

BEYOND ACCREDITATION: FIVE-STAR QUALITY

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Beyond Accreditation: Five Star Quality

We can clearly do better. Our “good” is not good enough...and our “wonderful” should move to “great.” For almost 60 years, we have been at this business, with government - sponsored money, trying to move people from being clients to citizens. Federally sponsored community services have been around since the 40's and 50's. We have spent billions and billions of dollars on programs to help people get outcomes that are often poorly measured, poorly defined, and mostly yield compliance rather than quality.

We believe that traditional disability systems can only bring people to three star quality. **No matter what we do, no matter what kind of staff we have, if it is disability system-based, it cannot achieve more than three star quality.** Three star quality is good. There is “really good,” “sort of good,” “pretty good,” but the adjective is still “good.”

There is a line, however, that delineates and differentiates level four and level five quality. **Four and five star quality can only be defined by the community - not by the disability system.** It is that line that distinguishes the journey that makes and helps people be better clients or allows people to practice citizenship, their birthright. Citizenship is not anything that we bestow upon people with disabilities. They have it as a result of their birthright.

Satisfaction surveys are not an indicator of quality. Historically, people with disabilities who have had very little choice, very little control, very little money, and very little experience report satisfaction with new services, if they offer something more than what they have had. In fact, most surveys report satisfaction upward of 90%. They are done at one point in time by telephone or mail and ask people with disabilities what they think about what providers do.

Surveys are about satisfaction. I believe we need to raise the bar. We need to ask ourselves whether we firmly believe that there are some universal human rights that people have as a result of their birthright. Even if satisfied, people should still have not only the opportunity but the responsibility as citizens to exercise these rights.

Demographic, historical, research, and census data say for anyone who wants to work in our field, whether in developmental disabilities or mental health, there are enough jobs for the next 25 years. That's the good news. However, here is the bad news. No one can be sure if the job will be with your current agency, with your current structure, or even with your job title.

We do not believe that our hardest days are behind us. We think our toughest days are ahead of us and, to paraphrase Dylan Thomas, we will not go gently into that good night.

Today we see an outdated skills set that many people in the field possess - CEO's, clinicians, case managers. If supervisors who do the hiring are looking to the future, some

of us would not be rehired for our own jobs. Some of us do not currently possess the skill set that would allow us to compete in the current and future marketplace.

Many people don't know yet how to define, much less achieve, four and five star quality. After being introduced to these concepts, people will say, "I get it now. I understand and embrace the 4 and 5 Star Quality template. **I just don't honestly have any idea how to do it!**"

Just because they are open to developing a different skill set doesn't mean that they know how to do something different than they are currently doing. We are talking about a discrete, learnable, teachable, observable, and replicable set of skills.

However, we cannot cross the bridge to the future with those who measure their success by how big the agency's name is on the marquee, how large the agency budget is, and whether staff are always prominent in people's lives.

This does not discount the importance of staff. In fact, we believe staff are more important than ever. We are going to need many staff with a skill set that transforms their roles to navigators, from pilots. If we didn't start as pilots, most staff, including me, got there quickly in our careers.

So the struggle, if we truly are going to embrace four and five star quality, changes the nexus, the lexis, the core, and the nucleus, of what current and future staff will need as skill sets. They may be able to describe how to do it and talk the talk, but may still be unable to walk the walk.

In this transformational activity, my definition of quality begins with some fundamentals. The journey is largely about the progress from three to five star quality, and what that requires in terms of personal and organizational transformation to achieve. The Five Star Quality chart (appended hereto) explains how these various elements interact and interface with each other in an understandable way.

Good to Great, by Jim Collins, has helped us to create a stepping off point for these concepts. This book should be required reading for everyone interested in personal and organizational transformation. In 2006, Collins made it even easier for the reader by publishing a supplement entitled Good to Great in the Social Sectors. He cautions the reader, however, that some of the principles in the book cannot universally be applied to the private sector.

Collins is a social researcher. His book was not written about our fields - developmental disabilities, mental health, and human services. He finds that many U.S. companies have achieved "good"ness but few are "great." In business, for example, money is both a necessary input and a desired output. Businesses need money as an input to stay in business. However, money is also an output, i.e. profit. A good company achieves success by making money, both as a return to stockholders and an instrument for company growth.

He studied hundreds of companies across the country and learned that a number of companies went from poor or mediocre to good. But he also observed that a vast majority of companies, no matter what they did, remained in the “good” category, but not “great.” Good, but not great. Whether they added a line of suppliers, started a new product line, hired a new CEO, had quality circles, etc., they remained only “good.”

It seemed that no matter what inputs they used, they kept getting the same output. He was curious about why some companies stay along the line of “good” and why there are some companies that are “great.” He found that there were some very specific transformational and ongoing actions that some companies undertook that moved them from “good” to “great.”

This concept resonated with me. We believe that we hit “good” in our field in about 1980. And we have been stuck there ever since.

One day we were discussing the fact that it is possible under one or more national accreditation systems to accredit an institution. We are talking about an institution in which people are separated from their brothers and sisters in society and absent from community for extended periods of time. We knew there had to be a better way. A way that defines quality on the basis of things that matter and challenge us to do more than what we have ever thought possible.

Mike Mayer (one of the authors) often uses a quote in his presentations that goes something like: “*If we only do what we have always done we and they will only get what we and they have always gotten – and that is not enough.*” If it was enough, we could follow a cook-book style recipe for quality and be done with it. He also ends many presentations with an exhortation to seek excellence. Excellence is elusive, but the closing he uses says:

Excellence can be attained if you...

Care more than others think is wise.

Risk more than others think is safe.

Dream more than others think is practical.

Expect more than others think is possible.

Our challenge is to figure out how to truly operationalize our desire to seek excellence for the people we say we care about. If you truly believe in citizenship for all persons with disabilities, we challenge you to explain how accrediting an institution can produce a “great” system.

We believe that a Supreme Court case ruled that “separate” can never be “equal.” We believe that unintentionally, unwittingly and with our whole hearts, minds and spirits, we have been marching towards “good.” We have said that for some of our brothers and sisters, this is the best we can hope for.

[Lest we appear to be a hopeless Pollyanna, we think there are people, given their behavior, history, our technology, and funding for whom we do not get an answer. We believe that there are people that have a lock for which we have not found a key. We believe for some individuals we don’t have the right match or the right supports. It has nothing to do with intent. It has to do with this thing called “life,” which is often messy, inconsistent, and unfulfilled.]

We need to continually ask this question: “**Is good our best?**” Are we willing to settle for what we have because of where we are?

We’re both pretty impatient people. Several months ago as Derrick was waiting for something to heat up in the microwave, he found myself wondering as it counted down from 20 seconds, “Can’t you go any faster?” The drive-through at McDonald’s seems to always have a long line. It is food, but it is not fast.

Twenty-five years ago, a supervisor called Derrick in for his first evaluation and said a number of nice things. Then he said, “Now I do have to tell you, I’ve been trying to think of some words to describe who you are, and I really find you to be a supersensitive malcontent.” As difficult as that was to hear, it made him think about why he behaved in a way that gave credence to this criticism. Derrick is a middle child. Middle children have this innate sense that it’s never good enough, that it’s unfair, that we can do better.

We know we can do better. And it has nothing to do with the good things we did before today. We are not going to accept our excuse that we are where we are because that’s all we know. The fact that we don’t know exactly what the future will hold does not mean that we should rush toward it rather than run away from it.

Here are simple, but profound, truths: **I know what I know and I know what I don’t know.** Those two things have gotten us in the past to operational thinking.

We see this often in new programs. Someone starts a new program and other people hear about the program. However, there is a delay between the time that the program started and other people embrace the concept. We’ve seen this with the group home system.

Group homes have been around for 40 years. Providers around the country still opening group homes. We understand why. If you define group homes as “wonderful,” according to the previous technology, then indeed there are “wonderful” group homes. We call this two star quality.

Some people that support people with disabilities in nursing homes or other segregated places, look at group homes as “wonderful” places given where the people they serve live.

We believe that modality is “platform thinking” or operational thinking. It leads to our jumping from here to there believing that “there” is a much better platform. And it is. However, the most dangerous thinking in our lives as professionals is this: **We don’t know what we don’t know and we don’t know that we don’t know it.** If we are moving to implement a technology based on the fact that it’s an improvement over what we’ve done, we have jumped to the platform.

Given that we’re on this platform, the questions should be: Should we be here? How much should we be on the platform or how little? Should we burn the platform? Should we give wings to the platform? These are strategic questions.

However, here is the difficulty: There are people invested in building a bigger platform. They include funders and providers. They also include some people supported by the system who believe that what they have is what they want. This works on the “satisfaction “ view of quality. As long as we attempt to define quality from the viewpoint of the disability system, the maximum it can ever be is three star quality.

We need to think about the fact that the future of our business may be dismantling the current platform one board at a time, as well as using some of the old lumber to build a different structure. We are not encouraging you to burn every board from the platform. There is still some good work happening there. Some of these nails can be reused. But the strategic question that must be asked continuously is: **“Is this the right platform?”**

Five Star Quality

In our evaluation of quality, there are five levels. If we are really about quality, we have to redefine our outcomes and start looking at 5 star quality. On the left side of the appended chart, below the line there are two boxes that contain the words, “Client” and “System”. Above the line on the left are two additional words, “Community” and “Citizen”. In the second column, start with **“ABSENT”** and go to **“OF”**. Each of these levels is accompanied by one to five stars.

If an individual with disabilities lives his/her life apart from society, his/her life can only and ever be one star quality. It doesn’t matter if the provider of services is accredited or gets all kinds of positive citations. If an individual is absent from community, that individual is also absent from citizenship.

This individual’s life has “one star quality.” In discussions with providers who are hoping to get their very nice residences (clearly still institutions) accredited, I say, “That’s OK.” However, it doesn’t matter if you’re accredited or not. This program can only be “one star quality” because the people who reside there are absent from community and from community relationships. This is unacceptable, and we need to say so.

“Two star quality” is a bit dicier. “Two star quality” programs are essentially mediocre. After almost 60 years, I believe we can do much better than mediocre even for people that are in the community.

For example, several years ago, Derrick was sitting at McDonald’s with a friend and a mini-van pulled up. The friend does not work in the field. Derrick turned to him and said, "It’s a group home". The friend asked how Derrick knew. He said, “I’m just telling you it’s a group home”. Four individuals and a staff person got out nicely and walked in. Two people sat down at a booth and two people accompanied the staff to the counter and ordered their food. One person ordered for himself. The staff paid for their food; they joined the others in the booth, ate quietly and left.

You say, “But families do this all the time.” That is true but we are willing to wager that if there was a video-camera in this restaurant that recorded the behavior of patrons for three years, it would document that every time these individuals go out, they perform the same ritual.

We would bet they would say that they don’t know anybody in their community. Eating in a restaurant in the community with staff is not good enough unless you measure that outcome as being the best we can achieve. This approach says that people will be in the community only as long as they are tethered to paid staff.

We think very highly of staff - We really value direct support staff and believe that the relationships that people with disabilities have with paid staff may be the most important relationships they have in their lives. But what we see too often are people entering the community in “the disability bubble.” The disability bubble describes the situation when all of an individual’s contacts are limited to either family or paid staff.

Therefore, even if that individual ventures into the community, is always in the company of paid staff and other individuals with disabilities, and makes no connection with other people in the community around him/her, that program can only attain two stars.

“Three star quality” is good. For example, an agency with whom I am familiar participates in its local festival each year. The agency has a booth at the festival with its name on the booth that is manned by paid staff, volunteers from the community, and individuals with disabilities. People with disabilities interact with people in the community in a typical integrated environment. These individuals have “three star” participation.

The reason it is only three star quality is that people with disabilities are participating as clients of a disability agency rather than members of the community. That is their identity. The agency’s name is on the marquee. Three stars is the highest level that the system can achieve. It is the highest level that traditional disability agencies can get to.

At a recent presentation Derrick did about Five-Star Quality a gentleman came up to him and said, "I have a story about Five-Star Quality." He proceeded to tell him that, at first, his organization was considering expanding its sheltered workshop. However, they reconsidered and recommitted themselves to the principles of supported employment and began to explore the idea of enclaves.

The organization had decided to buy an existing community business. He said that now people with disabilities would be integrated into the business. Derrick asked him a few questions. Whose name would be on the business? "The County Board," he answered. "Who would own the building?" Derrick asked. "The County Board," he answered.

Derrick had to then tell him that in that scenario the business could only ever achieve three star quality. He asked why and Derrick told him that if a generic community business, not disability specific, or the people with disabilities themselves owned the building, it could be four or five stars - but not if the County Board's name was on the marquee.

He protested and attempted to negotiate the proposal to four or five star. Derrick asked him to think about throughout the day. At the end of the day, he said, "You know what I realized? I had a lot of ego invested in saying that this was going to be **our** business. What I realize now is that it can't be our business, **it's has to be Jim's business and Susan's business and the community's business.**" He got it.

We are firm believers that part of this is about what we're willing to debate. What are we willing to say is truly the Holy Grail that we are searching for?

"Four star quality" could be described in this way. A provider who used to run the booth turns it over to a generic community agency who displays its own banner (e.g. Rotary, Elks Club, Humane Society, etc.) over the booth. The booth is still manned by people with disabilities, volunteers, and some staff, but the booth is under the umbrella of a non-disability agency. What separates three and four star quality is, frankly, whose name is on the marquee. Who owns the business?

There aren't that many five star hotels, restaurants or other businesses that merit five stars. Five star quality is something that is pretty rare and it may take a long time to achieve. We believe it could take us ten years or even longer to transform the system, but what we measure is not system quality but individual quality. Because this looks at individual outcomes, it doesn't look at programs. In this way of looking at quality, we don't accredit a program and label it a "program of quality". What makes something truly five star quality is when it is owned by the community, not the disability community.

For example, an agency that runs supported employment programs does some really creative things - micro-enterprises, etc. Jim, a person with disabilities works at a local supermarket and is supported by Bill, his job coach. One day the manager of the supermarket called the agency and said to the director, "Don't send Bill anymore."

Immediately the agency director got defensive, and offered an apology of sorts, “I’m really sorry, you know we can replace Bill with another staff.”

The supermarket manager responded, “No, no, no. We don’t want another staff.”

“But you know Jim needs some support?”

“Oh, we know. We have a weekly staff meeting and Jim is there with everybody else and we recognize that he is one of us. What we want you to do is stop sending your job coach and we’d like for you to pay us \$3 more an hour. We’re going to give \$3 to one of our employees who is going to provide support to Jim.”

That is five star quality, because the community claimed Jim. The community claimed him and determined what sort of support they needed. We can never be five star quality when our names are on the marquee. What we can do is to have the flexibility, the interest, the drive, and the passion to be able to figure out a way to get that supermarket an extra \$3 an hour - to figure out how not to run it through DVR or BVR who might not get back to us in three to six months.

We are in uncharted territory myself when we get into this four and five star discussion. We want to be as clear as we can that we not only are not there, we don’t even understand the full implications of what this means. What we have found most interesting is that very few people disagree about the principles of five star quality - **at least, and until, they comprehend what the implications are.**

The highest we have achieved within the Disability system is three star quality. We find that self-acknowledgement is incredibly powerful because it’s the first step toward getting it. Initially we thought that we would have a lot of argument about what four to five star quality is, and whether or not the system part of it can ever get to four or five star.

Here is the ultimate challenge for us: if you embrace four and five star quality, it redefines our success. It says that there is a different outcome.

Ten years ago, Derrick gave a talk to a group of parents (whose ages ranged from 60-80 years) in southern Ohio at their annual dinner. These parents were involved in the local ARC. There are roughly 100 families in the audience.

These are the parents upon whose shoulders we stood as we helped craft the community system. These are the parents who started services in each other’s living rooms and church basements. It started without any public funding. It started because of their passion about their child.

You’ve met these parents, you know these parents. Immediately after the talk, three hands shot up. What do you think the first question was from the mother of a person with a disability?

First question, **“Derrick this is all well and good, can you please tell me what I am supposed to do about my daughter after I’m gone?”** A mom who is 86 years old told Derrick not more than three months ago that she prays every day that her daughter, Barbie, dies before her, but she wants it to be just a minute before her own death. She said, “I cannot bear the thought of my being in the world without my Barbie and I can’t bear the thought of her being in the world without me.”

Can you imagine? Can you for a minute imagine a parent who at that age is getting out of bed every day to take care of someone she loves – not to play golf or take a walk or go out to breakfast? This mom and hundreds of thousands like her can think only of their child and worry about what his/her life will be without the them.

So Derrick asked the group a question which had never asked this question before and wasn’t part of my planned remarks.

“How many of you here can think of at least one person, just one, in your kid’s life who cares about them, who is not a family member, and is not paid to be with them? How many of you gathered here can think of just one, not five, not six, not ten, not even two - just one, who you know cares about him or her and you can put your head on the pillow confident that that person could step up if anything happened to you?”

Out of the audience of 100 families, how many raised their hands? Six. Six hands went up representing those who knew of someone outside family and staff who cared about their child.

That reality should impact all of us profoundly. At that point we have been in the field for almost 25 years and that we’d been talking up these things called “Community Inclusion, Friends, and Natural Supports?” Derrick’s audience was made up of families that started this system and sacrificed much of their own lives for their children. These were people who hadn’t had vacations in 30 years, who showed up at every staffing and desperately loved their children - and yet in the waning years of their lives, most of them cannot think of even **one** person that they can count on.

There is no program, no budget, no service, and no outcome that is more important than how we can assist people with disabilities and their families to connect with one person. We need to find just one person who is not a family member and not paid to be with them who would care about them. That is our challenge in four and five star quality. That is, as far as we’re concerned, the Holy Grail.

Our redefinition of “community” is based upon a concept that we learned in a philosophy class - **a necessary, but not sufficient condition.** Community is a necessary, but not sufficient condition for quality. In other words, just having people with disabilities in the community does not guarantee quality or that anyone will care about them, or that they’re going to have a great life.

But the Declaration of Independence guarantees life, liberty, and the **pursuit** of happiness. There is a no constitutional or preordained right to be happy. We have only the right to **pursue** that happiness. This means that the wonderful, important, new, exciting, and frustrating tasks that we as agencies and staff need to perform are how we help people pursue happiness one person at a time and measure our success differently.

“Are you saying it’s not quality if somebody’s friends are all just other people with disabilities?” Our answer is no, with a caveat. If someone is able to explore, experience the breadth of community and bump into many people with whom they have the opportunity to interact and their core contacts remain other people with disabilities, our response is very different than if somebody lives, eats, sleeps, plays, worships only with others with disabilities.

The first part of the sentence above reflects choice, the last part convenience. Once you understand that necessary condition of community, then the sufficient piece is: **community is no longer the places you go, it is the people you know.** We often talk about outcomes as “our people went here; our people are so busy; and our people are always out.” If the places they go are only with paid staff, that can never be more than three star quality at the most, no matter what we do within the disability system and the disability bubble.

We need to ask, “How many people that are not paid to be with him/her does he/she get to bump into in a given week?” To measure this, I use a tool known as “**BICE,**” Bumping Into Community Experiences.

We know we’re into outcomes. We believe in outcome funding and think outcomes must be measured. We think one of the performance expectations on which staff should be evaluated is this: **How many people have you helped this person bump into in the community?** Staff should be expected to document each month the number of people in the community they helped an individual bump into. It doesn’t matter if the person was liked, disliked, how long the conversation was, or how the community member responded. It doesn’t matter where they went.

Let’s define “bumping into.” “Bumping into” is what happens at the laundromat, at 7-11, at church, in the supermarket check-out line, at the post office, etc. It’s simply tabulating and we are very good at tabulating.

“Bump into” means the individual had at least a one sentence conversation with someone in the community. For example, the individual might say to the supermarket clerk, “Thank you for the change. How are you doing today?” It’s not about measuring friendship as an outcome. We have a personal struggle with the outcome that says people have friends.

To explain: Have you ever wanted to be somebody’s friend and they didn’t want to be yours? Did you ever feel attracted to someone, wanted to be in their presence and they

blew you off? Conversely, have you ever known someone who wants to be in your presence and you are not interested? ”What are you doing this weekend?” they might ask. “Oh, I’m watching the paint dry,” you might answer trying to discourage the attention. “Then how about tomorrow?” “Oh, I forgot, I haven’t lined up my sock drawer.”

And then there are other people. Derrick and Mike met twenty years ago and we became instant friends. At one point during that time, we did not see each other for four plus years. Subsequently, we ran into each other at a conference and picked up exactly where we left off.

It is chemistry and you know it when it happens. That is why I am not into measuring how many friends someone has. If friendship happens, it happens. But what I do know is that the more people I bump into; the more likely it is that I am going to make a connection which may lead to having a friend.

In our lives we’ve been incredibly blessed. Because of the nature of our work, as well as just having opportunities day to day to meet people in our homes, our neighborhoods, our churches, our communities, we bump into a lot of people.

If one of us gives a daylong presentation to 100 people throughout the course of the day, we may talk to 25 of them. That’s what we call Bumping into Community Experiences (BICE). If we meet 25, perhaps 5 might become acquaintances and maybe one or more of those relationships could blossom into friendship. Maybe not. The quality is not in making the friends or not, **it is in the opportunity to make friends**. That is what we need to measure.

Twenty-five years ago at a crowded conference keynote by Lou Brown. Lou is a special educator turned radical. Lou came out entirely dressed in black with an overhead and screen. You couldn’t see him onstage and it was a bit intimidating...scary...a bit like the scarecrow might have felt when he first met the Wizard of OZ.

He talked about quality and said, “The system measures quality in the wrong way. I’m going to give you a very simple way to measure the quality of somebody’s life.” Of course, we all got out our pens and papers because the great and wonderful Wizard was getting ready to speak.

This is what he said, “**You can measure the quality of somebody’s life by the number of rooms they are in on a given day.**” He stopped. We were all puzzled. Rooms? Did he literally mean “rooms”? Then it “hit”.

We need to find rooms. A car ride with a friend is a room, going out to dinner is a room, going to 7-11 is a room, getting your Starbuck’s, etc. A room implies an interaction.

We believe this system is broken. And we am not sure it is worth fixing. We don’t know if the system can fix itself and, even if the system can, it can never get us there anyway, if you buy the concept of four and five star quality.

The disability system is not going to get us to four and five star quality. This means we need to decide whether we embrace or run from this challenge. Select one person with a disability that you know and like. Picture in your mind the name and the face of this person. Now picture that person in terms of one, two, three, four, or five star quality? Ask yourself, “Where does this person fall on that scale?”

If he or she is at 2 or 3 Star quality, what do we do? Where do we start. In such a big system, we serve and support so many people. Can we transform it all at once? Is it fair or ethical to offer some 4 and 5 Star quality, but not all?

In platform thinking we assume we have to do it all at once. It must be big and we must announce that we are doing it. We make major policy changes and everyone needs to buy in.

We no longer believe that. As a matter of fact, We’ve seen that, in some systems, the more we announce what we’re doing, the greater the resistance. It has become clear to us that, in any system, we just need to figure out how to affect one to four people at the start. The number cannot be less than one, but it doesn’t matter if it’s one, two, three or four. Overachievers always pick five.

Once you’ve identified the person or persons, we need to be in sync with the values that will drive our journey to four or five star quality. We will not compromise on this one person or these four.

Next we need to find a core group that care about this person and are willing to embark on an uncharted journey. The difference between quality and compliance is manifest in the journey that the person will take.

In St. Louis a core group is working with individuals who have been institutionalized from three months to 44 years. The project is called, “One Person, One Wish.” We have gone into this institution and asked people who have been marginalized and excluded a simple question. **What is one wish that you’ve had in your life that you’ve never had a chance to fulfill?** Just one thing. We do not promise them friendships or that we can move them to the community. To do that would be to set them up.

We can unintentionally and unwittingly set people up. Tom Nerney taught us that most person-centered planning is actually person-centered *torture*. When we sit with individuals and dream wonderful dreams then they go back to a setting in which they have no power, no influence, no control, we’re setting them up.

We refuse to be part of a system of planning with people who are not really serious about it. Call it something else. Meet the minimum requirements, but do not tell me that you’re doing person-centered planning if the person with disabilities is not truly at the core.

People think that there must be a true believer. Not really. As a matter of fact, when we work with people on self-determination issues, we don't care whether they believe in it. The question is "what are we going to do from here?"

So the core group simply has to **have the outcome be the process**. That is a tough row to hoe for outcome people. The question is if the person tells us they want something, are we willing to try? **I don't know how to guarantee success, but I do know how to guarantee opportunity.**

Pam is a woman who has lived at an institution for the better part of 25 to 30 years. For those of us in developmental disabilities, you've seen others with Pam's diagnosis: profoundly MR, seizure disorder, hyper-extended tongue, blind.

In the early 70's, Derrick worked at a state institution for five years. He was (and still is) constantly amazed at how some places that are already the most restrictive setting can become even more restrictive. Some staff still don't get it. People don't know what they don't know and don't know that they don't know it. They may be good staff. These may be really good staff. They show up everyday, work hard and some actually care about Pam. They are as much prisoners of their own environments as is Pam.

Pam's entire life for the last 22 years has been spent in a one-story building the size of a very large conference room. She lives in a room with two other women with curtains separating the beds. That is her life.

There's only so much you can do in that environment. She goes from that corner into this corner where she has breakfast in the dining hall with the other people who live in this building. After she finishes breakfast, she goes over to another corner where she begins her day program. That is her life.

She has been off grounds only once in the last 11 years. **Even if the institution gets accredited, in our star quality system it cannot merit more than one star because she is absent from citizenship.**

How do we get her connected? How do we find out what she likes? How do we communicate with her? The key is to find someone who has good social skills.

This is particularly true in the case of staff. Some people just get it. You know it when you see it. These are the people who will get us to 4 and 5 Star quality. They get it because they have redefined success. Success is not about them. It isn't just **their** connection with the person. It isn't good enough for them to take the person into the community. It is about being able to connect others.

They get that it is about something much different. **Success is about the opportunity to connect the person with someone else** - someone in the community, someone who is not paid to be with the person. And finally, they understand that the most powerful way that we connect citizens in the community with the people we serve is **to ask them**. Ask

them to be involved - not to “volunteer” or just spend time with the person. Ask the community member to do something specific that the person with a disability wishes to do.

It might be helpful to find someone in the community who is interested in the same thing as the person with the disability. And then we bring them together. We need staff who are good at this. We need people who get it.

John is like that. He finds out amazing things about people. Now Pam is blind, supposedly retarded, and in less than a half hour, John finds out that she loves jazz! And not only does she love jazz; but she hates country music (which is somewhat easy to figure out if you like jazz).

In just a few visits, John connected with Pam: One Person, One Wish. It doesn't always happen that way, but with the right people, like John, it is more likely to happen sooner.

It would be setting Pam up to tell her that we will be moving her into the community soon. Budgetary issues and all the other usual obstacles will not allow it to happen quickly. It's going to take a long time. It really is.

Pam has never heard jazz live but she listens to it on her stereo through headphones. If you know anything about jazz, you know that you can listen to jazz on a CD, but there is nothing like hearing it live. Let's try to determine where Pam, her love of jazz and our ability to create opportunity fall on the 1-5 star scale.

What would one star quality be? Allowing Pam to listen to jazz. Staff would make a special effort, at certain times of the day, to let Pam choose the music she wishes to listen to through her headphones. Another option would be have jazz playing in the background for several hours of the day, which would make it immediately accessible to her. These options respect her wants, but essentially give in to the environment and say it is what it is.

What would two star quality be? Bringing in a jazz band or perhaps a trumpet player so that Pam could hear some live music. This happens in institutions all over the country – they bring the community in. So Pam did get to hear jazz live but only in her one star environment.

What would a three star quality be? Staff taking Pam to hear live jazz in the community. The key is who is taking her. If paid staff take her, she is in the community but not *of* it. **This can never be more than three stars.** This choice is good because we've permitted a staff member to take Pam into the community to experience a desirable activity that community members enjoy routinely. Is Pam participating in the community? Yes. Is she experiencing something in a natural environment? Yes. Is it likely that she will talk to other people while at the club? Yes. This is three stars and good quality.

But how do we get to four or five star quality? We will only make ourselves crazy if we spend a lot of time debating, discussing and arguing the difference between four and five stars. Don't split hairs about what is four and five stars. Let's get to four stars, then fine tune and afterwards debate whether it is four or five star quality.

The real bridge to cross is between three and four stars. We are a long way from being able to argue if an activity or choice made is four or possibly five stars? Let's have those debates down the road. The essential line of demarcation is between three and four.

So in order for Pam's experience to be four or five star, what needs to happen? Four and five star quality exists only when a person with a disability experiences community with another community member who is not paid to be with him or her. Pure and simple. **Four and five star quality only exists when we in the disability community become invisible supports.** Our job is to make sure that the needed supports are visible but we are in the background. Our name and the agency's name is off the marquee.

Drill deeper, but think simpler. The idea that we need to get people connected is not new. We have talked about that forever. However, this is a new platform for me. I finally figured this out along with some people I really care about.

The success of four and five star quality has nothing to do with Pam. It has everything to do with something that we have known for a long time and whose roots go back to fundraising. Do you know that in this country the number one reason people give? The number one reason that people in this country give money is not because of guilt. It's not just because of passion for the project. It's **because somebody asked them.**

That is the number one reason. Poor people give a larger percentage of their income than those who are rich. It is not about financial means. We must integrate what we learned about BICE. Pam may need to bump into more than a hundred people to find someone who cares about her. I would venture that not many who drive along I-270 in St. Louis are thinking, "Oh, there's the Institution. I think I'd like to go visit Pam." It just isn't going to happen and most people don't even know about all the Pams who live in institutions.

We have known all this forever. We can do this one person at a time. This isn't about implementing a global vision or resolving major issues for people in institutions. This is not about Pam moving into a community right now.

This is about a woman who loves jazz that we want to have a four or five star experience. It can only be done in the community and with a companion who is not paid to be with her and is not a family member. When there are medical concerns, it doesn't mean that staff can't or shouldn't go along. What we say to the staff is, if you go along on this outing, no offense, but you probably won't be sitting with Pam.

How do we do this? In Pam's case, a group of five of us began brainstorming and asking if anyone present knew a jazz lover. Bev who was sitting at the table said, "I really love jazz. I didn't know that is what it's about." Derrick said, "Neither did we."

We didn't have a laundry list. We learned about Pam's wish because John listened. We asked Bev to tell us about jazz venues in St. Louis. She said, "The best place to see jazz that I know of is Jazz at the Bistro, because you can go in the afternoon or in the evening. And it's a smaller, intimate kind of setting as opposed to going to a big place like the Fox Theatre."

All of us were excited and asked her if she would be willing to take Pam to one event. "Sure", she responded without hesitation. And why do you think she said yes? Because we asked and she loves jazz.

What other reason did she have? She cares, but even that alone is not enough. She said yes because **somebody asked her!** Had she ever met Pam? No. All she had was Pam's description. What do you think she wanted to know as a community person? "What kind of jazz does she like?" was her first question.

Contrast this with the system questions we ask. What about liability? How will we transport her? What if she has an outburst? **The system often starts with obstacles; the community starts with opportunities.** We do have to address the questions of liability, transportation, etc., but the first thing the community member who loves jazz wants to know is what kind of jazz did Pam like to hear.

We are learning that the more prominent the interest becomes, the less pronounced the disability is. Bev is being connected with Pam not because she cares about people with disabilities but because she has a good heart and she loves jazz.

A concert is a perfect activity for these two because they can listen and enjoy. There is no need or place for long conversation. Pam has limited verbal skills. Going to dinner and sitting across a table could make for a long evening for a first encounter. They're going to a venue where there is some opportunity for discussion, but the focus ends up being their mutual love of jazz.

One concern about this outing that cannot be ignored is Pam's serious medical condition. She has to take medications at a certain time and also has to have a nurse available to her within two minutes. Despite Pam's desire to go, it would be irresponsible to have Bev take her into the community without ensuring that Pam's medical concerns could be managed.

This is where the thinking changes. We are focusing on a four or five star experience for Pam. We have found a community member who is ready, willing and able to satisfy a wish that Pam has expressed. Even better, this person appreciates and enjoys the same activity as Pam.

Here is the beauty of this: we don't have to try and find a staff member that loves jazz. If we can find a way to provide the wraparound supports she needs, we can make this a successful experience. Guess what. We know a woman in St. Louis who has attended other meetings as part of our transition team. She happens to be an RN and she also has a good heart.

Shortly thereafter, Derrick bumped into her and asked if he could speak with her. "Connie, I've got a little bit of an unusual situation for you. We are working with this woman, Pam, who would like to go to a jazz concert." She replied that she is not really into jazz.

I said, "You don't have to be! We just need someone who would be willing to spend probably two or three hours to go with Pam from the time she leaves the institution, through the concert and then back the institution. When she's at the concert, you can sit either in the car or if you want to go in, I'll buy your ticket."

With cell phones, she can be immediately available if needed whether she is in the venue or in the car. In this way we have built wraparound supports that respect and recognize the need for safety/security. As an RN, Connie is the invisible support that makes this connection possible.

In this way of thinking, diagnosis, readiness, severity of disability or location do not sabotage Pam's desire to hear live jazz. You do not have to completely transform your organization to do this right now with everybody.

It is about one person and one wish. Is it possible that Bev and Pam might not hit it off? Absolutely. Is it possible that this may be a one time only experience? Yes. We have not arranged for this to be a recurring activity. There is no expectation that this activity will be repeated regularly.

We cannot guarantee friendship as an outcome, we are only providing the opportunity. We need to change what we are measuring and what we call personal outcomes. Any personal outcome that does not involve being in and of the community with other than paid staff can only now and forever be a maximum of three stars. It's good but it can never be great.

One person, one wish. We are asking another person if he/she would be interested in partnering with an individual with disabilities for **one** experience. What could happen? What do we hope for?

That they will connect. And that Bev may decide to become involved in Pam's life. There are no guarantees. That is why the outcome has to be the experience, not the individual's reaction to it.

We've got to stop measuring and start looking at what the person told us. We have merely enabled a connection with no guarantees of friendship and that is the way we

begin this transformation. So the key here, in my mind, is actually more of an administrative one than it is about staff.

We are not saying that staff can't be friends with the individuals they support. We're not saying that staff shouldn't take people home. We're not saying that staff shouldn't take people to Disneyland. We're not saying we shouldn't keep doing everything we are doing. These are things for another debate at another time.

The point is, any of the above conditions are not good enough, if we really believe in four or five star quality. We need to raise the bar. Mutual interest is the beginning. We then have to find a venue that will raise the level of commonality and lower the disability. Staff must agree to provide invisible support. That is the redefinition. We don't want to diminish what staff is doing at all. Any activity that gives people with disabilities a valued experience is good.

We need to cross the Rubicon to get to the other side. The other side is asking the community. It's not volunteering. It's not in groups. It's not canned. It's not saying everybody is going to go here. It's trying to find out from each person what is his/her wish. It is only hard if we don't ask.

The march to four and five star quality begins with a single step and a change in direction. We must redefine our success. It means our names comes off the marquee and we move to the background.

Why? Because the system can only and forever offer people with disabilities a maximum of three star quality. No matter how many staff we hire, how much we do, it can only be three star quality.

That's not good enough. The bar is too low. If we are not up to raising the bar then we need to lower and step over it and get out of the way. People with disabilities deserve more than a good program, they deserve a life. We need to stop being pilots who are in charge and determine destinations. We need instead to be navigators who chart a course to reach a destination determined by the person with disabilities to a rich life.

This march from clienthood to citizenship is a journey. It will not happen overnight.

We need to start now.

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