

Behavior Support

“You’ve got to have something to eat and a little love in your life before you can hold still for anybody’s sermon on how to behave.” Billie Holiday

Behavior is first and foremost communication. Our behavior is almost always a reaction to our environment, our life situation, an outward sign about how we feel inside. There is rarely any real mystery about a person’s behavior when we take the time to really look. Understanding the behavior and positively supporting a person to no longer rely on that behavior can be much simpler than we often make it.

Quality in Practice

Start with general questions:

- Who is this person?
- What does she most want and need in this world and is she getting it?
- Who does she love?
- Who loves her?

When the answers to these questions are unknown or are based in the negative (“she loves food, but is on a weight reduction diet and can’t have any of the foods she loves” or “she doesn’t know anyone who isn’t paid to be in her life”), then we know where to start.

Spend some time getting to know the person. Pay attention to how she reacts to things – music, light, animals, people, foods. Put a collage together made up of pictures of her favorite things from magazines. Notice when she smiles or frowns.

Ask what she wants to do and try those things to see how it goes.

Research her history to see if there is someone she was once close to – perhaps a former staff member or family member she has lost touch with. Send the person a card with an update about her life. Invite them to meet her for lunch or coffee. Put together a gift basket of chocolates for her to give them.

Another way to think about this is to ask yourself, “If I lived this person’s life, how would I feel and how might I act?” Be honest about what you see and feel and develop your own capacity to walk in her life in order to better understand her reactions. Your own behavior is likely to become much more positive when you have this understanding.

Work to build things into her life that she wants and needs. Watch her when she is engaged in things she loves with people she is comfortable with. Does she still need those behaviors or do they go away during those times? If they go away, then you know that the behaviors are her way of letting us know that her life is not right. Make those changes permanent and don’t focus on the behaviors anymore.

Hold only one standard for what is right and acceptable in life. For example, a group of people made up of direct support professionals, people they support and a few managers could discuss what happens when people attend a day program together and need to get along and compromise over how they spend their time and where they go. Most professionals would think about their own lives and they realize that they have control over so much more than the people supported and that they don’t always recognize it. Most people choose friends, while the people attending a service/support program don’t choose the people they attend with. And while most people always have the right and the ability to literally walk away from a setting the people we support don’t. So consider what might our own behavior look like in that situation?

continued on back

Behavior Support (continued)

How can we support people to have more control over their daily lives?

Be respectful. If the behaviors show up again, pay attention, figure out what is going on in the person's life now and do more to make sure her life is full of the things she finds important.

If you have honestly, with care, examined all these issues and the person's behavior is still a mystery to you, then look to all the "professional" assistance available, but only as a last resort. Assessments, evaluations, behavioral analysis and psychiatric referrals should be the very last thing you consider, never the first or the standard by which you operate.

The people we support already have enough labels. If the person already has the labels, work tirelessly to remove them and put behavior back where it belongs – a means for people to share information with us – information we need to take seriously and learn from.

Choice

Choice – it’s talked about all the time, occasionally used as an excuse to justify bad outcomes, rarely well understood or agreed upon. At once very simple and extremely complex, choice is our ability to determine the structure of our lives. Let’s say that again: *Choice is our ability to determine the structure of our lives.* Exercising choice allows us to feel we are in control of our destiny. Feeling in control allows us to feel content that our life is our own. The importance of choice in our life cannot be understated.

Quality in Practice

Choice includes everyday decisions like what to wear, what and when to eat, how to spend our time, and what time to go to bed and get up every day. It also includes life-defining decisions like where to live, whom to live with, whether to marry, how to express our sexuality, which career to pursue and who our friends are. Choice has something to do with everything we do every day.

Many of us believe that our choices are limited. But the reality – for those of us who do not depend on the human service system for our support – is truly that life is full of endless choice. We may have to live with consequences, or the outcomes of different choices, but in reality we have an enormous amount of choice.

Most of us absolutely take for granted that everyday decisions are ours to make alone. Our spouses, children, friends or colleagues may offer their judgments about our choices (“I love that shirt!” “Why do you cut your hair THAT way?” “That color looks great on you!”), but the choice remains ours and we know it. As adults, we may struggle with major life decisions – who and when to marry, what job to take, whether or not to pursue a college education, what car to rent or buy, what neighborhood to live in – but again, *we* make the choice. Often we understand that in order to do *this*, we give up *that*. Our choices may be limited by the amount of money we have or our education or how much time we are willing to devote to something. Yet we still have many, many options to choose from.

For people who depend on the human service system for support, choice is severely limited and often for the convenience of the system. Most of us working in the system don’t even realize the choices we take away from people.

Many people living within the system have everyday decisions made for them as a matter of course:

- the menu is decided by someone else
- bedtimes and wake-up times are the same for everyone
- staff grab clothes for people to wear in the morning
- a nurse decides whether we shower or bathe
- in the morning or at night, the radio or TV station is tuned by one person even though there are six people in hearing/viewing range.

We sometimes make attempts to increase choice for people by asking them to choose between a few things – like which type of cereal they want, since cereal is on the menu that morning. But most people wake up having an endless array of choices for breakfast – whatever is in their house (breakfast food or not), whatever any restaurant has to offer, what a friend or family member might have at their house that we can persuade them to make for us, something from the vending machine at work, or nothing at all. And these everyday decisions are the easier ones to remedy – we just have to be more aware of them and make an effort to assure that we offer more and more options to people everyday until people really are controlling their daily activities.

continued on back

Choice (continued)

Life-defining decisions are certainly just as important, or perhaps more so. However, it is much harder to offer real choice in meaningful ways. Our system is often not arranged in a way that choice can be offered or honored.

Organizations can do a lot to assure that people have as much input into major decisions as possible, even if full control is not possible.

For example:

- Including people served in choosing which house to lease or buy
- Creating a house-mate selection tool that fully includes people who may end up living together
- Refusing to have adults share bedrooms with anyone they are not intimate with
- Arranging supports so that people can practice their own spirituality in whatever way makes sense for them
- Supporting people's right to express their sexuality

Organizations can certainly increase a person's involvement in these important decisions until we can make fundamental changes in our service system.

Ultimately, our service system must be arranged so that people with disability are supported to have the same range of choices available to any other person. This is the only possibility that makes any sense. There are plenty of good examples of organizations supporting people in real lives, making all their own decisions. Organizations can choose to not develop any more services that limit people's choices in favor of creating supports that offer real choice to every new person they serve. Most states now have some type of self-directed waiver option that organizations can choose to utilize.

The choice is up to each of us.

Respect

Respect is a concept we are all familiar with, one that defies easy definition. We know very well when we feel we are being respected or disrespected, but we do not always understand what it means to “respect the people we support”.

Quality in Practice

Let's consider this quote from the Stanford Encyclopedia of Philosophy:

“It is part of everyday wisdom that respect and self-respect are deeply connected, that it is difficult, if not impossible, both to respect others if we don't respect ourselves and to respect ourselves if others don't respect us. It is increasingly part of political wisdom both that unjust social institutions can devastatingly damage self-respect and that robust and resilient self-respect can be a potent force in struggles against injustice.”

Respecting the people we support is fundamental to our work. In order for people to grow, develop and contribute to community life, they must be capable of showing respect for other community members. That is difficult, if not impossible, if they themselves are not respected. Since those of us who work in the system know the people best and spend the most time with them, it falls to us to be respectful in everything we do and say with and about the people we support. Simply respecting people for who they are and what their interests are can go a long way in supporting people in living the life they want to live.

Our system already potentially damages self-respect for the people we support by labeling, limiting choice, and segregating people. We must be vigilant in overcoming those forces. Some ways in which we can actively show our respect include:

- treating adults as adults no matter the level of cognitive disability
- being honest with people about their looks and behavior without being cruel
- finding respectful, adult ways for people to engage in their interests
- talking with and to people, not about them
- never making fun of a person due to his or her disability
- including people in every decision about their lives no matter how well we understand their participation
- always looking for new ways for people who don't use words to communicate
- always treating people the way we would treat any respected community member
- not settling for things just because the person has a disability
- supporting the person to create a personal style (clothes, make-up, hairstyle, home decorating) that reflects who the person is
- supporting people to be active in meaningful ways rather than wasting their time in programs that are simply day-wasting venues

Understanding Risk

Robert Perske said in 1972, *“there can be such a thing as human dignity in risk. And there can be a dehumanizing indignity in safety!”*

What is this discussion of risk all about, really?

Quality in Practice

First, it is often really a fear of liability. So let’s get that out of the way right now. It is important to note that the United States is a litigious society. We like to sue each other and anyone can be sued or can sue for anything, at anytime. Once we understand that, we can more easily move past it. Organizations purchase liability insurance and individuals can purchase liability insurance through their renter’s or homeowner’s insurance policy. Get the insurance you think will meet your needs for whatever role you hold within the system.

Safety is a worthy goal, but we must be cautious that we are not dehumanizing in our quest. We need to consider the unintended consequences of our actions. Our quest for safety, often via overprotection, can be disrespectful to people, causing them to lose self-esteem and become frustrated and depressed. These feelings can lead people to rely on behavior to let us know how bad things have become. We respond by attempting to control the behavior, make judgments that people are not ready for any more autonomy (risk) and create an ever-downward spiral where the person experiences more harm from our behavioral interventions than they ever would have from taking the risk in the first place.

Now let’s use some common sense. People with disabilities rarely ask or attempt to do things that are truly risky. Most often, people are trying to live their lives in a way that meets their needs. People may want to drive a car, spend some time alone, ride their bike around town, go swimming or spend time with

people who are not paid to be with them. These are all things the rest of us adults take for granted. We rarely, if ever, consider the risk too great.

So contemplate believing that the people we support are fully adults. What supports would we put in place for ourselves or any of our good friends who want to do things that they may never have done before?

- We’d talk about those things.
- We’d research the best safety practices and decide if that makes sense in our situation.
- We’d try something for a short period of time or with other people who have more experience.
- Then we’d evaluate that experience and make new decisions about moving forward.

Occasionally things will go wrong. If they do ...

- Take a look at what happened and think about what you have learned.
- Do not over-react.
- Do not write another policy that applies to everyone when something happens with one person.
- Be thoughtful. Ask people to think. Really think, not simply follow rules.
- Ask lots of questions and include everyone – the person you support, the direct support professionals involved, family, and community members involved in the activity.
- See where this leads you and your organization in supporting people to live lives of meaning and fulfillment.

Thinking About Responsibility

Responsibility is an interesting concept to consider in relationship to people with disability who spend all or much of their time within the service system. *Responsibility* is about having accountability for one's actions, things or thoughts. However, responsibility does not exist in a vacuum but is strongly associated with liberty and dignity.

Quality in Practice

Liberty, as defined by the Merriam-Webster dictionary, is:

the quality or state of being free; the power to do as one pleases; freedom from physical restraint; freedom from arbitrary or despotic control; the positive enjoyment of various social, political, or economic rights and privileges; the power of choice.

While **dignity** is defined as:

the quality or state of being worthy, honored, or esteemed.

The question that comes to mind then is to contemplate the relationship between these concepts. What is the impact of having a lot or a little of one on the ability to have the others? If we have little liberty, how responsible can we really be? If we have little liberty or responsibility, how much dignity can we hold?

It is widely believed that the more liberty one experiences, the more responsibility one can handle, leading to greater dignity. While we might like for people to show evidence of greater responsibility before they enjoy greater liberties, that is not in fact how it happens.

- A person cannot prove that he can handle money without having the money to handle. And he probably will need to make at least one mistake before really learning how to be responsible with his money.
- Someone cannot prove that she can have a relationship with someone not paid to be with her, until she has that relationship with someone not paid to be with her. And she might lose a friendship or two before learning to be responsible and reciprocal with her friends.

Most of us grow up being given more and more liberty in exchange for showing more responsibility. And we learn from our mistakes, mostly learning how to be more responsible, and the amount of dignity we hold increases along the way.

Many people with disability, especially those segregated in institutions, group homes, day programs and special education classes, have never been given the opportunity to experience liberty or to learn responsibility. Go ahead and reread the definition above and think about the people you serve and how many of them experience liberty. Some of our service models have led to a decrease in the dignity we afford people with disability.

Our job then is to increase liberty for each person we support, allowing them to learn responsibility and build a dignified life. The good news is that we have taken so much liberty away from people that we can find unlimited ways to do this:

- have people answer their own phones
- support people to get cell phones
- involve people in hiring/firing decisions
- involve people in policy writing
- let people who want to stay alone do so, for some amount of time and increase the time as it works out well
- encourage people to try new things
- give people their money
- have people document for themselves, even if on tape
- encourage people to take classes in subjects they love
- stop continuing guardianships and instead assist people to write wills, powers of attorney or other legal documents that will protect them in case of emergency
- make sure people have their own space and their own things with their own keys
- and ...

Family-Centered Supports

Family-centeredness is defined by CSHCN (the Center for Children with Special Health Care Needs) as “*care that ensures the health and well-being of children and their families through a respectful family-professional partnership that includes shared decision-making. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship*”.

Quality in Practice

Core concepts of family-centeredness:

- **Dignity and Respect.** Providers listen to and honor perspectives and choices. Family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of services.
- **Information Sharing.** Providers communicate and share complete and unbiased information in ways that everyone can understand and before any decisions are made.
- **Participation.** Families are encouraged and supported to participate in decision-making at the level they choose.
- **Collaboration.** Families are also included on an institution-wide basis in policy and program development, implementation and evaluation; in facility design; and in professional education, as well as in the delivery of services.

Assumptions of family-centered approaches:

- Families want to raise their own children.
- Families make good partners with all professionals and para-professionals – teachers, aides, therapists, doctors, etc.
- Families are worth fighting for because having people who care and are not paid to be in your life is best.
- Families can understand – it depends on how the information is shared, not on the information itself.

The following steps can help set a service provider on its journey toward family-centered supports.

- Implement a process for all senior leaders to learn about family-centered supports.
- Include people supported, families, and staff from all disciplines in this process.
- Appoint a family-centered steering committee comprised of people supported along with families and formal and informal leaders of the organization.
- Assess the extent to which the concepts and principles of family-centered supports are currently implemented within your system. On the basis of the assessment, set priorities and develop an action plan for establishing family-centered supports at your organization.
- Using the action plan as a guide, begin to incorporate family-centered concepts and strategies into the organization’s strategic priorities. Make sure that these concepts are integrated into your organization’s mission, philosophy, and definition of quality.
- Invite people supported and families to serve as advisors in a variety of ways. Appoint some of these individuals to key committees and task forces.
- Provide education and support to people supported, families, and staff on family-centered supports and on how to collaborate effectively in quality improvement. For example, provide opportunities for administrators and clinical staff to hear family members share stories of their experiences with the organization during orientation and continuing education programs.
- Monitor changes made, evaluate processes, measure the impact, continue to advance practice, and celebrate and recognize success.

Micro-Boards

“A micro-board is a small group of committed family and friends who join with a person with a disability to create a nonprofit corporation. Since the micro-board is a structured and legal entity, its purpose is to ensure that the person's circle of friends will endure. The micro-board is dedicated to providing support to that one person. Members of a micro-board have a personal relationship with that person. They act as ‘bridge builders’ to the community, and ensure that the person has opportunities to participate in their community in as many ways as possible.”

Community Opportunities of Blacksburg, VA, an affiliate of VELA Micro-board Association

Quality in Practice

Simply put, Micro-boards are non-profit organizations created around one person. The board is made up of family members and friends who want a structured way to support the person with a disability get the services he/she wants and needs AND to assure the person is or becomes connected to people who are not paid to be with him or her in the local community.

Micro-boards are:

- 501(c)3 organizations
- organized around one person (or two, if a couple)
- made up of committed family and friends
- able to negotiate with funding sources for services
- able to hire staff members directly or contract with an agency to provide services

Common Principles of Micro-boards:

- All board members have personal relationships with the person for whom the board is created.
- All decisions will be made with that one person in mind.
- The person is presumed to be ready to live life as a full adult citizen.
- The community is presumed to be ready to accept all members.
- All services are personalized and customized to the individual no matter how complex the person's needs are.
- Services will be developed if the appropriate services do not currently exist.

There are several micro-board associations that have developed to assist individual micro-boards with understanding all they need to know in order to excel at their work. These include:

VELA Micro-board Association
www.microboard.org

Community Opportunities
www.communityopportunities.org

Tennessee Micro-boards Association
www.tnmicroboards.org

Individual Budgets & Fiscal Intermediaries

Many U.S. states now have Medicaid Waiver options that allow people eligible for the waiver to determine how the waiver dollars allocated to them will be used within the parameters set within that state's waiver. Individual budgeting is used within self-directed service options not traditional group-based services.

Quality in Practice

The Centers for Medicare and Medicaid Services (CMS) defines an individual budget as “*the total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant.*”

CMS also requires individual budgets to be:

- **Evidence-based:** budget is based on actual costs and support needs that can be documented by some verifiable means
- **Consistent:** determination of support needs and budget is the same or similar for all involved in the process
- **Transparent:** open to public inspection
- **Regularly evaluated:** has an established method and time frame of evaluation.

How does a person decide what to buy with his/her individualized budget?

The first step to creating an individualized budget is for the person to decide what services and supports he/she wants to meet his/her needs. Most often people participate in a person-centered planning process to help them make those decisions. Family members and friends can also participate in the person-centered planning process.

Who can help the person figure out how to make decisions and manage the budget?

Generally, states will provide assistance to the person in making these decisions and managing the budget through an independent person – perhaps a supports broker, a facilitator or a consultant. It is this person's role to help the waiver participant in figuring out all the rules and practices associated with that state's self-directed program.

What services can be purchased using individualized funding?

The participant decides what services he/she needs. This means the participant may choose to buy any services, supports or goods if those services, supports or goods:

- Help the individual to meet his/her functional, medical and/or social needs and live life successfully
- Help the individual to reach the goals he/she has set for himself/herself
- Are not prohibited by Federal and State laws and regulations, including the State's Procurement Code
- Are not available through another source (i.e. covered by another insurance)
- Do one or more of the following:
 - The service or item would make it easier for the individual to do things that are hard because of his/her disability
 - The service or item would increase the individual's safety in his/her home environment
 - The service or item would lessen the individual's need for other publicly funded services

continued on back

Individual Budgets & Fiscal Intermediaries (continued)

Who determines the budget amount?

Generally speaking, states set the amount of money available to each person based on the state's criteria as outlined in their self-directed waiver.

Who handles the money?

CMS does not allow direct payments to waiver participants, so a fiscal intermediary handles the funds. A **fiscal intermediary** manages funds, makes payments, and accounts for expenditures made on behalf of the participant and according to his/her individual budget. The fiscal intermediary is not a direct service provider, but handles the business of securing services and supports. A fiscal intermediary can be a nonprofit agency, a payroll service, an individual, or any organization that the individual, family, or state selects. A fiscal intermediary must be able to provide payroll services, bill payments, benefits administration, contract negotiation, rate setting functions, and record keeping services.

The fiscal intermediary acts as a fiscal conduit, distributing funds as determined in the individual budget and keeping all applicable reports. Oftentimes, the fiscal intermediary also is the employer of record for persons providing support services and is responsible for completing tax, labor, and Social Security documents as needed. The fiscal intermediary as employer of record, calculates and files tax documents, distributes wages to support providers, manages workers' compensation, disability, and benefit insurances, and verifies citizenship/legal alien status of support providers. The waiver participant makes all decisions regarding hiring, supervising and firing support workers.

Are self-directed waivers the same in every state?

No. Self-directed waivers are optional, and every state sets its own criteria, policy and procedures in relationship to these waivers.

Why would someone want an individualized budget?

Self-directed waivers and individualized budgets allow the person to be an active participant in deciding how to live his/her life by choosing where and how he/she lives and what services and supports he/she buys. These may be new services, or services he/she now receives. With self-direction, the person will have more choice, more control, more flexibility and more freedom in his/her life.