

Being a Passenger Instead of the Driver

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What do Aretha Franklin and working with
parents have in common?

R-E-S-P-E-C-T !

When parents have a child with a disability, they are immediately or soon after thrust into “Service-land”. They hear a new language. They are often not treated with respect ... words, and acronyms (letters that represent a larger word or group name, such as IDEA is an acronym for the Individuals with Disabilities Education Act,) are thrown at them left and right. Their child becomes a label.

Whatever that label is determines the future of the child. They do not know they do not understand what these words and labels mean many different things.

They do not know that even though they have this child with a disability they need first and foremost to have a LIFE!

They can and should still do the same things as their non-disabled friends and family.

Sometimes, parents do not have someone to educate them or they do not try to become more educated themselves.

Often, agencies and professionals think they know what’s best for people and sometimes they do, BUT in past years there has been NO WHERE to go to learn what other parents know.

The following handouts are taken from the Partners in Policymaking® of Alabama Curriculum.

THE VALUES OF INCLUSION

We are all born as equal citizens and part of a community, we are only later excluded.

All means all

Everyone capable of breathing, even if breathing requires support, is entitled to be included. No one is too difficult, too old, too poor, or has too severe of a disability to qualify.

Everyone needs to be with others

Being there is necessary—but being with takes time and effort. A community is not just a locality – it is a network of connections and relationships. We have to help people be and feel a part of and belong to communities, not just be lonely residents with in the community or providing people with visitors to sit with them.

Everyone is ready

No one has to pass a test or meet a set of criteria (laws or rules) to be eligible--everyone is ready to be part of a community now and it is the community's task to find ways of including them.

Everyone needs support – and some need more support than others

No one is fully independent, and independence isn't our goal. We are working towards interdependence and differing degrees and kinds of support at different times.

Everyone can communicate

Just because someone can't or won't use words to communicate doesn't mean that they don't have anything to say—everyone can communicate and we have to work harder at hearing, seeing, understanding, and feeling what people are communicating to us and communicating back.

Everyone can contribute

Each person has their own gifts and strengths—and each person has a unique contribution to make, our task is to recognize, encourage, and value each person’s contribution—including our own!

Together we are better

We do not believe the world to be a better place if everyone is the same. We are not dreaming of a world when all differences are eradicated and all disabilities are cured—we believe that diversity does bring strength and that we can all learn and grow by knowing one another.

Sample List of Basic Human Rights

The right to have and express your own feelings and opinions

The right to refuse requests without feeling guilty or selfish

The right to consider your own needs

The right to set your own priorities and make your own decisions

The right to change

The right to decide what to do with your own property, body, and time

The right to make mistakes and be responsible for them

The right to ask for what you want, realizing the other person has the right to say no

The right to choose not to assert yourself

The right to do anything as long as it does not violate the rights of someone else

The right to maintain your dignity by being properly assertive, even if the other person feels hurt, as long as you do not violate the other person's basic human rights

The right to be independent

The right to be successful

The right to have rights and stand up for them

The right to be left alone

The right to be treated with respect and dignity

The right to be listened to and taken seriously

The right to get what you pay for

The right to initiate a discussion of the problem with the person involved and so clarify it in borderline interpersonal cases where the rights involved is not clear

Inclusion **By Robin Steele**

Fifty years ago, a parent felt the best way to protect their child who was born with a disability was to keep their child at home, securely protected by the four walls of his house.

Thirty years ago, a parent felt the best way to protect their child who was born with a disability was to build a school where the child could be “with his own kind”, protected by a segregated environment.

Fifteen years ago, a parent felt the best way to protect their child, born with a disability, was to provide classrooms where their children’s education could occur adjacent to the classrooms of non-disabled children so that planned interactions could occur at specific times during the school day, but so that education took place within the security of the four walls of the special education classroom.

Today, my child, born with a disability will walk with her fourth grade class into a public school building. Today my child, born with a disability, will be protected, not by four walls of a building or classroom but by the child sitting next to her in the fourth grade classroom...and her friends who care about her.

Taken from Down Syndrome News, May 1992

Tom's Speech

I've been in three different institutions in sixty years. If I had my way I'd close every damn institution.

Living in an institution is Hell. You never know what's going to happen to you. I've seen people die for no reason. I've seen people get punished for no reason. I am one of them. I've been put in a corner, facing the wall for hours on end simply for talking out of line. To me, all institutions are alike. One might be a little better than the other but not by much.

You can't do what you want to do.
You have no freedom.
You have no respect.
You have no dignity.

You have very few friends. What few friends I did have, I had to be careful of what I said.

In some places I've lived there have been bed bugs, cockroaches, anything unsanitary. Moving out was the greatest day of my life. I've been going places and doing things I've always wanted to. In order for me to get out of the institution I had to get a lawyer and fight in court for my freedom and for the freedom of others.

I felt like I was in a prison being punished like a criminal and all I had was a disability. I want everybody with a disability to be free as much as possible.

Thomas Allen

In the beginning
Poem by Michael McCarthy

In the beginning there were placements, and lo we were happy when it happened as placement was not mandated for adults who happened to experience severe disabilities.

So we said this is good.

And placements multiplied and filled the earth.

And then, we said let us make programs to serve clients,

And clients were defined and labeled and grouped according to their labels and assigned to programs according to their labels.

And programs created services for each label and state agencies developed unit costs for each service.

And programs prospered and multiplied and we said this was very good.

And as programs multiplied, a cry arose; "let us evaluate these programs to see how good they really are"

And program evaluation, state regulations, quality assurance, compliance plans, and other program measures were created.

And they multiplied and filled volumes

And in those times, a person who was a client, but was also a prophet said, "I don't want to be a client; I want to be a person."

I don't want a label, I want a name.

I don't want services; I want support and help.

I don't want a residential placement. I want a home.

I don't want a day program. I want to do meaningful and productive

things.

I don't want to be programmed all my life. I want to do what I like and go where I like.

I want to have fun, to enjoy life and have friends.

I want the same opportunities as all of you.

I want to be happy.

And there was a long silence.

And lo everyone realized they must look beyond the program.

But they were troubled, and they asked.

“How can we do this? Would not every person need their own unique program and system of supports and their own individualized measure of quality?”

And the prophet replied. “Even as you say, so it should be done – just as you do it for yourselves.”

“The truth is this: we do need you, not to be “experts” or managers of our lives, but to be friends, enablers and receivers of our “gifts” to you. We need you to admit cheerfully what you don't know, without shame; to ask us what we need before providing it, to lend us your physical strength when appropriate, to allow us to teach you necessary skills; to champion our rights, to remove barriers previously set in place, to return to us any power you may have had over our lives. We may also need you to remind us of our importance to the world, and to each other, at times of tiredness and discouragement. We can live without patronage, pity and sentimentality, but we cannot live without closeness, respect and cooperation from other people. Above all we need you to refuse to accept any “segregation” of one group of humans from another as anything else but an unacceptable loss for all concerned.”

Micheline Mason

Life Is About Choices

Adapted from an essay by Bengt Nirje

Life has a daily rhythm. We get out of bed in the morning. We choose our outfits, get dressed, and leave the house for work or school. We don't stay home all day. In the morning we anticipate the events of the day; in the evening, we look back on what we have accomplished. The day is not a monotonous (dull) 24 hours made up of endless minutes.

We usually eat at regular times of the day. If we miss a meal, or eat at a strange time, it's because we weren't hungry or because we were involved in something and forgot, not because someone else decided for us.

There is a regular rhythm to our week. We live in one place, go to work in another, and participate in leisure activities in yet another. We look forward to the weekends for leisure. We pursue recreational activities which we choose and which we enjoy. Hopefully, we look forward to returning to school and work after the weekend.

There is a normal rhythm to the year. We have vacations to break the routine of the year; seasonal changes that bring a variety of types of food, work, cultural events, sports, and other activities. We thrive on these seasonal changes which allow us to do new things.

We experience the normal changes of the life cycle: In summer, children—not adults—go to summer camps. In adolescence, we care about music, hairstyles, clothes, boyfriends and girlfriends, fitting in. In adulthood, life is filled with work and responsibilities. In old age, we have memories to look back on, and can enjoy the wisdom of experience.

In life, we have a range of choices, wishes, and desires. Others respect our freedom to decide and even to fail sometimes. Life is learning where we like to live, what kind of work we enjoy and do well, what kind of friends we like to be with, and what we like to do in our spare time.

We live in a world of relationships and we develop friendships and

bonds with other people. As teenagers we have boyfriends and girlfriends. As adults, we may fall in love and decide to spend our life with another person. We get married. We have families.

We have a normal economic standard. We have financial privileges and responsibilities. We have the right to earn money and to decide how to spend our money.

Life goes on in a regular house or apartment in a regular community. Not in a huge place where only people with disabilities live; not isolated from the rest of the world.

Life is being connected, but independent. Life is about choices.

The Opportunity to Fail

Success has been defined as the ability to go from failure to failure without becoming discouraged. It's the old familiar idea of trial and error. If at first you don't succeed, try, try again. Throughout various stages of life, we use this technique to find out what works for us and what doesn't. It means venturing into unfamiliar territory. It means taking risks. But from this process we gain the wisdom and toughness required for maturity and independence. The best educational programs are those in which we are given responsibilities and then allowed to make mistakes. We find out that mistakes are to learn and go forward from.

However, children with disabilities are often "protected" from this opportunity by those around them who want to shield them from the discouragement of failure, the realities of life. This negative "father knows best" approach emphasizes what can't be done rather than encouraging what might be accomplished by trying. It assumes failure instead of recognizing that even an attempt to try is positive in itself. This attitude fosters dependence instead of independence for people with disabilities. It overlooks the fact that children, even those with disabilities, will mature and accept responsibility if they are not forced into dependency.

Every developing human being, with disabilities and without, needs an environment which encourages trying. Everyone must have an environment which offers positive opportunities to learn from mistakes, instead of negative warnings of what can't be done. Everyone needs an opportunity to try and an opportunity to fail—in other words, an opportunity to learn.

PEAK Parent Center, Inc., 1988

The Dignity of Risk

What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn't get it?

What if you were always treated like a child?

What if your only chance to be with other people was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was act out?

What if you couldn't go outside because the last time you went, it rained?

What if you took the wrong bus once, and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember you're "trouble"?

What if you worked and got paid \$.46 an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping, but weren't allowed to do any because you were not able to do all of the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

From *Changing Expectations/Planning for the Future: a Parent Advocacy Manual* by Dorothy Sauber, published by ARC Minnesota, Minneapolis, MN.

The Grasp of the Dead Man's Hand

Taken for granted, unquestionable assumptions, and other creatures that keep people with disabilities from living the good life.

Stephen R. Hail, Ph.D., The Resource Exchange, Colorado Springs, CO

We think in words. It is the only way we can. Our reality is limited to the words that we carry around with us in our own heads. We have conversations with ourselves and it is the words we use during these conversations that limit or expand possibilities. I come from the Midwest and it was once said that you could spend your entire life in the Midwestern United States and never meet a person who had a thought that was different from your own. Today, I believe the same could be said about most any of us anywhere and that it was just the unique, self-deprecating (finding faults in ourselves) style of a Midwesterner who actually said such this.

You see, the words in our heads come from who we happen to bump into and if we continue to bump into the same people day after day then both the words we use become the same. These common words frame our reality and too often limit other possibilities and even stifle (choke) creativity. What's worse, even when we do bump into someone who "speaks a different language," and uses familiar words in ways that are different than we have used, we usually don't understand. "I heard what you said but I don't understand what you said."

Often, we don't understand something that we don't already agree with. We don't disagree. We simply have never heard something explained or talked about in such a manner and we just don't know what to think of it. And, I guess that's the problem. Often, we refuse to think about things that we don't already understand.

Someone said that the ultimate human tragedy would be to live your whole life thinking that you were singing your own song only to find that, at the end of your days, that all you had been doing with your life was singing an elegant variation of someone else's song. Another person called it being "in the grasp of the dead man's hand." What he meant was that men living years ago (for human services over a

century ago) had designed how things were to be done and that today's supposed innovations are nothing more than minor variations on these previously laid plans. Then, as now, many opportunities to realize real homes, jobs, and lives for people with disabilities are missed due to unquestionable assumptions and taken-for-granted that are seen as something called "reality".

Examples:

1. People with disabilities exist and it is okay to label people and call them these names.
2. Although we now spend hundreds of millions of dollars to help persons with disabilities, we need even more money, not less.
3. People who are dead are dead and persons who are living are alive---rather than seeing that some persons who are dead are alive in our minds everyday while others, particularly many persons with disabilities dependent on a Medicaid funding systems, are among the "living dead" slotted into programs and services where they have disappeared from the world.
4. It is assumed that people with significant disabilities cost taxpayers a lot of money. Because of this assumption we don't ask if we can really afford people who do not have significant disabilities. Why are we pouring the billions and billions out for highways, police protection, libraries, mortgage tax exemptions, and national defense for people who do not have significant disabilities? While people who do have significant disabilities have little or no use for highways since they do not drive or rarely take vacations, for police protection since they own little or nothing of value and don't commit crimes, for libraries since most have never been taught to read, for mortgage tax exemptions since almost no one with a significant disability owns their own house, or for national defense where it has been shown that persons with significant disabilities fare equally as well or poorly under fascism, communism, or democracy?

If we ever hope to produce real innovation and success in the lives of

citizens with disabilities, we must first discover how our own lens for viewing the world has been ground (set), what words and combinations of words we are now using in our own minds to frame “reality,” who the dead men were, what were their plans, and how we might avoid slipping from the grasp of one dead man into the grasp of another; and finally, how we might begin seeing the moments when we “just don’t understand” as the only chances that we will ever have to really help our fellow citizens who have been labeled and subsequently blamed for their failings. Maybe someday we will see there was never anything wrong with the people who were labeled by the field of psychology with its attendant curriculums and areas of study, but instead the retardation was never theirs, but ours.

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The Importance of Belonging

By David Pitonyak

Most of what I do in my practice is not very complicated. I spend time with people in ordinary places and situations and try to get to know them. I always ask the person for permission to meddle in their business, and most people, even those without a formal means of communication, let me know that it's OK. What I am most interested in is the person's story, the people and events that have shaped their lives, the highlights and disappointments, the ordeals and accomplishments. What often emerges, if I listen carefully, is a very human story, one that is easy to identify with, one that is all at once extraordinary and ordinary.

More often than not, what I learn from these stories is that the root of the person's difficult behaviors is loneliness. Many of the people I meet in my practice have one thing in common - they have lost connections to the most important people in their lives. Some people have no contact with their families, or if they do, the contacts are infrequent or tentative at best. Sometimes family members are there, but the person has no friends, depending instead on people who are paid to be with them.

Paid care givers can be wonderful company, but they frequently change jobs or assume new positions; the resulting instability can be devastating to someone who is fundamentally alone. Bob Perske (1988) describes how a person whose life is devoid of meaningful relationships might feel: "We have only begun to sense the tragic wounds that so many [persons with developmental disabilities] may feel when it dawns on them that the only people relating with them -- outside of relatives -- are paid to do so. If you or I came to such a sad realization about ourselves, it would rip at our souls to even talk about it."

I believe that loneliness is the number one cause of difficult behaviors. It is not the only cause; of course, it is just the most common one. We are relational beings and the absence of meaningful relationships makes us sick. It wears us down to the point where we can't see straight. If you have difficulty believing it, if it seems too "touchy-feely," imagine yourself without the people you love for thirty days. You have no idea where they have gone. Now

imagine being without them for sixty days...or ninety...or more. How are you feeling? Are you sleeping well? What is your mood? My bet is that you are falling apart. My bet is that you are spiraling out of control. You want to be logical about all of this, but reason has taken a back seat to longing.

I met a man once who was very much alone in the world. When he was a young boy, his family sent him to an institution. He had troubling behaviors, including self-injury, that would not go away, regardless of the behavioral strategies people employed or the medications he was given. He refused to do things with other people and preferred to isolate himself in his bedroom, wrapped tightly in blankets; they said he was "resistant to our treatment efforts." After getting to know him better, I came to believe that his troubling behaviors and his resistance to relationships were the direct result of the trauma he endured when he was separated from his family as a young boy, and from the systematic abuse he suffered at the hands of his "care givers," often in the name of treatment (e.g., time out, seclusion, over-correction). This is to say nothing of the constant turnover in his staff; losing them was common; losing the people he cared about was less common though far more devastating.

When I suggested that trauma and loneliness might be at the root of his difficulties, one member of his team said, "He's not lonely. He has one-to-one coverage." You can, of course, have ten-to-one coverage and be terribly alone. One way I like to explain the difference between coverage and relationships is to ask people to imagine that I have just returned home from a road trip. I pull up in my driveway, and discover that my wife, Cyndi, is not home. Another woman is standing at the door and I ask, "Where is Cyndi?" She replies, "Cyndi is not home, but don't worry. We have you covered."

People generally laugh at this scenario; it's silly; preposterous, really. But it is exactly what happens to people who experience our services time and time again. The very fact that people laugh at the joke of another woman "covering" for my wife is indication that they know there is a huge difference between "coverage" and "relationships." Our field keeps giving people coverage (and interventions) when what they desperately need is to belong.

There are many things we can do to help people find meaningful and

enduring relationships (Pitonyak, 2004). As a starting point, I like the questions posed by Mary Romer (Romer, 2002). They strike me as fundamental to anyone's success: "Are enough people engaged in the person's life?" "Are there people who are imbued with the belief and hope for a brighter, better future for the person?" and, "If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?"

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3 <http://www.tash.org/express/06janfeb/belonging.htm>

Service Quality Is Not Assured Simply By Spending Money

While it is true that you get what you pay for, it's also quite possible to pay a lot and get very little back. If it were not so, then one could assume a simple correlation between price and benefit with the latter rising or lowering with price. Such an assumption is misguided since it falsely pre-supposes that any human being or agency already has what it takes for quality and secondly that such persons or bodies will somehow 'release' quality in proportion to the funds assigned. Even a naive person could quickly appreciate that funds could be squandered if they are given to people who lack the substance to use them well.

Quality does not derive (come) from money but rather from people. For good people in human service, the motivation and ability to do exceptional work on behalf of those they serve is not typically driven by money but rather from a sense of mission, commitment and values. Most of these people will 'give' the same kind of effort irrespective of the level of payment and thus do not 'hold back' quality until sufficient payment induces its release. One could assume that most of these people would be offended by the suggestion that the reason they provide good service to people is because they are induced to do so by increased payments. In essence, the simple correlation (relationship) model is a false depiction of what's really at work in excellent service.

Sometimes the things that people really need cannot be bought in any case. This might include security, love, relationships, hope, community and other such things which are the gifts human beings give to each other rather than sell to each other. Acquiring valued social roles within community life is not equivalent to obtaining a 'product', though its co-modification is verbally achievable as can be seen by recent efforts to linguistically commercialize human services, e.g. referring to service users as customers, referring to services as 'products', agencies as 'businesses' etc.

Michael Kendrick

A CREDO FOR SUPPORT

Throughout history, people with disabilities have been abandoned at birth, banished from society, used as court jesters, drowned and burned during the inquisition, gassed in Nazi Germany, and still continue to be segregated, institutionalized, tortured in the name of behavior management, abuse, raped, euthanized, and murdered.

Now, for the first time, people with disabilities are taking their rightful place as fully contributing citizens.

The danger is that we will respond with remediation and benevolence rather than equity and respect. And so, we offer you A Credo for Support.

Do Not see my disability as the problem. RECOGNIZE that my disability is an attribute.

Do Not see my disability as a deficit. It is you who see me as DEVIANT and HELPLESS.

Do Not try to fix me because I am not broken. SUPPORT ME. I can make my contribution to the community in my way.

Do Not see me as your client. I am your fellow citizen. SEE ME AS YOUR NEIGHBOR. Remember, none of us can be self-sufficient.

Do Not try to modify my behavior. BE STILL & LISTEN. What you define as inappropriate may be my attempt to communicate with you in the only way I can.

Do Not try to change me, you have no right. HELP ME LEARN what I want to know.

Do Not hide your uncertainty behind “professional” distance. BE A PERSON WHO LISTENS, and does not take my struggle away from me by trying to make it all better.

Do Not use theories and strategies on me. BE WITH ME. And when we struggle with each other, let that give rise to self-reflection.

Do Not try to control me. I have a right to my power as a person. What you call noncompliance or manipulation may actually be the only way I can EXERT SOME CONTROL OVER MY LIFE.

Do Not teach me to be obedient, submissive, and polite. I need to feel entitled to say NO if I am to protect myself.

Do Not be charitable towards me. The last thing the world needs is another Jerry Lewis. BE MY ALLY against those who exploit me for their own gratification.

Do Not try to be my friend. I deserve more than that. Get to know me. WE MAY BECOME FRIENDS.

Do Not help me, even if it does make you feel good. ASK ME IF I NEED YOUR HELP. Let me show you how you can best assist me.

Do Not admire me. A desire to live a full life does not warrant adoration. RESPECT ME, for respect presumes equity.

Do Not tell, correct, and lead. LISTEN, SUPPORT, AND FOLLOW.

Do Not work on me. WORK WITH ME.

Norman Kunc and Emma Van der Klift, 1995