feathers to make community employment, home finding, and personal ties come true with people.

While political lefties and right-wingers decry the role of public agencies or lazy bureaucrats, leaders are not looking to the community to solve their common woes. Reminding the American public about what they can do for the country has gotten to be too much of a 1960's thing, I guess.

As far as today's system leaders see it, the future would look a lot like today, with incremental progress whether lasting or not. Changes in current practice would continue to be run through interest groups, consultants, and wordsmiths before anything happens.

It's clear now that holding leaders accountable to community outcomes is not possible without taking system ways out as controlling factors in people's lives. Between the rapid turnover of leadership and political exigencies, it's easy to see how even those who want change have little hope.

Accountability requires persistence throughout the support framework, however that plays out. It means rapid system deconstruction with the passing of responsibility to community ways and resources, and leaders with a different staying power and agenda.

Those in traditional control modes today can't stay on. They're too conflicted and their focus is not on what people want, or even defensible.

The price tag is too great to continue with these systems at the sake of depriving opportunity and support. Costs are not going to get any better, and outcomes won't either on the course systems are on.

The will power of current leaders to achieve community support outcomes is gone and has been for some time. Case management directors and the heads of program monitoring operations are in no position to turn off the public funding that keeps people in demeaning activities and restrictive living arrangements. They'll continue to find some excuse to avoid supports that are natural, cost-effective and community-based, like they always have.

It's remarkable that after all this generation did to develop community services across the country, there is no national leadership circle of conscience apart from TASH that can be counted on to keep the faith and help the nation visualize support in everyday ways. Why Democrats and Republicans, Greens and the Tea Party can't come together along these lines baffles the mind.

The maladies of confined togetherness that systems impose can't be turned around or fixed. They underscore the fatal flaws and evolving consequences of failure that just get worse the more systems stay engaged.

The country can only leave what we've created here or suffer the consequences of this mess falling in around us all for generations to come. That's where we're at today.

Raising Each Bar

Accountability agents can no longer be satisfied with programs "trying" to do what's right by people, or documenting how their service tasks are in line with some vague notion of what their plans dictate. This nation can't afford being scammed any longer by professional assessments of disability that only serve to confine people to special programs and places, and render them much more disabled than they really are.

The outcomes demanded from support today do not mean assigning blame on a segment of the system or requiring punitive action within the confines of programs that really tried their best. What's done is done.

Nothing is going to change the past, and no one aspect of the system is more culpable than another. We danced the dance together, and now it's time to leave for better places and times.

In a world of real community outcomes for people, we are all responsible for supporting one another in our jobs, and in our home life, as well as in our neighborhoods, family and public connections. Life in the community is viewed in ways that intentionally include people with disability. Only by experiencing life under these terms will we be able to leave the old ways of system-controlled living behind.

Given the paltry effort systems make in promoting employment and other community outcomes for people, who needs them? Systems only foul up the works with their singular drama around compliance and relating along lines of authority. Systems have no intention of honoring individual talents and abilities anymore.

What systems expect is that formalized frameworks will cater to the lowest common denominator of need, making sure people stay where they are in the service structure as long as they qualify. In this process, systems honor caregivers and colleagues, as though people are commodities.

In reflecting its point of view, systems get away with limiting quality assurance measurements to areas they can control. By limiting their measures to minimum standards, systems avoid accountability to outcomes of an everyday life. By focusing on processes that make the system work efficiently in regulated frameworks, systems avoid engaging community resources, ways and norms.

By avoiding accountability to everyday outcomes, systems keep the public believing that their programs are doing the best they can. By stressing the disabilities of the people they serve instead of everyday missions, systems keep everything strapped in.

Only public awareness can begin to change the state of don't ask, don't tell. Only the community's concern going past the point of 'three hot's and a cot' will do it. It's time to unveil what is going on -- right and wrong, well or not well at all.

It doesn't take a rocket scientist to see that the system is shielding deficit funding schemes that dig people deeper and deeper into system dependency. Rather than let systems continue in this hideaway tradition, communities need to open their eyes and begin to appreciate new ways for themselves.

Letting life in comes into being where the new world of accountability to outcomes begins.

Honesty

So let the truth be told through some questions too:

How could systems be more disingenuous than to teach people to be self-reliant in programs and in the same breath deny them the opportunity to move on to an everyday life?

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Why would the public ever go along with funding services of this nature?

What kind of society condones people being used in this way?

In the country today, it's not enough for adults to be occupied with busy work when they can be supported to secure real jobs that pay a decent wage. There's no room for wasting lives when people can and want to contribute to improving their own lot and the community's too.

Though advocates for people with disability are helpful in spreading this message, we're beyond the point where we can rely on the good will of some citizens, neighbors, professionals, family and friends. While it may only take a few dedicated people to change the world, we've had our share of preaching to the choir.

A new guru or government leader isn't going to change the tide. It's going to take a village. It's going to the take the community to rise up.

In the final analysis, our challenges in supporting everyday lives with people will not be addressed in the same old ways of trying harder, doing more, and tweaking. We need to offer support differently, based on a new direction and accountability to everyday living outcomes, like we started out to do.

We need to work through community resources now, not through systems of care that are terribly wasteful and ineffective in achieving the outcomes people need to live an everyday life. This is our time to make these moves, as we learn from our missed takes and actions.

This system demise is not a public or private thing. It's not about pointing the finger at government, families, people or individual providers who don't want to change. It's more than our individual agency failures and challenges.

Change agents are not saying that private enterprise could do things better if left along by government, or that government needs to have more control on services. We're talking about getting communities in the mix, and letting them take the lead for a change.

The system is the whole pie and all the pieces that influence and comprise what it has become. The blame, the responsibility and the credit for its outcomes are shared proportionally. Each service entity is as responsible for the impact of their work as any other.

Taking out a piece or changing roles within the system doesn't present solutions to the challenges that we face. Pointing fingers at one agency, the feds, courts, or a powerless case manager isn't going to help matters either. The whole crew needs to take responsibility for not only getting it wrong, but for also staying with what's wrong for so long.

The system's days have become numbered because of its collective inability to be accountable to community norms, outcomes and values. In the community structures that take the system's place, the community will be able to ensure people live their own lives with the assistance the community can provide. That's all that we can expect and strive for.

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Toward this end, the public and its leaders have come to a point where decisions must be made and commitments kept. They must decide how they are going safeguard support that enhances everyday outcomes and stop protecting arcane systems of care.

They must decide how to redirect funding that has been going mindlessly to systems, so that it goes instead to workers and families, employers, sponsors, community organizations, and friends that join with people to take on their challenges together.

Chapter 14: Employment

This Person I Knew

A middle- aged man I knew was placed from an institution into a group home. In less than a year he was considered their "star", an individual who loved his new community life and adjusted well to group activities and rhythms.

While the man didn't speak in words, he was outgoing and generally understood what others said. He used expressions and grunts to communicate too, and appreciated it when others took time to show him things were done.

Given his cheerful personality, it wasn't surprising that the man started up an acquaintance with a neighbor, Mr. Jones, a widower that his friends called "Jonesee". Over the course of a month or two, the men exchanged greetings and visited in their adjoining back yards.

That was in late March and April. By May, the man had made arrangements to cut Mr. Jones' lawn. Mr. Jones taught the man to properly start and fuel the mower, closely supervising him over the spring.

The man caught on quickly and did an excellent a job. The yard was cut precisely and raked of all the clumps of grass. Jonesee also taught the man to use a power edger, that he soon managed on his own too.

Mr. Jones paid the man $25 every two weeks this work that included some weeding, with another $5 tossed in for trash and other odd jobs. The man was also getting paid for doing the lawn at the group home too after that.

Mr. Jones informed some other neighbors about the man's work, and it was plain that he was proud of what he and the man had accomplished together. In June, the man was introduced to neighbors at 'Jonesee's picnic'.

This was an annual event going back fifteen years when he and his wife first moved into the area. Mrs. Jones passed away a few years ago, but Jonesee continued the picnic, saying that she would have wanted it that way.

The man bought his first pair of short pants for this affair, and a new summer shirt too. Sporting a haircut and cleanly shaved, the man beamed when Mr. Jones introduced him and pointed to the work he'd done in the yard.

After this introduction, the man procured another half dozen jobs from the neighbors and had to scale up his operation. In addition to the lawn work, the man began to do a lot more gardening, too. He also planned on raking leaves and shoveling snow come winter.

With assistance from Mr. Jones, the man purchased a used mower advertised in the newspaper for less than $100.00. He also obtained a bunch of shovels, hoes, a pick,

sledgehammer and rakes for $5 at a local auction that he attended with one of the group home workers.

For his birthday in July, Mr. Jones bought the man a lightweight aluminum shovel in anticipation of snow clearing jobs later in the year. By the end of summer, he had six winter shoveling jobs scheduled in the neighborhood, on his way to over a dozen at last count.

With all the chore services he had scheduled, the man cut his hours at the day activity center from five days to three, and then two days a week. The man really liked this freedom, and he began to spend more and more time in town which he could walk to from the group home.

He used his earnings to purchase breakfasts at a local diner and enhance his country western cd collection. Another resident started helping the man too, and there was talk about a yard service full time for both of them.

On one of his downtown walks that summer, the man met a woman and they started dating. He got some more nice clothes then and they attended church services together regularly.

The man was on a roll, but that was all about to change. The problems started around his income.

The man kept his earnings from the yard jobs in a locked metal box in the corner of his bedroom closet where it was usually covered by a stack of dirty clothes.

The man kept one of the keys to the box around his neck, and gave the other one to a staff worker to keep in the office safe. Only workers had access to the spare.

The man didn't have a savings or other account with the bank, and the other residents didn't either. Agency policy required savings to be kept an agency account under the person's name. Cash for each man was kept in the office, in the agency's locked safe.

Basically, the men at this home all received about $80.00 a month from their SSI benefit payment for personal use, with the rest going to the agency for room and board costs. The men generally kept their funds in the office safe, although the man had his safe for this purpose.

At a planning meeting in late August, two group home workers mentioned feeling uncomfortable with the man keeping cash in his closet. Even though the man locked the door to his private room, the workers expressed concern that the strong box could be lifted, noting how residents in another home had been robbed a year or so ago.

The workers were also leery about the man's spending and being out in the community so much. While they appreciated how independent he was becoming, it seemed more and more difficult to relate to him like "the others", as one staffer put it.

The workers also went on record about the man being able to retain financial eligibility for his Medicaid funded home and community services with the money he stashed. They said the agency might be vulnerable to an audit.

After this exchange at a home meeting, changes happened quickly. Not having any precedence for dealing with this matter since only the man had any money to speak of, the program director looked at the situation as a "new wrinkle" he'd have to address.

Wanting most to avoid potential problems with the man's eligibility for service, the director decided to be safe, not sorry. After consulting with his staff, he decided that putting the man's funds in 'their proper place' was what the regulations called on the program to do.

The director then instructed two workers to talk with the man, which they did that weekend. The other residents were watching a ball game on television when the workers invited the man to have coffee with them at the kitchen table.

The workers started out by explaining the rules to the man. They told him the regulations that allowed him to live in the home required that he give up some of his money to the agency for safe keeping.

They told the man he would have to hand over his money and future earnings to them on this basis. While they assured him that he would be able to get back this money if he asked for it, the workers stated emphatically that there would be records of all withdrawals.

The man didn't understand what a withdrawal was for starters, but he nodded his head anyway, and smiled while enjoying coffee and donuts. His demeanor changed when they went to his closet and used the staff's spare key to unlock the strongbox.

The man looked on in disbelief when the workers counted out $650.00 dollars that they proceeded to put in the office safe using an envelope that bore the man's name, leaving $80 in tens and twenties. Rather than object, the man gave out a long somewhat harsh humming sound which was different than any of the communication forms he used before.

Still humming, the man accompanied the workers as they took the handful of cash from his room to the office safe. While the workers described everything they were doing and why, there was no sense of acknowledgment in the man's expression, just growing disbelief.

Bear in mind, this man went into a bank in his life. He didn't understand how money was kept, and how it would buy things beyond a small stereo, clothing, meals at the restaurant downtown, or his tools. The institution where he lived before used tokens to pay for work chores he did.

His confusion didn't improve as subsequent transfers continued to be made with his earnings in September and October. There was a grim look that came over the man during these transfers that lingered into a change in his overall demeanor.

As the man figured it at this point, workers were either taking his money to cover the cost of services at the home, or using this for their own purposes. Either way, the man didn't think this treatment was fair since it didn't happen to any of the other residents.

Over the following months, the man never took a dollar out of the resident account that the agency set up for him. The man limited his expenditures to the $80.00 a month that was allocated to him from his SSI benefit payment, which he continued to stash in the closet safe.

Just before Thanksgiving, the man had an altercation with one of the workers. According to the incident report that this worker prepared, the man pushed him to the ground when the worker took a rake from the man after he refused to give it to another resident. The report didn't mention that the rake in question was part of the lot of lawn tools the man purchased at the auction months earlier.

In accordance with state policy, this incident report was shared with the agency's human rights committee, the man's case manager, and an official from the regional office. Pursuant to state policy, the committee reviewed the incident in 4 working days.

While the worker who was pushed attended this meeting, the man was not present, and it all went down pretty quickly. Based on the report from the worker, the committee found that the man put himself and others at the group home in danger by his pushing the worker onto the ground and making threatening gestures.

While nobody was hurt and the men shook hands after the incident, the committee didn't want to give residents the impression that such behavior would be tolerated. They recommended that the director take 'appropriate', but otherwise undefined, action to prevent any future occurrences.

The committee report included a statement that the man had come through a honey-moon period at the group home and now had to 'settle down' into a 'routine'. While unsubstantiated, the committee also mentioned the worker's testimony that the man was said to have a history of outbursts at the institution.

In response to this report, the director took a number of steps. In this process he consulted with the workers, but not the man. The first thing the director ordered was a review the man's medications.

The second action was to have workers speak with the neighbors to see if the man's yard work should continue. In accordance with state procedures, the man's case manager signed off on the corrective action that the director prepared, and so did the regional office.

That next week, two group home workers, including the worker who was pushed by the man, talked to neighbors about the man's work. Taking liberty with the director's instructions, they told the neighbors that the man had been involved in an incident and that the agency was considering cutting off his jobs until 'things got back to normal'.

On hearing this news, Mr. Jones expressed surprise and disappointment, but didn't question the action the workers. While Jonesee and the other neighbors stated emphatically that they never had any trouble like this with the man who was always well behaved, none felt qualified to question the man's treatment team.

Over the course of the next month and a half, the man lost all his jobs in the neighborhood without knowing why or what happened. Not long after that, the man's medications changed after an appointment with the psychiatrist.

The man also returned to his old schedule at the training center. The agency put the man into a group therapy session for the first time to 'discuss' anger management as a result of the incident, which the director also approved, which was a joke because the man didn't get any of this.

When he wasn't in group session, the man made potholders for the agency's upcoming fundraiser. His meager checks from this were mailed to the group home and processed like the others, so he never saw a dime of the little he made.

By the holidays, the man's dating relationship completely ended. He stopped going downtown too. In the daily log, workers attributed this to problems in adjusting to medication changes, never mentioning that he wasn't tapping into his account.

During the winter months that followed, the man began to refuse to do work and activities at the adult center. Once he even locked himself in a bathroom stall causing the agency bus to leave an hour late one afternoon.

During this period, he was described in the record as withdrawn and occasionally "ready to blow". His carefree and agreeable personality seemed to have disappeared, and he was definitely no longer the program's "star".

That February, a second psychiatrist changed the man's medications again as a pattern of negativity and withdrawal began to emerge. The new drug regimen resulted in the man losing weight, drooling, and being more lethargic over the following months.

By May, about a year after the man began his jobs with Mr. Jones, the group home director got promoted to head a new division in another catchment area. Over that same period, all the other workers, including the two staff members that raised concerns about the man's income, left the program too.

None of the replacement workers or the new program director had any knowledge of what the man or other residents had been experiencing over the prior year. While the records of the prior year were available to review, nobody took the time to read them carefully.

The relationship with Mr. Jones and the neighbors ended once he returned to the activity program full time. Jonesee also began to experience health problems that kept him indoors, and he passed away that summer, just before the time of his picnic. None of the residents or staff from the group home attended the viewing.

In a couple of years, the man also moved from the group home to another setting at the other end of the county. Then he moved again a year later to an apartment the agency rented in the outskirts of a small town.

The man really liked this country place for its peace and quiet, and a buddy he made there. Before long, he got a job sweeping and doing odd jobs at the corner store nearby.

Today, the man is living in an apartment he rents above that store, and he's going out on Friday night with a lady friend, I'm told. The agency doesn't have any more contact with him, which the man likes.

Beyond Correctness

Even though system workers and community employers talk about 'the potential' people with disability have to be employed in the community, their general impression is that only people with mild forms of intellectual and other disability can be economically productive members of society in a narrow spectrum of jobs. There is also a pervasive belief that adults with disability shouldn't be expected to earn a living through regular employment, and that they should have the choice of age-inappropriate activities and perpetual training in adulthood.

Some citizens also maintain that people who don't receive disability services or benefits should be given preference in obtaining jobs. As early as pre-school, toddlers with disability get saddled with assumptions that they will never work in a regular job, and need to stay on a less rigorous track with others labeled with similar classifications or diagnosis.

Taking on these assumptions means applying cost-effective ways to ensure people become valued employees, business owners, neighborhood workers and community volunteers. In achieving employment outcomes with people, support means achieving very doable tasks, as long as systems are taken out of the driver's seat.

Securing community employment means taking on the impressions of helplessness given out by the system's program management, policy, and public relations. It means laying out the truth about the ways systems have discredited and maligned Federal and State work incentives for their own benefit.

Thanks to the system's practices and public relations, the general business community is led to believe that people with disability are helpless, and that employing them entails a liability. The shadow of added costs associated with health care, sick leave, and physical adaptations causes employers to opt out with people, and to leave well enough alone.

As we've seen in the system's handling of the Medicaid Buy-In program, which allows people with disability to be employed without losing their Medicaid health care benefits, the system is by far the worst source of information about available federal and state work incentives for people. Most employers, families, and other stakeholders remain uninformed about these incentives, while systems have not integrated them into their funding design or program training.

Prospective employers, which include a vast array of small, medium and large businesses across the nation, haven't been exposed to financial supports that are available to them through the vocational rehabilitation system, the tax code, and supported employment programs. Thanks mainly to system neglect in making links with employers, stakeholders show no interest in utilizing these or any other available resources.

Incapability is the biggest lie that systems spread about people in the area of employment. Service agencies, from vocational providers to administrative entities, peddle this myth because they don't want to deal with the disarray job finding in generic settings would cause.

Even when employment and career opportunities are clearly the most appropriate option, systems prevent job finding and supports through a variety of tricks of the trade. For example, count on programs continuing to scapegoat family resistance as the top barrier to people getting jobs, completing ignoring their responsibility to deal with this issue in a constructive manner.

Operatives also assert that people can't fit into a competitive environment without the ongoing engagement of service agencies workers. They even insist that sheltered workshops constitute employment even though people are given no opportunity for advancement or career development, no work benefits, no choice about working elsewhere, and no good pay.

Tales of Two Worlds

Employment is a valued pursuit that sustains survival, individual and family identity, and healthy lifestyles. Work, whether volunteer or remunerative, brings self-esteem, along with respect and recognition.

Employment contributes to personal and community wealth. People with jobs pay taxes, take a vacation now and again, contribute to the economy, open a savings account, and have a stake in their community, neighborhood and nation. People who don't have jobs are substantially less likely to get married, have a home and live satisfying lives.

Citizens with jobs obtain them by going to interviews with prospective employers and utilized their community contacts and relationships to get a foot in the door. They have a sense of jobs as part of a career which they are good at and enjoy.

People with disability don't get jobs, and they have a much harder time in being considered for career paths than others. Living on public benefits like Social Security and Medical Assistance becomes a lifeline for people, instead of earnings, savings and the like.

Employment of people with intellectual disability is rare and not improving despite on and off again efforts by Federal and State governments since the late 1980s. The unemployment rate for people in service system approaches 95% in some states, while people with all forms of disability are hovering around 70% unemployed.

Instead of jobs, people with disability are placed in sheltered workshops, so-called affirmative industries and adult activity centers. Many also do nothing, wasting away their adult lives watching the tube at home.

People are transported to sheltered settings by their family, agencies providing services and some area transportation authorities. Well over three quarters of working aged adults in systems today spend their weekdays in these settings without any other earned income, like a part time job.

In a third of the states, there are practically no supported employment options for people apart from sparse allocations through the state's VR (Vocational Rehabilitation) agency. States where people have access to employment support also have different definitions of employment and services, making claims of employment outcomes difficult to verify.

Counting a job as an enclave where people are served under sub-minimum wage conditions is one the common inconsistencies in defining employment, and there are others. School systems in Pennsylvania, for example, consider placement in an adult day care program as an employment outcome for students transitioning into adult life.

In today's world, services like sheltered workshops are supposed to act as a critical link to employment but are instead a bond to poverty, exploitation and dependency. The devastating combination of work and activity programs systems operate control the fate of people like no others.

Congregate work facilities also contribute to keeping people devalued and apart from the general world of adult life. They prevent people from exercising self-determination and their rights to accommodation under the ADA.

Heavily invested parent advocacy groups and non-profit agencies dot this vocational program landscape. In Pennsylvania, there is a sheltered workshop or adult activity program serving each of the state's 50 counties, with larger cities having ten or more providers serving hundreds of people each in so called 'day program'.

While the reasons for operating facility based programs are different among these operators, non-profit entities predominate. The boards of these agencies are composed of family members, business interests, and civic leaders that want to see sheltered ways of work continue.

Operators most often have purchased settings in industrial parks and business areas, or have taken out long term leases. Agencies locked into mortgages have found it particularly challenging to tear themselves away from shut-in ways, particularly after leveraging their real estate for equity loans over the years.

People who attend workshops sit on assembly lines and at workstations shared by colleagues who have a disability too. Government funding that is supposed to be limited to employment directed training actually goes to supervising work tasks that have no link to community opportunities of any kind.

Exacerbated by a shortened workday and limited contracts from area business in stressful economic times, wages at the workshop are generally meaningless to securing a person's economic stability or independence. People who have to cover their transportation costs to work barely make enough for this expense.

The jobs at workshops come from contracts with local business and industry, as well as government agencies that have set aside programs for organizations that employ 'the disabled'. In almost all of these situations, workers put utensils, screws and nuts in bags; fold paper and cartons; apply labels; and organize bulk items like books, magazines, and other merchandise for shipment.

Some workshops offer cafeteria and catering services along with janitorial crews that take sub-contracted jobs in the community. While not as popular today, people considered "home bound," still accept work where they live.

Apart from low paying back room jobs in sanitation, housekeeping services and food service, people with intellectual disability are not associated with valued occupations and careers. Talk within program circles of promising practices like 'customized employment', 'job-carving', and 'discovery' finds precious little traction.

People working in sheltered workshops are still subject to sub-minimum wage provisions of the nation's labor laws. That means that a full time worker generally takes home less than $100 a month.

As explained further in an early chapter of this book, sub-minimum wage levels are established based on a time study that determines what a non-disabled person would earn in a comparable job. While the approach sounds fair, it's not.

In the first place, service industries that constitute a majority of this country's economy can't be evaluated on a piece rate basis. While manufacturing tasks can theoretically be assessed in this manner, the small, light industrial jobs workshops accept are anomalies within the general business community.

Others businesses don't do the type of sub-contract work that workshops take, and when they do, they rely on modern machinery and automated practices. While sheltered workshops make their niche in taking jobs other industries can't do any cheaper, there is no trickle down to people with disability doing the work.

Sub-minimum wages doled out in the workshops keep people poor and restricted to forms of labor that are not at all suited to their talents, the labor market, or their personal career

choices. Sub-minimum wage also gives workshops a considerable advantage over would be competitors who must pay their employees a living wage and benefits.

Make no mistake about it. Workshops are a good business to be running in many areas of the country. Vocational training has made many executives wealthy from juicy government contracts and cherry deals with area businesses.

Having existed since the 1840s when the Perkins Institute for the Blind opened in Massachusetts, workshops changed from teaching people professions and lines of work, to training centers focused on sub-contracting as they became larger and more self-contained. They've continued in this mode throughout this generation, although some of the more profitable ventures have gotten into specialty lines and even high-tech manufacturing.

The origin of sub-minimum wage for people with disability stems from the National Industrial Recovery Act, one of the early pieces of President Franklin Roosevelt's New Deal. Under an FDR executive order, it became permissible to pay people with disability below the minimum established by law.

In 1938, another law, the Fair Labor Standards Act was passed under the New Deal, too. It specified standards for basic minimum wage rates and overtime, along with special exemptions for employers of people with disability. While these standards were created with disabled veterans in mind, returning soldiers rarely enrolled in these programs, opting for GI bill and other veteran benefits instead.

Sub-minimum wage has been has been subject to rampant abuse, as evidenced by Congressional exposes over the years, especially Senator Teddy Kennedy's senate hearings in the year before his recent death. Between 2004 and 2009, the Department of Labor conducted an average of 135 annual reviews of workshop payrolls across the nation, representing less than 4 percent of all the facilities claiming sub-minimum wage exemptions.

The Kennedy Commission Report in 2009 found rampant government and private industry collusion, with some executives making million dollar salaries among many other questionable practices. Most of the report's recommendations have not been implemented, and sub-minimum wage work for people continues to hold on despite declines in workshop clientele and an increasingly aging workforce.

Despite their financial advantage in utilizing people with disability as a work force, workshops continually struggle with local economic pressures. They have been especially vulnerable when area industries close or ship their subcontract work oversees.

To prevent lay-offs, numerous vocational training programs have retooled to selling recyclable items and accepting charitable contributions for resale. Some agencies have ventured into recycled electronics despite serious health risks to workers.

Big box agencies like Good-Will have second-hand materials as a primary means of income and do well all across the country. While many of these agencies also dabble in

supported employment, their primary line of work continues to be with sorters, material handlers, and other manual labor congregated on the basis of their disability.

In the roles they've carved out, workshops continue to take the messy jobs, and the little jobs that other manufactures won't touch. They also provide accommodations to people, which the rest of the business community should be doing to, but doesn't since they've been immune from this taking this population in as regular employees.

When subcontracts with area business dry up, workers experience extended periods of 'downtime' which can occur on a regular basis. While estimates on this vary greatly depending on what sources are asked, agencies rely on government funding and community contributions to keep the lights when there is not enough work to go around.

While supervisors and executive personnel most assuredly do get paid for organizing busy work and activities during these periods, people don't get paid for downtime and must be satisfied with waiting for weeks or even months on end for their next paycheck.

Why Workshops Hold On

It's not surprising that workshop programs continue to hold on in rural, suburban and urban areas across the country. With multiple income streams from private and public sectors, workshop executives still do quite well for themselves, and having a component of the system where adults can go works well with other stakeholders.

Vocational programs are in fact lucrative enough to assist multi-service agencies offset funding shortfalls in other programs they operate. Workshop operations in state and private institutions also return income to facility coffers, but rarely get invested in any form of supported employment. As long as sheltered and congregate care alternatives remain an acceptable option for people and their families and funded by state programs, that isn't likely to change.

These vocational programs, like group homes, characterize themselves as the real McCoy in terms of a place of work. They insist of using time clocks, work lockers and other physical appointments that make their settings "as close as possible" to what the community has to offer.

To keep their services in demand, workshops vie for young adults transitioning into adult life in cahoots with school officials most often. While transition rates vary across states, about 2/3 a third of all high school graduates with multiple disabilities went directly into sheltered work and activity programs after they graduated in Pennsylvania for many years.

Rather than getting part time jobs after school like their classmates, young adults in special education are introduced to sheltered work while still in school. Schools have been sending 16 to 20 year old students with disability to workshops and adult day centers for decades; and in Pennsylvania at least, income from public schools accounts for the second or third top funding source for sheltered workshops today.

Considering funding from school systems, Medicaid home and community based (HCBS) services and ICF/MR institutions, vocational service settings rake in an estimated $3 million a year, based on a setting serving 80 people at $18,000 a person for 240 service days of service. This represents no small change when considered with additional income from job contracts, grants, state vocational rehabilitation agency payments, endowments and trusts, community fund raising, transportation service accounts, and other charitable donations.

Also bear in mind that all this funding flows directly to the providers, not to the person or community employer to manage. No wonder vocational programs refer to people using these services as "clients" and "consumers."

System ways could have changed dramatically by now if people didn't have such a rich commodity value to the disability systems that provide their services. As long as systems are paid to keep people in the workshops without being accountable to employment outcomes, this isn't going to change.

Today's vocational workshop epitomizes how the economic relationship created by a person's disability overshadows attempts to support people in community life. As the saying goes, follow the money.

Sheltered Worlds Are Not Worth Saving

While public resources are necessary to support people with disability in securing employment and other facets of everyday life, public expenditure levels can be expected to be much lower outside of system controlled ways. For example, many businesses would be pleased to accept a "difficulty of care" stipend of $8,000 for a few years to support a person on the job, which is half the cost of many sheltered workshops.

The public would also be happy with such an arrangement too, as two years or three years of $8,000 to a job coach is a much better deal than the prospect of $18,000 a year for 25 years at the workshop. Conservatively speaking, employment support promises to save the public $28 million in public funding for every 100 people served over a worker's lifetime, not to mention the benefit from people paying taxes and using their incomes to stimulate local economies.

It's not a matter of people with disability taking jobs from "able-bodied" adults or keeping the nice employees at the workshop employed either. People with disability have the same right to obtain a job as anyone else and to follow a career path of their choice.

People with disability aren't expecting anything more than the accommodations they deserve. They expect a square deal and equal opportunity, and if anyone doesn't believe this, just ask some students or family members of young adults transitioning into adult life.

While system advocates don't expose this fact either, employers generally make ADA required accommodations for people with minor additional expenditures. When more resources

are needed, there are various tax write-offs and state vocational rehabilitation grants to offset these costs too.

The last 25 years of supported employment history demonstrates that people with disability succeed in positions that have been a challenge for employers to fill. In hospitals, warehouses, and offices, people have been excellent and loyal employees in all sorts of careers and occupations.

One of the loaded questions system proponents like to throw out on this topic is whether people with disability are "really ready" for employment in their lives. This question of readiness is put on people without examining the support they receive, their career choices, and the role services and families are playing in promoting employment outcomes.

The question also presumes that disability, as opposed to denied opportunity, dictates the work and employment and career paths people take. By asking about a person's readiness in general terms, the system gets to ignore its responsibility to achieve employment outcomes through its practices and programs.

The readiness model that systems invoke is a hoax whether it's in a residential or employment context. Readiness reinforces the lie that makes disability into an absolute impediment to community employment which it is not.

It also assumes that people are unable to adapt to the rigors of a job culture, multi-tasking, and other environmental conditions without going through a system phase of training, again a hoax without any basis of fact. People get jobs when they have the opportunity for one and the support to keep it going.

There's also an employer concern with the image of employing people with disability, and whether people will be safe from abuse, or create liability concerns. These hesitations are best addressed by employers who have already made a commitment to hire and support people, and they'll say that none of this is true.

Mendacity unfortunately comes with the territory where adult and vocational training programs have a virtual monopoly over promising practices and common sense approaches. The lack of truth telling forms the foundation for making a meal out of blaming the victim, questioning people's capacity for success, and pointing to a handicap or social condition as the root cause of disappointing service performance.

The question about the future for readiness model programs is not what becomes of the sheltered workshop and all the nice folks that have been employed to serve people in these places. It's time to stop feeling sorry for human service workers who may have to move on to other forms of employment in keeping with the times.

The challenge around employment is not about sorting out what works for people who attend workshops and what doesn't. The question is whether people with disability will be

supported in employment as part of their everyday lives, regardless of the settings where they are placed.

The solution to employment has nothing to do with places that keep people bonded to services for the system's self-interests anymore. The future has nothing to do with government agencies continuing as mediators of how these relationships transpire, or trickle down funds for training without accountability to employment outcomes.

The fact is: nowhere are the disparities in opportunity more apparent for people than in their work lives. Either people get the support to achieve employment outcomes, or they'll stay as the long-term care commodity they've been for a hundred years and more.

Either resources move away from system-fed organizations that do not deliver on employment outcomes, or people remain in their disenfranchised class. The public can keep paying systems to keep their little secret that people are much more able than they are interpreted to be, or they can see the truth.

While vocational providers and the organizations that feed off of them would take their sweet time to address the issues at hand, the county doesn't have this luxury of waiting for the next half-hearted "ah-ha" movement. Push has come to shove.

It's time to admit that certain parties can't see the light, as the Bob Dylan song goes, "that never shined." We must leave workshops and centers to the past once and for all.

The Rub

The rub is that people who secure steady employment in the community find their jobs and pursue careers on their own, with the assistance of friends and family, and sometimes service providers too. Systems are not engaged in these situations most often, and tend to stand in the way through sluggish practices and procedural obstacles.

Systems deny the sense of urgency we all need in taking the job when the moment is right. While some venturesome big businesses, including Lowe's, Walgreen Pharmacies, and some hospital chains, are beginning to actively recruit people with disability, most industries and businesses sit on the sidelines, waiting for systems to sort these employment out.

Vocational rehabilitation agencies established under the Rehabilitation Act of 1973 have been helpful in achieving employment outcomes for people over the years; but their resources have remained extremely limited. Supported employment services for people with intellectual disability generally constitute less than 5 percent of state vocational rehabilitation system budgets in most states.

While state and local service systems for adults with disability are supposed to collaborate with vocational rehabilitation agencies to help people prepare for community employment, they don't do this well at all. They have trouble have trouble navigating funding barriers, and lack effective employer, family and community outreach. To make matters worse,

state vocational rehabilitation agencies find their efforts thwarted by resistance from adult service agencies and families vested in sheltered work styles.

Over the years, rehabilitation agencies have also gotten into the practice of funding employment supports within narrow spectrum of job opportunities that people with "milder" forms of disability have done successfully. While these agencies are supposed to focus on people with the most severe disability, they don't, and really can't without the infusion of additional resources from the public and private sector.

"VR" has also been known to take on a proprietary role with their customers and like to consider themselves as the main employment link for people with disability across the country. The fact is, home and community services funding under Medical Assistance spends more on supported employment than Vocational Rehabilitation does in many states.

Time limits imposed on vocational rehabilitation services are also very problematic, with supported employment funding limited to 90 days or less in most states. Although other funding streams, like Medicaid home and community services, are supposed to pick up after this initial 90 day period of job finding and support, follow-along funding is notoriously unavailable, delayed and inadequate. Since many adult service systems refuse to commit to funding after this 90 day period, vocational rehabilitation agencies are often forced to turn down people who would be great employment candidates.

Apart from these coordination challenges, the biggest deficit in securing employment through both the VR and adult service systems is their tendency to rely so heavily on agencies providing supported employment services, instead of employers and other sponsors. This tendency also ignores accessing employment support directly from other support specialists like families, friends, and community contacts.

As evidence of the system's blinders in this area, it's telling that major national firms like Walgreens are taking on the challenge of supporting employment with people outside of funding streams and systems calling the shots. Witnessing how some service systems are beginning to catch up to business initiatives would be amusing, if they weren't so inept and long overdue.

Relying on the system's agencies to locate and secure employment with people is recipe for disaster. Under the system way of doing things, employment becomes a function of referral from one agency to another, rather than an outcome to be achieved through a personal career assessment or discovery process, followed by job matching and support.

To keep supported employment as dysfunctional as possible, funders stubbornly resist outcome oriented payment approaches, and remain heavily invested in paying for the time that providers put in regardless of the employment outcome. Providers also don't tap the traditional routes citizens take to locate jobs through family and community contacts, and practically none of them participate in shared payment approaches with employers.

In their frameworks of caring for people, systems fail to acknowledge that employers won't accept intrusion or any agency monitoring requirements taking over their culture. By

refusing to deal with paper work and visits by system intermediaries and monitors, businesses have been real clear about their position.

On this basis, it is no wonder that so many employers find good jobs for people without tapping government subsidy or tax credits at all. Storeowners and corporate leaders alike can't be bothered with bureaucratic rules and practices that systems bring with their promise of additional dollars.

While it should have been possible to develop effective policies over the years to coordinate employment support resources, this hasn't been done. Even states that have adopted employment first policies resist moving funds outside of the vocational training domain.

For these and other reasons, systems have proven that they can't be relied to secure employment for people, time and time again. It's time to for doing this support differently, as the old ways continue to be a shame on us all.

Stages of Support

The state of the art in supported employment is at an early stage across most of the country, with many human service organizations stumbling and unaware of what business and industry require of them, let alone people these employers hire. Introducing people to a potential employer is too often done in a manner that ignores the employer's way of doing things, without an appreciation of employer needs and business practices.

The culture of government supported service also turns off many prospective business owners and human resource departments. Employers haven't bought the line that 'we're from the government and we're here to help' before, and they are not about to change their ways now.

In all but a handful of adult disability systems today, less than 5% of people have full time employment. The great majority of jobs people have are very part-time and limited to an array of occupations where people are last hired and the first let go. The rate of employment for people with intellectual challenges has not improved in over 30 years, despite spikes of hope and infusion of new funding from the late 1980s on.

The national trend in employment of people in service systems has also declined over the last six years, despite the infusion of Medicaid waiver services, federal and state work incentives, and Department of Labor infrastructure changes. While systems like to attribute these declines to the economy and people with 'greater needs', there is nothing in the demographic statistics to bear these assertions out.

Whether the economy is good or in the tank, people with disability have not had any improvement in their job prospects or trends since the millennium. The basic problem is that there's nobody in systems to provide the resources for job finding and support, and the rest of the nation isn't interested enough to pitch in.

Apart from this, one of the pitfalls in developing supported employment has been the protracted periods of assessment and job finding activity that agencies enter into. Practices like mock interviews and other virtual activities take months or years, eating up limited resources without achieving outcomes.

Without a discovery process that accounts for a person's career track and job experience, agencies tend to keep people on pre-determined low-pay job paths that suit a limited skill set. While this makes sense on the surface, the fact is people with disability have shown real promise in fulfilling complex and routine types of work that other people just get tired of doing accurately.

Programs are also often too ready to return people to workshop life after initial lack of success. Even one failure at a job arranged through system services can trigger a lock on working with a person to try another opportunity, ever.

System rules and regulations put employment into a choice pocket that people with disability tend to believe they have. This choice of employment or not finds no corollary in everyday community life where adults in this country get a job to earn a living for themselves and family. People by having the disability label get taken out of this expectation set.

Given the number of supported employment service providers that also provide sheltered work, it is not at all surprising that so few employment-only agencies help people with disability find jobs today. Here again, the penchant for the system to keep services "in house" has proven to be an unmitigated disaster in achieving real life outcomes with people.

Rather than making sure that supported employment personnel, called job coaches or employment specialists, fade out once people become accustomed to job tasks, programs hold on to units of service beyond the period where their support is helpful. Agency employed supported employment specialists have been known to do work tasks for people at community jobs for a decade instead of making sure informal supports in the workplace take hold with the employee. Although maintaining ongoing contact can be warranted, protracted periods of unnecessary services are not cost effective, although done all the time.

 Making matters worse, job exploration is not at all person centered. Programs invested in systems tend to limit people's horizons to safe havens for people with disability, rendering individualized career-oriented job finding the distinct exception to the rule.

Agencies that focus on securing employment for people with disabilities in careers with good paying jobs enjoy a difficult status with their system colleagues. While provider associations and service system appreciate such programs for the diversity they offer, employment only service providers operate on different principles and don't tend to mix that well with their sheltered counterparts.

In fact, there are generally few effective employment advocates within vocational provider associations or administrative entities. Those practitioners that push for change

understand the forces they are up against especially in terms of developing employment friendly policy and funding.

Supported employment programs also have the ubiquitous challenge of operating with inadequate rates and no community support to speak of. Instead of finding new workers with marketing and business backgrounds who can seal the deal with people, providers who have begun to dabble into job finding tap their workshop staff with disappointing results.

Setting themselves up to fail like this has been the hallmark of systems and their provider networks over the years. Trying to keep everyone happy by continuing outmoded sheltered ways, while staying attuned to emerging trends has resulted in a lot of too little too late.

Commitment to employment is so fragile in many areas that agencies still can't get past resistance from board members and families who have adult children in the workshops. Knowing their jobs will be threatened by cutting out facility operations, otherwise wonderful program directors shy away from closing these places down.

The 'someday over the rainbow' quality with supported employment just has to end with people. Achieving employment outcomes must be demanded and planned for in a way that is meaningful and expeditious.

Providers that want to make the shift must be supported to do this, and the others left to make it on their own. It's time that existing services begin to face the fact that excuses won't cut it anymore.

Programs caught up in the old ways need to adapt and change now, or be passed over. This train for employment is leaving the station, so those who want to, need to get on board.

Changing Perspective

A fundamental change in perspective is needed to achieve employment outcomes with people and begin the wheels to set societal change in motion. The message needs to get out that supported employment programs means engaging employers as the primary lifeline, stakeholder, customer, and source to success.

The time for relying on agencies vested in sheltered workshops, vocational facilities, and adult activity programs is ending. Employment support for people must open the door of business and industry and leave behind service system practices and practitioners, lingo, and hubris, once and for all.

Because of their investment in sheltered settings, systems and their programs have been unable to allocate adequate resources to individual supported employment ventures. While funds could follow people from workshops to job supports, the sheltered service industry fights this approach tooth and nail, and consumes all the funding that it can.

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In the big picture, system operatives don't want people to succeed in securing employment beyond the work their programs offer. This point of view is unmistakable when the topic of employment opportunity is broached with many vocational services providers.

The defensiveness of their words, and how they point to families and community employers as culprits, continuously reinforces how they are unwilling to change their sheltered ways. Grasping for experts that agree with their point of view, traditionalists claim to be justified in utilizing sheltered settings without a scrap of evidence to demonstrate that any of their methods are effective, or even legitimate given their mission to support people in locating jobs.

Adding insult to injury, system proponents point to failures in starting up half-baked employment pilots as proof that people belong in sheltered settings. Claims like: 'We tried that already', or 'this works for a few of them'…are mentioned time and time again.

In declaring that people must have the choice of a workshop in today's service lexicon, traditionalists ignore that people with disability don't actually choose to attend sheltered programs in the first place, and the reality that families have no other place to turn than congregate settings. In the choice card they play, traditionalists ignore the issue that their workshop programs are wasting public funds and reneging on their social, let alone regulatory, responsibility to prepare people for jobs.

People are placed in workshops because of selections made by family members, school counselors, case managers, and residential providers. While people who go to workshops like being with their friends from school, people make friends elsewhere too.

What's culturally appropriate about this friendship argument anyway? Does this type of question enter the consciousness of community employment for other adults and job-seekers? Who cares if a person is employed with others they didn't already know and like?

Systems can't relate to people as self-determined adults when they view them as eternal children like this. Passing on this juvenile message to stakeholders plays out disastrously in establishing adult responsibilities of all kinds.

The National Disability Rights Network is a nonprofit membership organization chartered to protect people with disability and their families through legal support, advocacy, referral and education. In a 2011 report, entitled <u>Segregated and Exploited: The Failure of the Disability Service System to Provide Quality</u>, the Disability Rights Network wrote this summary about sheltered workshops, that says it all.

> *"Unfortunately, sheltered workshops and the sub-minimum wage still exist today because of self-interested employers and systematic neglect by federal agencies, buttressed by outdated stereotypes of people with disabilities and the low expectations held by the general public, lawmakers, and sadly, even some families and the disability rights community.*

Simply put, sheltered workshops are just another institution where segregated people with disability are put away because of our unwillingness to accept perceived notions about their ability to work may be wrong."

As this statement attests, the basic reason sheltered work has survived is not because of the inability of people with disability to work competitively. The problem is with the agencies that run the systems and the neglect of the community.

It's not a problem about people finding jobs either. Successful supported employment agencies report no shortage of appropriate job openings and receptive employers.

The problem is with systems not wanting to give up their monopolistic commodity and human tender. This just has to change, this usury.

Achievements Nevertheless

After World War II, people with certain forms of intellectual disability began to be recruited at the Library of Congress in Washington D.C. to ensure the nation's vast collection of books, periodicals and other reference materials were organized in card catalogs that lined rooms of this vast institution.

People with disability were selected for these jobs because they were able to do the work of organizing information better than others without a disability. Somehow the library discovered that people with had inherent skill sets that were more precise, and less prone to error than other workers in doing this cataloging work.

Until computer software took over these functions in the late 20th Century, people with intellectual disability held good jobs with benefits through their positions in the Library of Congress. They worked side by side with librarians, scholars, students, and the public at large.

They paid taxes and supported families with their living wages and benefits. They retired with pensions and health coverage. They became valued colleagues and friends with the people they worked with for years.

There is still a sprinkling of success stories like this today, thanks to struggling supported employment efforts in states, but they are not strong enough to begin to move away from the status quo of sheltered work and day activities programs. People living in institutions funded by Medical Assistance, like ICFs/MR, almost never get jobs, although support for job finding is provided under these funding streams without any change in regulation.

Group homes also have a particularly dismal record of supported employment too. Due to staffing patterns and liability policies, these programs are prevented by their own operational barriers from providing the employment-related services that they need to.

People in service systems face any number of employment barriers due to agency practices and relationships that serve to keep people from moving on to employment, full and

part time. Refusal to get people into the position of securing a job is unflinching in many state systems.

People are locked into sub-minimum wage workshops by their sponsoring associations and system decision makers too. Local ARCs, the largest volunteer association in this country representing families of people with intellectual disability, operate some of the most restrictive work activity programs and workshops in the country.

Even incentives by Congress to dismantle employment barriers in Medicaid and Social Security haven't altered the main course of sheltered programs and day wasting activities. In state after state, providers of vocational services routinely refuse to enroll in very promising work incentive programs.

Meanwhile, government agencies that should be insisting that these incentives be tapped don't have the gumption to apply any pressure, or issue an employment policy with teeth. Somehow in Pennsylvania, where existing law clearly mandates the use of third party sources before public funds are expended, there is still no requirement on providers to use work incentives under Social Security and Medicaid whenever possible.

Most disturbing of all is the low rates and limited funding afforded by systems to achieve employment outcomes through their service offerings. Agencies that provide supported employment acknowledge that their costs of support exceed financial assistance they qualify to receive, requiring them to tap other funding sources to stay afloat.

To keep their supported employment operations going, some agencies rely on returns from congregate workshops and funding drives to make up for shortfalls. While there are a few states that reward supported agencies for keeping people on the job, most states perpetuate a host of perverse practices that have no way to reward outcomes that are maintained.

The truth is: government agencies don't really want to change any more than the providers do or many families for that matter. To keep operations from achieving employment outcomes, government agencies routinely limit their role to providing information and training about employment, or funding incidental pilot projects from time to time.

While more states have made a stand to secure employment first with people, practically none have been able to demonstrate progress in the most fundamental of ways. Some, including Pennsylvania, have found it difficult to even report information that would demonstrate outcomes and cost that could form a basis for additional quality improvement.

State and local agencies also avoid committing themselves to employment- first practices that would require case managers and programs to introduce families and young adults to employment opportunities. This is more than laziness that keeps them from taking these actions; its malfeasance and a serious dereliction of duty.

While some people with disability are working and earning living wages in today's mailrooms, banks, warehouses, law offices, and hospitals, more industry and businesses need to

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get involved, in both the private and public sectors. Turning away from people with disability isn't the option it has been.

People with disability also require support to start their own businesses and join in with a family venture. They deserve assistance in building a career like anyone else would.

Today, employment remains the last outcome tackled, instead of the first, in both school systems and disability systems across the nation. This above all has to change.

Chapter 15: Day Programs

Play Time For Adults

Over the last couple of decades, day activity centers have been the fastest growing segment of the adult day service sector throughout the country. In these centers, participants receive little or no compensation for work or anything else they do.

The men and women in these settings spend most of their time in group activities like puzzles and games. "At work," they dance, color, paint, sing songs and plant seeds. They practice identifying and counting currency using play money, and they stay occupied in tasks such as hooking rugs, doing gift cards, and other niceties.

The workers in day activity centers sit in rows of long, cafeteria tables on folding metal chairs occupied in worthless tasks, waiting for a supervisor to tell them it's time to eat lunch or prepare to leave for the van ride home. Adult activity programs are the epitome of busy work that people with disability have to endure.

In terms of fulfilling valued social roles for people, activity programs for people are the embodiment of nothingness and irrelevancy. They're as deviant as programs get today, and for most people, there's no way out.

These programs occupy a wing of a workshop, a church basement or sometimes their own building, often tucked away on some cul-de-sac or non-descript street. They are generally operated by the same agencies that run residential programs and sheltered work sites.

Adult centers have the feel of twisted elementary school classrooms, with ubiquitous displays of child-like sketches on the wall. Like schools, they operate four to five hours a day with time for lunch, breaks, and even naps.

Like students in school, adults in activity centers have assigned places, like a chair, room or circle. Adults have school like lockers too, except theirs don't have locks on them.

That's how it is in places where getting up from your assigned seat gets to be a big deal, requiring raising your hand and reporting to a worker about where you are going. So-called "clients" there are shuffled from station to station and task to task, sometimes holding hands with friends or staff members.

The interest levels of people in the centers fade in and out despite their short day. After the first hour or so, people 'nod-off' at their station or become pre-occupied in a world of their own.

Some people get real fidgety too. When this happens, workers walk people around the room or talk to them softly to get them back to their chairs. Acting out requires people to sit or stand in the corner. Activity programs have been notorious for time out rooms and procedures that at least some states have prohibited by now.

There are not a lot of developmental options playing out for people in these activity centers today. While some programs engage modern technology and teaching techniques, such as computer-aided instruction, tools are at an elementary level rarely generating any interest in people at all.

Mostly, adult programs choose the pedagogy of games, cartoons, and G rated films with lots of animals, music and children playing, along with group discussion, crayon art and puzzles. This form of program shouldn't have a place in a paradigm that purports to be securing everyday lives with adults.

When center programs schedule daily living skills training, they use make-believe environments, like a play kitchen with plastic fruit or a classroom with a bed and dresser where people get practice changing sheets on a single bed. Adult enrollees spend 25 to 40 minutes here, and another there, like they're on a conveyer belt to keep them busy.

The likelihood of people being able to transfer relevant content from activity programs to home or community life is basically non-existent. There's nothing therapeutic, community based, or constructive going on, just deviancy through and through.

If it weren't for the charade that these centers offer training, the community would assume that they are modeled after nursing homes for patients with dementia. At least senior centers regularly include day trips, cultural events, and community participation.

People are trapped in these places, pure and simple. Their programs have become among the most devaluing and inappropriate places for adults in this country to be.

At the activity centers, lunches are served on premises, and people rarely go outdoors. Program time is not structured for community outreach or individual pursuits. People are not engaged in or prepared for volunteer community work or other socially valued enterprises outside the facility's doors.

Yet despite this deviancy, activity programs are the most common system experience for adult with intellectual and other disability across the country today. That's right, more people attend these life-wasting programs than get support to find a job or obtain vocational training.

Horrible as they are, activity centers have been growing at a steady pace as a direct result of the shortages of work in the workshops, and the systems failure to find another way. About 40 percent of all adults in service systems attend these programs today in Pennsylvania, which is probably true in other states as well.

With economic downturns and the reduction of sub-contract business at sheltered workshops over the last decade, activity programs have surged. Systems that perceive themselves

in crisis due to budget difficulties and cuts, also race to the lowest common denominator of care offered in these programs, time and time again.

Service systems invented these activity programs as a plan b to workshops back in the 1950s and early 1960s. They began to pop up and spread as federal and state courts began to rule that institutions couldn't require people with intellectual disability to work without pay.

The so-called peonage statutes that resulted from institutional practices were finally extended across most of the nation's institutions by the 1980s. These laws affected state and privately run institutions, as well as county operated institutions which relied on resident workers to support agricultural work on grounds, laundry services, infant and childcare, cafeteria duties and all forms of building maintenance.

Before the peonage law changes, workers in institutions generally supervised people with disability to make sure institutions made the most of their free labor source. Photos of work crews going back to the 19th century offer clear images of strapping and well groomed men and women in fields, laundry facilities, nurseries and food service.

After peonage ended in the institutions, the systems closed down these work operations completely, or had civil servants and contractors take over the work previously done by residents. Institutions sold their livestock and leased their farmlands and orchards. They contracted out their laundry services, commissary and childcare, leaving people with essentially nothing to do.

To keep residents who used to be working in the fields and buildings busy, facilities created nebulous programs so people would not be idle. These programs were called therapeutic activities for lack of a better term.

In fact, these programs rarely followed a pedagogical method because they didn't teach anything of value. With plenty of room to innovate, various quackeries emerged that promised amazing transformations of people through movement, water and healing treatments.

These therapeutic programs set the stage for similar approaches in the emerging community services arena during the late 1960's and 1970's. Taking their cue from what worked for the institutions, community services discovered activity programs and have stayed by them ever since.

The legions of people who attend activity centers in the community and institutions across the nation today have no expectation of a service beyond their current situation. People in these centers expect to continue in their life wasting placements for 30 to 40 years, costing the public between $15,000 and $20,000 a person each year.

In my home state of Pennsylvania, we learned that less than 5% of people move from activity programs into any form of vocational training, community employment or volunteer work. Stagnation of people in these programs undoubtedly occurs in similar ways across other states as well.

As long as the public's money holds out, systems are good to go with adult activity programs, pure and simple. If money for adult day activity centers runs dry, rest assured systems would find even more demeaning and obscure programs to replace them.

Although finding something worse than activity programs is difficult to imagine, there are ample examples of people with mental illness being released from state hospitals without any support at all. There's always a new bottom for systems to settle with, and systems are very good at finding it.

As we review the situation with adult activity centers, it's important to underscore that people with disability are disrespected in these settings, and only comply so long without making a statement, even if that means some form of behavioral outburst. People deal with this systemic disrespect day after day, year upon year. It takes a toll.

The solution to adult centers is clear. People need something that interests them and has value beyond being kept busy, having friends to talk with and staying amused. People require job opportunity first of all, and the assurance that all support is intended to lead them to this outcome, regardless of their degree or type of impairment.

When employment isn't immediately feasible, people deserve to be in community places that bring social value and promote self-determination at least. Opportunities are available by tapping into the needs of volunteer community organizations and businesses, colleges, trade schools, and the like.

Unfortunately system resistance to reach out to generic organizations keeps this from happening, and activity programs underscore just how low systems will go to keep their people in the fold. As this nation takes into account that more people in service systems continue in this vein of non-work than any other pastime, it's obvious that this too must change.

Community Coaching

In additional to the structured adult services in agency-controlled settings, the system has begun to venture into a service called 'community coaching'. Community coaching is a process of introducing people to community resources that they are expected to utilize in everyday life.

Community coaching includes assisting a person to ride a bus, shop for groceries and other essentials, and interact appropriately in public settings. Its major thrust is to assist people develop competency in community ways and secure lasting ties.

While justified by its community outcome orientation, community coaching often goes nowhere in achieving its objectives. Providers are set up to fail by limiting the exposure of people to prescribed aspects of life, and by failing to focus on outcomes like jobs and community connections.

Sadly, the service of community coaching is generally geared to participating in a mix of recreation and social activities that are available in communities. Community coaching designed around going to the movies, a buffet restaurant, or a walk in the park lack a coherent approach to expose people to a range of integrated resources, supportive peers, and challenges.

Even when coaching is applied in more integrative settings like coffee houses, there's not a sense of connection like there is in generic social clubs of young professionals, civic groups and fan clubs. Incidental and occasional interactions are about all programs deliver; and there's a lot of outside looking in. Opportunities like garden clubs, habitat for humanity building projects, and meals on wheels are left out of the mix.

Like other system designed services, community coaching doesn't engage in rudimentary ways. While some individuals may have some say on where they go or what they do with their program time, people are generally handed a complimentary ticket to the museum or amusement park, and expected to go along with whatever their supervisors want.

Coaching programs are also renowned for their so called "van therapy" component. This play on words expresses the sad reality of a group of people jammed in a 15 passenger agency van for hours, racking up units of billable service for looking out the window. Similarly negative aspects play out in other forms to the therapeutic horse-back riding, as well as garden and recreational therapy done in groups.

Therapies have evolved in the service lexicon, and become more common as states have embraced a medical model that fits with Medical Assistance and other funding streams. Support couched as therapy reflects the power of the medical establishment and is yet another example of just how willing service systems are to sell themselves to the highest bidder.

Fortunately, there are effective community coaching programs, too. One of my favorites was in a metropolitan area where people without jobs buddied up to experience the push and shove of commuter life.

New agency workers joined people in this experience as part of their orientation, and some people continued using this opportunity for an extended period to explore new opportunities and develop their independent living skills. Young adults and people returning to the community from institutions were primary users of this support, and just about everybody loved to be involved.

In this program, people dressed like commuters and patterned their behavior after them. On this basis, people gave up their seat to people who needed to be close to the door and reminded each other to have exact change for the driver. People were coached to be observers primarily.

The routine was for people and coworkers to meet at a certain diner, or other public place for five days in a row, usually starting on a Monday. At the meeting place, people and their companion workers matched up for their trips.

In some cases, coworkers were advised of medications in advance, but most of accommodations got covered at the meeting place. Before getting on the bus, people were encouraged to be careful, respectful of others, observant, and to 'have fun'.

As part of their orientation, the 'easy trippers', as they were called, were also instructed to interact as they would with anyone they were meeting for the first time. They were encouraged to talk with proprietors, the bus driver and waitresses directly. They were coached to be friendly, but not overly so.

They were asked to bring a map, their medication, home contact information, and a fully charged cell phone if they had one each morning. People without experience were asked to follow the lead of their partner, so there was no distinction made between people with or without a handicap.

After the pairs left on the bus route they selected, they took their routes and checked out the neighborhoods and points of interest along the way. They toured the one or two area where they got off the bus, and had lunch or snack as time permitted.

Back at the rendezvous point by 1:00 or 3:00 depending on the routes, the teams would summarize their experience over a cup of coffee or juice, and occasionally a beer. If people wanted to check out something more in an area, they were generally given this opportunity the next day or later that week.

If someone had difficulty or got lost, they'd review that too. The discussions at the end of the day were all business and often pretty lively. Each person who took the trip would discuss what they saw, who they met and talked to, what they liked and didn't. People who couldn't talk signed or communicated in some way on these points too.

The variety of experiences shared was phenomenal, often touching or funny, affirming success and cooperation. Since the pairs were always on the lookout for opportunities, a number of people found employment as a direct result of this experience. Others developed friendships or found volunteer opportunities.

While most of the travelers with disability were not able to take bus rides independently after that week or even two, fears about the community were greatly reduced as a result of this support, and people's confidence grew too. The experience also contributed to an important baseline for people who had more work to do in improving their community orientation.

There have been other programs like this too. There was a community coach I knew whose only job was to set up young people in volunteer jobs, and she was great at it. Recently, a friend who lived next door fulfilled a coaching function while teaching another old neighbor to read after never being taught his letters at the institution where he grew up.

One of the persistent problems with community coaching has been that people with disability are hardly ever hired in this capacity. Peer support workers, while used in the mental health service arena for years, have not arched into other disability systems.

I know a number of people who want to be community coaches and could do it quite well as a career. My good friend, Bill Krebs, a self-advocate from the Philadelphia area has been telling people for years this is what he wants to do in life, but who's listening?

While systems support "self-advocates" in some limited ways, hiring practices within civil service and private agencies preclude employment of people doing this work in a paid capacity. If there ever was a system that didn't walk the talk of employing people first, it's the one supporting people with intellectual disability today.

People who want to provide community coaching services with people are also blocked by a myriad of requirements and negative attitudes. Despite the ADA, people with disability have no access to jobs supporting others and get no assistance to deal with Social Security and Medicaid eligibility issues related to their earned income.

Another untapped form of community coaching area is 'citizen advocacy', which was a key part of the Normalization movement in the 1970's. Citizen advocates are people who assist people deal with real-life, everyday challenges from a basis that utilizes community resources. It's not a system service in any way.

The challenges citizen advocates tackle range from helping a person on fixed income procure a used dishwasher, to finding a lawyer to assert a parent's custody rights. Citizen advocates set a tone of respect and self-determination in how they mediate support, rarely engaging case managers or other system entities.

Citizen advocates put the person and community first. They act as ambassadors who open doors and opportunities that have been closed. They obtain access to places and organizations that have had no interest in supporting or even relating to people.

Unfortunately citizen advocacy never got a foothold in most communities, despite inspiring results in pockets where it thrived. The basic reason for this was the failure of systems to appreciate the importance of this function being run out of the community as an independent venture.

A.J. Hildebrand was the greatest citizen advocate I ever met. He lived in Western Pennsylvania and had a nice office in the middle of the county seat they they worked out of with his associate, Denise Shaw. They called their agency, One to One: Citizen Advocacy.

A.J. spent his career doing citizen advocacy. It was his calling and he eked out a living for his family from contributions from area philanthropists, grants and other sources outside the system. Talking with him was always so different compared to service workers that I'd been trying to work with on system matters, and sometimes manage.

A.J would send me flyers from time to time. Here are excerpts from one of these, written by George Durner, as printed in <u>The Whole Community Catalogue</u>, back in the day:

> *Sometimes it appears that we have unintentionally created obstacles that block friendships….Too often it seems that we have set up staff/client, teacher/student, care-giver/patient relationships in people's lives. These supports may be important but they will not answer the more fundamental need for a caring friend….*

> *We have placed people in homes that are not really homes but rather training centers, schools, and miniaturized institutions. It is important that we become more sensitive to the basic human need that people have for a true home – a place where one can relax and have a sense of peace and security; a place where one is allowed to escape for a moment from the stresses or the world....*

> *Home is where people accept us and value us because of who we are, not because of how we perform. Perhaps we are trying to do too many things for people under the same roof. That is always the case in institutions. The result is that we lose the space, that sacred space, called home where relationships are held more important than anything else.*

That was A.J.: all about sacred qualities of relationships and being valued for who we are. While system folk have these sentiments too, only individuals like A.J. really walked that talk with their communities. He was a conscious guy and as sincere an advocate as I could ever imagine.

In retrospect, it's clear that this country should have invested in the citizen advocacy movement instead of case management and systems like it did. People with disability and their families need community centered champions too.

Over the last few decades, we all should have learned to rely on citizens like A.J. to link people with the community resources through friendships and other ties, instead of relying on wet-behind-the-ears case managers to locate and monitor programs that never touched people and communities in ways that brought them together.

While a lot of the work that citizen advocates did was included in the job descriptions of case managers, workers in the system never had time to locate and coordinate community support, or advocate for people's valued roles. If you asked case managers, they'd tell you that they didn't do the things that citizen advocates did.

The gap between what is valued with people and what was done in systems is as evident with community coaching as it is in any other area. Volunteers, boy scouts, student groups, neighborhood associations, unemployed people and retirees, neighbors and friends, church and social organizations, have important roles to play here. So do people with disability who want to take on this role of supporting people in community ways.

It's time to take community coaching, peer counseling, citizen advocacy and volunteer support out of the closet. It's time for community partners to figure out how to deliver assistance that secures valued roles.

Community resources have a role in letting life in too.

Workstations In Industry

Using whatever means possible to ensure their continuing hegemony, agencies have begun to invest in serving people in workstations over this generation. These workstations, also known as enclaves and work crews, imbed small groups of people with disability into community business settings.

Workstations have some distinct advantages for the system:

- They begin to integrate people with disability into generic businesses and industry
- They are generally revenue producing or profitable for agencies as they still allow for sub-minimum wages
- They are financially advantageous for contractors who don't have to employ workers for their jobs to get done
- They generally pay people better than workshops do, and
- They keep control with the system, not employers or people.

Under the workstations approach, crews or groups of workers with disability are employed by the service system agency to clean office buildings, maintain grounds of public buildings and shopping centers, and perform similar jobs. Agency workers supervise people in separate rooms apart from the general workforce more often than not.

Businesses that provide the space for workstations to operate don't commit to employing people after their work period is completed. In this model, people are transplanted into generic settings, but are not working side by side with other employees, or even taking breaks or lunch time with them.

Many people who are reported by systems to be employed today are actually in workstations and enclaves. These workers often take part time work on the crews, while maintaining their spots at the sheltered workshop for at least part of the week.

While people on these crews generally earn better than minimum wage, some continue their work at sub-minimum wage levels. Regardless of their pay grade, people in workstations have no more likelihood of moving into a regular job than a workshop client or ICF/MR inmate.

Meanwhile, the agencies that arrange for work crews to clean the county court house after hours, cut grass for the State police barracks, or mop-up rest stops along the highway, receive Medicaid home and community based funding and other public resources for the so called services they offer. Certain questions are bound to surface at this point.

What is it about an agency worker supervising five or six men cutting grass that makes this work a service appropriate for Medicaid or other forms of special funding?

What should be covered in service rates and what shouldn't be?

Why should the public be expected to pay for a service based on a person's disability when the assistance the agency provides is really nothing more than using the person as a worker to perform a service that the agency has arranged with a third party?

How can systems get away with calling workstation functions an appropriate opportunity for people when they have no choice about taking their skills to comparable a generic service or business, or starting up a similar service on their own?

These questions about what constitute a service vs. a regular supervisory relationship aren't only restricted to workstations either. They echo across the full sheltered work spectrum, whether it's in an enclave, or a sheltered workshop site.

Why isn't there a line that programs aren't permitted to cross in using people for their economic value as clients?

Why do systems cover their eyes to the damage done to people's employment potential by placing them in segregated work groups?

When does an agency's interest in money making on the backs of people making sub-minimum wage become an imposition to society that could manage support in much more cost effective ways?

Affirming Difference at Any Price

Another extension of the system's sheltered work culture consists of businesses that focus on employing adults with disability at a competitive wage but within a sheltered environment. These businesses are called "affirmative industries" in the trade.

These enterprises are different from regular businesses to the extent that affirmative industries rely on people with disabilities as their primary, if not exclusive, workforce. People without disability don't get hired by affirmative industry, unless as management or professional personnel.

Affirmative industry finds a niche in landing pricey government and large business contracts carved out by different laws for 'hiring the handicapped.' Some affirmative industries are also specialized businesses in themselves, doing things like making wooden skids, or doing heat sealing of magazines for a multi-state distribution company.

The Javits-Wagner-O'Day Act of 1971 is one of the pillars that support this industry's survival. This law, that's come to be known as the Ability-One Program, requires federal

agencies to purchase specific supplies and services from non-profit agencies serving people with disability.

Federal programs under Ability-One, like NISH operate non-profit entities that contract particularly with the Department of Defense. NISH contracts keep thousands of people with disability locked into affirmative industry jobs across many states by packaging automatic weapon and parachute clips, and various forms of medical and food supplies.

While NISH jobs in affirmative industries pay well by any standard, they also keep people from taking jobs in the general community. Following the same restrictive principles that enclaves and workstations adopt, these industries are also big money makers all around.

While affirmative industries are not generally profit-making enterprises like a corporation, executive positions in the agencies pay very well, so well in fact that they were subject to Senate Hearings by Senator Ted Kennedy just before his death. The Kennedy Commission's findings disclosed how affirmative industry operators made millions in annual salary, benefits and perks, and were linked to powerful movers and shakers with distinct political ties.

Fair wages for taking jobs out of the business mainstream is the deal people with disability make by joining on to affirmative industry. While advocates point to affirmative industry as proof that people with disability can work in skilled jobs and earn a decent wage, they'll be loath to discuss how this approach achieves outcomes of choice, inclusion and independence in everyday life. People take jobs in affirmative industry so they can enjoy decent pay, just like other adults, and because there are no other opportunities available to them.

Affirmative industry operates as a vestige of the country's separate-but-equal doctrine that should have been taken care of with the passage of civil rights legislation of the 1960s. In "cherry picking" people from within service systems to be their employees, affirmative industries have had a lock on a competent and motivated workforce that deserve to get regular jobs too.

Affirmative industry recruiters tend to select young to and middle-aged adults with physical strength and endurance, good health and a decent work ethic. Affirmative industry holds on to these people for all they are worth, while the system goes along and even encourages their placement as the ultimate employment outcome.

In parts of the country, it's not uncommon for agencies that have an affirmative industry to also offer disabled workers with room, board and other support services. In these situations, affirmative industries become part of a grander economic engine that supports whole villages where only people with disability live and work.

In arrangements like this that I have seen, people go to the affirmative industry during the weekday, and walk up the road after work to their dorm-like quarters for meals, bathing, and clean sheets. They are encouraged to join up by administrative entities as well as school counselors.

While people in affirmative industry get paid well, these places also seem to violate a lot of what this country stands for. In its profiteering ways, there is nothing affirmative about an industry that compels people to stay outside the mainstream of community employment. What other line of business in this country, except perhaps prison industries, operates in this type of segregated manner?

Using affirmative industry to deprive people of the opportunity to be employed in community ways is as unjust as discriminating against people during a job interview or in determining their pay scale. The prospect of fair wages does not hide similarities with Jim Crow laws in the early 20th century down South. It's remarkable that a 'separate but equal' situation still exists with affirmative industries over 50 years after the Supreme Court's Brown vs. the Board of Education decision.

Indeed, NISH still hasn't curbed its enthusiasm for set aside government contracts for industries that work people in segregated settings, despite pressure from government agencies and Congress. NISH hasn't moved to make their contracts available to regular industry that doesn't have ¾ of their employees disabled.

Instead of adopting methods used in Europe, Israel and other countries, Congress hasn't considered other ways to ensure that hiring expectations outside of these set aside programs be established. Regular businesses should not be restrained from accessing resources like NISH just because they employ people with disability as part of their diverse workforce. These set asides must go.

Government incentives should be directed toward employing people in everyday ways and sharing the wealth that this brings. Government contracts and other resources that support people on jobs need to be where everyday jobs and opportunities find themselves, not in a pool of well-connected charlatans that rely on people with disability to get rich.

As we look at the affirmative industry way, its remarkable how systems have turned a noble concept related to affirmative rights that was codified in the Civil Rights legislation in the 1960s and 1970s to fit a segregated agenda. There's nothing affirmative about these programs as they exist.

One National Disgrace

Taken in its entirety, the spectrum of adult work related services for people with disability, from adult activity programs to affirmative industry, constitutes a national disgrace. After over 30 years of community services, only a handful of states like Vermont and Washington can claim to have done away with facility based forms of sheltered work through a combination of community and job support.

Despite a more concerted effort to promote employment outcomes in recent years, forces representing the old ways continue to double down on families and school systems, making them willing to expect less for themselves, their families and community. Vocational providers and

their systems still beam out their message that people with disabilities are too needy to be regular employees or community volunteers.

The lack of engagement between the service world and the community is so pervasive that one has to ask: Where's the community been? Neglecting people by ignoring their potential isn't any better than keeping people in congregate services for economic reasons, after all.

System advocates continue to insist that people with disability belong in settings where they can be trained and properly handled. Community organizations that assert social justice and equality remain silent to this drivel.

In truth, employment can only be achieved by taking segregate work and activity programs out of the equation and by leaving them behind. The programs offered by service systems perpetuate a "can't do" mentality that severely compromises people's ability to succeed.

As long as people are not working in regular jobs or volunteering in community organizations, they will continue to be beholding to the system. While this is how systems see their work, communities can't unquestionably go along with this point of view any longer. As long as people with disability continue to be directed and influenced to stay away from jobs in the community and other opportunities through these programs, the country will continue to be short changed.

While cash and other forms of assistance will continue to be needed to support people who cannot find jobs or give back to the community in other ways, public benefits should never be devoted to keeping people separate and distinct. People who can be employed and joined with community resources with reasonable accommodation need to be, just as others individuals without a disability are.

While employment support and accommodations have been established as a right afforded under the Americans with Disabilities Act (ADA), people can't begin to exercise these rights until resources are channeled to employers and people first, and not to programs or affirmative industry. We need to end funding for programs that congregate people apart from the general workforce under a pretense of training, or the allure of fair-pay at the price of personal liberty and social inclusion.

Sheltered workshops and activity programs perpetuate a servitude that people with disability continue to endure. More than any other programs today, these services have become the system's fundamental way to justify itself; its needs based mentality, and paternalism.

Adult services are the closed door to opportunity and the wall that people can't climb over to be free in modern society. These services are the gilded trap that keeps people from self-determination, going places, economic prosperity, new relationships, marriage and family life.

Taking the fear, misunderstanding and unfounded mandates out of the American with Disabilities Act (ADA) becomes a crucial hurdle in addressing challenges around employment.

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Clearly, the task at hand is to replace interpretations around "unfunded mandates" with a clear path to resources that people and their employers can readily access.

For this to occur, sheltered work in all its forms must be discredited and taken out of the service equation. Vocational programs that exist without demonstrated employment outcomes with people must end.

Adult day programs must find ways to link people with community resources of close. Agencies can no longer be permitted to ignore Federal and state work incentives out of their own self-interest.

The question is who will take on this responsibility for changing ways in employment and community support. Even though most states have the authority to require provider networks to utilize work incentives under Medical Assistance and Vocational Rehabilitation, practitioners don't exercise their authority or even pressure programs to utilize existing employment resources.

It's particularly instructive for change agents to realize that systems hardly ever enforce requirements or opportunities such as these that could lead to people leaving system ranks. As far as getting jobs and volunteer association goes, systems still get pretend that these roles belong to others.

While it's fair to state that employment brings about complexities, the challenges people with disability bring to employment and the volunteer world are not that different from what people without disability have. Transportation to a job, following standard practices, maintaining appropriate appearance and relationships are what all employees have to handle, disabled or not.

What Stands In the Way

The barriers people face in securing jobs is still overwhelming, though probably less so today than 20 years ago.

Group home staff still can't leave their sentry duties at the home to take a person to work, especially at off-hours. For liability reasons agencies still won't let staff use their own cars to give a person a ride to his or her job.

System service funding still can't be used to pay a relative for the cost of driving to work. Overburdened case managers still don't have time to locate car-pooling, public transportation, or arrange rides with coworkers. Adult activity personnel still have no outreach planned for volunteer jobs that might lead to a paid position or valuable work experience.

Requirements of the IDEA are still co-opted by disability systems that accept child-like activities in adult day programs as suitable and appropriate 'post school employment outcomes' for transitioning young adults. In Pennsylvania, school districts are told to use a standard interview that doesn't provide any information about leading an everyday life in jobs or anything else.

While school systems in some states make sure adult service representatives develop relationships while students are in school, most adult agencies still don't engage with schools until the last possible moment, making planning for the future outside of facilities impossible.

Out of utter frustration, young people and their families still find themselves taking whatever the adult system can offer after their loved ones graduate. Young adults, who dare to hold out for something better than piecework at the sheltered workshop or puzzles at the activity centers, still find community job support sporadic and ineffective.

Collaborative bodies with responsibilities to work toward employment outcomes together still fail miserably in bringing about improved employment outcomes too. The connection between the support that people need to get a job and the services systems offer still could not be more broken.

From young adulthood onto retirement years, what starts out as inappropriate and demeaning becomes routine. In their state of impunity, disability systems show communities that legitimate employment outcomes are irrelevant for people and meant to be gamed.

Workshops and adult day therapy programs point to their own failures to justify operations that demonstrate how there is no future for young adults apart from what the system offers. People and their families know that the system has failed them in the area of work, perhaps more than any other.

Systems have failed to make the community contacts and connections they need to, and to use resources and information they have readily available to promote employment outcomes. The system hasn't assisted people in identifying careers.

With no intention to change, it's time for the country to go elsewhere for the job and career support people with disability require. In today's systems, resources are not channeled so people can live life with community interdependence. Program plans do not connect people and employers first.

There is no clear path established by states and the Federal Departments of Health and Human Service, the Justice Department or Labor to ensure people have equal access to post-secondary trade schools and apprenticeships. State vocational rehabilitation agencies, while accountable to employment outcomes, aren't connected with adult service systems, which are singing from a different song sheet altogether.

There is no demand for employment first practices on a state policy or provider practice level either, let alone agreement on what these policies or practices mean. Advocacy agencies are conflicted and scared to take a stand.

A raft of delaying tactics by provider associations has been employed to keep the pressure of employment for off the front burners in state after state. The cowardice of officials to deal with employment first practices and stand up to these associations is truly amazing.

Thanks to the neglect of service systems, people with disabilities aren't invited to be in a job corps, the Peace Corps, or a disaster cleanup. Even though Ameri-Corps has gone out of its way to accommodate people with disability in their programs, systems have been disinterested in following up on these overtures.

Profound disconnects between community resources and specialized services are everywhere and they are not being bridged. Arching tales of opportunity lost affect thousands of young adults across all parts of the country.

These are tales of self-determination stopped before they ever get a chance to begin. These are tales of hundreds of thousands of people stalled and forgotten, ignored and trivialized.

Association Impediments

Influential national and state associations have teamed up over the years to keep adult activities and workshops as the centerpiece of community service systems. They've been making the same pitch for decades, beginning at a time when conditions in the country were much different than today.

Despite lip service to employment and community outcomes as their goal, influential family and provider associations still defend keeping people with disabilities clustered outside of the mainstream of the community life. These associations also claim that institutional living and work training programs should continue to be a choice for people that the public pays.

While these assertions might be expected from provider groups protecting their turf and proprietary interests, it's remarkable that family-based associations have continued to take a similar stance so far into the community movement. Even emerging associations that claim to represent people with disability directly, like the newly formed National Alliance for Progress, have joined in the chorus to retain sheltered work programs within the system's continuum.

One bright spot in the Association picture is the leadership being offered by the National Association of State Developmental Directors (NASDDDS). Their State Employment Leadership Network (SELN) is taking a methodological approach to system reform so that outcomes will be achieved.

While success varies greatly in the 27 or so states now enrolled in SELN, the NASDDDS initiative is making the right moves in terms of accountability to outcomes first and foremost. It is also making sure that states amplify their employment first policies with sound standard practices, data collection and continuous quality improvement measures.

Another champion of employment first, APSE, has also begun to make some inroads on the state and national levels. While an effective agent for change in some states, APSE chapters

still suffer from more talk than action in directing the discussion away from piecemeal changes within service systems.

Apart from these and other occasional bright spots, it's clear that organizational hesitancy at all system levels has carried over to families, advocates and the community at large. Without a concerted effort to change the way work related services are structures, systems will continue setting the course, agenda, and tone.

While some family associations have expressed limited support for 'employment first' practices, the likelihood of these organizations changing from their advocacy for sheltered work is doubtful. From the provider association viewpoint, change agents can expect a good fight on this one.

Needing To Leave This

Simply put, funds for achieving employment outcomes need to be channeled into business and industry for employing people with disability, not into program intermediaries that aren't doing the job. Funds need to follow people out of these segregated programs so employers can take hold of the situation with people they employ.

If an employer needs a trained professional from the system to assist in job support tasks, fine. The point is: under the new way of support, the employer and employee control support resources, not the system any longer.

Adults with intellectual and other disability can succeed in completing necessary job tasks of an employer, when the needed support is there for them. The issue is that people and employers haven't had this support in pursuing careers and jobs of their choosing.

Systems are painstakingly slow in authorizing support for job finding and have had no sense when it comes to recognizing that job opportunities are time limited. System practices like traditional case management monitoring just don't work in an employment arena.

What system loyalists also don't point out is that people with disability who have had trouble completing tasks like counting or communicating point the way for generic solutions that employers will find useful too. Physical and support modifications that work for people with disability improve working environments all around, and promote longevity of valued employees.

Competence and inclusion are qualities communities respect and value too. The return on investment to support people is real, multifaceted and impressive in various aspects.

As to the downsides of assimilation of people on the job, many are fear based and a consequence of being uninformed or distracted. Employers have been genuinely pleased with impact that accommodations bring to the table.

While ADA lawsuits have materialized, businesses that demonstrate a supportive relationship with workers haven't suffered. Employers that support people in good faith aren't sued, they're rewarded.

The science of task analysis is clearly the path for accommodation that employers can follow, whether they happen to be a hospital or a vegetable stand at the local flea market. These measures break down job tasks so people can do them. Using simple and direct methods that include physical cues, hand-over-hand instruction and other well tested approaches, task analysis has the benefit of establishing an array of efficient practices and adaptations that serve to benefit the whole business and all its employees.

While people's disabling conditions may cause them to be distracted at work from time to time or have trouble moving from one task to another, colleagues and floor supervisors can manage these differences with cost-beneficial results. With technology already at hand, there is a lot of success waiting to happen.

We've seen this success already, but again, not nearly enough. The gap between what we say and what we do just has to get closed, along with the gap between what we know and use effectively, as in the case of task analysis.

In any event, the system's tendency to keep changing ways constrained to the sidelines and margins just has to end. It's time for the community to benefit from employment related support knowledge that systems have really known for years but have not found a way to share.

It's time for this to work for everyone.

Back To The People

Time after time, people with disability demonstrate that they have the skill and dexterity, perseverance, and tact to be successful in community employment. People with a diagnosis of severe intellectual disability complete complex tasks better than people without a diagnosis in many endeavors.

People with the most damning disability labels have gone on to become brilliant scientists and teachers. People with disabilities I have known claim success with job titles of pastor, writer, consultant, saleswoman, counselor, handyman, advocate, road worker, staff supervisor, legal aid and receptionist.

There's a woman, Ms. Debbie Robinson, a self-advocate and friend. She's also at the head of one of the first self-advocacy associations in the country, called Speaking for Ourselves.

I'd work for Debbie Robinson any day of the week, and I've told her so. She'd be wonderful boss, supervisor, even head of any Department of Human Services. I consider her one of the most competent people I have ever met. Ms. Robinson should be running states and this nation with the skill set she has.

She isn't qualified to take on leadership roles in spite of here disability, as much as because of her experience with it. Apart from her God given talents, Ms. Robinson has taken advantage of opportunities, tapping leadership, friends and workers along the way.

The combination of opportunity and support plays out in many ways, for other people too. We've seen repeatedly over the years how augmented forms of communication and adaptive equipment have turned a person who was wasting away in an institution or sheltered workshop to a productive civic minded adult with all kinds of ways to contribute and give back.

With commitment to making accommodations work on the job, many more people can secure gainful employment. Accommodations work for employers too. Universal design elements are sure winners in businesses of all sizes and shapes, as is the understanding that people with disability represent a significant customer base.

People who are successful, like Ms. Debbie Robinson and others, have put their disability into a context where it belongs, as a challenge in the work place and living in general, but not as a condition that will keep them from taking responsibility or seeking happiness in life . People with disability deserve the opportunity to show what they can do, in careers especially.

People need that chance, the push and the support to pursue life outside of training and activity centers. They need to be able to put their disability in the context of an everyday life for a change. Families and systems have no right to stand in their way.

When the community gets it right, people go into a job interview knowing what they have to offer employers to ensure their success. They understand what business practices might need to be accommodated and how that would be handled.

When they are effective, support workers and people relate to each other in down-to-earth terms that employers understand and apply to their business at hand. Issues like scheduling, time-off, and transportation are framed in ways that work and really matter. Families know this framework and have faith in it too.

With the introduction of community support networks instead of services, the wishy-washy processes that the system follows don't set the agenda. Employers and people that work for them have control over their support as part of their job relationships.

In this schema, businesses and industry, not the system, know that a person's health care costs won't increase the company's insurance premium, and that costs associated with additional training or physical adaptations are covered. Without system hassles and equivocation, families finally see that the community is behind them and their loved ones.

Shifting from system to community control is critical in this area of employment, for sure. The change has already begun in some where workshops and the activity programs are closed and replaced with support that is focused on employment and volunteer work.

Unfortunately, the game most of the other states are still playing continues to toy with work incentives and half-hearted job demonstration projects. That's simply not enough. Families and young adults shouldn't be standing for this, any more than the public.

While the ramifications of change in the world of jobs will not be welcomed by entities used to exploiting people with disability, the charade these systems play, with the tacit approval of federal and state agencies, must end.

Employment plays an important part in the everyday lives of people. Valued social roles require access to jobs and careers.

Lingering Questions Here Too

As we go about achieving employment outcomes with people, and as we begin to find our ways out of this mess of congregate adult training programs and sheltered workshops, let's consider what the public has done right and wrong over the last 30 to 40 years.

To discern what to keep and cast away in this inquiry requires questions we haven't wanted to broach. Based on what we learn from these questions, we need as a country to be accountable to taking the right ways.

Where did all the good ideas and working models around supported employment go?

What has happened to the approach taught by Marc Gold in the 1960's that showed people with disabilities doing complex assembly skills through the application of hands-on teaching methods?

Why aren't people with severe disabilities putting together bicycle brakes with over a hundred parts, like they used to, in industries today?

Why haven't approaches that rely on community resources prevailed over congregate care programs and sheltered workshops?

How do system leaders and national associations still get away with resisting employment first practices and policy? Why do congregate care programs refuse to change?

Where is this sense of social responsibility with employers? What do change agents need to do to secure employment outcomes for people?

Who is benefiting from keeping things the way they are and at what cost to people, communities, and the country?

How can communities prevent people with disability from being exploited through work training and activities programs?

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Chapter 16: Change Agent Primer

Lifesharers Sing Out

During a visit to an intentional community that was just getting started in Minnesota in the early 1980's, I wrote this song for the guitar. It's called "The Lifesharers Song". Readers can listen to it, along with collections of other songs on my website at Dawaho.com.

The Lifesharers Song is written about people, any people really, who find a way to offer support to others in a valued community manner. The song speaks to the unity of people who work at improving human conditions for themselves. It's about the feeling these people have when they're together, as they reflect on their experiences.

The Lifesharers Song is for change agents too, as it unites people in their struggle to improve living conditions over lifetimes and generations. Like union songs and church hymns, the "Lifeharers Song" celebrates our common ground and aspirations.

The song carries the praises of valued lives in ways that arch time and space, as naturally 'as a spring flows from the ground'. It cherishes people who join together for common good and to be 'eternally bound'.

The verses go:

We've been together from the first time we met

We've partied, reunioned and dined

We've been together from the first time we met

We're from the beginning of time…

We've been together from the first time we met

Our paths are eternally bound

We've been together from the first time we met

Like a spring that flows forth from the ground…

We've been together from the first time we met

Our chorus sings out from afar

We've been together from the first time we met

Lift your voice from the place where you are…

In The Face Of Resistance

New ways, by definition, challenge the status quo.

The system will want to go as slow and meticulously as possible before changing anything. For each step forward, there will be stumbles and retreats, and times you feel like crying.

Physicians and psychiatrists, researchers and other social scientists, case workers and policy wonks, politicians and leaders will stand up for what systems have created. Those who stay are stuck in the mud will give a litany of excuses or profess plans to 'expeditiously' improve conditions by making the system more responsive and accountable.

There will be champions on behalf of group homes and activity centers for adults, sheltered workshops and institutions too. There will be people and families who resist new ways, working in tandem with powerful interests. Expect at any time to be terribly inconvenienced by the pain and suffering effective advocacy brings with it.

Starting out, it's good to realize that none of the naysayers to change are going to raise their hand hands and say:

> *"Ok we give up. Take it from here. We did our best - now it's your turn."*

> *"I'll support you in whatever you do as long as community outcomes are achieved in valued ways with people. We appreciate that we need to change with the times."*

There are big time players on the field of service delivery today who have links beyond the level of system administrators and provider association directors. There are powerful financial interests at stake and jobs in the tens of thousands across states.

Knowing how to approach change in such an environment is not only a good idea, it's fundamental. If a change agent can't or won't talk to power sincerely, stay home. Knowing what you have to say in making the case for community ways, and learning from what you're told isn't optional.

Change agents make supports work with people in their communities. That's the pitch, the mantra, the truth and the bottom line. That's what brings you to the community's door and keeps you in the public's good graces.

In this process of communication with the community, taking on the system through dueling position papers, research or debate is not welcomed. Change agents avoid working within the system to change it on this basis alone. Believe it; no one down those halls and offices are listening, and even when they are, it's a toss-up whether anything could ever be done.one.

Change agents today operate in the world of community resources. They demonstrate their commitment to building on community ways with employers, families, friends and other citizens, in ways that are generally familiar and understood.

They find champions outside the system to work with and watch their back. Change agents develop their own playbook and form their own teams.

Outside the closed world of service systems, with all their "who's who" intrigue and banter, change agents already have the ability to demonstrate that the map of doing things right is found in taking community ways, using tested and true methods and resources. They show how employment works with people, and how sharing a home life with friends and family works, too.

Not only do community supports work well, they work best, and 'the best' is where effective change agents aim. We aim at the heart of the problem, root causes, and the range of possibilities for people to achieve everyday lives.

In this process, change agents establish relationships beginning with people with disability and their support networks. They assist community resources to achieve everyday outcomes and reject practices that stop with service practitioners putting in their time. They behave like responsible citizens, and indeed are just that, first and foremost.

From the change agent's viewpoint, support networks ensure that people achieve their life's potential. These assurances are built on valued relationships within families and the community. They don't interact with or rely on service systems any more than they need to.

Change agents shun systems for their superfluous qualities that end up taking up time and space that people would use to grow and develop. They make clear distinctions between community support and system ways that case managers and programs have been instructed to follow.

Change agents don't pretend that some easy alteration of schedule for group home shift - personnel will ever bring meaning to people's relationships. They understand that there is nothing to be gained by continuing models like group homes, adult activity programs and sheltered workshops, and that the traditional system cannot coexist without someone being hurt and marginalized.

They appreciate that there isn't room for oppressive practices like we've been used to for so long. They call for institutions to close now, and workshops and activity programs too.

For change agents, this is not a live-and-let-live scenario anymore. It's time to draw the line based on achieving outcomes with people. Let the chips fall where they may.

Positively Your Street

Change agents, as people vested in community outcomes, behave like it's the community's time to shine. They are adamant that there are no surrogate ways to sustain people in an everyday community life.

With a basic message that people with disability deserve opportunity and support, just like everyone, change agents gain the public's interest and participation. In its mustering this interest, change agents demonstrate how people personify success and competence, strength and belonging.

They demonstrate that community support approaches work for people like they do with anyone else. They underscore how community support benefits everyone.

Change agents shows how community supports cost less and do more good. They share more than feel good stories, or just statistics about the system's decaying state of the art, and stick to the truth.

They bring their messages home to the public, irrefutably, showing how community benefits society and how services don't especially on a long term basis. They do what it takes to get their point across to a wide array of different audiences.

Since change agents already know people with disability seeking everyday lives from their personal experience, appreciating people's talents and gifts is never an issue. Making the point of togetherness, advocates share all the rewards of their work with people who they work with, side by side.

Together, people and change agents look sharp, stay engaged, and contribute to one another's success. Change agents make sure they accommodate, listen and take what people say to heart and the next step.

In their work, change agents seek out allies more than partners, understanding the distinction in terms of focus, roles and achieving objectives. Change agents align with people who struggle to find jobs, friends and supportive families, and they make sure their actual struggles are remedied.

Through these experiences, change agents learn to appreciate what it means to cross over to ways that a community values because they don't depend on systems like they may have in the past. Change agents know that communities can do what systems can't.

They know how systems are inherently brutish and rigid, ignoring obvious ways that work better with people and the community alike. They know the effect system fed myths and interpretations have had on the ability of people to secure jobs, homes and community ties. They're sick of all the cowardice.

Change agents are also eager to relay their arching tales of struggle and triumph. They testify to their successes and seek truth to share in the best ways they know how.

Change agents take direction from people in community first and foremost, accepting ways that may not seem to be the most expeditious. Change agents work as hard to make others' approaches succeed as they would their own.

Change agents are committed to securing leadership positions for people, not as tokens, but as leaders who call the shots in how support frameworks are developed and maintained. Change agents work to secure freedom, participation and independence with people and for the good of us all.

There's a sixties or seventies phrase that sums it up, this change agent thing. The phrase goes: 'Get real.' Change agents get real all right.

They know the facts, implications and benefits of taking new ways and the pitfalls of not. They know who's on their side and who is not.

They bring about bring about better ways with others so inclined, together with people and their communities. They're glad to be part of it all.

Changing Roles

In the 1960's and 1970's change agents were called on to advocate for the creation of community service systems and institutional reform. Today change agents are needed to transfer power from systems to community ways.

Make no mistake: thanks to the systems we've created in this generation, there are yet hundreds of thousands of people dependent on public resources in this country that shouldn't be, and millions beyond them affected as family and friends, neighbors and associates. We're wasting billions dollars annually letting systems do their thing.

The hold that systems have on resources keeps people from getting jobs and homes of their own and from exercising social responsibility. Change agents can't support these system states that don't arch into community ways.

It's not just one thing, such as licensing or case management, that change agents object to. It's the whole thing; it's the whole way services are constructed and mediated, offered and reviewed. There's nothing right going on except in the margins, and the margins aren't good enough any longer.

It's not just providers or the state, or administrative entities, or advocates or misguided directors of provider associations, or families either. It's all these parties together, as they stay caught up in service worlds where they don't have a sense of the forest through the trees.

It's not that these stakeholders can't see the mess we're in either. They won't see. They just won't.

Change agents help community resources recognize and develop support with people in mutually beneficial ways. In this process, they refuse to buy into promises of system reform as the answer to improving outcomes.

Systems are the lost cause and change agents know it. They understand how many dozens of adult day activity programs are still in driving distance to their home and how many scarce resources are being wasted on services that have no more relevance than kindergarten for adults.

They appreciate that institutions are still an entitlement for people who can be much better served in the community, at far less cost. That and other injustices drive them, and keeps it all clear.

Change agents know that workers are far too focused on in doing their supervisor's bidding than to take responsibility, deal with the consequences, and realize who is benefiting from keeping life the way it's been. They accept that many workers are too afraid to lose their security, or invested in service structures more than people.

They don't expect that executive directors will agree to divest themselves of real estate holdings or sell their fleet of special vans. It comes as no surprise to anyone that leaders remain enamored in their states of imminent collapse. Change agents see how system leaders are trapped too.

Change agents also know that community, families and system defenders will be skeptical of new ways, if not downright resistant. They realize that community ways won't happen when strapped down by rules and delays.

Change agents pledge that the system's pace and ways will have no bearing on what they do in interacting with community stakeholders. They don't buy into agreements or actions when the community is not fully represented.

To avoid getting stuck, change agents stay away from system antics. When involved with the system and a third party, change agents stay focused on community outcomes.

Since systems cut their deals behind curtains of secrecy, change agents take their game elsewhere whenever possible. They welcome the opportunity to meet with new people and families, and refuse to go back.

As far as change agents are concerned, it's not about them. Their work is a vehicle that helps get the community to different places together with people.

As systems harp on technicalities, the sanctity of precedence, rules and unavoidable delays, change agents stay on message. They take on what they are serious about achieving with people.

As systems suggest ten to twenty year time frames to change regulations, change agents remind decision makers that solutions have nothing to do with these structural elements, and that's all about how the dollars flow. They see that how funding delays are fundamentally system ways of saying no.

As system defenders drop names and quote spurious numbers to make their case, change agents meet in the community, in homes and small gatherings with their base. There's not that much rest for the weary.

Their message in these forums is personal. Change agents use the press and news outlet of all forms too, putting out a fresh viewpoint that differs from the so-called experts, at first. Once in the door, they make a point of taking on the system's hubris whenever the opportunity rises.

Change agents talk with their local Kiwanis meeting, at picnics and wedding receptions too. They pass leaflets under doormats and march with placards too. They wear sweatshirts and eat quiche and cauliflower if they need.

Change agents are sometimes puzzling in their statements and provocative. Some use prosthetic devices and talk through a machine. Some have long hair and some have none. Some would like to be remembered for what they've done.

Even when there are spotlights blazing on system failures and neglect, change agents know that the public's attention fades. They have seen how leadership hides out on issues until the coast is clear.

During these times, change agents know deals are being turned behind the scene, but they don't get worried about any of that. They don't care where the system is going because they know it will always always be lost.

They know that there's nothing they can do about moving it anyway. Only the community does that.

Those that take on the cause of liberating people realize that don't have much of a safety net. In the free fall of taking on powers that be, change agents are prepared to have their reputations tainted and motives misinterpreted.

They know they don't start out with the immediate resources their opposition does. They know that interests that control services influence friends and family members in high places.

Change agents recognize that the system will rally beholding frightened stakeholders and make all types of questionable claims to divert the truth. They aren't surprised when new factions arise, taking a stand for free-markets over socialism.

In order to succeed in a climate like this, change agents stay focused on the prize. They refuse to get caught up in the fray. They don't get diverted or give in to sympathy for system ways and the hope that they'll get it right next time.

Change agents know that there's no winning this struggle by taking on the system directly. Instead, change agents walk away from the rigged arena where systems operate and find different forums where the real power lies.

Only by stepping out of systems can change survive. Only by playing their roles intelligently, can a wider and more powerful leadership circle begin to be involved and take form.

Getting to community movers and shakers requires change agents to deliver their message in new ways. These ways engage private foundations, independent entities and community groups, family associations, unions and civic societies, businesses and religious centers. Change agents go to the public directly.

They make sure families and people walk the talk in contributing to their support as much as they can. They explore untapped and unfamiliar areas of community support and share it with others.

In engaging with the general community and its leadership, change agents demonstrate that they know where support for people with disability is going and that the system doesn't have a clue in getting there. Instead of putting on the gloves, change agents focus on opening up support to the greater community, and convincing community leaders that they have a stake in forming new ways.

Change agents come to the community table equipped with dollar and cent explanations that the community understands. They don't appeal to pie in the sky notions or anything close to a pity approach. They know the facts that matter.

Instead of trying to close all inappropriate programs immediately, change agents see the necessity of prioritization so the community succeeds where it can. They begin the process of change by turning off the tap of outmoded services to new placement, and by making sure resources follow people into least restrictive settings.

Choking off new recruits starves agencies invested in isolating people at the source. It also affords the system a reasonable amount of time to bow out gracefully, dispose of the real estate holdings where people have been housed and worked, and get on in new ways.

In applying age and regional priorities, change agents engage school administrators and parents of young adults in forming new support structures like college curricula and other career directed training. They hang in there with those who step up and take a leadership role.

Change agents speak to the needs and resources of the community. On a practical level, they create new practices that get young people from school to employment first and foremost. They find and develop local champions who keep the spirit of community enterprise alive.

In school to work transition, change agents ensure that schools adopt cost effective job experience alternatives throughout the school year and during summer breaks too. They work with school boards to develop community-based instruction that gets people jobs at age during the summer months, and in their mid-teens.

Change agents also make sure the support practices they espouse save money for school districts compared to old ways, and that cost effectiveness continues to improve. They facilitate work groups if they need to and orient others, including the press.

They implement changes in a matter of months, instead of years, and they bypass regulations and other impediments instead of changing them. There refuse pilots, demonstrations, or delays.

Shortfalls, pitfalls and issues are addressed along the way. Change agents keep going, build their planes in flight, and plow on.

As they proceed, change agents turn away from what hasn't worked with people and go forward with what does. In lieu of being drawn into new rules, they find alternate routes without the system rigmarole. They go to the community as their source and stick there.

As system proponents resist all this, change agents stay on the path of reminding the community of their support roles and the benefits of change. Even as system recalls misgivings and concerns, change agents persevere with the same message they started with; namely, "We have to get out of here before it's too late."

Knowing that agencies will be pressured to hold out and resist change, change agents wait for cracks to appear. As agencies and workers begin to leave systems, change agents rescue those who want to carry on in new ways.

Making Tracks

To get beyond where we are, change agents bring truth to power, and pound that truth home time and time again. They emphasize that system planning and programs have not met community outcomes for hundreds of thousands of people, for decades on end. They are honest in the accounting of public funds supporting people in isolation and inappropriate activities.

While legislators are useful allies in this pursuit of changing ways, they will rarely be the first to be out front, and often hesitate on making any commitments due to constituent interests. Fortunately, politicians are not as critical to the success of community supports as employers, civic organizations and other grass roots groups.

Neighborly ways make it in a community support context. Change agents get this right, or forget it. Making tracks and progress is all about neighbors. We're all neighbors in the world of community support.

Neighborly, family and word-of-mouth channels are used frequently. Change agents use the potential offered by their own experiences, including picnics, get-togethers, dog walks: you name it.

Neighbors take us beyond family and systems. We're in places with them where life gets good and stays that way. In approaching community support on this basis, change agents keep their movement grass roots.

They honor their neighborhood knowledge and experience; they act in ways that are accountable in their locale. Before taking their act on the road, change agents discover legitimacy locally.

If they don't live in or have a personal sense of community, they join one. Then they join another and another. They pick and choose and learn how communities work. Change agents are always learning about communities.

Change agents also learn to associate cost effectiveness with generic services, such as banks for managing people's support accounts, and civic organizations for engaging people who want to volunteer. The more tasks change agents convey to the community, the more effective they are.

As change agents step out with communities to improve everyday living conditions with people, count on service systems to resist early and often. Count on restrictiveness of people accelerating too, as programs will reflexively keep people from showing themselves, and engaging with everyday citizens. They'll hunker down.

Systems will not deconstruct themselves voluntarily from this point either. They are used to the amenities of power and won't take kindly to being left out and ignored. Change agents can expect to hear a chorus of "How dare you" from there on out.

In community forums, where the merits of system vs. community ways will inevitably be aired, the system side will argue that they have kept people safe and out of the community's way. Change agents let them have their peace, and they don't get hung up in their appeal for input, help and partnership, collaboration, and shared pain.

Change agents see the narrow mindedness and over-protection inherent with these overtures. They ask questions that shatter the system's thin and shallow credibility. Knowing full well that the system has no plans to dismantle itself, change agents translate buzzwords and pilot projects into what system talkers are 'really saying'.

Change agents make sure the public gets the story of people's arching tales, too. They hold back no punches when it comes to exposing how systems deny access to community resources in order to perpetuate a narrow band of special interests.

As loyalists extol the virtues of regulatory frameworks for community support ways, change agents counter by exposing regulations as the traps they are and by reminding leadership that systems cannot deliver the goods beyond facilities and other establishments. They keep the public's attention on the quality of their own lives, not those of people set apart as disenfranchised.

Change agents are frank about program structures that keep people from achieving outcomes of a job, a home place, and relationships. When status quo advocates feign confusion, change agents repeat it all, all over again.

'We're here,' change agents say, 'to support people to get homes, jobs, and a sense of their value in the communities where they live.' 'We guarantee that our work to achieve these outcomes is going to cost the community at lot less and be better all around."

In making this point repeatedly with community leaders, change agents convey a new reality in supporting people. They articulate how systems are broken and incapable of addressing the rights, needs and aspirations of people like they should.

The country has all the reasons it needs to forge new ways that go beyond manipulating people in the course of what their services offer. All change agents do is to tap into this reasoning and shake the tree. Awareness falls out from this point, as long as change agents stay engaged in charting new ways.

With all this marvelous work they do, change agents articulate how this nation has no choice but to move resources from programs that won't work. They point to community support as the only way to achieve everyday outcomes for people in a cost effective manner.

They stress that waiting lists will never be served under current constraints, and that there is no "doing more with less" in systems like we have to today. They emphasize how services cost the public too dearly, with lousy results.

What carries this community message over the top is the change agent's focus on community ways and means. Success, as the change agent sees it, comes in applying community resources already at the public's disposal, and by achieving outcomes the community has an obvious stake in improving, together with people they support.

The change agent's bottom line is that community support is no big deal. It's already there. Citizens already benefit from support regardless of disability anyway.

Change agents close their day with: "We have the where with all to provide this support together. So let's get going. There's no better time than now and no better place than here."

Starting With What We Know

The country's social experiment called deinstitutionalization, affecting people with intellectual and other disabilities, has lasted for over 40 years now. Under its banner, tens of thousands of people have been moved from institutions into community programs.

Some of the people that entered community services have matriculated into a self-determined life outside of programs and system control. Many public institutions have been closed and they are still closing.

Young people with disability today will never have to live in an institution or facility for the infirm, insane or mentally retarded. Despite all this, many people remain in these places, too.

Applying what we've learned from the deinstitutionalization era is a part of the discussion today, but not everything. This era of experience brings with it some things in terms of what works with people and where the community support roles reside.

We as a nation don't want to lose this.

For starters, **we know that supporting people is not a one-way street**. A community benefits when people have jobs and resources to give back. Support from the community brings new strength and vitality to friendship circles, neighborhoods and families. That sense of mutuality frames our way.

We know that community support is doable outside of system control. People with significant disability do connect with friends, utilize generic resources, share their home with a friend or family, find work in the community and manage relationships. People with disability do learn to cook, clean, and take care of themselves. They do become good neighbors and friends when they get the chance.

To achieve everyday outcomes, people with disability may need the support from a worker or two from time to time, and some may need support most of the time every day, which is all right too. Community resources can be applied to ensure that people are as included and self-reliant as they can be. **We know that communities can apply these resources too, because we all come from community ways, too.** Whether support is compensated by a state program or not, it works in community ways.

We know that generic resources and settings, from banks to stadiums and from day care centers to pizza parlors, can accommodate people with disability of all ages. **We know laws, like the Americans with Disabilities Act, are there to back us up if we them.**

We know relationships and assistance come naturally with time, not out of program manuals and touch-and-go visits by monitoring agents and public charities. We've come to appreciate the roles shop owners, clerks, and everyday people on the street play in affirming a person's legitimacy and value. We've learned that people in the community are available to step up and provide assistance when they are called upon.

We know it's hardly ever a matter of people with disability not being able to do things; it's that people don't get opportunity or exposure to real life experiences. People are not encouraged to interact and develop in real ways toward an everyday community life.

We know that family support is needed for children to grow up to be responsible adults, and that a quality education assists people with young adults move on to obtain successful careers and become responsible citizens. We know how to focus on assisting young adults establish their career paths early in life. We know how to do this without new laws and programs. We know the success that comes with engaging community resources, like family members, teachers, friends, and caregivers, who have a stake in the young person's future too.

We know service systems lack relevancy and the flexibility of common sense approaches that would protect the public interest and achieve what they were intended to. While systems talk a good line, they don't deliver on their promise of supporting everyday lives. They point to program deficiencies as the consequence of a lack of community support structures, problems with payment rates, and low motivation of the people they serve, when the major problems lies with the system itself.

We know system ways have no heart and sense of personal connection. Only people with people have these qualities in the context of their community ways.

We know that walking the talk of community living just doesn't get done. While the system's framework of policy and program requirements continues to fool communities into believing that programs actually practice what they preach, their charade is getting old. Getting systems to deliver on outcomes, like jobs and places for people to call their home, continues to be a disaster.

We know that a system can't be the community, or even counted on to work effectively within a community framework. Systems are too competitive and proprietary to get along and follow direction outside their self-interest hierarchies, neatly defined parameters and strict program domains. They don't have a sense of ownership in community ways, and without that their lost.

We know that case managers who are supposed to advocate for people in the system are powerless to help people achieve an everyday life given the limitations placed on them by the powers that be. Most case managers have given up entirely on achieving everyday living outcomes due to paperwork and other hassles. Case managers monitor programs as the system's watchdog, enforcing rules and policy set by those powers that be. They see that their role is to keep people in services. When progress toward everyday life is not achieved, as it mostly isn't, case managers use their good offices to bless downgrades of program expectations so system funding can continue. There isn't much magic going on with case managers anymore.

We know that we need to create supports that work to achieve outcomes. Pundits have avoided addressing everyday lives but we need to, not for the sake of improving the systems that care for people now, but for getting people into a community support venue where they belong, where lasting relationships and achievements can develop and be sustained.

We know that the discussions that formulate new ways must include many other parties than the select crew who have been invited in the past. It won't be system movers and shakers taking the lead**.** System operatives have talked these topics to death, to no avail. A full-throated community dialogue is required that takes our character into account.

We know we need to fashion support that preserves outcomes in the course of ever-changing times. We need to be about what works in meeting everyday living expectations for people. We need to apply technology. We need to use our public resources where we can. We need data on actual outcomes to demonstrate whether progress is occurring in everyday lives. That's where the future is taking us, even urging us to be.

Building Consensus

Exposing system weaknesses and community strengths cannot have the desired results outside the context of a greater community. Dismantling systems occurs when community resources are engaged. This engagement involves different workers, people and organizations than systems have to offer.

In fact, systems need to be out of the process of engaging the community as much as possible. To the extent system representatives are involved in linking to community ways, community leaders must be able to take necessary precautions and firewalls to preserve integrity.

Citizens representing various points of view should be able to agree to certain fundamentals. They should understand that community resources contribute to the quality of people's lives in various ways. A contribution can be monetary, like with taxes, or giving time, helping a person along a career path, or just knowing what the issues are and where you stand.

A contribution to support people with disability can even be as simple as listening to what others say, or having your voice heard on another's behalf. Certainly, the fact that the nation's treasury dedicates itself to services for people with disability is enough to get each and every taxpayer a chair at the table, if they want to be.

Individuals with divergent views can also agree that communities have different forms and functions, fulfilling different roles in different times of a person's life. There are communities created in on-line social networks, after school activities, fraternal orders, sports teams, music groupings, congregations, and political affiliations.

Tapping into multiple communities seems to be the modern way, which gives yet greater and grander options for people with or without disability who may find it difficult to fit into one standard group or association. The point is to engage with people so they find their right personal matches.

Those of any political party can acknowledge that a service system is an artifice that can grow or wither depending on what its roles are. If functions that the system have done in the past can be community directed, most reasonably minded individuals would concur to move these

roles and responsibilities on to the community, together with the resources needed to carry out these functions in a cost effective manner.

Family, workers and friends who know people with disability, who disagree on just about everything else, can even agree that achieving everyday living outcomes of a job, a home and community connections makes sense with people. While agreeing to make the system accountable to achieving these outcomes on a permanent and universal scale gets difficult, having a base of understanding involving people others know is essential. Losing touch on this reality, even with critics, can be perilous to securing new ways.

The public can also agree that people with intellectual disability, like others without disability, have a responsibility for achieving everyday living outcomes, and need to be acknowledged as being more than passive players in their lives. The public can relate with people who take on responsibility for their lives.

Workers across the system spectrum can accept that there is a need to change how people with disability are assessed for needing services and support. They can acknowledge that the contribution of families and other community connections are not considered like they need to be in their assessment and program planning processes. They see that service structures tend to steer people away from community and family support options.

While stick-in-the-mud system proponents will argue about the extent to which people will ever live everyday lives, they will generally agree that movement out of the system into community life is a good idea and warranted for people who want this. Talking with the system on this basis offers some hope of common ground.

The To-Do List

It's time to expose how:

1. *Nursing facilities in the service system designed to care for elderly people are holding thousands of young, alert, disabled people who could be employed and living everyday lives with the proper support. PASARR that was supposed to ensure people are not indiscriminately placed into these facilities has been gamed mercilessly.*
2. *States routinely ignore their responsibility to implement provisions of the Olmstead Decision of the Supreme Court by depriving people in institutions the opportunity to live in the community in the least restrictive manner and by refusing to officially recognize private institutions, sheltered workshops and other segregated community programs as subject to the court's decision.*
3. *The conditions and wastefulness of large public and private institutions still exist, and how their continuation denies people their right to live everyday lives, mocks the Community Imperative, and denies cost effective services for others.*

4. *Medicaid and other federal and state funded home and community-based services fail to achieve what they are supposed to with people, using their resources to continue egregious forms of service and programs that segregate and exploit people. HHS and State agencies must be held accountable for achieving everyday outcomes with people now.*
5. *Systems get away with no life-based quality improvement, ignoring their accountability to improve everyday outcomes and living conditions equivalent to those of average citizens based on jobs, a home and community life.*
6. *Regulatory agencies and administrators routinely strip away and water down program standards designed to hold stakeholders accountable to community outcomes. With civic responsibility as a guide,, it's time to recast these traditional overseer roles.*
7. *Systems use a freedom-of-choice charade to justify keeping people bonded to and dependent on congregate care programs.*
8. *Educational and adult services collaborate in ways that channel children and adults into special services and programs that keep them from realizing everyday lives.*

Forging Agreements In Practice

Change agents organize their community around tried and trusted approaches, leaving behind system methods. Based on lessons of the last 35 to 40 years, consensus points are reached with the community at large, not among the tightly wound world represented by system heads and intermediaries. It all has to happen in the community context now.

Here are some agreements for change agents to work on now with their communities:

Let's agree to ensure that community resources, from doctors and therapists to pre-schools choir directors and cops, are able to do their thing without the system taking over inherently community functions and managing people's lives in areas they don't belong. Let the pharmacist fill the prescription without having to log it into a separate program log at the institution or group home. Let the person take a ride on a horse or play a musical instrument without making it into a therapy.

Let's agree to stop having systems be the center of people's lives. Let's find space for community and individual relationships to develop outside of professionally directed programs. Let's encourage a resident to stop in at the lounge downtown with a friend if she wants to. Let's expect programs to continuously fade away as people are able to manage their own affairs with the community support they need.

Let's agree to reward everyday outcomes. Let's be sure resources follow people from congregate care into community support. Let's be sure facilities and programs don't restrain people in inappropriate programs when they could be living or working in community ways, even part of the time. Let's be sure people who move from congregate care settings to lifesharing relationships with families and friends, or to their own home,

have resources they need to cover their community objectives. Let's make sure people have opportunities for developing long-term relationships.

Let's agree to close off admissions to congregate care facilities including group homes and vocational facilities for anyone who chooses to be served in community ways, giving credence to permanency and a commitment to people's chosen ways of life. Let's be sure that anyone who wants to leave congregate care has the resources to locate a place to work and live with whom and where they want. Let's be sure families stay informed about how support in the community can work for them and their loved ones. Let's be sure that people leaving the system secure everyday living and employment.

Let's agree to ensure that people's choices and services align with parameters of outcome based community support. Let's agree to stop pretending that people with disability should have a choice about whether to be a contributing citizen or to be the recipient of services that keep them outside of an everyday community life. Let's accept that the common ground with community and people is that each fulfills their social roles and responsibility by securing jobs, home places, and community connections. There should never be a question of choosing community support, just questions about how it will be sustained.

Let's agree to end the garbage-in, garbage-out parade of case managed care systems that only end up denying people a reasonable future. In lieu of the system approach to managing people's lives, let's agree to ensure that friends, families, advocates, employers and community organizations that directly contribute support to people get the resources they need first, and that specialized program resources be limited to supporting these community connections.

Let's agree to support what people want and their community can do for a change, and not get conned by congregate approaches that systems offer. Let's be doubly sure that public funding is put in the hands of people and the community resources that are most directly responsible for support and doesn't get tripped up in supporting service systems, intermediaries, and checkers checking checkers.

Let's agree to take nothing for granted about what program practices should be or what federal or state requirements need be. Let's curb assumptions that policy handed down by service systems is necessary, accurately interpreted, and sacrosanct. Let's end presumptions about service imposed limits in keeping people safe and services accountable. Let's ditch special program rules and physical site requirements on homes and work settings all together. Let's ensure that our community frameworks universally adapt and accommodate, and are not specific to any one group.

Let's agree that people can live in any number of ways, alone or with others, and can secure jobs and pursue career opportunities. Let's imagine all the resources that openness to community brings and pursue what we see as possible, not just what is available. Let's imagine what support could be and how support could work, instead of following a worthless written plan. Let's make sure workers are rewarded as community

outcomes are secured. Let's make sure systems don't limit the home or employment opportunities people pursue through limited service definitions and funding.

Let's agree to allocate no more public resources to support people with disability until systems shed their costly care-dependent approaches that don't work and to develop ways for community resources to take their place. Throwing public resources at the "disability problem" isn't going to work anymore. We need resources to follow the solutions. The solution of a community framework needs to come first, and then the funding follows.

Change agents hold fast and insist that taking new ways means that people move out from the system's congregate care programs, and into situations that support everyday living. No matter the heat of a particular matter, change agents urge communities to act now to end what has become a generation's malaise in the face of cruelty and segregation, separation and bondage of people under the guise of care.

Naming the Not-Applicable

Taking new ways requires moving beyond today's laws that form the parameters of the current service system's operational framework. All regulations and policy are supposed to emanate from powers granted to public agencies and providers of services under these laws. By blowing away the basis on which today's programs rest, systems will begin to lose their grip on people once and for all.

Pulling out the legal rug of current systems requires change agents to enter into an exercise of "naming the not applicable" in current statutes that form the basis of today's service system structure. These change agents may be disability lawyers, scholars and practitioners; the more the merrier.

The process of naming these statutes is easy enough. Much of the legal basis for community programs harkens back to institutional days, at least 50 years before community services were ever conceived. These laws and codes were established to protect people who would be placed in outside of the community in facilities and institutions.

For example, the practice of licensing lifesharing homes in Pennsylvania is based on Article X of the State Public Welfare Code established in the early part of the 20th century, with numerous provisions going back to the 1800s. These homes are owned or leased by the lifesharer who provides support for one or two unrelated people with disability living there.

According to the state's current interpretation, the Public Welfare Code is authorized to be licensed as a "mental health establishment" which is established solely for the purpose of housing and caring for people with disability. On the basis of this definition, the Department is authorized to establish and maintain standards for mental health establishments, issues licenses to their proprietors, and inspect them on a regular basis.

In the mid-1980's, the state decided that lifesharing homes needed to be one of these mental health establishments, even though the character of the shared living experience was much different than living in a group home or a residential facility.

By making this decision, lifesharing became administered by the state much like group homes and facilities owned and operated by agencies with paid staff. The designation placed unreasonable requirements on lifesharers and compromised the quality of their lives due to various types of inspections, physical home requirements and the like. It's continued status affected funding of respite care and other forms of support that are typically available to families, but not mental health establishments.

The "not applicable" side of this designation is that the Public Welfare Code defines a mental health establishment as a setting that cares for people with disability as its main function. The change agent's "not applicable argument" needs to point out that taking care of people with disability is not the primary purpose of a life sharing home, and that the statute was never constructed with this type of arrangement in mind.

Continuing this line of thought, the primary purpose and function of lifesharing is to offer people the opportunity to share lives with unrelated adults in a mutually supportive way. That one or two people in this household need support is governed by accommodation requirements already required under the Americans with Disabilities Act.

People shouldn't have to have their homes licensed on the basis of wanting to care for someone they choose to live with, whether or not they are related. While lifesharers may need to have certain training and experience to offer the type of support people need, this can be managed through funding and in other ways than licensing a home.

People's right to live with and where they want supersedes any power of government oversight, or should. While people may obtain financial support and be subject to safeguards and standard practices to ensure health and safety of people receiving care, having this responsibility cannot continue to result in intrusive practices that are designed for agency owned and operated congregate care programs.

As an added insult, designating lifesharing as a mental health establishment results in barring needed safeguards and practices that are not applicable in licensed establishments. An unfortunate example of this is the home study process, which is a fundamental element for successful lifesharing, but not required in Pennsylvania because it's not a licensing provision for other mental health establishments.

While community safeguards need to be sustained for lifesharing and other community supports people choose to use, these safeguards don't need to be based on any institutional line of authority between systems and community resources they fund. Taking the system's authority into private homes can only be a disaster, as it has been with lifesharing under the licensing arm of Pennsylvania's Department of Public Welfare since the program's inception.

As an alternative to licensing lifesharing homes, Pennsylvania could very easily certify provider agencies that offer support to shared living participants. The Department could also certify funding for lifesharers on the basis of their training and experience. Alternatives such as these would meet state assurances for health and well-being, be cost-effective, and respect the independent role of lifesharers in their own private homes.

Instead of having state inspectors check homes for compliance with rules, independent monitors could also be employed or volunteer from the community to promote continuous quality improvement and ensure health and safety under federal and state codes already in effect. Instead of placing people in lifesharing homes like systems do in mental health establishments like institutions and group homes, home study alternatives would be used for this purpose too.

Pennsylvania is not alone in creating harmful system controls through outdated statutes that are no longer applicable in today's society. Many other states use archaic codes and institutionally based laws like the Public Welfare Code as their basis for the community service programs too.

States have a way out of this legal framework by making by recognizing that community support is harmed when built on or forced into these old stereotypes of care and institutional life. The 'not applicable' approach takes an important step in this direction.

Naming the 'not applicable' is fundamentally necessary for life sharing and other community supports to be freed from the constraints of licensing and other regulatory constructs, so community resources can take on relationships that become the deciding factors in what and how support is offered. Since it is always possible that state governments in their infinite wisdom will create a new service definition under its codes to capture new forms of support, change agents and advocates must be on constant guard to prevent these power grabs from coming to be.

A major aspect of the 'not-applicable' approach is how this remedy doesn't rely on the creation of new systems or laws to take over from the old ones. It doesn't require development of new regulations and all the endless constituent meetings and hearings associated with this type of framework. It says its ok for lifesharing roles not be limited to a property, a limited set of expectations, or relationships that have strict professional limits.

The 'not-applicable' approach requires only that old systems be taken down for their archaic and irrelevant qualities in taking community ways. Change agents utilize also this method to find an opening whereby community resources become free to take responsibility for functions.

Without a regulation to require that homes be inspected by government workers which is done through licensing, lifesharers would be free to obtain physical site reviews for health and safety by their local health department, or not at all depending on how that plays out. 'Naming the not applicable' take's off the community's chains and forces public agencies to discover new ways of supporting people in this way.

Chapter 17: The Community Imperative

Arching From The Early Years

The work of change agents begins to bear fruit with the realization of a Community Imperative, building on the paper with this title formulated in 1979 at the Center on Human Policy at Syracuse University. Dr. Burton Blatt, who also authored <u>Christmas in Purgatory</u>, a famous institutional pictorial every advocate should know, wrote the paper.

The original <u>Community Imperative</u> described conditions and requirements of community support when people lived in sprawling public institutions or private facilities.

When the <u>Community Imperative</u> was first published, young people with disability were just beginning to be reintroduced to public schools and classrooms. Normalization and advanced program concepts were just taking hold. Deinstitutionalization was not a decade old.

There were 40,000 people in community living arrangements in across the country then. There are over 10 times those numbers now.

The <u>Community Imperative</u> in 1979 was akin to a Declaration of Independence, and it applied as much too confining systems and institutions as it did to communities, families and people themselves. Fundamentally it was about people achieving a good life, evoking a sense of commitment to take on anything that would get in the way.

One of the important aspects of the <u>Community Imperative</u> has been its resiliency and ability to draw a series of lines in the sand. The <u>Community Imperative </u>leaves no room for equivocation and foot dragging. It remains the change agent's manifesto and a call to action.

Change agents can readily approach the <u>Community Imperative</u> as a reference in dismantling system controls and developing community frameworks in their place. The frameworks the imperative describe are accountability to everyday outcomes using community resources first and foremost. Under its banner, advocates help communities see that people with disability receive the fair deal they deserve as valued citizens.

There's also no debating the urgency the imperative. It's a must situation that we're dealing with, not something good for some of the people, some of the time. There's also nothing later about now.

Restatement of the <u>Community Imperative</u> is called for today in light of current challenges. There has been a load of manufactured confusion around what constitutes effective services and community support that needs to be addressed.

What's important today, and for the future, is that this declaration remains alive as a unifying callout to systems to put up or get out of the way, so real and enduring community support structures can unfold. A restatement of this imperative is also helpful in reminding us

about the nature of the community's role in supporting people under a different set of circumstances than we had 40 years ago.

Under an imperative footing, institutional settings of all sorts need to be dismantled in a period of years, not decades, giving agencies an opportunity to operate programs with a whole new set of expectations and outcomes. In this dismantling, there is no deal that some people stay in the facilities to satisfy families, or funding sweeteners to assist agencies in transition.

In the context of this updated Community Imperative, providers of all congregate services would have the responsibility to maintain an open door policy to community support ways, so that sponsors who would offer people everyday living and employment supports are able to engage with people and offer them real choices for a change. That open door policy would apply to employment agencies, civic and volunteer groups, job recruiters, colleges and realtors.

The Community Imperative that spoke to contemporary matters would help define the public's stake home finding, job finding, and related support. By embracing the imperative in ways that take funding into account, change agents would be able to develop supports that are lasting.

Without the link to funding change away from system control, failure in achieving community outcomes is inevitable. While community support frameworks can turn the tide without another red cent of public funding, they require the ending of congregate care approaches that have been with us far too long.

Keeping It Real

By its very nature, the Community Imperative has a way to take people who believe in empowerment to new depths and places, specificity and hope. People with different ideas will have their own lists and priorities of what needs to be done in realizing the Community Imperative.

In this respect, having the imperative is what matters most. It is better when people work out what liberation, inclusion and justice mean on a personal level anyway. There will be lots of common ground.

Whether a person's Community Imperative flies under the banner of Normalization, self-determination, civil rights or something else, what's important is that people recognize the imperative and relate to it in the context of their lives and particularly the country's future. While it helps to be definitive in what the Community Imperative means at any one point in time, it's most important that the imperative be tied to the everyday outcomes people achieve over time and that the spirit of community lives on in this way.

Taking in the spirit of this declaration is the most important thing of all. This spirit makes believers who want to hold the imperative out as their declaration, while keeping it close for guidance, reassurance and comfort. The Community Imperative is a rallying point that bridges

generations and holds those on a change agent trajectory together. There is no need to reinvent it, relocate it, or rename it.

Fundamentally, the Community Imperative becomes a source of courage that change agents embrace in taking on the challenges ahead. As long as there's a genuine statement like this for people to mold and hold on to, there is something important to express and achieve. Expression is what change agents are all about in this new way. We're about combining our beliefs with reality as much now as ever.

Here are ten elements for change agents to consider in framing the Community Imperative for today's world:

1.   The Community Imperative does not mean empowering institutions, community based or any other systems or organizations to control where or how people live in the community, work, or associate with friends, citizens and their family. Where systems control people's choices and opportunities through restrictive funding, service definitions, admission criteria, program design and practices, the Community Imperative demands that these barriers be summarily dismantled.
2.   The Community Imperative requires that community resources be engaged as the primary source of support for people with specialized services offering additional assistance to community resources, as needed. This applies to generic community resources from banks and other financial institutions, to stores and recreational and social activities, to community employers and family resources.
3.   The Community Imperative demands all resources be directed by employment-first and community-first practices in individual planning, assistance, funding program practices and monitoring. The Community Imperative rejects the use of specialized service approaches, which do not directly lead to everyday living outcomes for people with disabilities, including congregate services of all kind and description.
4.   The Community Imperative rejects traditional forms of program-structured training, assistance and other practices utilized by service systems, workers and organizations that are not accountable to achieving everyday living outcomes, including a career and community job, a place to call home, and reciprocal non-paid community connections. The Community Imperative applies community outcome measures in an accountability way.
5.   The Community Imperative requires that any system that supports people with disability measure everyday living outcomes, including participation in employment, community volunteer participation, and use of generic banking, family, neighborhood, social and recreational; as the primary means of accountability tied to funding and policy development. The Community Imperative requires that measures regarding the achievement of everyday living outcomes be shared with legislators, community leaders and the public at large for purposes of continuous quality improvement.
6.   The Community Imperative casts off measures of health- and safety- bound systems, including program monitoring that perpetuate the legitimacy of institutional and congregate approaches to living, work and opportunity. It rejects case management, disability classification systems, eligibility standards, monitoring and quality assurance measures that rely on compliance to disability norms, policies and practice that serve to deny or compromise

opportunity for an individual to live an everyday life, get a real job, and develop relationships of their choosing.

7.   The <u>Community Imperative</u> requires services offered by specialized entities to intentionally fade out as generic and informal community support structures within community settings take hold. The <u>Community Imperative</u> requires funds to follow people out of services into support frameworks that people and their community control.

8.   The <u>Community Imperative</u> entails continuous public education and information sharing directed to ensuring that community resources have the information and resources they continue to use to support people with disability outside of service systems.

9.   The <u>Community Imperative</u> demands, pursuant to the Americans with Disabilities Act and the Olmstead Decision of the Supreme Court, that institutionally equivalent services of all kinds, including state and private facilities, workshops, adult day programs and other segregated system endeavors.

10.   The <u>Community Imperative</u> requires a personal and organizational commitment to influence legislators, businesses, community-based organizations, and community leaders, using whatever legal means necessary, to ensure that people have opportunity to live an everyday life.

Taking on the Maybes

When approaching service systems in the spirit of the <u>Community Imperative</u>, change agents see how barriers to change get dressed up in many forms of equivocation, or 'maybe'.

Unlike saying "no" to a change, maybes allow those that have control over resources to remain uncommitted, wavering, and aligned to traditional approaches, even when these old ways are clearly harmful and counterproductive to the work systems are supposed to be doing.

When it comes down to it, maybes make decision-making in systems a whole lot slower and perplexing than it needs to be. Maybes are no way to manage situations that affect people's lives.

When attached to excuses like Federal and state prohibitions under regulations and law, maybes take over; forming a psychological barrier to problem solving that is hard to get past. Even when there are clearly cost effective and appropriate solutions to address pressing problems, persistent feelings of inadequacy in the face of perceived barriers prevail.

From the perspective of a change agent or petitioner seeking to apply new ways, maybes elicit false hope. Buttressed by a maybe, people who want something different can at least say they tried; even when their experience tells them that efforts to address the problem by those in control will be at best -- half-baked.

Maybe makers know that inherent program obstacles and time will generally wear down even the most ardent petitioner's enthusiasm and stamina. Those in control find maybes as an effective tool to avoid adversarial situations and strife.

Workers who don't want to make a stand find maybes an easy out. It's no wonder that on any given day or topic, system vendors toss maybes out like trinkets to the crowd at a Mardi Grass parade on Fat Tuesday.

When all is said in done though, these ubiquitous maybes come to mean that new ways will not be formed, and that hard and fast barriers will be erected if change agents persist. In terms of system change, maybe has become code to mean: "Calm it down," "Get out of my office," and 'Know that the change you want won't be happening in view of other priorities."

In dealing with leaders who use maybes as a big part of their work, it's important to realize that being at the top of a hierarchy doesn't mean putting oneself on the line or taking a position that could be dangerous or misunderstood by parties that helped the leader along the way. Sadly, many leaders in service systems, from government to providers, are basically appointed to keep the lid on what's happening and make sure people with disability are safe and secure. They are rarely innovators and many of these get the boot sooner than later.

Unlike their counterparts in 1960's and 1970's, leaders today don't generally get their marching orders to improve employment or everyday living outcomes for people, or even to reduce the use of institutional facilities and congregate programs. They're put in place to hold the line, keep costs down, and not make stakeholders too upset.

Their toolbox for change is generally too full of maybes and broken promises to mean anything tangible for people expecting an everyday life. They are so much in a bind; they don't know to where to start to get out.

Leaders in the service system become the kings and queens of maybe, holding court on their maybe thrones and rattling their maybe swords once and a while to show others that they are the boss, or to point out a new culprit. Maybes have become a powerful tool for system leaders who view success as holding back people from progressing through a system and into community ways. People in control of systems use maybe all the time.

Maybe-laden approaches permeate decision making at all levels within private and public providers of service, academia, consultants, management information contractors, health care professionals, case management and others. Maybes abound in discussions dealing with alterations to salary and benefit structures, priorities, litigation, and program direction.

Maybes also dislocate any sense of urgency to take on new ways and cast off institutional forms and practice. With billions of dollars at stake in keeping systems going, maybes become automatic in making sure nothing too unsettling happens with the dollars on hand.

By virtue of their sheer size and complexity, systems cling to maybes to manage decisions in light of the varied influences constituents claim. To deal with their partners, special interest groups, and critics, service systems peddle maybes to keep the lid on.

Systems thrive in the world of maybes because it validates their power and ways. As stakeholders dutifully stand in line to retain their precious contracts, they have come to expect maybes as the rule, instead of the exception.

Systems get away with maybes all the time because they can in this respect. Even agencies that are doing definite harm to people by denying them the opportunity for an everyday life, keep their damaging ways from being addressed using maybe as their theme. For them, maybes are necessary to justify keeping people in institutions, and out of community ways.

Maybe we can find something better, they'll say, and maybe we can't. Maybe this person needs to stay here, at least for a while. Maybe only the higher functioning 'ones' should be considered for a community life.

Maybes are like mine fields. We get past them by staying out of their way. While maybes wouldn't matter if the system didn't call the shots, they do. We have to deal with maybes, like we do with other barriers, starting form realizing what they mean.

Maybes are mostly no's. They are also gut wrenching and demoralizing. Maybes make us put away our creativity and resourcefulness. They destroy momentum, crush mo-jo, and take credit where none is due.

Experience suggests that there is one area where maybe does not apply in services. Maybes are not to be heard when systems are pressed to reduce or cut off the system's traditional funding base through state and federal sources like Medical Assistance waivers and ICF/MR.

That's when stakeholders get together and throw out their claims of not enough funds, and storm the halls of power. That's when system leaders talk-the-walk about self-determination, employment, and lifesharing initiatives their "working on".

When cash flow is threatened, there is a universal chorus: Don't... Can't… Stop… Hold off… and No. Systems see their way clear to being definitive about funding, if nothing else. They rally people, families and agencies to make sure funding reductions are reinstated, or minimized, without taking the opportunity to adjust their culture of control and consider how to serve more with less.

Getting past maybe means nitty-gritty, no equivocation, no lousy deals and no turning back. It means exercising power so maybe current system tactics that restrain people are out of the question.

It means taking money away from doing what may have worked once but hasn't in some time. It means drying up systems and getting out of them before they collapse and hurt anyone else.

Change agents deal with maybes repeatedly, from different sources in different ways. The best advice is to spend no time debating the maybe-makers. Rather than address false

hopefulness and maybe inspired spins, it's better not to ask for anything from systems in the first place. Expectations are best set at nil.

Change agents need to be moving on to the work at hand in the community and not be diverted by discussions around another conference table trying to convince leaders to make a commitment that they will consider with a host of other options, and get back to you.

Change agents can't count on maybes would be the primary lesson here.

Maybes For Now

Here are some examples of maybes that change agents face repeatedly.

Maybe we should accept that social attitudes won't change, that people with disability will always be felt sorry for by the public and be pampered in their systems of care.

Maybe we need to realize, like Franz Kafka in the Castle, that individuals in society are powerless outside the structures and practices authority creates for its own purposes.

Maybe society's way of contracting out care to specialized service systems is inevitable given this county's history.

Maybe the fate of people with disabilities to be under the control of corporate and special care interests is sealed.

Maybe people with a disability label will always have to accept surrogates to speak for them.

Maybe people who can express themselves in ways only friends and family understand shouldn't be expected to venture into the cold, cruel world.

Maybe advocates and change agents should just relax and let others decide the future.

Maybe it's just too much to ask of society to adjust itself to those who don't keep up to society's normal pace and complexity.

Maybe health care empires have become too big and powerful to be taken over by diffuse community resources and pockets of pie in-the-sky iconoclasts who condemn that system approaches are not working and never will.

Maybe change agents need to be patient and wait for a point when their moment is right.

Maybe the system sees now that it can do better in discovering people's talents and objectives and assisting them to meet their goals, and do more in engaging community resources like employers.

Maybe we're asking too much of the community considering how people with disability have lived for so long and the challenges they face. Maybe accommodation and community support won't be enough.

Maybe the ways the country invests in the lives of people with disability are insignificant compared to the overall economy and issues like taxes, war, education and the environment.

Maybe the future of disability services is such as small matter that it doesn't register in the boarder health care debate involving hospitals, doctors, drugs, and professional services.

Maybe demanding community outcomes like jobs, a home, and community connections is being too stringent.

Maybe holding system accountable to achieving these outcomes would be unjustified and we should just be satisfied that workers put their time into keeping people safe and occupied.

Maybe accountability to outcomes apart from keeping people safe is tertiary, and more like icing on the cake.

Maybe there is no metric of success that this country can apply in supporting people, no simple outcome construct, and no common sense path that can be found to secure a viable community framework for success.

Maybe community support is just wishful thinking, mental masturbation and all the fluffy stuff dreams are made of.

Maybe workers, families and change agents have too much to risk by losing a job, program funding, or reputation to make a stink about the current state of services they endure.

Maybe those who want something different shouldn't be making mountains out of molehills. Maybe they should find a way to be more content with where we are in the evolution of support and services. Maybe seeing the glass half-full would help.

Maybe getting systems to admit to their failure will be cleansing and cathartic enough for starters. Maybe systems will be convinced to form new community structures and move people out of system ways. Maybe systems will rebuild from the rubble they've created, walk away from their comforts of control and power, and chip in so we can get back on a reasonable path.

Maybe the public should have more faith in system leaders to find ways out of the problems the country faces in securing everyday lives with people. Maybe maybes are O.K. given all the responsibilities the systems bear, and we all just need to be more patient.

Seizing Opportunity

So what do we do with these maybes?

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Taking on the "maybes" means knowing what response helps in achieving everyday living outcomes for people. Tasks along this way involve a lot of bringing truth to power in situations where the system is forced to take heed. Taking on maybes also means ignoring steps and approaches that systems would suggest taking.

The work of taking on maybes relies on finding out what is working in the community and making these things accessible to people with disability too. It requires using community leverage to shake off the remains of the system that wants to hang on.

The only rules in taking on maybes is that new ways must be reasonable and doable with the community resources at hand, while doing no harm to people and the community. There is nothing new being invented here.

There are no special safeguards, just the guarantee that accommodations will be made as needed for the person to achieve his or her community outcomes.

In the framework of support, there is no need for another congregate disability setting to be built, another group home to construct or a new fleet of eight-passenger vans to purchase with public funds. Agencies won't be picking up adults at the UCP dance anymore or at the YWCA after the "retarded swim".

In the support framework beyond maybe, there are no more professionals doing what everyday people do as well or better, not to mention at less cost. There won't be a way for the system to snake its way out of doing what's right in this framework either, or worm its way back into controlling people's lives.

The metric for success in adopting community ways is not magic. It has five basic elements that are summarized here and discussed in detail in Book II of <u>Arching Tales</u>.

1. Step one is to build support beginning with the person and his/her key relationships that share a stake in the person's success.
2. Step two is to ensure that workers and sponsoring organizations support employment, home places, and necessary connections first and foremost.
3. Step three is to make sure resources are controlled by people receiving services and the community resources they utilize, not systems or programs, surrogates or intermediaries.
4. Step four is to ensure that frameworks that are established for channeling resources improve the community as much as they do people's lives, and that these frameworks do not re-create or otherwise empower specialized systems to remain in or retake control.
5. Step five is to utilize existing community resources to continuously improve community outcomes one person at a time, building on success.

During the construction of community frameworks, there is no need for being quiet or hidden, especially when dialogue with status quo forces tends to get heated. The time for

pointing out problems and deficiencies in the system, as well as what's working or not in the framework, is always now.

There is also need to create anything new during this construction stage of community frameworks. The personnel, buildings, and practices people require are already in place and often occupied.

Frameworks don't need a new workshop building or professional assessment of service need. They don't want the baggage of the old world in with the new. Frameworks start from what exists and continue their vigilance in avoiding all that is specialized in vernacular, practices and relationships.

In speaking out about frameworks and support, there is no need to sift through situations for their essence or a best time to make a move politically. There is no magic threshold, channel or trigger point. It is always learn baby learn as a change agent. Every challenge is teachable in some important way.

Change agents that are effective know where to be and where to look. They know that changing ways is not going to be found in a court of law or in a ten-second commercial on donating to United Way.

The change they espouse is a part of a larger social movement that requires constant, redundant, and always truthful reminders to the public about the condition of people's lives. Change agents say it loud, say it clear, and say it often.

The community hears their voices and appreciates those who have the courage to speak out. It's okay that the community feels uncomfortable about this and embarrassed some too. Some catharsis is necessary at this point.

Piling on the ugly truth about systems and its contrasts to community structures is a perfectly legitimate tactic in exposing system deficiencies and the efficacy of new ways. It takes redundancy for truth to finally sink in and catch on.

Redundancy is also important in order for change agents to experience the power of issues themselves in different times and places. Since the message of change agents is essentially the same everywhere, it's helpful to bring out that facts and truth time and time again.

Chapter 18: Out of Here For Ever

A Future Glimpse

The following transcript is from a hypothetical meeting between a worker responsible for program intake and a young adult interested in registering for community supports the first time. It takes place in the not-so-distant future.

The paradigm that the dialogue depicts is one that successfully divests itself of the most overt and abhorrent practices of the current system. It works to assist people live an everyday life.

In this interview, the intake worker is introducing the young adult to the types of supports the community can offer in accommodation to her disability.

"That's all we do," the intake worker states confidently.

"We'll help you develop your abilities to live in the home and community, provide you with additional support to live where and with whom you want to and help you get a job or volunteer opportunity in the community. We'll provide support at your job site or where you live. We'll help you access transportation if you need it, too."

"If you want to live or work in a facility like an institution, group home, sheltered workshop or day program, you can apply for that separately. We don't fund services in these settings for people your age any longer. Adults that are living and working in these places are being introduced to other options, too, and will be expected to leave these programs shortly to locate homes of their own and participate in volunteer and paid work."

"I see from information you've provided us earlier, that you may need support to live where you live currently with your family, and that you would be interested in finding your own place in a year or two. You're planning on getting married I see and would like to pursue a career working with children."

"We have resources for physical home modifications if you need that or support from a friend or other family member to provide extra home assistance. We can also help the family in transportation and other assistance that they may need for you. You can get these modifications in any other home or rental property you decide to obtain."

"If you would prefer to live at home with your family part of the time, and in some other home setting part of your time, we can help you arrange this too. People can live in more than one home and receive support from roommates, neighbors, family members, or classmates. We will also be happy to arrange family counseling and help you planning for your new home."

"Any of these supports would be eligible for reimbursement from a stipend that would be authorized to you for support. The amount of support check is based on the amount you decide on based on your objectives at home, your job, and the community. Support stipends are in the range of $2,000 a month."

"Once accepted into the program, you would have funds advanced to your account to pay for the support you choose. These funds can only be used for their intended purposes, and doing otherwise would be subject to penalties. The funds will be replenished on a monthly basis, as long as you spend them. If you don't spend from your account for a period of time, funding will be available when you decide to take them out for these purposes again."

"We expect all people who register for support to live as independently as possible and to develop community-living skills to the best of their abilities. When you are able to live more independently, we will assist you adapt to new living arrangements and community experiences that support your home life, a job, or secure community ties you require. Your stipend will also continue if you decide to live independently for a period of time, so there is a definite incentive to live in more independent settings."

"Support workers are available from a list of qualified practitioners or you can select a family member or friend who is willing to undergo some training. It is up to you to choose each support worker."

"As you become able to live more independently, support will fade out. If you experience a difficulty or problem after support is faded, supports will be reinstated immediately at your request."

"There is no need to reapply for support once you are authorized to receive. There is no waiting list for services of this nature. Your stipend will be available in any event for a minimum of 5 years, renewable in three year increments thereafter."

"If you, or you and your fiancée, want to move out from your family, we'll help you find a host family, friend or relative to live with, or set you up on your own. We'll ask you to go through a home study with the new family or friend before you decide on living together."

Depending on the results of the study, an additional stipend can be provided for this type of support to cover such items as home renovations and respite care. In any event, it's always your choice that matters to us.

If you don't want to be somewhere, we're not about to put or keep you there. We will also work with you to move from a place to another whenever you want."

"We don't directly handle medical services or health care in this program. If you need a therapist, doctor, dentist, hospital or medication, these services are outside our scope of practice. While we can help you access these generic services with transportation and make sure people that support you know about your medications, our primary focus is on home living, employment and community support here.

"To safeguard your interests, independent monitors may ask to visit to see how you are doing from time to time. While we encourage you to talk with these monitors, you don't need to oblige them.

"We'll intervene in the support you have when you ask for it, or if your family asks us too and you have no objection. Nothing about you goes on without you."

"You may leave the program at any time too, and we expect that you will be able to live without public assistance based on your success with the support we're offering, together with other assistance you receive from your family and community. As far as we're concerned, we are all in this together."

"You have access to me at any time if there is an emergency or crisis in achieving these ends. You can expect me or any other support workers to be your advocates too."

"As a young person transitioning into adult life, you will need to agree to pursue community employment as condition of participation in our program, along with lifesharing or a home of your own. There are no placements in any type of facilities in the support we provide."

"In terms of employment, we'll offer you support in finding a job and keeping that job, or in continuing your education leading to a job and a career. We'll help you access financial incentives to work, and funding that your employer may want in providing assistance on the job."

"If other parties help you in securing employment, we will coordinate with them directly if you agree. We will provide you with professional assistance if you want to start your own business venture too, or work with a friend or family member with this goal in mind."

"If you choose to attend a transitional work or vocational training program before getting a job, we can only support this type of program if your work pays at least minimum wage. All training must be in generic settings, such as a trade school or technical institute that is attended by people with disability too."

"Our payment structure with transitional work programs in industry is also time limited, as we expect people in these programs to move on to individual employment in a year or two at most. There will be no community support funding of these programs beyond two years."

"If you cannot seek a job right now or want to find another job, we will also support community volunteer work with a community non-profit agency or through some other sponsor of your choice. You can use funding in your support account for these purposes as well.

"Since our priority is employment first, resources for volunteer pursuits may be limited, and priority will be given to volunteer pursuits that are expected to result in a paid position within a year or two."

"Depending on the availability of funds, we can generally connect you with a volunteer community organization of your choice. If you like birds for example, we can introduce you to people in a local bird association and help you get to meetings if that's an issue."

"There are many organizations in the community that welcome people who want to get involved as volunteers. Your support check can be used to pay a group or organization that sponsors you as a volunteer. Also anyone providing personal care or other forms of assistance to you while attending these programs can be paid from funds available in your account."

"If you are not able to agree to pursue employment outcomes with us, we can refer you to adult day care and sheltered employment settings that can be obtained privately. Our public funding doesn't support new placements into these types of congregate services anymore."

"Do you have any questions about what I said before we begin talking further about your future, the community outcomes you expect to achieve and how we can help you achieve them? Let's talk more about your objectives."

Where Nothing Is the Same

The new ways to support people with disability won't be about cajoling system partners anymore. Solutions are not going to be about changing rules to provide better forms of specialized care. Emerging practices will outpace politically correct, half-hearted measures and foggy future adjustments thrown out by worn out leaders.

New ways will be framed by a social will that's centered in common understanding, information and practice. These ways will rely first and foremost on community resources, not specialized programs. They will be alive in the spirit of community and real in how people with disability live as everyday and valued members of society.

The future isn't going to be about getting issues resolved so systems work better and more efficiently or having more comprehensive management information systems to document payment flow and program compliance. There will be no more groping for something nice to say about caregivers of special people in special places.

New ways of support will be about achieving everyday living outcomes and passing by the old ways for good, with everyone, everywhere. Now is about supporting people to secure a job, a home, and connections they need to live in the community. These objectives are not for some future anymore.

New ways are about achieving everyday outcomes, not just trying or believing in them, or selectively agreeing to pursue them once in a while, for a select and chosen few. Support is about staying true to these outcomes, not getting diverted into playtime for adults, horseback therapy, and other abominations of care.

If people want a horse to ride they'll have to find one just not on the public's dime. In the ways of support, people get what they need to get jobs, a stable place of their own, and relationships to help keep them secure in community life.

Since systems won't be organized to serve people like they've done in the past, we won't have to navigate their restrictive networks and processes to make things happen. We won't be wasting time listening to the system whine about what a difficult job they have on society's behalf because community resources will be doing that work from here on in.

Service systems for people with disability have run out of time and excuses. It's over for them. This world of special rules and checkers checking checkers is down for the final count. Gone is their nasty old brew of restrictive practices, which was neither good nor healthy for decades already.

Nobody who really knows what's going on in systems is buying the hype anymore, anyway. They're just holding on too.

All that pabulum dressed in regulation and treatment plans can be left where it is. Let it gather dust and rot for all we care. We don't need new regulations. We don't need old ones either. None of that world applies to a community framework.

Instead of systems, we require citizens to assist each other with the resources they require to conduct their lives. We're not asking for anything except the opportunity we need to succeed. We're not asking for anything special here.

This framework is a general thing, a blue print at best, with four of five pages of guidelines and the rest based on discernment, independent assessment, and experience. It relies on people to be resourceful and respectful of each other.

It operates like Head Start does, with people and families having the biggest say with the community at large. There are no system people to be involved as resources flow directly to people and their community sponsors.

With the real world as their common reference, all those system controls and practices can finally be trashed. We'll be back to individuals again and their community support network, and that's where we're going to stay.

It's time for that final bow and certain exit of systems in this process of community building. We've played around enough. Adieux.

The credit for achieving everyday living outcomes will now be for the community to enjoy, ponder and share. New ways are already formed as the basis for community-driven futures to emerge, so we don't have to start from nowhere.

There's lifesharing and employment and independent monitoring for starters. There are public television channels for information, and alternative forms of expression easily obtained

through the internet and commercial software. We can share and experience all this, and more, from here.

We've got a new look to show, a new way to be. We're out to do better. We know what we want and how to get there too. We won't take no, later, or maybe for an answer anymore.

We are here to succeed and we're sure that we will. Standing in our way would not be recommended, as surely tides under a new moon rise.

In a popular track, Mr. Dylan wrote: "Stay out of the new ways if you can't lend a hand, cause the times they are a changing." Indeed they are, Bob Dylan. Indeed they are.

Taking Employment First

In order for people to achieve employment outcomes as a basis of their self-determination, public funding that is now provided for vocational services and activity centers can't stay where it is. Public resources, instead of going to sheltered work and day programs, need to support business that employs people, not agencies that intentionally game systems with their sheltered work practices and failed readiness approaches.

Community enterprises that employ people with disability deserve to be supported first and foremost. Specialized services controlled by programs can't be calling these shots any longer. They can't be controlling which businesses get approached to offer employment support. They can't control who provides employment support either, or who does the outreach in the community either.

Support for employers means resources diverted from the system to employers. Employers must be assured they have immediate access to financial and other resources they need to succeed with people. When compensation the employer's support is in order, they are paid expeditiously and without tax or liability implications.

Under the banner of employment first and foremost, support approaches play by community's rules. Communities, not conflicted adult programs, support transitions from school to careers. Communities reject calls for custodial care and sheltered work approaches that lead nowhere too.

Communities take responsibility out of their own self-interest to derail tracking young adults transitioning into congregate care programs like activity centers and workshops from public school. They ensure resources are available to promote employment outcomes for people because it's for the good of all citizens and the community at large.

Communities appreciate the vast capacity of their resources to address the demands of people. If people need support to learn a job, that support is readily available to the employer first.

Employers that want the know-how of an outside specialist to manage or coach employees on individual disability related issues will have this support when they need it too. Employment related support areas like job readiness and adaptability at home, transportation assistance would also be reimbursed to a reasonable degree.

Compensation to the employer supporting a person will be based on the extraordinary support the employer provides or authorizes. This means that employers obtain direct compensation for extraordinary conditions presented by the person's job support, including environmental adaptations, supervisory time, quality control, etc.

It's time for those providing support to be rewarded for sustaining jobs, not intermediaries and program monitors. Jobs are not programs. They don't belong to systems. They can't be controlled by them anymore either.

With the freeing of public resources to employers, business leaders can step up to find everyday solutions that work. They'll work on integrating people into their workforce in business circles.

Confidence building and momentum in community approaches gain strength with resources changing hands. Even as systems try to hold on to people in programs, public funders step in with business owners and community organizations to address exploitation and make sure people have clear access to careers.

Communities start all this by committing to employment outcomes. This involves key community players and an educated public with regard to the benefits of taking community ways as opposed to systems.

Sports figures, entertainers and other popular figures reflect an understanding of this commitment in their organization's hiring practices, public relations and associations. Local advocacy associations direct themselves to business leaders for support, instead of government agencies that have been bogged down in specialized services.

Those government and provider agencies that continue to support people after the system's fall take a lead and hire people with disability. The media tracks how people with disability find satisfying careers, satisfying family lives, and interesting life experiences. Colleges, trade schools and employers apply their knowledge to ensure people get the training in careers they choose.

Within a community framework, communities have the primary responsibility to find jobs with people and ensure that enduring support is there to make them successful. Communities create the culture of employment that includes people, their families, schools and employers. Communities make sure that employers have the support they need to make this employment experience a success.

In this schema, community resources are also available for volunteer agencies that offer people a way to contribute to the community outside of their jobs, or to prepare for a job. There

are no special rules around this participation, just the expectation that people have the necessary ties to live secure and satisfactory lives.

Forging New Ways

As the arguments against taking new ways lose their steam, we'll find paths to using public resources easier and more predictable. We'll find new ways to craft support for people in communities, not programs in systems.

While the composite of these new ways will vary and evolve, common themes will be established. New stakeholders will emerge from the ranks of employers and community sponsors. People with disability will be on their way to be part of the community again.

When arching out of system ways, it helps to visualize what this community support paradigm will look like and how it will function. In the area of employment support, a person would have resources in his or her account for employment support. Depending on the situation, the employer could receive this support from an individual's account or through an intermediary on the person's behalf, preferably a family member or friend.

The public, represented by a community board or other entity, would take responsibility to ensure the employer's support is cost effective. There would be no system intermediaries, like case management agencies or administrators to monitor safety or a written plan of care.

Under the community approach, there wouldn't be a plan of care. There would be outcomes that people and their sponsors are on the same page in achieving.

The employer would obtain financial support for securing the person a job, one of the three basic outcomes the individual's account could be used to fund. As long as the person held the job, the employer would continue to receive financial and other support for a prescribed period of time. Similar dispensations would be available to landlords, neighbors and others offering residential support.

Considerations of continued funding would be reviewed by the community board based on what the employer continued to require in order to retain the person as an employee. There would be no documentation required to continue payments apart from verification of employment.

For people with persistent challenges that cannot be accommodated outside of support funding, employers might receive financial support for the duration of a person's job, with community reviews every couple of years to verify whether stipends and other financial assistance continue to be justified.

Allocation of continued resources would always be assessed against informal supports within the workplace taking hold. Difficulty of care guidelines would be adopted to ensure cost-effectiveness and fairness overall.

One thing is for sure: under the community approach, the employer makes decisions of support with the person, not a government agency, administrative entity or specialized provider of service. The person and the employer decide together, not the system, what type of support a person gets, and how that will be done.

Even though specialized programs could be used to compliment generic resources, the employer and the person, not the system, would determine when and how these resources are engaged. People and employers would be rewarded for keeping people on the job.

Within this structure, there would be no wasted years of training people to get ready for a job. Other supports, including transportation services and visiting nurses would take on responsibilities of support to a reasonable degree when needed.

By virtue of the payment mechanisms support networks establish, providers focused on preparing people for community life would no longer be in a position to game the system and keep people from engaging in community ways. Workers and organizations providing traditional services would have to adjust to a new set of players and expectations or find themselves another product line.

In this support paradigm, people who cannot work for one reason or another would be supported in community volunteer work. Financial support would be available to verifiable community volunteer organizations, like churches and civic groups or individual workers and colleagues willing to take this support role.

Much like employment, the volunteer organization sponsoring the person would receive funding from the individual's account based on the support or additional assistance the person needed. The organization could also engage the assistance of a qualified professional or agency sub-contractor in this respect. While people wouldn't necessarily be paid for volunteering, doing internships, and other career oriented work, they would be exposed to fulfilling valued social roles for a change, and they'd be individually participating in life with people outside of the closed disability circles.

People who are not employed or in a community volunteer program could also be supported in engaging in various forms of community outreach in order to secure ties, including medical professionals, a social club, etc. This aspect of support could also assist people in job finding or securing a home of their own.

To underscore the person's role to direct support, people would have a personal account from which the employer and other support entities are paid. That's right: we'd be placing the control of public money and human resources with people, not programs.

Congregate care programs and services would clearly be disallowed in this approach. Only expenditures related to achieving community outcomes would be included in the stipend people and their sponsors received. Safeguards in the payment and accounting of these funds would prevent fraud and abuse.

There would be no disability labels and levels of need applied to divine how resources flow in these community support structures. There wouldn't be applications for service either. Support would be situational, distinct and eminently personal.

Checks could be attached to a person's social security check where it belongs. Funding under Medicaid would be dropped, leaving the medical model for good.

People who wanted support in this paradigm would select an independent community support representative who could link the person with any number of community resources. We'd be rid of special places with special names, as well as the special rules and case management monitoring that keep people trapped in system-controlled programs.

Funding transactions that now occur through accounts of government agencies and providers would transpire through banks and financial institutions. Any qualified adult, including an employment specialist, family member or friend would assist the person locate a job and provide ongoing support. Payments for support would be automatic, based on payroll verification information that employers already provide.

Earned income would be subject to personal income tax exclusions that are already in place under Medicaid Buy-In Programs and similar Social Security work incentive programs. These would be automatically engaged through the financial institution the individual chooses to manage their support account.

There would be no people or support entities drowning in paper work, monthly care plan update meetings, and all that. A hot line would be made available for technical assistance or to access a support professional.

Generic financial institutions, like banks, would handle the payments from multiple agencies. There would be almost nothing about the system's operations today that is preserved.

The extraordinary safeguards that systems established to prevent fraud and abuse of funding would no longer be necessary, since payments would be tied to verifiable outcome data like a person's paycheck at work or home address. Reporting by family, friends and independent monitors would be sufficient to ensure the health and safety, and verify satisfaction with support.

There would be nothing institutional or sheltered about anything the community supports. In charting this new course, program developers would face the reality that the system is no longer useful.

There would be nothing medical about them either. New funding and safeguards would be positioned under Social Security or other similar framework where funds are made to people not programs, and the focus of social security aligns in achieving community outcomes.

Achievement

Living in real life outcomes is where we need to be headed. This outcome focus is not a fad. It's a modern day and common sense necessity. We can't determine how well we are doing in supporting people, unless we know our purpose in doing what we do, and how well we're achieving our objectives.

As our purpose is to support people to live an everyday life, jobs, community connections and home places become the outcomes we measure. The framework is very direct and simple in this respect.

It's also urgent. This country can't afford to ignore outcomes or services that are just off track. The public can no longer tolerate paying for system controlled settings that treat people like objects and take all the resources for themselves.

Communities can no longer tolerate the make believe worlds the system creates, instead of support at job sites, private homes and community places. They can no longer go along with young people trapped in nursing homes, institutions, adult activities, and the wide variety of congregate programs that dominate the offerings of systems today.

Communities have the capacity to understand what they can and can't afford in supporting others. They see how taking groupings of people with disability to the park, grocery store, and shopping, like freaks on parade, has something to say to us all.

To be successful in community support, developers of the community support paradigm stop sustaining placement in group homes, residential facilities like ICFs/MR and adult day programs that keep people from getting into the real world. They make sure that the benefits of community achievements are shared.

They also take away the system's ability to set boundaries on people's liberty, freedom, opportunity and gain by restrictive service definitions. They make it possible for people and community resources to manage to the outcomes they want to achieve.

People with disability belong in this paradigm. All citizens do. This is the reality: every citizen deserves it – achievement that is.

Without maybes, it is time to end the standards that encompassed services system for generations so that community approaches can rise up and take over. In this process, a lot will be exposed about the abuse of system ways. That brand of mean-spiritedness, power mongering, and incompetence that will come to light.

There will be no small degree of hiding going on too, along with finger pointing and bemoaning. These responses are expected and must be managed. Whatever the problems, systems have to come down, even if the process isn't painless or polite.

As this deconstruction occurs, the public gets information. It gets the truth about outcomes and information on support networks success in moving people into everyday lives.

In defining outcomes in community terms, program developers set the stage for achieving employment, home living and strong community ties. This is the minimum data set on which any enhancements are built.

As citizens and organizations change their deviant interpretations of people through use of community resources, it becomes accepted that just keeping people safe with others having a disability won't cut it anymore. Support funding for segregated programs of any kind, from horseback therapy to support for van rides to the special dances, are no longer accepted for public funding purposes.

Neither are adult day care programs, no matter what systems call them in the way of an activity center or training site. Case management that doesn't assist people achieve everyday outcomes is gone. Residential facilities and group homes are emptied, much like the first wave of institutions were in the 1970s and 80s.

As the public continues to appreciate new ways with people, supports evolve more effortlessly than we could ever imagine. While quality measures require modifications of practices and safeguards from time to time, community resources essentially govern themselves within the context they already exists.

People that have problems with the quality of support go to a town meetings and their lawyer instead of to internal grievance channels going nowhere. Community leaders see clearly that the country does not need special government inspectors to monitor homes and system guardians to take care of people's personal funds. They appreciate how good accommodation gets.

Family and friends declare how well they manage support with the resources at their disposal. Neighbors and friends see that community resources work for people in regular ways, using accommodation that makes sense for everyone.

We appreciate people helping people now. We recognize how supports achieve community outcomes. That's what we're measuring from here on in.

We let people and communities do their thing, pay them for extraordinary efforts when they want to financial consideration, and make sure everyday outcomes are achieved effectively in exchange.

We don't create new special laws or regulations about how people with disability have rights to be part of society. We adopt outcomes that work. We shed all that is special.

As the country engages in changing ways, we reflect on what we're doing to get where we want to go. We check ourselves in forming networks and frameworks and associations. We learn from what we say and do.

We keep asking questions too. Here are in another handful:

How are we applying what exists in the community?

What system influences and programs are shifting to support ways and closing?

What are we doing to bring people and their communities together on an individual basis?

What are we doing to realize everyday living with people who have not had it or who are at risk of losing it?

U and Bo

Hi, my name is Urilla, but my friends call me U. This is Bo.

I work with Bo here. I don't really have a title. We're finding him a job now, as part of a path we're on.

That's what gets me paid for helping Bo these days. I don't know how long we'll be doing this. It's really up to Bo.

Bo doesn't talk in ways that most people can understand, so I'll translate, and tell you about this job finding we're doing. He'll tell me if there's something I say that's missing, and I'll tell you.

Bo will also make some points himself, and I'll tell you what he's talking about if you can't follow his words.

That ok with you Bo? Good. You ok with his talking about this, right? Good.

I live down the street and met Bo about four years ago at a block party cook-out. I was grilling Katie's fried chicken and he was eating it, a little too much then, but that's changed.

Right Bo, we were both a little heavier a couple of years ago, remember? We shook our bellies then, but not now, not anymore. No more seconds for us… Small helpings.. Right salad, no bread. (Laughing between U and Bo).

Yea, we lost some weight, and Bo got some nice clothes, decided on a line of work, and we've been doing interviews with a small area company and two non-profits. That's been for the last month or so. We figure we'll a match pretty soon.

Government isn't hiring in this area or we'd be looking into the civil service route, too, like people in other states already do. Bo and I know what's going on in our field. We're well informed through the work channel on public TV.

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This show we watch gives us a lot of good information and links. They have the news there about jobs and people with disability, and we love the reports. They're very interesting even for people who are not in the field.

We have a joke about this, don't we? Bo says we're the only two people he knows that get paid to watch television once in a while. Didn't you tell that joke, Bo? You know you did too. (Everybody's laughing).

We're at the point of choosing between three companies for Bo's work. One is relatively close to our neighborhood, another pays better but is farther away, and the third company wants to start Bob in a part time position.

Can I tell these folks about the work you're looking for Bob? Ok then.

Bob wants to be a painter, like in painting rooms. He doesn't like the big jobs, like industrial sites. He really likes to use small brushes and tiny rollers. He's a finisher.

He paints using a device strapped to his good arm. He's not real fast, just good. He's meticulous even and really into safety masks too.

He doesn't smoke and can't stand certain fumes too well. So it's good he's careful. Employers certainly appreciate that, from what we've seen.

Maybe he's too interested in the masks at this point, but whatever. It's a matter we're discussing at least.

He's got a great little fan he uses on the job now. He brings it with him to draw off fumes and such. Depending on the job, that sometimes is not that practical.

I probably shouldn't be discussing this any further, so I'll stop. Should I stop Bo? Yea, I did.

Let's leave it at this: Bo wants to specialize in painting house interiors, and he's great with trim and all the finishing work. He has a good eye for evenness and tone. He'll tell you if colors don't mix well, too.

At the stage of job finding we're in now, we're showing painting contractors how Bo paints, how he communicates, and what support I provide or arrange in terms of job set up, transportation, etc. We talk about payments, safeguards, and how I fade out as the contractor takes on more responsibility.

We plan to do this fade-out in 60 days, but would be willing to work together further if that's what it takes. It's up to the employer and Bo.

We make it clear on these interviews that Bo could be doing this painting himself if companies don't want to be involved. He's got all the support he needs to start his own business this way, if he wants to.

We're selling Bo to these companies, and frankly they're interested.

Ready to be your own boss, Bo? Yes, I know you like to be with other people, but you can do that as a boss too, right?

Yes, I'll tell our friend here that you want to work with the painter we talked with the other day. Remember we have to wait on what he has to say next, right? We'll call him later in the week. Don't worry about it, the date is on my phone. I won't forget.

Bo shows his painting skills in a video clip at these interviews we go on. The video is on his phone. The clip shows him getting to work, setting up a job, painting, and then cleaning up the site.

The video looks like an painting instruction booklet you'd buy at Lowes, he does so it so well. Isn't that right Bo?

Bo's teachers at school helped in creating this video a couple of years ago. The teachers have a nice part in the second clip, too, where they explain Bo's skills and progress. Most contractors haven't wanted to see this second clip, but they've really liked the first one.

Got a lot use of that video haven't we Bo? Yes, I mean your cell-phone there, yea that one. Sure we could show him the clip, too. Do you want to send a copy of the clip about your painting to our friend here? Great, check it out.

Bo's all business, right Bo?

The funding for the support I provide Bob works like this. Bo gets a payment as part of his social security check. As I understand it, the check Bo gets is the same for three years, and then it gets reviewed.

Depending on what the employer wants after that time, and the person wants, the support is dropped or changed.

I get paid to support Bo from the check he receives. Bo also gets to keep some of the check for being involved to cover his expenses and time. He and his sister decide on how the checks get cut.

We're all making money, right Bo?

For the initial period of job finding, I've been getting the 75% of the total rate, with 25% going to Bo for his expenses and effort.   Once Bo selects an employer or decides to set up his

own company, that employer will get an immediate cut of at least 30%, resulting in Bo and my rates going down.

To a large extent, the cuts in our pay are Bo's call. Another neighbor and Bo's sister sit in on meetings where we decide things like this.

Once job finding and initial support stage is done, the employer automatically receives 60% of the rate. If Bo starts his own company, that 60% is his to keep for the business.

Employers also receive automatic tax credits tax credits for physical adaptations financing, or grants if needed. My job includes making sure these incentives are used and linked up. I also take charge with Bo on anything job related, and that includes family and using community resources.

I'm Bo's man, and we both know it. He holds me accountable and so does his family.

Who's the boss Bo? You bet you are.

This year's rate for Bo's employment path is just over $8,000. The rate is set by the state for anyone with disability who wants a job, and there's nothing to negotiate. Bo has funds deposited to his support account at his bank every two weeks. The bank cuts the checks to all of us.

Employers like this way of doing business because it's simple and straightforward with no red tape. There's another incentive too, since all support income is untaxed for whoever receives it.

These tax exempt payments are called support stipends, and they work. Bo and I call them something else, but that's okay too.

What do we call them, Bo? You know, tell our friend here. It's the bonus with the Big B, right? Right, we call it the bonus. It's our work bonus, and we share it together. Yea we do.

For me, I like the idea of being paid like this, and continuing to get funds for the time Bo's in a job or looking for one. I like having entre with Bo and his work, as long as they'll have me.

I also like having the ability to be my own boss and to be rewarded for our success. I'm working with Bo and four other people at this point, and may take on another assignment soon too.

I like this payment process most for Bo, because it keeps him in charge. If I move on or he wants somebody else to do support, that's always an option. He could have his brother, mom or his niece be his partner in this too, too. I understand that situations change.

So the payment thing is good all around. If I find that my cut for doing the work lacking, I'll talk to Bo about this and he'll decide to make any adjustments.

These stipends work in the public's interest too. The rate Bo gets depends on the success we have in choosing a job path that is self-sustaining. If we're in this job finding mode nine months from now, the rate for Bo would be down, and it keeps going down as long as the job is not obtained.

The one requirement for Bo in all this is that he pursues full employment. There's no moonlighting during the times we're working on the job. He's not going to a sheltered workshop or anything like that.

Its employment first, isn't Bo? Isn't that what we're calling it?

Yes, Bo says it's work getting this job. We're earning our checks.

Bo said to tell you that he's the boss, like I said.

That's about it, about the support we do together that is. It's been good talking with you again.

Let's go Bo. Yea, the interview with our friend is over.

Bo says nice meeting you.

Appendix

1. Visitation Report

This report is a record of a visit I completed as part of a series of independent assessments in the 1980s and 1990s. The account was selected from over 60 individual assessments completed in West Virginia between 1987 and 1992, reviewing its Medicaid Home and Community Based Waiver Program. The names of individuals and agencies have been changed for confidentiality purposes.

Based on this experience, I found that the Behavioral Health Services Division of West Virginia's Medicaid agency, headed by Jim Greene at the time, was exemplary in many ways especially the development of shared living that they operated through the State University in Morgantown. The State Medicaid agency in that era was ahead of the curve in fashioning support and services with people.

West Virginia's lifesharing stories in particular, including the one that is included in this appendix, are testament to how and why support works for people, and formalized services generally don't.

I completed these evaluations with a team of trusted colleagues, Yvonne and Miguel, the same Miguel I wrote about in an earlier chapter of this book. Our team also conducted evaluations in Maryland, and Delaware during the 1980, and I took on similar tasks with other colleagues in Utah and Texas too.

The interviews we conducted occurred with direct support workers, people and families where they lived or worked, or in some situations, places in between, like a hospital or a diner. Each reviewer would be scheduled for two evaluations a day, with each one lasting at least three to four hours, counting the time on site in preparing scoring sheets.

While the assessment report from which this story is taken was completed a decade after the early period covered in this volume of <u>Arching Tales</u>, the service approaches the teams observed during this time had been in place since the late 1970s.

The people in the West Virginia samples had all been receiving home and community based services for at least 2 years in their residence, with the average stay being 7 years.

The assessment utilized elements taken from Normalization although they did not precisely follow the formulation and terminology that Wolfensberger and Glenn laid out in the <u>PASS Instruction Manual.</u>

The reports included in the appendix should give readers an idea about what evaluations that embody Normalization principles were like and to obtain a glimpse into the life of people receiving services during this time. Accounts of other visits are expected to be posted to my website, at Dawaho.com.

I'm also dedicating these stories to a departed colleague and friend, Gary Smith. Gary was an early community service pioneer, working out of Colorado before he came to represent all states in the Washington D.C. area later in his career. Gary was a great advocate for employment.

When Gary first read these assessment reports back in the 1980, he said I should put them together and publish. Here they are my friend, and thanks again for the good advice.