

Ziyayushchie Vysoty (The Yawning Heights)

A critique of the disability service system by Amy Walker, Systems Change Activist, Illinois Voices

What do drawing “overlapping pencils”, trying to do 50 sit-ups in five minutes, cutting out a perfect circle along a black straight line, and trying to deal with a tight and unsupportive job market all have in common?

They’re all things I’ve had to do in the past, but never did very well—all because of “the system”. “The system” here refers to not only society as a whole, but especially the disability service system that helps people (or not) such as myself in Illinois. Before I critique and analyze the system any further, I’ll briefly explain this report’s title.

During the Soviet period in Russia, Alexander Zinoviev wrote a book called *The Yawning Heights*. Zinoviev did not like the Soviet system, even though the leaders of the time compared following it to climbing a mountain and reaching great heights. Zinoviev thought that these “heights” of the Soviet system were only illusions, appearing to be mountains but actually being yawning canyons that people fell into and were swallowed up. I believe the system is that way.

Why? The way I as a person with a disability see it, it has five foundational flaws:

1. The System is Primarily Based on the Medical Model of Disability

Okay. I know this heading sounds even more weird and technical than the actual title, but fear not! Even this has an easy-to-follow explanation applied to it. What is the “medical model”, or more exactly, “the medical model of disability”?

According to me, the “medical model” is a way of thinking and working that says *if you have a disability, then the best things for you are to be treated by professionals and work towards becoming as normal (read: non-disabled) as possible. If you can’t be cured, then through medical methods, you should at least try to be fixed.*

Don’t get me wrong. I’m eternally grateful for the walker, crutches, braces, and physical therapy I received through Shriners Hospital and other doctors as I grew up. Without these critical supports, I wouldn’t be able to walk and move as well as I do now (though that’s still very sub-par compared to “average” people)! I’m not saying therapy is bad in and of itself, or that no one should get any help if they have a disability. Rather, I’m saying some other “therapeutic” qualities are bad.

Like the quality that says, “I know you really hate this, but it’s for your own good.”

And one that says, “We know what’s best for you, so buck up and do it anyway.”

And, most of all, one that says, “If you work hard enough, you’ll be just like us!”

As a child, I could never understand the sinking feeling in the pit of my stomach whenever I went to physical (*time to try to do 50 sit-ups!*) or occupational (*time to cut out a circle along the black line and draw "overlapping pencils!"*) therapy. It was just *there*, fear-inducing and persistent, sometimes dull, sometimes not so dull. Now that I understand the true roots of this past fear of mine, perhaps I can finally "get over it".

I wish I could do more for the people who have this feeling and don't know why.

A system of helping us people with disabilities based on the "medical model" is bound to set us up for failure, not success. No matter how much therapy you give us or how many orthopedic and other supportive gadgets you create for us, our disabilities aren't going to go away. We aren't going to be considered completely "normal" in the eyes of the system until we get cured (by a miracle?) or until we get "fixed" (according to whose standards? Probably not our own). The goal of being "normal", for us, is not only unreachable but unrealistic as well. The biggest thing that's wrong with the "medical model" is that it treats our disabilities as burdens, illnesses and diseases rather than a natural part of our lives and the human experience. No one explains this better than Kathie Snow does on her fantastic, eye-opening, and brutally honest website, *Disability is Natural* (<http://www.disabilityisnatural.com>).

When people think you're sick and treat you like it, they will never be satisfied until you're "all better". I'm sorry, but we haven't "recovered" yet, and we will not.

That's why it's all the more important to base the system that supports us on a new way of thinking and a new model, which I'll explain a bit later. Right now, I'd like to explain what the medical model means in terms of dollars and cents.

The medical model is expensive, both in terms of money and lives affected. Did you know that in the words of Mary Johnson, author of *Make Them Go Away*, adult undergarments that could typically be purchased at your local grocery store for a cheaper price had to be bought and billed for in Medicaid under the name of "female urinary collection devices"? That fancy name (and medical label) upped the price.

Undergarments aren't the only expensive things that the medical model pays for. Institutions (which might be called "developmental centers", "state-operated developmental centers", or, for the less politically-correct among you, "state schools") are too. Illinois has nine of them, and the cost of supporting the people living in them is far higher than it would be if the people lived in the community instead. This doesn't even cover the cost of certification and re-certification by state and federal agencies every year or staff wages. I think it's a shame that support staff who work at institutions make fairly good money while community support staff clamor for more.

Why should someone who truly wants to help people with disabilities be forced to work at another job (even a fast-food or housekeeping job) just to be able to pay their bills?

If we close down institutions in Illinois, then the Medicaid money that funds them *must* go somewhere else, preferably to community providers and community support staff.

After the Howe Developmental Center was de-certified, I read about some family members complaining that their kinfolk received excellent care at Howe and could not get the services they needed, such as 24-hour medical care, in the community. Thus, Howe should be re-conformed to acceptable standards and re-certified.

My question was, "Why *can't* we have services like 24-hour medical care in community homes such as CILA's? If there were no institutions in Illinois, then the homes would *have* to provide those services because of client and family demand." I haven't gotten any good answers to this so far. (Hint: In this case, "funding" is a very bad answer.)

The ultimate evil of the medical model of disability (which I grew up unsuccessfully trying to please) is that it used to make me ask myself every day, "Am I normal yet?"

The second flaw of the disability service system in Illinois is as destructive as the first:

2. The System Does Not Treat its Clients as Full Equals and Partners

What is a "client"? When I used it earlier, I wanted "client" to mean shorthand for "a person with a disability who is served through 'the system'." In the unspoken rules of many human service agencies and the system itself, however, "client" means "someone with a disability for whom we care who is not equal to us in power, education, intelligence, or even what we call basic functional skills." Funny. That isn't what I meant at all when I used the word "client". What gives?

Maybe in the world of human services, training is to blame. The things that staff are taught in the classroom really do carry over to how they may behave on the job. Dave Hingsburger proves this point with retrospective horror in his book *i to I*:

"I got in this field through training; I took classes...called Mental Retardation 1 and Mental Retardation 2. We were shown a film in my first year that now sends shivers down my spine. It was a movie on syndromes. A doctor in a white coat stood and with a wooden pointer pointed to the naked bodies of people with different disabilities to show the camera and us how the various syndromes evidenced themselves on the bodies of these people. I remember the movie because I remember being slightly repulsed at the physicality of the film but also because we all sat there in that room and stifled giggles of embarrassment. Then I watched the movie and identified with the man in the coat; now I wonder about the naked person at the end of the pointer. This was not a demonstration of syndromes; this was a demonstration of power."

Who knows how many more support staff, like Dave, were trained in this school of thought? All of us as human beings, with and without disabilities, have the responsibility to challenge and change it. This is a massive part of the reason for Flaw #2.

The other part of the reason seems to have to do with “roles” and “boundaries” on the surface, but is actually about power—who and who should not have it.

WHAT GETS SAID: *“I work as a support staff member at this agency, and I have to keep my role clear. I’m not paid to be Client X’s friend, but to care for him or her as my client.” (Parents may say something like this in relation to their kids. Connection...?)*

WHAT THIS REALLY MEANS: *“Client X is not my equal. Client X is the person that I’m paid to support and care for. I have the power to do so and tell Client X what to do in order to make progress in his or her goals, but Client X cannot do the same to me.”*

WHAT GETS SAID: *“Client Y should not attend one of our official meetings.”*

WHAT THIS REALLY MEANS: *“Client Y won’t understand what’s going on/will have inappropriate behavior/will not give us meaningful feedback or relevant insight about our issues/all of the above, and thus does not deserve such power and responsibility.”*

WHAT GETS SAID: *“If we let people with disabilities know what’s really going on in the service system, they’ll freak, and then they won’t trust us to help them anymore!”*

Oops! That last one never gets said, or at least in my experience it doesn’t. What people in the system aren’t counting on is that some clients would feel better if they knew the truth about their services and wanted to help the people in the system *fix it*. Ignorance isn’t always bliss, and knowledge can mean power and freedom. Even though I’m sad because of what I know about the system, I’m also hopeful because at least I *know* and am not lost in a “protective” fog of “everything’s hunky-dory, so don’t you worry about a thing”. I consider myself lucky that the people around me believe I’m savvy enough to be “in the know” instead of “out of the loop” when it comes to the system. I wish the system would believe that about others with disabilities as well. Right now, however, it seems to settle for having the people it serves remain as “outsiders looking in”, if they look at all. I’m the exception, not the rule, in Illinois.

It may be *easier* this way, but it’s certainly not *better*. This relates to Flaw #3:

3. The System Continues and Perpetuates Itself through the Status Quo

In biology, living things reproduce more of their own kind. Cats have kittens. Trees produce seeds that will grow into new trees. Humans have children. This is perfectly logical and natural, and nature allows for adaptation and change. Over time, humans lost the need for their wisdom teeth, for example, and now some people are being born

without them (like my co-worker's daughter Hannah). Even though the system is not alive in the same sense that we and our pets are alive, it still has to "live" and "survive" in order to serve people with disabilities. Money must get sent from governments to agencies, staff must be paid, and services must be provided. However, unlike nature, the system does not readily allow for adaptation and change. At least in Illinois, it seems to perpetuate itself and survive more easily if things remain the way they are.

It's easier if professionals do all the "professional" work, for example, such as creating goals for people with disabilities to reach by law if they want to keep getting money for services. It's easier if staff write and implement Individual Program Plans (IPP's) in a way that they themselves understand, regardless if the person served does or not. It's easier if institutions remain open and group homes remain rather large. (Did I have eight to sixteen roommates in college? Nope. The maximum allowed was four in the "quad suites" at Illinois State University.) It's easier if the system continues to pay to support sheltered workshops and for some people who work in them to earn far less than \$5.15 per hour (and dream of making the minimum wage).

All these things are *easier*, but I do not believe for one second that they're *better*.

For example, would it really be better if Lincoln Developmental Center were re-opened under the less-Draconian moniker of "Lincoln Estates"? Somehow, I don't think so. We'd just be giving an old institution a new name, it seems to me. Besides, when I hear the word "estates", I think "luxury mansions", not "state facilities". Remember that song by The Who? "*Meet the new boss—same as the old boss,*" lament the lyrics to *Won't Be Fooled Again*. I hope that talk of re-opening the center under a new name is just that—talk, rumor, and speculation. If it's not, I wonder how committed we are to "progress".

Why is the system so afraid of change? Change is hard, and change is scary! I know this from personal experience. I was scared to move out on my own, but I did it anyway even though I knew I'd have to work hard to take care of my own bills, my own apartment, and my own cat, Sasha. I was also scared to try and go to college, but I did it anyway because it was my dream. (That doesn't mean I got a degree, necessarily, but I put a lot of work into the classes I did take.) I always try to adjust as best I can.

If being difficult and scary were the only obstacles preventing change, however, the system would have done it long ago because changing for the better is the right thing to do. The other two barriers to making positive change are power, as I've said before, and money. Power and money are hard to get, but far, *far* harder to share.

If we change from a "system-centered system" to a "people-centered system", that means bureaucrats who write goals for people with disabilities to reach by law are going to have to give up some power and let people with disabilities write their own goals that *they* want to reach. What legislator in power would want to do that? If we change the system, that means institutions are going to have to close if people with

disabilities do not want to live there. I bet the directors who run those institutions and the support staff who work there wouldn't go for that. If we change the system, that means group homes are going to have to be the size that the people who live there want them to be (which may not be 8 or 16 beds, but only 2 or 3). Who in power right now in the system wants to give that power up, even for the sake of people served?

The other barrier to change is money (or the lack of it), which constitutes Flaw #4:

4. In The System, Funding is Everything (But It Shouldn't Be)

I once wondered why people who were supported by the developmental disability service system were sometimes referred to as "slots" and "beds" and the like. To me, this seemed dehumanizing, not to mention callous and mechanical. Am I a "slot" to be filled in my place of employment? Am I a "bed" in my own apartment? Of course not. These terms are only used when people are given services *en masse* by the government, but I don't think they should be used even then. Do people who work for the Social Security Administration call Social Security recipients "checks"? Perhaps, but not likely. People *get* the checks, but they *aren't* the actual checks themselves. So why should we with disabilities be known as "slots" at our jobs and "beds" in our homes?

One of my mentors says the answer has to do with money. If slots and beds are filled, then the system (and people with disabilities) get funding for services. If not, then not (or not as much). So, oftentimes the system refers to the people that it serves by the mechanisms that provide money to support them. Is this fair? Not really. Respectful? Certainly not. Prevalent? Oh, yes. It happens every day.

Maybe I shouldn't be so surprised that I suspect the bottom line of the system, even a human-service system that supports people with disabilities, is money instead of people. After all, without money, how could we help any people? Still, when we consider dollars and cents to be a higher priority than the people who use them, service quality is sure to suffer in both big and small ways. And what about the "funding card"?

Not the "Medicaid card" or "Social Security card". Remember the O.J. Simpson trial? O.J.'s lawyers were accused of "playing the race card" in order to defend their client and win their criminal case. Just as "playing the race card" means using race as an excuse to dismiss the evidence and arguments of the "other side", "playing the funding card" means using lack of funding as an excuse not to do something that would be in the best interests of the people served in any given system (like this one). I've heard the "funding card" played a million times, and it's higher than an ace could ever be:

QUESTION

"Why can't we have better transportation?"

ANSWER

"There's not enough money."

"Why can't institution staff work in the community?" "They'll take big pay cuts."

"Why can't we have more choices in housing?" "There's no funding for it."

*"Why is there talk of imposing parental service fees?" "To get more funding."**

"Why are so many still on a waiting list for services?" "Where's the funding?"

Lack of funding for services and supports for people with disabilities is a critically important problem in Illinois right now. I'll grant the system that. However, more often than not, it seems to me like "funding" is used as an easy answer and an easy cop-out when it comes to explaining why we can't improve the system and how it works right now. It's like answering "Because!" to a small child's question. Sure, it may be an answer (and a way to quiet the child), but it's not a very satisfying one.

The system, I believe, will always want and need more money than it currently has, especially during its tough times here in Illinois. Jesus once said, "You will always have the poor among you, but you won't always have me". There will always be *some* lack of funding for the optimal services people like me want and need. What there won't always be is a variety of creative and innovative ideas to do more with the funding that the system already has. If the system spent more time thinking up and implementing these kinds of ideas and less time using funding as an excuse not to do anything about improving itself, the better off all of us would be, whether we have disabilities or not.

**Note: There was recently a presentation at one of our Illinois Statewide Advisory Council meetings about having parents (if they supposedly could) start paying for some of the services their children with disabilities received. This sounds fair on the surface, but the cut-off point for starting to co-pay for services is \$37,000 for a family of four. Especially with the high prices of gas and energy nowadays, \$37,000 isn't much. That means you can spend only \$9,250 per person per year, which is probably less in real life because it doesn't count mortgages and medical emergencies and things that everyone in the family needs. Sure, other states have gone this route, but if the other states jumped off a bridge, would Illinois join them? This is one bandwagon I hope we don't get on. To me, this is a subtle but insidious start toward shifting the cost of disability services from the State back onto the backs of people with disabilities and their families. Whether people with disabilities and families can pay is another matter.*

Human lives are precious in an intrinsic and innate sense, our "worth from birth". They are also expensive to support. However, when the disability service system puts most of its emphasis on the money and politics flowing in and out of it instead of the human lives that are at stake, then I'm likely to think the system views human lives as cheap.

If lives are indeed cheap and funding is indeed precious in the system as it is right now, then this leads to the condition present in its fifth and final flaw:

5. The System Is Both Too "Open" and Too "Closed"

According to William L. White (my supervisor's brother) in his book *Incest in the Organizational Family: The Ecology of Burnout in Closed Systems*, organizational systems lie on a continuum of being "open" and "closed", to varying degrees. "...Open-ended organizations," White says, "[are those] which struggle not for maintenance of the status quo, but for growth, change, and ongoing evolution of the organization (Clark, 1969)." In contrast, "closed organizational systems were characterized as reactive, homeostatic, defensive, and resistive of change (Allport, 1960)." The way I see it, the system that serves people with disabilities in Illinois is both too "open" and too "closed". Systems with these mixed characteristics need double the help.

The system is too "open" in that for the most part, the people "at the top" (the legislators, bureaucrats and directors running the system) are disengaged from the lives, concerns, and day-to-day struggles of the "people at the bottom" (case managers, direct support staff, and most importantly, the people served who have disabilities). One sure sign of this disengagement is when the system indirectly forces sexual offenders and their victims to live in the same group home because of a lack of resources and insufficient accountability on the part of the offender and justice system. There's no money for the offender and/or victim to live somewhere else, so one or both of them stay put. If the system were more connected to the lives of the people involved (and sufficiently outraged), it would resolve this problem quickly, "funding" be tossed to the wind. However, this kind of monstrously unfair situation still goes on today.

It seems to me that the bigger and more expansive any system is, the more disengaged it can become from its workers and clients as it tries to run and manage itself efficiently. When was the last time you contacted and received a response from a family member? Families are highly interpersonal systems. How about the last time you contacted and received a response from your mayor or a member of your city council (assuming you're not on it)? Finally, when was the last time you contacted and received a response from the President or other high official in the U.S. government? This progressive disengagement on the part of large systems may be perfectly natural, "the way things are", but what kind of a message is the system sending to people with disabilities when they (and I) feel like it doesn't care enough to deliver for *them*?

On the other hand, in its various departments and within its various agencies, the human service system that supports people with disabilities such as myself is much too "closed". A closed system is resistant to change and committed to perpetuating itself through the status quo, as I mentioned earlier (even though as a whole, the system is open to the point of disengagement from the people it serves.) Rules in a closed system are, for the most part, literal and inflexible. Everyone working and living within the system must conform to these rules, whether they be written, spoken, or part of the "unspoken language" and way of life in the system. An example of a written rule might be a policy or procedure in which those who live in CILA's and cannot give themselves

their own medicine must have a nurse or someone trained by a nurse go with them on outside trips. If this nurse or trained person can't go, then the CILA dweller must stay home. (In Illinois, this is a real policy and procedure that I'm yearning to abolish.) A spoken rule might be a "Shh!" or a "No!" or a "Stop that right now!" that a client hears whenever s/he seems to be having a "behavior". As for unspoken rules, I've personally seen that the system has its *own* system of what you must and must not say and do.

THE SYSTEM GAME!!!

DO

Use technical jargon when you speak and write

View clients as clients and yourself as an expert

Only focus on goals related to someone's diagnosis

Focus primarily on funding and how to get more

View disability as a burden and medical problem

Practice conformity to system rules in your ideas

Give feedback that the system wants to hear

Agree with proposed plans regardless if you really do

Only view feedback from professionals as valid

Act in the interests of money and system preservation

DON'T

Use plain language at work

View clients as experts too

Focus on a person's own goals

Focus primarily on service quality

View it as normal and natural

Think of creative/innovative ideas

Say what you really think and feel

"Rock the boat" or "make waves"

View client feedback that way

Act in the interests of fairness

Does anyone think the unspoken rules of the Illinois disability "service system game" need to be switched around just a tad? These are the rules of a closed system, and even a closed system that seems far removed from the everyday lives of its clients.

Now that I've laid down the five foundational flaws of the system in clear terms and examples, how do we resolve them? Complaining is easy, but real and workable answers are hard to come by. I'm still struggling with all of the issues I've mentioned. Changing a system, unlike changing a diaper or a worn-out part in a machine, takes lots of thought and years and years of work. I have five "solutions" to these foundational flaws in the system, but they can't and won't be put into place overnight or in only one step. I'll give examples of how this might be done, but again, think of your own ideas!

1. Base The System upon the Civil Rights Model of Disability

According to Advocating Change Together (ACT), a powerful self-advocacy group based out of Minnesota, *"The civil rights view of disability is the powerful idea that people with disabilities are regular people with the same civil rights as all other citizens. This is the idea that people with disabilities are a minority group in our society. In this view, the problem is not people with disabilities. We don't need to be fixed. Society has the problem—a problem with justice—and society needs to be fixed. Like other minority groups, people with disabilities are working together to demand and reclaim our civil and human rights."* (http://www.selfadvocacy.org/SARN/sarn_2007May9.htm).

This civil rights model, not the medical model, is what the system should be based on. After all, we are human beings first, and no system that looks at our disabilities first truly deserves the money we pay it. We want to be known and respected as people.

What does it look like when the system is based on the civil rights view of disability? I honestly don't know, because in Illinois, the "medical model" of supporting us still strongly prevails. I do have some ideas, though, about what I believe it *might* look like:

- People with disabilities feel respected in and valuable to the system.
- People with disabilities feel like equal partners in the process of systems change.
- People with disabilities feel like full equals with their peers and support staff.
- Support staff are respected, honored, supported and paid a fair, living wage.
- Creative and innovative ideas are sought out and put into place in a timely way.
- The system constantly challenges itself to be *better*, and not just *bigger*.
- People, and not funding or lack of it, are the main priority of the system.
- System rules are fair, logical, and flexible, assuring quality yet allowing change.
- Gross injustices are resolved with cooperation from all "system" people involved.
- No "turf wars" or "that's not my responsibility"—all departments work together.
- The system gives people with disabilities choice, freedom, and human dignity.
- The language in paperwork and "the system" is easy for everyone to understand.

I could go on for pages with more wishes for the Illinois disability service system, but I already *have* gone on for ten pages! With that, I present my Solution #2 to Flaw #2:

2. Have Clients In The System Act as Equal Partners With Its "Staff"

Remember when I referred to the "yawning heights" of the system in the first part of this report? There are actually canyons there, and these canyons are carved by the deep and wide gap in power between staff who run the system and the clients they serve. The only way I do not feel equal in power to my supervisor, for instance, is that she supervises me. In all other respects, I know and feel that we are equals in every sense. Unfortunately, I cannot say the same for my friends with disabilities at work.

I've seen someone with a disability falsely accused by staff (in front of a whole cafeteria, or at least me, in a noticeably loud tone) of stealing someone else's lunch when she was only trying to retrieve a sandwich the other person was throwing away.

I've seen someone else being lectured by two staff (in the cafeteria hallway, where other people could hear) about playing a Game Boy during developmental training class. That was a mistake, but if I were in that person's shoes, I'd prefer to be "chewed out" in private. One passer-by even repeated a comment the person being lectured made while trying to defend himself. I felt embarrassed and skittered out of sight.

Most of all, in terms of the system, I've seen people with disabilities stared at and talked down when they wanted to speak and make suggestions and comments at some of our Illinois Statewide Advisory Council meetings. I'm sure staff did this only because they were afraid that the people with disabilities they supervised (notice I did not say "supported") might say something off-topic by mistake, but how are people to overcome their own fear of public speaking if they know staff are afraid for them, too?

These three situations are symptomatic proof that a power difference still exists between clients and "staff" in the disability service system, and the difference is huge.

When I go to official meetings and conferences, such as the Statewide Advisory Council, or even if I'm a presenter at another one, I try my sincere hardest to change some attitudes along with my fellow self-advocates. Note to "staff": Just because we have disabilities, developmental or otherwise, doesn't mean we aren't paying attention and can't understand what's going on in the system. It doesn't mean that we're bored or that we don't or won't care about system issues; it simply means that we may not understand all of the long and technical words you use when you talk about them. Most of all, it doesn't mean we don't have a voice, just that we want the chance to use it.

What are some ways in which the system can treat clients and "staff" as equals?

- Invite people with disabilities to participate in private "back-room and boardroom" meetings where decisions get made within the system that the general public doesn't get to hear about until after the fact. Knowledge is power.
- Tell people with disabilities the truth about the system and their services.
- Always seek out "client" input before making new "system" or government rules.
- Reimburse for transportation to public meetings if clients can't get there alone.
- Give out handouts at official meetings that are easy for everyone to understand.
- Use clear and easy-to-understand language when speaking of "system issues".
- Focus on encouraging people to speak instead of chiding them for their mistakes.
- Avoid the "Surrogate Parent Trap". Sure, staff may feel that they're not paid to be Client X or Y's "friend", but they're not paid to be parental replacements, either. What if the word "comrade" or "colleague" were substituted for "friend?"
- Most of all, treat people with disabilities as you would any other "staff" member.

Remember when I said easy answers were hard to find? Same with Solution #3:

3. Rebuild & Recreate The System so it Encourages and Adapts to Change

This is more than a tall order. I think that perhaps building the Sears Tower from the ground up was an easier task than rebuilding and recreating our disability service system will be. For starters, the design of a building relies upon up-to-date architectural logic and what will be best for the people who'll be using the building. The design of our present service system relies on an outdated "medical model" of disability and deep-rooted assumptions and attitudes about what people with disabilities can, should, cannot, and should not do. Logic and common sense aren't always the law of the land.

Now for a hard truth: In order to re-build anything, it first must break. We as people with disabilities have admitted that many times, the system doesn't serve us as well as we would like it to. It's time for the rest of Illinois, especially the managers, directors, and legislators running the system, to admit that as well. Our system breathes, but it's *broken*. It functions and helps us to function, but we want to do more than that. We want to thrive. It's time to break our pride and confess the system needs a new start.

After we do that, we need to take a hard look at all of our "system rules" and ask:

- "Does this rule make sense in the 21st century on a logical and a 'gut' level?"
- "Whom/what is this rule protecting? Does it really guarantee his/her/its safety?"
- "Is following this rule worth restricting the freedom of people served?"
- "What is the rationale (reasoning) behind this rule besides, 'That's the rule'?"
- "What choices do people served and their staff and families have in this rule?"
- "Is anybody making a big profit because of this rule, and it only benefits *them*?"
- "Can we adapt this rule as the needs of our clients and system needs change?"
- "Is this rule really about protecting political interests and not clients' well-being?"
- "Will we listen and value the input of people who disagree with this rule?"
- "Does this rule *have* to be written in language the average person doesn't get?"
- "Is this rule fair? To whom? Staff? Clients? Directors of agencies? Politicians?"
- "How does this rule protect the dignity, freedom, human rights, and choices of the people with disabilities that we serve?" (If the rule does not, then is it fair?)

Of course, if we ask ourselves these questions as people with disabilities and members of the system, we must give ourselves and others honest answers. If we don't, then this exercise is a waste of time and we'll end up with the same system we had before. Ever hear the phrase, "cutting out the dead wood"? Usually, it refers to unnecessary or non-contributing people, but in this case it applies to rules as well. Rules are either useful and contribute to our well-being, or they're just dead wood. Do we really need so many rules when we're preaching "choices" and "freedom" to the people we serve? We need to question everything, re-evaluate everything, and decide what our real priorities are in the system if we're ever going to make positive changes in it so it will "evolve".

Speaking of questioning, re-evaluating, and deciding on real priorities, that applies to money, too. Here's a "solution" to Flaw #4, which I'd like to deem the "Funding Flaw":

4. DE-Emphasize Funding; RE-Emphasize People and Innovative Ideas

Ever watch the NBC television program, "Deal or No Deal" and/or heard the phrase, "Money is the root of all evil"? More and more often, I've seen contestants come on the show claiming they want to buy a house for their family, donate money to their children's college funds, or even start an animal shelter or other charitable cause. Then they pick some lucky briefcases with low dollar amounts, and the show's banker keeps offering them more and more money to surrender, take the "deal", and go home. It takes a lot of guts to keep playing and "go for the million", but in my opinion, it's far harder (and more noble, and they would have gotten the money besides) to take the lower "deal" and give up the chance at the million so your cause would get the money.

What people who "go for broke" after getting high offers forget is the people they claim they want the money for. I've seen shell-shocked sisters, mortified moms, devastated dads, hurt husbands, and crestfallen children who can only stand and look on in stupefied horror as their well-meaning family members turn down deals upwards of \$200,000 for just one more shot at the million. The "big money" was already there!

(I pray I have the courage to make the "deal" sacrifice if and when I get on the show!)

In our disability service system's constant scramble for funding—all the waivers we apply for, all the grants we write, all the lobbying and letter-writing and protesting and phone-calling we do in order to get just *one* important government official to listen to us—the system has frequently forgotten the people it's fighting for the money to support. Because of it, the people that the system serves have noticed this. No wonder they often feel left out or that they don't have a voice—they're not U.S. dollar bills.

It's like we as a system see that there's still a million (or several billion) potential dollars lit up on our collective "Deal or No Deal" board. We push and push for more, hoping that with just one more persuasive or pressuring tactic, the Illinois state government will finally cave in and give us the resources we need and ten thousand blessings beside. The State, being our "banker", keeps setting aside money (however inadequate) for the disability service system in its annual budget. This is the "deal" Illinois offers us, and on principles of justice (I hope), we keep shouting, "No Deal!"

I hope we don't push our luck too far. Why don't we spend more time thinking of efficient, helpful, and creative ways to spend the money we *have* on supports and services for people with disabilities and less time figuring out what "cases", or cans of worms, to open next so the State will give us funding? Why don't we spend more time getting input from and listening to the people that the system serves and helping them to have a voice in the decisions that the system (and the Illinois government) makes?

If you think de-emphasizing money and re-emphasizing people is hard, try Solution #5:

5. "Open" System Departments and "Close" the System as a Whole

It's a sad irony that right now, the disability service system that supports us in Illinois is just "open" enough to be disengaged from us and just "closed" enough to "close us in" with far too many "rules and regs". How did it get this way, and how can we fix it?

The system became this way, in my view, because of practicing "medical-model"-based, traditional ways of serving people with disabilities for so long that these ways became almost completely fixed. If "it's always been done", that means it's hard *not* to do it.

Fixing the system requires a twofold strategy: "closing" it as a whole and "opening" its various departments (all the way from Medicare and Medicaid to provider agencies). I now present some rough action steps to start making this strategy work, but I also warn you, gentle reader, that the "how" of putting these steps into place will be time-consuming and difficult, requiring planning and innovation. Is the effort worth it? Yes!

How to "Close" The System as a Whole so it Becomes More Engaged with Our Lives

- Let people with disabilities meet, write letters to, call, e-mail, or gain other access to the high-ranking people who "run" the system that supports them. The more that "people at the top" know about those at the "bottom", the better.
- Work with the people who "run" the system to decide if any parts of "the system" are inefficient, unnecessary, poorly-run, or are not living up to the vision of providing quality services for people with disabilities. Then, fix those parts!
- Offer to share the load and responsibility of "fixing" the system with high-ranking government officials and managers. Ask what actions *you* can take to help.
- Talk with others to assure the system's goals are clear, fair, and easy to follow. Do people with disabilities know "the rules" of the system? If not, inform them!

How to "Open" System Departments so the People "Closer to Us" Give Us Freedom

- As I said before, question and re-evaluate all the "rules and regs" the system has to make sure they meet the standard of giving people with disabilities choices, dignity, and freedom. If a rule or regulation does not, modify or nullify it.
- Think of each department of "the system" as a living creature that must work together with all other living creatures as part of an ecosystem. If one part dies or isolates itself from the others, the whole system dies. All parts must coexist.
- Most of all, ask people with disabilities for their input on how their home, agency, and "the system" itself should be run. After all, they're the ones receiving services from the system. Who better than to change and improve it?
- Work to change attitudes of support staff, case managers, and the workers who are closest to the people served in the system if their attitudes seem restrictive.

Afterword: What Happens if We Don't Rebuild "The Yawning Heights"?

So what happens if we don't rebuild the disability service system in Illinois, which I liken to the "yawning heights" of Alexander Zinoviev's novel? What happens if we don't work for change, if we're content to let the system continue to run and remain the way it is? The answer is: *nothing*. Nothing will happen. The sky won't fall, the sun will shine, and the Earth will keep turning on its axis. People will go on about their lives, making money at their jobs, and raising families and children. The world will thrive just as it has for thirteen billion years, with the exception of extinct plants and animals like dinosaurs.

The thing is, for people like me who have disabilities, *nothing* is a terrifying answer. We'll keep on having to wait for supports and services we may or may not get because of supposedly "fair" criteria that grant help to a few while excluding many. We'll continue to have our choices of housing, employment, and personal goals ignored because "there's not enough funding" (big shock) or "that's not a part of what you have to do for your IPP plan" or "you're not ready to do this or that, so let's work on your prerequisite skills" (which we'll spend anywhere from a month to forever doing). We'll stay stuck in the double bind between self-advocacy, which means speaking up for ourselves and our choices, freedom, and human rights, and complying with group home rules, system rules, socialization rules, behavior rules, and all the other "rules" we're supposed to follow if we have disabilities. In this double bind, we'll wonder how to get out of it, but we won't know how. If both "sides" are right, where does that leave us? If we don't work for system change, as human beings with and without disabilities, then nothing *will* change. Either there are enough people satisfied with the way things are and think change is unnecessary, or there are too few people dissatisfied and wanting change. In this case, I believe both things are true, and the system looks "safe" for now. Some people ask me, "Will you get a college degree and become a professional part of the developmental disability services field?" My answer is, "Ha, ha! *No way!*" I will never get degree-paid to fall into "the yawning heights" until they're *solidly* rebuilt.

In this song, to the tune of "O Holy Night", "we" refers to us people with disabilities:

*Oh, yawning heights, your summits brightly shining,
We have tried to scale you since our birth.
Long have we all been climbing, climbing, climbing,
To be "normal"—at last, prove our worth!
Is there still hope for a "patient" who rejoices,
Or will you, system, stay beyond her reach?
Fall on your knees
And listen to our voices!
Oh, heights, it's time
For you to be reborn.
We've won our fight and climbed—
Oh, yawning—heights!*