Chapter 13
Person First!

We rely on different systems of expertise, services and care to meet different needs at different times in our lives. Most of the time we remain directly involved in the decision making process involved with such services. For example we choose the doctor we go to for a checkup. We may hire an accountant to help with taxes. Our dentist may recommend not eating sweets at night in order to fight tooth decay, but doesn’t sit at the dinner table to assure that this guidance is followed. In other words, in most cases we still retain control and direction of our lives and can normally take steps to change direction.

Of course there are instances where we hand total control over to others. For example, we don’t tell the surgeon what to do and most of us would surely rather be unconscious and unaware in the operating room. We are grateful when others jump into action without consulting us first to save our lives or the lives of people we care about. Many of us complain about how crowded and inefficient airline flights feel these days, but few would assume the ability to fly the plane.

In each of these cases, we may temporarily give up our direct control to others for a given goal with the understanding that we will reassume this personal authority. Most of the time, the people who assume these interim authorities are also under specific guidance and expectations, and the process works reasonably well. Problems can develop however, when authority is not returned or the goals and focus change without our input or consent. Person first programming recognizes that all goals, programming, services begin and end with the individual.

Consider how anybody would react if control and authority of daily events violated expected boundaries.

Examples of response to lack of control:

We are grateful when the pilot makes an emergency landing in St. Louis and saves everybody on board even though we were hoping to fly to Los Angeles. But imagine how you would react if the pilot chose to land in St. Louis instead of Los Angeles because she thought it would be a nicer place for the passengers to visit!

The surgeon who stops unanticipated and life-threatening bleeding in our stomach while operating on our leg is a hero. A different fate awaits the surgeon who independently decides to do a tummy tuck after the leg surgery because he thought that the patient would look better!

It doesn’t take much to imagine the behavioral and emotional reactions that the recipients of such decisions might display; and it has nothing to do with brain injury!

Unfortunately, we unwittingly place many people who experience disability under such circumstances despite the best of intentions. We do this when we inhibit their return to the seat of personal authority and accountability. This is often an insidious process of thinking that the individual may need a little more time; focusing on what a person can’t do over what they can do; relying on our own (or the team’s) judgment of what is acceptable and unacceptable, or good and not good; over protection; or “simply knowing what’s best!” The longer we do this, however, the further we are likely to travel from that person’s goals, hopes, interests and focus. Too often we end up assuming our goals and values for theirs with the same deleterious results as the previous examples.
Who is in Charge?

Simply stated, whoever is the focus of programming and supports at the time is the President and CEO of ME! and sits at the head of the team. Other people may sometimes need to assume important roles to help this person identify specific goals or to develop, apply and evaluate programming results. However, little is likely to occur without the individual’s direct involvement. Even when a person is not able to verbally express themselves they are still in charge relative to the manner in which they respond or behave in situations. Hopefully, if a person does not react in the desired manner, the people and program make changes, to the best of their abilities, to promote effective change by the person.

Inaccurate rehabilitation and behavioral programming approaches often assume that others can create programs for behavior change without this person’s participation. However, most of these programs fail without the principal’s direct involvement and support. Why should anyone want to do anything that they don’t have a say in or agree with, especially when it could significantly change their life?

One concern about person first programming is that this individual may not be able to assume this type of responsibility. If the person could, he would not need this level of help! Problems with awareness, memory, insight, problem solving, attention, concentration, frustration tolerance and other factors can clearly affect personal participation. Although these issues clearly challenge anyone’s ability, they must not exclude the person from the process. When necessary, other people within the individual’s circle of support can assist this person’s participation.

Inclusion is the standard of person first programming. Exclusion is the exception!

Examples of inclusion:

In one situation, the wife of a man with severe injuries attended all program planning and evaluation meetings, but insisted on her husband’s presence and participation. The wife offered important input into the process, but always deferred to her husband for final answers, even when it took significant time for him to understand and make decisions. The time spent was well worth it as nobody but the husband could explain what he really felt like or wanted. Sometimes, even he was not sure! The “inconvenience” of the added time that planning meetings took to assure his comprehension and agreement was more than paid for by the success of subsequent programming and supports that were developed. It also avoided the need for costly crisis intervention.

In another situation, each client in a rehabilitation program chose the staff member who they felt most comfortable with to help represent them at team meetings. This staff member spent time with the client before each team meeting reviewing goals and progress with the client, formulating questions and suggestions that the client wanted to present, and otherwise preparing for the meeting. During the team conference, this staff member assisted the client in participating in the meeting. After the meeting was over, the staff member reviewed the meeting with the client to assure that he understood the process and outcome of the meeting and that all of his questions and needs were met.

There are innumerable problems when people presume for others. Alternatively, many different benefits occur when the person is involved in planning from the beginning, including:

- **Eliminating guesswork** The specific interests and motivations of the individual are readily apparent. Nobody has to guess what he or she likes, wants or needs.

- **Involving responsible people** Other people who are directly involved with the individual also usually join the process. These are often the people who will be responsible for supporting or sustaining any developed programs on a long-term basis. Their needs, abilities and goals are just as important.

- **Increasing the likelihood of success** The direct input of all involved parties into the programming and support goals makes it more likely that such efforts will be successful.

There can also be problems when the person can’t identify goals, keeps changing his mind, or feels that nothing needs to be done, despite the perceptions of others. Again, these types of issues may delay or draw out the process, but should not form the basis for excluding this person. This does not exclude the need for limit setting or boundary definitions for any member of the group at different points in time. We all need this at some point or another. However, it is also important to remember that the person who may need sup-
ports or services at any given time is not always the person who experiences disability. It can be anybody who is involved in their circles of support.

Finally, there are occasions when it may not be possible to involve the person of interest in parts of the process, due to illness, severe impairment, clinical emergencies, or other factors. Again, such exclusions should be the exception, rather than the rule.

**Personal Regard**

**Self-concept**

People who feel good about themselves are more likely to succeed. However, self-esteem is something that others can’t force on another person. It is not unusual for anybody to feel very insecure, unsure of the future and unsure of themselves after a catastrophic injury. Re-establishing one’s personal regard is not surprisingly a delicate and time consuming process.

For many people, this develops over time by virtue of one’s personality, past experiences, personal opportunities, resources, current daily experiences, challenges and demands. Some people are born optimists and take these challenges in stride. Others are born pessimists and cannot see beyond their immediate loss. Negative self-concept is contagious. It not only eats away at the individual, but also how the person views others and other opportunities. Most people can make the transition, but it takes the patience and support of others. These are all critical components of positive supports.

- **Respect the individual.** One way that other people can help this process is in their honest regard for the individual. Your non-verbal communication can say more than your words. Think about how you approach, look at, respond to and posture yourself with another person. Do you convey respect and collaboration, or do you look down or respond in a superior manner to the other person? Remember, actions speak louder than words.

- **Emphasize strengths over weaknesses.** Too often people focus on what they do wrong and the need to fix their faults. While this is important, it is even more important for people to be able to recognize and be recognized for what they do well and how to build on their assets. Recognize each person for their talents, interests and what draws you to them.

- **Encourage the person to get involved.** People with poor self concept or self respect often don’t feel that they have anything to say, that their words and efforts are not valuable, or that others have better ideas. You can’t make anybody do anything they truly don’t want to do. There is no need to get into power struggles when trying to encourage others. Still, there are ways to build in opportunities to increase a person’s interest to become involved, especially if they don’t feel vulnerable or threatened, if the activity is time limited, if it can occur in familiar territory, if it contains an element of personal interest, and if others that the person knows or likes are also involved. Simply stated: *You can lead a horse to water, but you can’t make it drink ... but you can feed it salty peanuts!*

- **Involve the person in discussions and decisions.** Don’t exclude the person from meetings, assume to talk for the person, or talk over others. Listen to what the person is saying, watch what she does and work to validate her feelings. What you feel or assume may not be important. However, it is important to understand where each person is coming from. It has often been stated that people cannot negotiate until they can both understand and explain the other person’s position. The first parts of this book were designed to help that process.

- **When possible, refrain from further work or progress on a topic until the person has weighed in with an opinion.** Let the person know how important their input truly is and then involve that input in the continuing process.

**Being with people we like**

Having the opportunity to be among people one likes and who hold similar personal interests is also very important. As noted in earlier chapters, friends and acquaintances all too often disappear following a catastrophic injury, or any situation in which a person demonstrates persistent behavioral or personality changes. Opportunities to get together quickly fade. People who don’t move in similar circles don’t often think of getting together anymore - out of sight, out of mind. Loneliness is often cited as the most significant long-term challenge following brain injury or most any catastrophic life event.
Too often we try to help people regroup and develop other social relationships based on their disability or challenges. Brain injury support groups and other similar events can play an important part in helping to adapt to life following brain injury. However, these usually are not the most effective way to meet and keep new friends. Think of how you would like it if your only chances to meet new people were based on having contact with people who share some of your own problems! This wouldn’t be very interesting or productive in most situations.

Instead, we all need opportunities to meet others who share our interests and abilities, exclusive of whether or not we have a disability. Transportation, incompatible schedules, and limited resources can easily challenge this seemingly simple goal for people with limited resources. Unfortunately, this is a frequent fact of life when someone experiences disability. People with poor self regard may also be resistant to try new things or to take chances. They may view themselves as “damaged goods” and believe that no one else would be interested in them, or that they are not worthy of others. People with poor self regard may also fear how they would feel if they failed or were rejected – rejection and abandonment hurt!

People may need help finding other personally interesting people. Finding just one person to share one interest or positive experience can open up a wide range of other venues and resources. Connecting with people of similar interests provides the context, structure and natural supports for:

- conversation
- staying connected
- intimacy
- engaging in activities that are inherently motivating
- seeking other opportunities
- finding other people with shared interests
- reducing boredom
- reducing loneliness
- improving self-esteem
- identifying personal purpose
- self-validation
- new resources, and
- so much more.

This can sometimes occur via the internet, though we put too much faith in this process, probably because it is so easy for us to recommend to others. However, there is no substitution for face to face contact in real life situations where all parties are involved in activities or purposes of personal value. Start with what the person considers to be important, likes and believes in. Help this person find places to convene with others of similar interests and persuasions, such as classes, activities, places of spirituality, and so on.

**Choices and Responsibilities**

It is also important to recognize the types of choices, levels of control and accountability in each person’s life.

Too often we presume that people can’t make “proper” choices or take responsibility for their actions following a brain injury. Lack of opportunity is usually a bigger contributor to such problems than lack of ability. There can be a wide range of challenges after brain injury that can interfere with making choices or recognizing responsibilities. However, successful supportive approaches seek to work with a person’s strengths across problem areas to help them gain better control of their lives. People may still need assistance and support from others to make some decisions and assume proportionate responsibility. However, they may be more willing to accept this assistance when they feel you are working with them instead of against or over them.

### Example of assistance:

A number of years ago I was helping James, a member of a Clubhouse program move into a newly rented apartment. We were loading furniture into a borrowed a van. Our progress was slow as I coordinated the packing. It was going to take all afternoon. Taking a bathroom break I came back to see the van fully loaded. James was smiling. “Thank goodness you had to go,” he smiled. It turns out that he had worked for a moving company early in his career and never forgot how to do it. I never thought to ask.

People who have no control or perceive that they have no control or responsibility are more likely to become depressed, withdrawn, angry or simply give up. Many people in such circumstances ask, “What’s the use of trying?” Oftentimes when people find that they have no control or responsibility in one part of their lives, they assume that they have no control or responsibility in other areas of their lives as well.
For example, a person who is unable to return to work or to drive may feel unable to do anything else. The person begins to sleep more, pay less attention to dress and hygiene and withdraw from other activities. The process is known as learned helplessness and is a significant cause of clinical depression.

One of the best ways to avoid or try to resolve such issues is to collaborate and help people recognize the areas of their lives where they do have control and then to supportively expect them to exercise control. People always have choices.

**Example of choices:**

One person I met is unable to vocally communicate, but has two different tools to “talk” with people. One tool is a spelling board that she can use to point out individual letters in order to spell words and create sentences. Because of her tremors and problems with motor coordination she does not always point to the correct letters, making it necessary to start all over again. As a result, it can take her a long time to spell out what she wants to say.

She also has a computerized spelling board that helps her pick out whole words and put sentences together more quickly. It will even “speak” for her. However, she doesn’t want to take the time to learn how to use it, even though she is capable of doing so pretty quickly. She also likes the undivided attention that people have to give her when using the old-fashioned spelling board.

The problem is that she feels that people won’t always spend the time to listen to her or what she wants. People have told her that it takes too long to talk with her with the old fashioned board as compared to the computerized board. They have too many other things to do and if they spend all this time with her they can’t assist others. She knows that she could get a lot more accomplished with the computerized spelling board, but feels that people should respect what she wants.

We discussed this issue in terms of not only what is important for her, but for others in her community as well. This is the nature of social commerce. She can choose less frequent opportunities of more personalized attention with the older device, but also know that when people don’t have the time to talk with her with this device they may make decisions for her. Or she can learn how to use the talking computer to make it easier for both she and others to communicate. Again, she is clearly capable of learning how to use this computer and directly states that she does not want to.

Important things happen when people are able to reassert their authority and assume personal responsibility. It is important to understand that both must happen together.

Authority without responsibility can lead to belligerence. This type of situation gives us control without responsibility for our actions. Anybody in such a situation can quickly become a “little dictator.” Responsibility without authority can lead to anxiety and depression. How would you feel if you were responsible for all that was going on about you, but you had no say in events or decisions?

As individuals assume more control and authority for specific areas of their lives, they also assume responsibility for their choices. They begin to feel real and whole again.

Thoughts and actions have consequences which bring about new situations and opportunities. It is the difference between being in a simulation as opposed to actual situations.

In simulations we often act differently because at some level we know that the situation is not real and that it will eventually end. Also, simulations rarely contain all the intricacies and demands of a real situation. Sequences of events, reactions of people, and effects of decisions rarely occur with the same speed or intensity in simulations as they do in the real world. Many people talk about this distinction between simulations and actual situations as the sense of being alive.

People who have not had the opportunity (or simply have not taken the opportunity) to make choices for a while may need help and encouragement to begin doing so. They may initially be timid or afraid.

**Example of reassuming authority and responsibility:**

In one program in which participants took responsibility for most daily activities, almost every newly entering participant relied on others for basic decision making – even asking whether or not they could sit in a chair or move about the program’s space. Assured that these were their choices and encouraged to take matters into their own hands, each participant soon expanded their horizons and opportunities, making choices of where to live, how to get involved in community activities and establishing new friendships. For many participants this occurred one step at a time, assuming a little more control and authority, experiencing the responsibilities and
benefits that came with this authority, and then taking another step.

By following this process, most people established a balance of what they could do and where they needed help. In most situations this balance was different than either they or other people in their circles of support anticipated. People were more open to both feedback and assistance from others when they had participated in this collaborative process.

Additionally, many individuals demonstrated greater awareness of both their abilities and challenges because they had the opportunity to experience each repeatedly in daily – real world settings. Here they could directly see the results of their efforts. They also had the opportunity to receive feedback from others in a non-directive and non-judgmental manner.

Of course, there are some people who will presume full control and authority without assuming concurrent responsibility. Unfortunately, such people exist throughout society and few of them experience disability following brain injury! There may also be cases when individuals clearly do not see or are not aware of their limitations or their impact on others. In these situations, relying on “stop it” may work in the moment, but is not likely to establish collaboration on a long term basis. Time and patience are the keys, but we must respect everybody’s time and patience.

It’s important to find ways to work with the person of focus to attain common ground. There are times and situations when limit setting and management of a person’s daily affairs may be important, but overall success is more likely when such limits are set in collaboration with the individual. Finally, there are people who will require formal and active direction by others, but this point should only be assumed after inability of self-direction has been aptly demonstrated.
Summary

This chapter has emphasized the importance of respecting the roles and responsibilities of whoever program and support efforts are directed towards. For some people the concept of person first is so obvious that they assume it occurs naturally and assume the same of their colleagues. By not emphasizing its prominence they inadvertently contribute to its minimization. At the other extreme, there are people who find the concept foreign, ineffective or even dangerous. This may be based on their assumptions about a person’s abilities, the mandates of their organization or position, or because they find it personally threatening. For most people, the concept of person first programming lies somewhere in the middle. Unfortunately, this often places the person of focus in purgatory!

Of course, few of us can always claim to be the absolute President and CEO of our own lives. It just doesn’t work that way relative to our daily demands, responsibilities and the social and cultural pecking orders that we inhabit. But, for the most part, our relationships with others are based on our positive traits and abilities. Many of us have options, not always ones that we might like, to redirect different aspects of our lives. Many people who are identified by virtue of their disability lose this power and these options. Sometimes this occurs from the direct effects of impairment and disability, but more often it occurs because of presumptions about the disability. Then people become identified by what they can’t do rather than who they are. The resulting functional, behavioral and emotional deterioration is obvious. That is why it is so important to put person first first!

There are many different ways to promote person centered involvement including:

- Remember that the person who is the focus of our attention may not be the person with the brain injury.
- Get to know the total person and not just the problems or impairments.
- Make that person’s involvement in all meetings, service development and decision making the rule rather than the exception.
- Incorporate person first philosophy in all aspects of a program and not just during meeting times.
- Assume ability over disability until aptly proven otherwise. Then find another way to support opportunity!
- Find ways to sustain the person’s true participation and involvement when problems develop. Don’t use the event as proof of a person’s incapacity to participate. This might involve changing meeting formats, or involving advocates to assist the person, among other options.
- Let all parties, including the President and CEO of ME understand their responsibilities and create ways to monitor accountability.
- Respect the total context of the situation.

This chapter is a first step. In future chapters we will focus on strategies to communicate, identify realistic goals, create and assess change, incorporate and integrate people and resources into supports, how to maintain effective changes.

Workbook Exercise

Please turn to Section 13 of the Workbook. In this section you will identify the processes and impediments that presently exist for person first programming in the situation that you are involved in and strategies to improve this effort.