

## Searching for Quality in the Crooked Map Zone

John O'Brien\*

Andrew Power, Chair of People First in the Australian Capitol Territory, explained the behavior of service managers who speak of choice and integration at the same time that they expand group homes and day activity centers –professionally controlled, segregated services. He said (personal communication, August 1993),

Things have changed, but the managers and the staff haven't caught up yet. Now they are looking at a map that has gotten all stretched and crooked.

When you drive with a crooked map, you get lost. The faster you drive on a crooked map, the faster you get lost.

Reflection on Power's insight suggests at least two ways that our maps can become detached from the territory we navigate in search of better quality services.

- Our mental models can poorly represent the experiences and aspirations of people with disabilities and their families. This happens when we ignore the effects of a long history of low expectations and segregation on a person's decisions, and declare, without considering what kind of assistance or further experiences might make a positive difference, "Supported living is not for her; she chooses to stay in the group home with her friends."

---

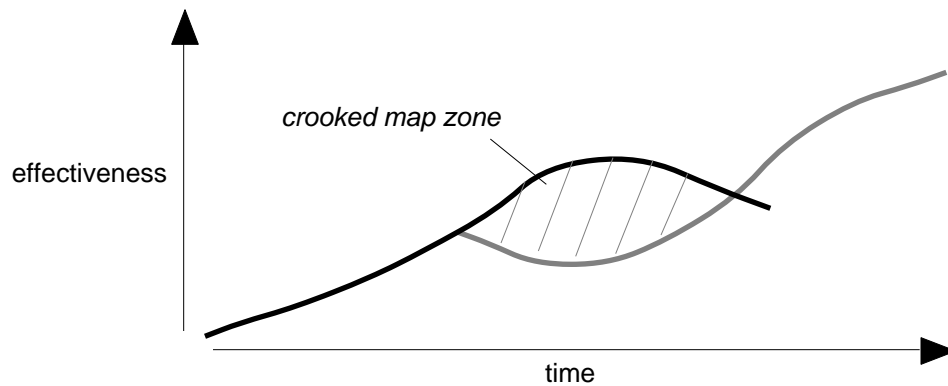
\*Preparation of this paper was partially supported through a subcontract to Responsive Systems associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

- Our talk about quality improvement can be disconnected from the everyday constraints of service provision. For example, we sometimes talk about people with disabilities as if they were customers. This happy mistake feeds the illusion that people's choice of a service warrants its quality, because customers could discipline ineffective services by simply taking their business elsewhere. We say this despite the market imperfections that arise from almost total control of expenditures by the agents of overcommitted bureaucracies, and from waiting lists for places in the only available services. We pretend that people could choose which mall to shop when they are, in fact, in hock to the company store.

This paper recommends that those who care about services for people with developmental disabilities practice their map making skills by reporting the outlines of what they can see from their corner of the crooked map zone. As an aid to this kind of rough and ready cartography, it presents a simple image of change with some thoughts on how we lose our orientation. This image guides two preliminary exercises in making such maps, one through day services, the other through improving our system's ways to improve quality. Three reflections on these sketches –on emotion, on thoughtfully interpreting the lessons of quality improvement, and on the importance of design– suggest some likely places to carry on the search for quality in the crooked map zone.

### **Losing our orientation**

To make our crooked map a bit straighter, or at least to notice when we start to get lost, we could try to better understand what stretches and twists it.



Charles Handy (1994) offers a helpful image for understanding the general structure of our situation. Visualize interlocking “S” curves, each tracing the life of a way of working (like those above). In this evolutionary metaphor, activities, ways of working, and models of the work and its environment (maps) have a life cycle. Learning how to work better increases effectiveness incrementally, as long as there is a reasonable fit between the work and its changing environment (the map fits). Over time, the work environment changes as new technologies create new possibilities, negative effects of past efforts accumulate, and preferences change (the map gets increasingly crooked). Effectiveness peaks and then begins to diminish rapidly (the faster we drive, the more lost we get).

The image of the interlocking “S’s” suggests that an organization’s stakeholders must enact a paradox in order to give their organization a chance to stay relevant. While one way of working still has potential for improvement, the organization begins to invest in a different way of working, which it bets will better fit the possibilities and problems emerging in the environment it is helping, in small ways, to shape. Waiting too long to make this shift –that is, waiting until after effectiveness has peaked– means trying to learn a new way while living with the rapidly accumulating problems of a failing way of working. Think of the dilemmas and incredible costs of pulling ourselves out of institutions that lost their rationale nearly a generation ago. But investing in

learning a new way means accepting both the organizational costs of pursuing incompatible ways of working and the costs of trying new things. So, along the new way, effectiveness will most likely decrease before it increases. This will seem ill advised to many people, who will say, "It ain't broke, don't fix it." If their advice to stick with a winner is ignored, they will greet struggles with new problems by sympathetically observing, "Told you so."

Because most people with disabilities and their families have few if any alternatives to the existing services in their town, they directly bear the increasing costs of ineffectiveness, while service providers can maintain relative immunity. Unlike hula-hoop manufactures, service operators do not face the prospect of going out of business due to overlooking new opportunities to serve the people who rely on them. Indeed, they can happily listen to total quality training tapes while driving company cars to dedication ceremonies for obsolete new facilities. When fundamental change comes to today's human service organizations, it will come because innovators choose to listen carefully to less demanding signals than the messages generated by people with disabilities taking their business elsewhere.\* It will come when innovators learn to listen carefully to the hopes and aspirations of the people who rely on them, not primarily because it is good business, but because it is right.

People need foresight, good judgment, and courage to decide when to begin investing in different ways of working and what new ways to develop. The more different a new way of working is from the old way, the harder it will be to make these judgments and the harder it will be to persuade other stakeholders to join in the change. Two factors bedevil these judgments:

---

\* Some people argue eloquently for fundamental change and call for the creation of a freer market in services by providing people and their families with cash and the responsibility to purchase the services they want. While I think this line of argument has much to commend it, and I would like to see it tried, I estimate that the current distribution of money and power will likely to continue in enough places and for long enough to make the rest of this paper worthwhile.

- Innovators are discovering new ways of working at a rapid pace, so the period of the curves grows shorter. As Donald Schön (1972) observed, the life of many important problems has become shorter than the time it takes to implement the solutions we conceive for them. Instead of building investments into structures with thirty year mortgages or expectations of life time career stability, we need to invest for much greater liquidity.
- Boundaries around work environments have weakened, greatly increasing unpredictability and decreasing the confidence that we can steer our own course. More than one innovator in residential services has been unpleasantly surprised by the amount of management attention claimed by occupational health and safety regulations and labor laws. And more and more discussions about the future of services for people with disabilities turn on participants' predictions about the future of the world economy.

Maps become more crooked (less reliable) as new ways of working develop alongside established ways of working. The more difference in assumptions, relationships, and methods there is between ways of working, the harder it will be for people traveling on one curve to understand those who are traveling on the other. What is more, travelers on both paths are likely to be people of good will, whose fates are closely linked, who use the same words to express increasingly different experiences. These difficulties in understanding will fragment a previously united field, at least for a time.

If we follow Bateson's (1972) definition of information as "a difference that makes a difference", the amount of information generated in the crooked map zone increases rapidly. When this information overwhelms our capacity to pattern it, we are disoriented and irritated by chaotic noise and we look for ways to damp it. We build privacy fences, "They are wrong and crazy, don't listen to them." We try to soak up difference, "We are doing the same thing as they are; there is no real difference between us." We bury our heads in routine, "We are too busy doing our work to take the time to listen to all that." We re-direct attention to less chaotic topics. "Let's talk about paradigm shifts as if they were

fashion decisions –we’ll take the Swatch as our example of a paradigm shift.” Deploying these simplifying tactics in a reasonable attempt to avoid the anxiety and irritation of too much information (too much difference), compounds the crookedness of our maps.

### **Map making as a basic skill in quality improvement**

Finding our way through the crooked map zone calls for us to develop our skill as map makers. These will be rough sketches, more like the initial log of a new terrain than like the maps that come from the automobile club with the fastest routes traced and the speed traps flagged. Because disability is a civic issue, involving many stakeholders, we need to create public readings of maps through our changing services. Unless we can focus involved people on sharing their different perspectives and making and revising a common picture of the systems we want to improve, efforts at improvement will be shots in the dark.

The more accurately our maps reflect our current reality, the more complex and overwritten they will be, and the more frequently we will have to redraw them. Much of this complexity simply reflects the different interests and perspectives of...

...the people with disabilities, families, and staff who experience a system whose environment and fundamental technologies are changing in uncertain ways, and

...the neighbors, classmates, co-workers, and politicians who, for the most part, live at some distance from people with disabilities and regard them as strangers, well cared for by patient professionals.

Designers of quality improvement programs who do not consider the messiness, uncertainty, variety, conflict, and stress that characterize the terrain of service delivery will encourage people to look at a map which is fundamentally misleading because it looks neat and complete.

People who want to change the opportunities available to people with disabilities will judge such neat and complete maps as largely irrelevant to their work. They will pay polite attention until they can leave the planning meeting and return to their daily mess, unfortunately minus the learning that could come from thoughtful discussion. People who want to avoid change will use these maps' imaginary clarity as an invitation to take a vacation from the challenges of increasing the day to day opportunities for people with disabilities. This vacation can be a busy one, filled to the point of exhaustion with customer surveys, focus groups, quality circles, and nifty exercises in listening and problem solving. But unless these potentially useful tools help people work together to change relationships, boundaries, tasks, and ways of understanding, they are only a diversion.

Making better maps can take some courage, because their patterns include ourselves and often conflicting judgments about the effects of our own actions. It requires acknowledgment of conflicting interests and understandings. It shapes a demand for learning new ways to do new things. It calls for recognition of a growing and often painful gap between our vision of what is possible and the reality of our own current practice.

### **Reading the map through day services**

Consider a rough and ready history of US day services through the image of the interlocking "S" curves.

For more than thirty years, providers have worked to learn their place in a continuum of services that classifies every client according to disability related needs, and provides a service that matches the needs common to that class of disability. Based on this image and logic, we have built buildings, adopted assessment methods, defined entry and exit criteria, written curricula, delineated staff roles and career structures, negotiated methods of fiscal and programmatic accountability, formed associations, and built a constituency among people with disabilities and their families, employers, and politicians.

Based on this stable understanding of who people with disabilities are and what they need, day services grew steadily more effective. Needs poorly met within existing classifications led to the elaboration of new classifications and corresponding new programs. For example, distinct day programs opened, often in the back rooms of existing facilities, for people who exhibited great difficulty in complying with the expectations about routines, roles, and relationships that were embodied in the typical program for people with their class of need. And, entrepreneurial managers applied new classifications in order to tap different sources of funding and thus expand the capacity of day services, as in some state's creation of "medical day care".

About twenty years ago, awareness of new problems and possibilities began to grow. Careful observers noticed the collision between fact and optimistic assumptions about people flowing through a continuum of day services toward independence. A few people with substantial disabilities got well publicized opportunities to demonstrate their ability to do work that was far beyond the capacity assumed by existing program types (e.g. Gold, 1976; and summarized in Bellamy, 1979; Gold, 1980; Wehman, 1981). Some innovators began to shift their efforts into new ways of employing people. As they began to actively test assumptions about employability and discovered that many ordinary workplaces welcomed the contributions of significantly disabled people, supported employment took form. Most providers carried on with realizing the still increasing benefits of business as usual.

About ten years ago, advocates of supported employment captured an important share of policy attention in the US Office of Special Education and Rehabilitation Services (Will, 1984). This initiative signaled the states to move resources from improving congregate day services to learning to provide supported employment services. This shift has occurred, but in the US as a whole the re-investment curve has not been particularly steep. A decade after the call for system change, the share of attention given supported employment in meetings and plans remains disproportionate to its share of day services

resources. By 1992, only about 18% of people in developmental disabilities day services were engaged in supported employment, although, encouragingly, the state of Vermont reported that almost 85% of people in day services receive supported employment services. (Braddock, 1994).

Recently, leaders in the supported employment field have begun vigorous debates in order to accelerate the movement of resources from congregate day services to supported employment (Mank, 1994; Wehman & Kregel, 1995). Based on the success of people with substantial disabilities and their co-workers and employers, they re-assert that supported employment is for people with substantial disabilities, not just for those people who look ready from the perspective of the old way of working. The effects of these efforts, and the growing trend toward supported employment for those entering the adult service system for the first time, will further shift the demand environment for both supported employment and congregate day services. This will further increase differences between ways of working, and further distort our map.

For those providing supported employment services, the experience curve has not been nearly as smooth over the past ten years as the interlocking “S’s” diagram suggests. The supported employment field grows more and more differentiated as some agencies shift their ways of providing supported employment, re-focusing, sometimes repeatedly, from one curve to the next (O’Byan & O’Brien, 1995; Wehman & Kregel, 1995). A growing number of providers are shifting their ways of working...

... *from* a concept of supported employment that included work crews, small businesses, enclaves, and individual employment *to* a singular focus on individual jobs.

... *from* primary emphasis on entry level jobs *to* a concern with career development.

... *from* job development strategies aimed at finding jobs and then selecting people with disabilities to fill them *to* individualized job development

strategies, which begin with a profile of each person's interests, capacities, and preferences.

... *from* service staff as primary providers of training and supervision *to* service staff as organizers and consultants to employers, supervisors, and co-workers.

... *from* measuring success by comparing the wages of participants in supported employment with the wages of people in congregate day services *to* comparing the benefits of supported employment to the outcomes typical workers enjoy in terms of earnings, benefits, opportunities for personal improvement, working conditions, and job related social opportunities.

Not only does our initial image of neatly interlocking "S's" overstate the smoothness of the path, it also understates the discontinuities between the two curves. Judgments are difficult enough when they concern the timing of major variations on existing technologies, tasks, and processes –such as Canon's development of a disposable copier cartridge (Nonaka, 1991). But the shift from congregate day services to supported employment involves much more fundamental change than that –it is at least as big a change as if Canon decided to go into the manufacture of aircraft. It means...

...accepting a new primary task and, thus, detaching from the familiar buildings, curricula, schedules, programs, and task assignments that grew up around the old primary task

established primary task

training and otherwise readying people whose success in employment ultimately depends on themselves (i.e. their level of skill and motivation) and forces outside our responsibility (e.g. local patterns of discrimination)

new primary task

being responsible to support people in employment

...adopting new kinds of relationships with people who rely on services:

established pattern of relationships

classifying people into groups and  
dealing with performance  
problems through re-diagnosis  
and re-assignment of the person

new pattern of relationships

understanding people's  
requirements for accommodation  
and assistance in the context of  
their changing job interests and  
opportunities; shared  
responsibility for performance  
problems

...re-drawing the space and time boundaries of work

established boundaries

clients come to you and follow  
your schedule

new boundaries

joining in, and positively  
influencing, the rhythms and  
routines of different work places  
and different family and residential  
support situations

...re-imagining the logic and the image of service work

established logic and image

matching services to groups  
formed by abstracting disability  
descriptors from clients' life  
experience

new logic and image

centering service and planning on  
particular, changing people in  
specific, changing work situations

understanding service as if it were  
work on an assembly line

understanding service as if it were  
organizing change in complex  
human systems

While these changes call for vigorous practical action, they also have subtle aspects. For example, the image of the assembly line has great power to organize our activities. Even while we trashed the concept of a service

continuum on the T-shirts we bought at conferences (“Pre- means never!”), we could be busily reconstructing the same pattern under different headings. Steven Taylor (1988) revealed this pitfall when he observed our tendency to match people to different forms of supported employment in a way that looked like matching people with greater apparent disability to services like work crews and enclaves and then matching people with less apparent disability to individualized supported employment. Even in reformed services, people with greater apparent disability still ended up in services that grouped and separated them, though in smaller groups, and sometimes on the premises of community businesses. His observation that we were erecting a “new continuum” won somewhat more irritated denial than thoughtful consideration among supported employment advocates. The years since Taylor’s observation have seen practice divide along this dimension. Some programs focus on individual supported employment for all. Others entrench the assembly line idea by offering supported employment as one of a comprehensive array of rehabilitation services, bolted on to the side of existing day activity and sheltered work facilities.

### **Reading a map through quality improvement**

Consider a rough and ready history of US efforts to improve service quality through the image of the interlocking “S” curves.

The dominant curve for the last thirty years has been plotted by two complimentary policies:

- Assure the presence of a sufficient number of staff in adequate facilities. These staff are trained in a variety of clinical disciplines and work in multi-disciplinary teams to classify people with disabilities into appropriate groups, and then to assess, prescribe, implement, and revise individual programs for members of those groups.
- Based on expert opinion, judicial judgment, and political compromise, define standards by specifying procedures, facility characteristics, and staffing ratios;

inspect to assure documentation consistent with procedures and compliance with facility and staffing requirements; and, enforce correction of deficiencies through threat of sanctions including loss of funds or loss of operating license.

These policies have reinforced each other. Documented implementation of procedural, facility, and staffing standards is a condition of funding and sometimes a condition of compliance with court decrees. And detected deficiencies have driven the allocation of funds, especially when tied to the enforcement of federal court decrees and the maintenance of federal financial participation through the ICF-MR program. In some states, this reciprocal influence has been strong enough to direct a hugely disproportionate share of available funds to institutional facilities, and to meticulously regulated services for the people who have survived them; these systems have been surprised by a ballooning waiting list of people who grew up outside surveillance in their family homes.

For at least ten years, these standards led program implementation through a time of growing public investment. Most people interested in progress were lobbying for funds, drafting consent decrees, designing programs and policies, and training staff to catch up to the image of service so effectively communicated by the standards.

By the mid-1980's, the limitations of the established process became more clear. The problems seemed less with the content of the standards than with the sense that somehow the intent of the standards was getting lost in the way states applied them. Criticisms often included these observations: standards increasingly lagged ideas about good practice and contributed to inflexibility in implementing new approaches, they were dragging systems toward a least common denominator rather than pulling them toward higher aspirations; most people found enforcement procedures punitive and unhelpful, while at the same time facilities with widely perceived quality problems continued to operate unscathed; compliance and correction efforts promoted attention to paperwork and organizational activities over practical improvements and

accomplishments; and there was far too little investment in improving program capacity to meet the intent behind standards.

In this context, two ideas began to gain currency:

- Balancing the common focus on enforcement with methods for service enhancement (e.g., Bradley, et al, 1984, and summarized in Bradley, 1990). This emphasis drew on the growing interest in quality improvement in industry, and it opened channels for exporting many ideas about industrial quality improvement into services for people with developmental disabilities.
- Focusing attention on outcomes for people with developmental disabilities rather than on compliance with detailed specifications of service process (e.g. Bellamy, et al. 1984; Conroy & Feinstein, 1990; O'Brien, Poole, & Galloway, 1981). An outcome focus was congenial to many people trained in applied behavioral analysis, and it promised greater flexibility and encouragement for emerging efforts in employment services, family support, and residential services.

While logically independent, these two ideas have become strongly associated in many efforts to reform quality improvement. Probably their clearest integration is embodied in the methods and standards of The Accreditation Council on Services for People with Disabilities (1993; 1994). These approach produce a coherent approach to improving quality by blending an outcome focus with concern for enhancing organizational capacity, a strong interest in importing ideas and methods from business, and a structure for involving organizations in a network to promote quality.

As the publication of five editions of *Reinventing Quality* (Blake, Prouty, & Lakin, 1995) since 1992 demonstrates, the past five years has seen a rapid increase in the number and variety of efforts to improve approaches to quality improvement. A reading of the brief accounts of innovations described in the current edition of this collection suggests that emerging approaches to quality improvement are developing around one or more of these themes:

- Quality measures are developed consultatively, rather than being defined by state authorities acting alone. State authorities increasingly refer to their relationship with service providers as a partnership. Accordingly, some initiatives have involved service providers in the definition of quality standards and methods, others add the participation of representatives of advocacy groups (family members, and sometimes people with developmental disabilities themselves).
- The attention is shifting from primary focus on judgments about conformity to process standards. Innovations balance inspection for conformity by giving increasing weight to judgments about people's quality of life. Often these judgments are made by inspectors or monitors on the basis of brief observations and interviews, and lead to recommendations for change.
- In some initiatives, there is a clear connection between efforts to improve quality measures and the statement of system visions, missions, and strategic directions. These statements frequently focus attention on people with developmental disabilities' experience of choice, integration, and productivity. These system aspirations have been interpreted to demand new ways of measuring and improving the kinds of things that matter to people as expressed in the system's mission.
- Some initiatives distinguish "health and safety" issues –which they see as requiring standard, authoritative enforcement– from "quality of life" issues – which they see as allowing service providers wider latitude and greater variety of approaches. On this understanding, a minimal set of regulations confines itself primarily to matters of "health and safety".
- Responsibility for identifying quality problems is more widely shared, rather than being the sole duty of inspectors. Some initiatives include program self-surveys, others organize volunteer groups of citizen monitors. In some places there are organized supports to include people with developmental disabilities as program quality assessors.

- Inspectors and monitors focus less on paperwork and more on observations and interviews as a basis for their judgments.
- Surveys and interviews allow people receiving services, their parents, and staff who work closely with them to express opinions about the quality of people's lives and their satisfaction with the services people receive. Some of these surveys allow comparisons over time, and Colorado's approach allows comparison between the answers of people with developmental disabilities and people without disabilities.
- While some initiatives extend to all community services, most involve only a part of the service system. They are either linked to new funding (HCB waiver services or CSLA services), or to people moving from institutions, or to pilot projects.
- Some state authorities recognize a distinction between the kind of relationships and processes necessary for enforcement and those involved in service enhancement. There are varying approaches to this distinction: for example, Connecticut separates compliance activities from voluntary enhancement activities, while Massachusetts reports their integration into a single process.
- The concepts and techniques of quality improvement often inform the design and justification of these efforts. While there are many different approaches to improving quality, Deming's is the only approach specifically mentioned.
- Service providing agencies and other organizations have initiated their own quality improvement efforts in three, sometimes overlapping, areas of activity...
  - ...learning about continuous quality improvement techniques and implementing quality improvement teams.
  - ...improving program management through management development and mentoring and through internal reorganization.

...adopting an approach to person centered planning.

- Efforts to disseminate learning have different emphases. The New York State Commission on Quality of Care publishes case studies of neglectful or abusive service providers in a series called “Could This Happen in Your Program?” The Oregon System of Continuous Quality Improvement publishes descriptions of “Best Practices.”
- The importance of the relationship between service coordination and quality improvement is highlighted, especially in quality improvement efforts that view the person with a developmental disability as a customer.

On this map, the discontinuities between emerging approaches to quality and established methods look less clear than they do in the map through day services. There are deep contrasts between supported employment and previous day services. In comparison, changes in quality improvement efforts seem more cautious and tentative., No clearly differentiated alternatives have yet emerged, though there is some experimentation with new emphasis and new techniques, and there is much new vocabulary.

Of course it is much easier for a few people to set up a supported employment program and set a clear new course than it is to change pattern in a function that affects a whole system. For many stakeholders, licensing and regulation have come to represent a promise that people will be healthy, safe, and decently looked after. Some stakeholders associate regulation with assurance that public funds are being well spent. And many state managers see the regulatory process as a necessary lever for control.

Redesign of the quality improvement process would require careful examination of each of these assumptions and the consideration of alternative ways to understand and satisfy the interests underlying them. The context for such discussion needs to be a common picture of the whole system as it is developing. This process of development includes not only our vision for better services but also the emotional responses our organizations have to stress and

change, our opportunity to find ways to bring important lessons from other fields, the challenge of fundamentally changing the design of our services, and the emergence of new images for our work. All of these issues have to influence the redesign. Otherwise, quality improvement will be a tangential enthusiasm.

### **The feel of the crooked map zone**

Shifts in the fundamental dimensions of work life deeply stress organizations, groups, and people. So our ability to navigate the crooked map zone depends on our recognizing ourselves as unavoidably part of the system we are changing, and to understand the many weird effects of organizational, group, and individual emotion on our work. Fear, anger, anxiety, and envy are as much a part of changing ways of working as rational planning, creative problem solving, skilled performance, and thoughtful negotiation are.

When we can support one another to work effectively with these emotional reactions to stress, we can be energized by them. When we try to banish them entirely –as when we try to look at ourselves simply as “objective” clinicians, or “hard nosed” managers, or “no nonsense” advocates for rights– we will become preoccupied and entangled in emotion no matter how bland or busy the tone of our discussions (Obholzer & Zagier-Roberts, 1994). As the official doctrine of the US Marine Corps (1994) notes:

Leaders must study fear, understand it, and be prepared to cope with it. Like fear, courage takes many forms, from a stoic courage born of reasoned calculation to a fierce courage born of heightened emotion... Strong leadership which earns the respect and trust of subordinates can limit the effects of fear. Leaders should develop unit cohesion and esprit and the self-confidence of individuals within the unit... (p. 15)

In order to help people develop the cohesion and esprit necessary to cope with fear, quality improvement efforts can make time and space for those involved in change to meet person to person; express and name their

frustration, confusion, and uncertainties; offer one another practical help, challenge, and encouragement; deal with emotional pressures to create false enemies or counterfeit saviors; and make sense enough of things to allow movement.

Self-confidence grows as people work together on the difficult problems of expanding the real opportunities available to people with disabilities. As the map through day services shows, this means fundamental change in the boundaries and the work of most established organizations. Unless quality improvement efforts reach past existing boundaries and beliefs, people will have limited chances to develop confidence.

Weak managers pretend that fear is not part of improving quality. Nothing about their work confuses or daunts them, things are predictable; they never need to reach out for support, they already have the answers. They delegate quality improvement techniques to subordinates within narrow and well defended boundaries. They refuse to move beyond slogans to engage in the emotional work necessary to change themselves and their own role and relationships so that they can meet new demands and realize new possibilities. They will have little authority when important change generates fear. Because they cannot face the effects of fear, quality improvement efforts under their authority will be superficial and dominated by fads and exhortations. In their artificially steady hands, quality improvement efforts will be too tame to matter.

### **Being good interpreters**

For at least three generations, engineers and manufacturers have struggled to formulate a body of theory and practice that will increase the reliability with which people and machines can design and make things that will interest and satisfy customers.\* The past ten years have seen these efforts move from

---

\* There are, of course, other applied disciplines for understanding and creating quality, including sociotechnical design (Trist & Murray, 1993) and Christopher Alexander's ( e.g. 1994) approach to

backstage in the factory into the spotlight of public attention. First, general managers of manufacturing companies, and then managers of services like airlines, financial institutions, and merchandisers sought competitive advantage by focusing on quality and appealing to the image of quality. Then politicians and public administrators looked to the discipline of quality improvement for some of the tools to reinvent government and for some of the justifications to legitimate their agenda.

How does the discipline of quality improvement help us find our way in the crooked map zone? There is hard won knowledge in the effort to improve manufacturing, but if people with developmental disabilities are to benefit from it, we must work hard to be good interpreters of theories and techniques developed and tested in a different economic context and on types of work that differ from the core work of supporting people to expand their opportunities in community life.

If we make our plans for quality improvement by copying diagrams, algorithms, and slogans from business best sellers, our efforts at quality improvement will, at best, be entertaining distractions, beside the point of relevant change. We will miss opportunities to thoughtfully consider the lessons learned through improving the quality of goods and services produced in much freer markets than the near mynopsomy\* that governs services for people with developmental

---

design, architecture, and building. These disciplines have an important contribution to make to improving services to people with disabilities, but they are not in nearly such good currency as ideas related to continual quality improvement.

\* A monopsony is a condition in which there is only one buyer for the product of a number of sellers. The frustrated service manager who interrupted a conference presentation by an expert in customer satisfaction caught this point, "You are from another planet. My customer isn't the person with a disability. My customer is the state." As fiscal crises deepen, even states that delegate purchasing to regionally based case managers exercise increasingly rigorous control over the agents who act as surrogate purchasers for people with disabilities –the current slogan misapplied to this form of rationing is "managed care". State experiments with vouchers and cash

disabilities. And we will miss opportunities to contribute to the discipline of quality improvement by inventing new ways to improve the real systems that influence the lives of people with disabilities and their communities.

Clearly, many human service system functions are similar to the work of manufacturing, and especially service, industries. Providing information on an organization's services, filling in forms and processing information, and dealing with billing are examples of important activities that, no doubt, can be significantly improved through processes that are similar whether the transactions relate to operating a catalog sales operation, or an ambulatory surgery center, or a case management service.

Some of the tasks of the established services that congregate and therapeutically control people fit the logic of routine service. Treating guests with fairness and courtesy and maintaining cleanliness and order might be systematically improved in similar ways whether one operates a hotel or a group home. Continual improvement in the accurate and efficient administration of prescribed treatments might follow the same procedures whether one manages a hospital or an ICF-MR.

But what about the case of supporting people to live successfully in their own homes? It seems an odd proposition to have the people whose help you need to make it through the day think that the way to improve quality is to learn to treat you as if you were a guest in your own home, or like the resident of a world class one bed treatment center. This is assuredly an improvement over being abused, or neglected, or controlled arbitrarily; but it is a different matter

---

transfers, while important for other reasons, are so small relative to overall expenditures that they have little effect on the shape of the service market. Interestingly in the case of people with developmental disabilities, the state monopolist not only controls demand, and thus has great influence on price, but can also dictate the details of the production of services, both through the exercise of police power (licensing) and through programmatic regulations imposed as a condition of purchase.

altogether than the possibilities that emerging supported living services demonstrate.

The task of interpretation grows more interesting when we consider how the discipline of quality improvement can contribute to our search in the crooked map zone. Especially when we explore that edge of the crooked map zone inscribed by emerging support services. Here the core work is assisting people with developmental disabilities to participate in community life as valued citizens. Consider what differences there are between this sort of work, and a broad class of important human activities that includes designing and making things, moving things and people, processing forms, administering routine medical and surgical treatments, and creating moments of delight for diners, hotel guests, or passengers.

One obvious difference is that when we work on improving the quality of supported employment and supported living we are working with exploratory efforts; not with stable systems whose range of outcomes has settled into a predictable pattern. This difference will decrease with time, but at least three important differences will remain:

- Many people with disabilities seem to come to life in new ways when service workers choose to develop and maintain relationships that communicate a clear sense of belief in the person's worth, a strong sense that the person can achieve things that matter, and an active willingness to work alongside the person. Usually, this kind of relationship grows over time, as people experience ups and downs together. It is less about defining and following and refining correct procedures than it is about living out a shared history that builds confidence and trust.
- The process of developing community support is the art of re-defining boundaries. Banks, landlords, employers, teachers, and community associations have drawn boundaries that leave people with developmental disabilities on the outside. And the experience of being on the outside creates

a mutual sense of unfamiliarity and ineptitude that makes the boundary stronger from either side. Artful service workers find ways to encourage the re-drawing of boundaries, so that people inside community settings make room for the participation and contribution of people with disabilities, and people with disabilities make room in their lives for participation in community life and relationships. This work is in-between, finding and shaping and repairing opportunities for connection and contribution. It's general outlines can be sketched, and maybe even reliably tracked, but the art finds expression in what can be made of the unpredictable details arising in each situation. At least at this point, it is much harder to imagine what the process of support would look like when it is "in statistical control" than it is to see the meaning of a control chart that plots the accuracy of inventory counts over time.

- It's hard to define the product and the customer and the producer in stable terms. The primary task of support services is to create many constellations of people with developmental disabilities, support workers, and community members who co-produce mutually valuable experiences. Think of a worker with a developmental disability, a co-worker, and a job coach collaborating to refine a job to even better accommodate the worker's disability and thus increase the worker's contribution. It is hard to decide who is the customer and who is the producer; it is more fruitful to see a constellation of people creating value for and with each other, both throughout the economic contribution their work makes and through the benefits of their relationships with one another (Normann & Ramírez, 1994).

There is some danger in minimizing these differences out of hand. Saying, as a quality improvement enthusiast did in keynoting a recent conference, "Quality is quality. Service is service. Why should we human service workers be so precious. Whether you're selling shoes to shoppers or selling people with disabilities to employers, the same tools will work to make improvements." The danger is that our efforts to improve quality might thoughtlessly encourage forms of service that treat people with disabilities as if they were objects to be

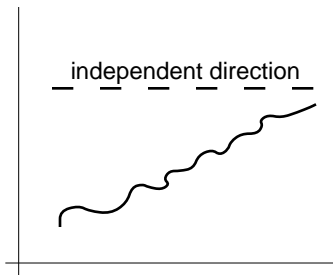
shaped according to a blueprint, moved, stored, processed, and marketed; or as if they were patients, experiencing life as an endless series of routine treatments; or as if they were temporary guests, enjoying endless episodes of delightful service on a plane that they can never get off, and from which their cheerily impersonal attendants can only escape by quitting their jobs.

As an exercise in interpretation, we can look at an important issue in an emerging support service through the lens of an important idea from the discipline of quality improvement. The first results of such a look might horrify an experienced practitioner of quality improvement. “That is not it at all,” she might say. So much the better, because the mistake will clarify understanding in terms of important work in support services, instead of keeping the concept in more abstract and analogous terms.

According to Deming (1993), knowledge about variation, its sources and its messages, is one of the four related parts of a system of profound knowledge necessary for improving quality. “Life is variation.” he says, “Variation there will always be, between people, in output, in service, in product. What is the variation trying to tell us about a process, and about the people that work in it?” (p 101). He then goes on to make important distinctions between special causes and common causes of deviation and between stable (i.e. predictable) and unstable states in a system. These distinctions are based on the image of a control chart, an array of data that displays variation in discrete events over time.

A group of people involved in the Oregon Supported Living Network gathered to help one of their members deal better with a significant quality problem: the turn over of live-in companions. While all of the stakeholders involved in the program are highly satisfied with it over all, each is concerned about turnover among these key people. The program is small, supporting 18 people in 16 households. Nevertheless, analysis revealed at least six apparently different sources of variation related to staff turnover.

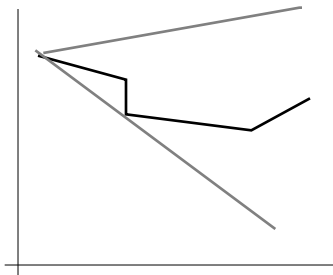
Following are brief summaries of the four sources of variation that originate with the person with a developmental disability. The graphics are not attempts at control charts, they are simply a notional representation of the way the variation manifests over time. For example, in this program, people’s capacity to direct and supervise their assistants was extremely low at first. But everyone has increased this capacity gradually, usually in a way that combines small changes with periods most people described as “bumpy”: periods of relative stability followed by jumps that surprise both the person and the live-in assistant. Companions who match well with a person who has little to say about how they do their work often have considerable difficulty as people become more assertive. This is one of the reasons that several companions reported leaving.



**Individual capacity to direct**

- For most people, will increase gradually, with experiences that develop confidence and skill.
- For many people, will not increase enough to allow complete independence

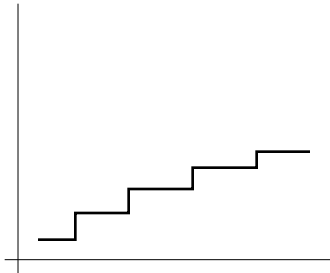
Offer mentoring, training, & support



**Individual need for assistance**

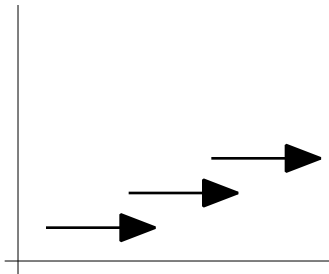
- Difficult to predict
- Varies within relatively wide limits.
- Can shift suddenly (e.g. decrease, if a person becomes able to stay overnight without paid help, or increase if a person has an accident.

Maintain flexibility



### Individual preferences

- Change occasionally as people experiment, or get bored and want a change.
- May require careful listening and observation or responses to changes.
- Expression is often much stronger in good relationships.
- Listen & observe
- Invite people to try new things.
- Adjust & check



### Individual sense of future

- For some people, new ideas about a desirable future call for new kinds of basic support (e.g. marriage or deciding to live without overnight staff, or desiring to buy a house).
- May take time and negotiation with person, family, program funders.

Redesign

Note that each of these sources of variation are intended, positive results of the program, which also play an important part in increasing turn-over. Increased independence in directing necessary help, matching amounts and kinds of support to changing need for assistance, supporting greater choice in daily activities, and encouraging a new sense of a desirable future are all reasons to provide a supported living program. In a sense, the intended result of supported living is greater variation, at least along these dimensions. A successful program will see difference increase, both for the same person over time and between the people the program serves. This supported living program is and wants to be a variety generator, a task that calls on them to continually increase personal and organizational flexibility and to increase the resiliency of their relationships.

In this case, discussion of the sources of variation led to a better understanding of the quality problem. Some turn over happens for reasons outside the relationship between the person with a developmental disability and

the companion, but much of it happens because of the way the relationship develops as the person with a developmental disability changes in desired ways. This understanding led to a different plan for quality improvement, including the development of ways to support open negotiation in changing relationships, ways to strengthen continuity of important relationships as turn-over happens, and ways to assist people who do not want the live-in companions at all.

So, while a control chart on the incidence of turn over is helpful, variation has even more to say in this situation. The concept of variation becomes more useful when practitioners invest attention in interpreting it from within the crooked map zone. There is every reason to think that the other foundations of quality improvement would be equally helpful as ways to make sense of the complex and changing situation of emerging services for people with developmental disabilities.

### **The Problem of Design**

To increase understanding of one of his seminal papers, Jay Forrester (1976), asked his students, “If we wanted to make the greatest difference in the overall performance of a supertanker, whose performance would we focus on?” Answers included: the captain, the team of ship’s officers, the crew, and the cook. In response, Forrester argued that the naval architect who designed the ship established its most important limits and possibilities. He said that organizational design is the neglected discipline in the search for better quality. By analogy with the tanker, the greatest leverage for improved quality in any organization is not within worker’s performance or within manager’s efforts to deal with the stream of daily problems, but in careful design and redesign of the organization itself. The paper he was teaching contends that common forms of business organization are fundamentally mismatched with the tasks required of them in a rapidly changing environment. Only a few organizations heard him.

Forrester's example of the supertanker resonates with Deming's (1993) repeated advocacy for a difficult idea. He said that the performance of a stable system cannot be materially improved by those working within the system. The performance of a stable system is the responsibility of those whose job it is to design and work on the system as a whole: it's management. That is why he believes that rewarding and punishing performers within the system, on the basis of different levels of performance is unfair, senseless, and wasteful. He noted ruefully that this is one of the most difficult ideas he tried to communicate to managers. Many managers seem more interested in abdicating responsibility for quality by blaming or praising workers, and delegating quality concerns to them, than they are in doing their own work by improving the design of the system as a whole.

Wolf Wolfensberger and Linda Glenn made a similar argument when they decided that *PASS 3* (1975), their instrument for measuring the extent to which a service follows the principle of normalization, would award the highest proportion of the possible score to the fit between the program's overall design and the most important needs of the people the program serves. This view of program design, called model coherency, looks at the harmony between the most important needs of the people who rely on a program and the interaction of five elements of the program: the overall model of service that the program embodies, the goals it pursues, the processes it adopts, the way it groups the people it serves, and the identity and competency of the workers who staff it.

Those of us who learned to see services through the lens of model coherency quickly faced a sobering lesson. Most programs were simply not designed in a way that was consistent with the goals they espoused. In those days, espoused goals commonly included maximizing individual potential, offering life conditions and experiences that were as close to normal as possible, and providing for social integration. In program after program, the issue was not poor performance of particular tasks that made sense in terms of these goals. The overriding issue was counterproductive design: groupings, settings,

methods, and staff roles and relationships structured as if to achieve the opposite of the program's stated goals.

A second lesson followed the first. Most programs were not designed at all; they were assembled like the plastic model warplanes boys used to glue together. Funds arrived with all the specifications attached. The job of managers was not to collaborate with families and local community members to plan a program that expressed a sense of place; the job of managers was to assemble the pieces as quickly as possible, with as much local involvement in fund raising as possible, and get on with doing good. In those days, managers of day centers and group homes learned as much about program design as did the managers of the MacDonald's hamburger stands that popped up at about the same rate and in about the same way. A system wide pattern of expecting someone else to do the thinking about program design was reinforced by wave after wave of train the trainers workshops aimed at teaching people "the model" solution to every problem. In such a climate, the only people who grow smarter and stronger at designing and redesigning services to better match a deepening understanding of the local situation of people with disabilities are those who do so at considerable personal effort and with low doses of external reward.

A third lesson followed the second. Discussing the issue of program design in a helpful way was very difficult. Once they got the idea of model coherency, people found it easy to see basic design problems in programs other than their own, but facing the re-design of one's own program was daunting. Defensiveness was high, and angry rejection of the entire process for unarticulated reasons was common. Some new programs –including some early supported living and supported employment projects– were designed with model coherency in mind, but reconstructing programs from the foundation seemed too heavy a burden to lift.

Today's common goals of independence, productivity, and inclusion have refined our sense of direction. But today's established programs were built with

the same templates, and the same disregard for the design task, as the programs that taught the difficult lesson of flawed design twenty years ago. Today, there is often greater regard for people's choices within program walls; activities and routines may be more engaging and less silly and childlike; and people may be better dressed and go on more outings. But typical programs still congregate, segregate, and control people by unconsidered design. Reform efforts are most likely to add on supported employment or supported living. Few reforms result in what some people aptly call conversion; that is, closing the activity center or the congregate residence and reinvesting fully in a program designed around the possibilities of the people in a particular place. The usual methods of quality improvement continue to better the ways people are congregated, segregated, and controlled. This is worthy work as long as people with disabilities are congregated, segregated, and controlled, but it won't contribute much to fundamental change. It does not raise the basic question of program design, "Can you get there from here, or do you have to start somewhere else?"

One of today's challenges is getting over the habits of passivity that lead service managers to avoid working on re-designing the systems in which they hold authority. The most important work to be done involves collaborating with people with disabilities, family members, and community members to shape and sustain a growing variety of opportunities and supports. It would be nice if this work could be done in a climate of widespread appreciation for human services and in a time of rapidly increasing budgets. But no matter how the wider environment may be, the importance of the work remains.

The highest leverage today is probably in the re-design of state service systems. In most states, enough positive things bubble up from the crooked map zone to clearly show the way that supports can and should develop. There are also enough large scale problems whose intractability could signal the defeat of the established way of organizing the system. A re-design process could outline the modest but important long term contribution the state level system can make

to better lives for people with developmental disabilities. But there are big economic stakes in the established system, and powerful people whose careers are stable within it. Many constituents have good reasons to fear that change would as likely be for the worse as for the better, and many politicians feel that they were promised a stable solution to the developmental disabilities problem some years ago. Room enough for some good things to grow can be found in even the most rigid state system. And so the time may not be ripe for state level change.

All over the world, people with developmental disabilities, and their families, and a remarkable number of ordinary community members have joined service staff who want to learn better ways to work. These constellations demonstrate unforeseen possibilities in the way real people are living and working and learning and recreating and otherwise contributing to civic life. Will they get lost in the crooked map zone, wandering in small bands, increasingly detached from the main body of service provision? Will their work lead the field out of the crooked map zone, and into a new period of common understanding and systematic improvement, based on a recognition of the importance of joining people with developmental disabilities to build more inclusive communities?

The answer to this cliff hanger lies in an episode of the serial that we have yet to write. Some people want to continue to go in two directions at once, stretching and distorting our common map still further. But Andrew Power has made up his mind about the future he wants to work for (personal communication, August 1993):

We don't know where the service managers and the staff will be. But we know where we'll be. We'll be fighting for our rights. As many of us as can get the help we need will be working in real jobs in the community and living in real homes that we have the key to. We'll help each other out with this as much as we can. We hope the system people will see the right way and come along and help too.

## References

- The Accreditation Council on Services for People with Disabilities (1994). *The quality consortium*. Landover, MD: The Council.
- The Accreditation Council on Services for People with Disabilities (1993). *Outcome based performance measures*. Landover, MD: The Council.
- Alexander, C. (1994). *A foreshadowing of 21st century art: The color and geometry of very early Turkish carpets*. New York: Oxford University Press.
- Bateson, G. (1972). *Steps to an ecology of mind*. New York: Ballantine Books.
- Bellamy, G. T. (1979). *Vocational habilitation of severely retarded adults*. Baltimore, MD: University Park Press.
- Bellamy, G.T., Rhodes, L., Wilcox, B., Albin, J., Mank, D., Boles, S., Horner, R., Collins, M., & Turner, J. (1984). Quality and equality in employment services for adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 9(4), 270-277.
- Blake, E., Prouty, R., & Lakin, C. (1995). *Reinventing quality (1995 edition)*. Minneapolis, MN: University of Minnesota, Center on Residential Services and Community Living, Institute on Community Integration (UAP).
- Braddock, D. (1994). New frontiers in mental retardation. *Mental Retardation*, 32, 6, p. 441-442.
- Bradley, V. (1990). Conceptual issues in quality assurance. In V. Bradley & H. Bersani, Eds. *Quality assurance for individuals with developmental disabilities: It's everybody's business*. Baltimore, MD: Paul Brookes Publishing Co., pp. 3-15.
- Bradley, V., Ashbaugh, J., Harder, P., Allard, M.A., Mulkern, V., & Stoddard, S. (1984). Assessing and enhancing the quality of

services: A guide for the human services field. Cambridge, MA: Human Services Research Institute.

Conroy, J. & Feinstein, C. (1990). A new way of thinking about quality. In V. Bradley & H. Bersani, Eds. Quality assurance for individuals with developmental disabilities: It's everybody's business. Baltimore, MD: Paul Brookes Publishing Co., pp. 263-278.

Deming, W.E. (1993). The new economics for industry, government, education. Cambridge, MA: MIT Center for Advanced Engineering Study.

Forrester, J.W. (1976). A new corporate design. In The collected papers of Jay W. Forrester, Cambridge, MA: Wright-Allen Press, pp. 93-109.

Gold, M. (1976). Task analysis of a complex assembly task by the retarded blind. *Exceptional Children*, 43, 78-84.

Gold, M. (1980). *Did I say that? Articles and commentary on the Try Another Way system*. Champaign, IL: Research Press Company.

Handy, C. (1994). *The empty raincoat: Making sense of the future*. London: Hutchinson.

Mank, D. (1994). The underachievement of supported employment: A call for reinvestment. *Journal of Disability Policy Studies*, 5 (2), 1-24.

Nonaka, I. (1991, November-December). The knowledge creating company. *Harvard Business Review*, 96-104.

Normann, R. & Ramírez, R. (1994). *Designing interactive strategy: From value chain to value constellation*. Chichester, England: JohnWiley & Sons.

- Obholzer, A. & Zagier-Roberts, V. (1994). *The unconscious at work: Individual and organizational stress in the human services*. London: Routledge.
- O'Brien, J. (1995). *Living-in: Summary of a learning group visit to Albertina Kerr Centers*. Lithonia, GA: Responsive Systems Associates.
- O'Brien, J., Poole, C., & Galloway, C. (1981). *Accomplishments in residential services*. Olympia, WA: Governors Council on Developmental Disabilities.
- O'Bryan, A. & O'Brien, J. (1995). *SEQA: Supported employment quality assurance*. Manchester, England: National Development Team for Services to People with Learning Disabilities.
- Schön, D. (1972). *Beyond the stable state*. New York: Norton.
- Taylor, S. (1988). Caught in the continuum . *Journal of the Association for Persons with Severe Handicaps*, 13(1), 45-53.
- Trist, E. & Murray, H. (1993). *The sociotechnical perspective. Volume II: The social engagement of social science, A Tavistock anthology*. Philadelphia, PA: The University of Pennsylvania Press.
- US Marine Corps (1994). *Warfighting*. New York: Doubleday Currency.
- Wehman, P. (1981). *Competitive employment: New horizons for severely disabled individuals*. Baltimore, MD: Paul Brookes Publishing.
- Wehman, P. & Kregel, J. (1995). *At the crossroads: Supported employment ten years later*. Richmond, VA: VCU Research & Training Center.
- Will, M. (1984). *Supported employment for adults with severe disabilities: An OSERS program initiative*. Washington, DC.: US Department of Education.
- Wolfensberger, W. & Glenn, L. (1975). *PASS 3*. Downsview, ON: National Institute on Mental Retardation.