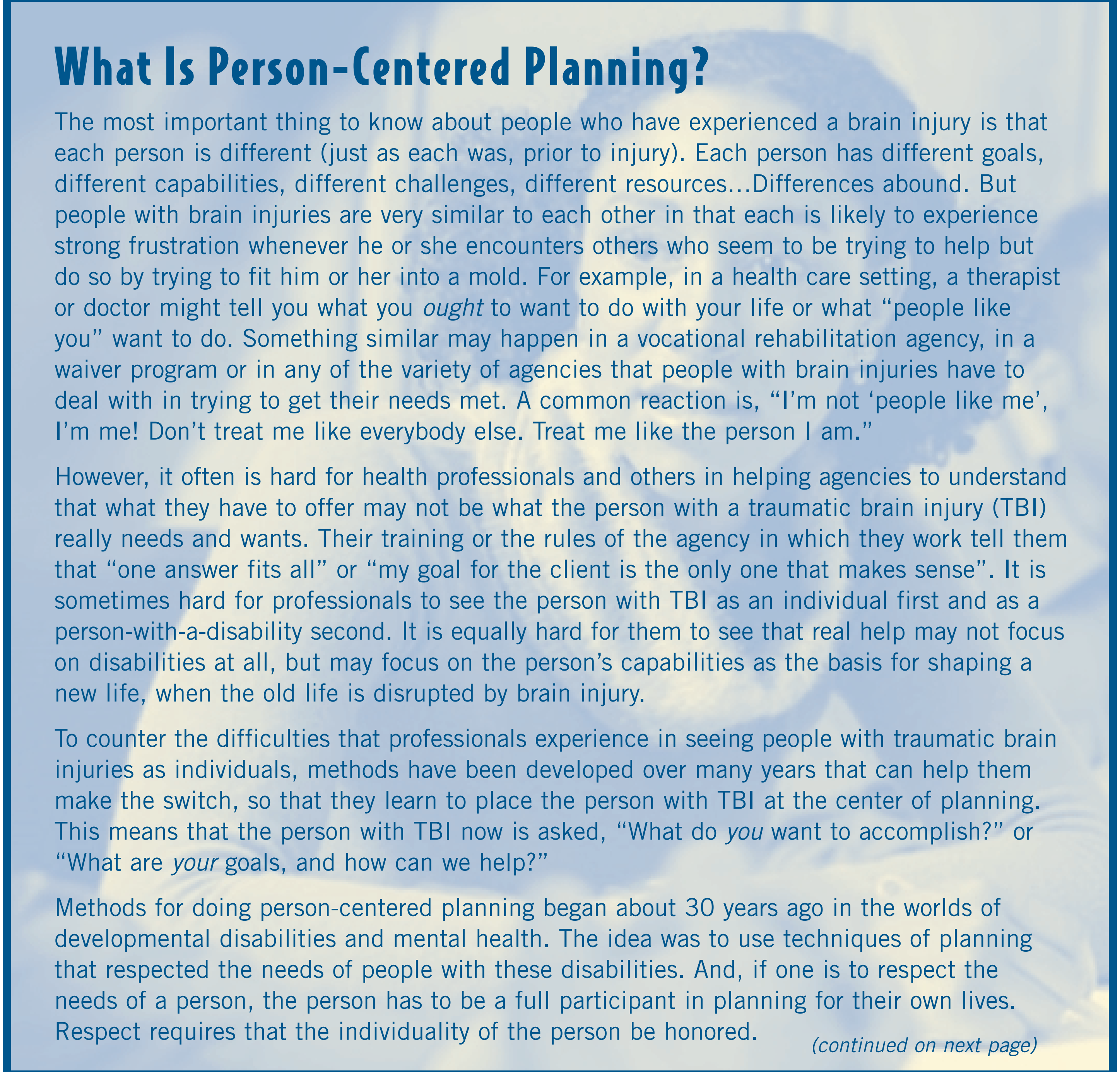
TBI
CONSUMER REPORT #8

PERSON-CENTERED PLANNING



What Is Person-Centered Planning?

The most important thing to know about people who have experienced a brain injury is that each person is different (just as each was, prior to injury). Each person has different goals, different capabilities, different challenges, different resources…Differences abound. But people with brain injuries are very similar to each other in that each is likely to experience strong frustration whenever he or she encounters others who seem to be trying to help but do so by trying to fit him or her into a mold. For example, in a health care setting, a therapist or doctor might tell you what you *ought* to want to do with your life or what “people like you” want to do. Something similar may happen in a vocational rehabilitation agency, in a waiver program or in any of the variety of agencies that people with brain injuries have to deal with in trying to get their needs met. A common reaction is, “I’m not ‘people like me’, I’m me! Don’t treat me like everybody else. Treat me like the person I am.”

However, it often is hard for health professionals and others in helping agencies to understand that what they have to offer may not be what the person with a traumatic brain injury (TBI) really needs and wants. Their training or the rules of the agency in which they work tell them that “one answer fits all” or “my goal for the client is the only one that makes sense”. It is sometimes hard for professionals to see the person with TBI as an individual first and as a person-with-a-disability second. It is equally hard for them to see that real help may not focus on disabilities at all, but may focus on the person’s capabilities as the basis for shaping a new life, when the old life is disrupted by brain injury.

To counter the difficulties that professionals experience in seeing people with traumatic brain injuries as individuals, methods have been developed over many years that can help them make the switch, so that they learn to place the person with TBI at the center of planning. This means that the person with TBI now is asked, “What do *you* want to accomplish?” or “What are *your* goals, and how can we help?”

Methods for doing person-centered planning began about 30 years ago in the worlds of developmental disabilities and mental health. The idea was to use techniques of planning that respected the needs of people with these disabilities. And, if one is to respect the needs of a person, the person has to be a full participant in planning for their own lives. Respect requires that the individuality of the person be honored.

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“I get so angry with my case manager. He thinks he knows what’s best for me, but never asks me, just goes ahead with what he thinks I need.”

“Sounds like my doctor. She looks at me and only sees my injury, not what I can still do.”

Many methods for doing person-centered planning have emerged over the years, but they have certain common elements[1]:

- First, planning involves not just the person with TBI (who we will call the "focal person"), but also friends, family members and others who are identified by the focal person as important to his or her life. This is often called "the circle of support".
- Second, the basic principle underlying all planning activities is respect for the focal person: it is his or her life, and it is his or her voice that has primacy in all activities of the circle of support.
- Third, a focus on capabilities and strengths replaces the usual 'tunnel vision', in which only the person's deficits and challenges are seen and then get defined as 'what gets worked on'. The focal person's challenges are not ignored, but they are not set at center stage.
- Fourth, the focal person's hopes and dreams for the future are the starting point for goals to be developed in the planning circle. A positive vision of the future is insured.
- Fifth, the plan that emerges from the circle of support (with the focal person still at the center) is a statement of priorities, with small action steps defined, as well as commitments from members of the circle of support. The focal person is alone neither in planning nor in carrying out the plan.

Our Research and Training Center (RTC) has been involved since 1993 in developing and evaluating methods specifically for doing person-centered planning with people with TBI. The RTC staff worked with Dr. Beth Mount in adapting techniques and materials she and colleagues had developed[2] for use with individuals with developmental disabilities. The adaptation was necessary as people with TBI who want to engage in person-centered planning differ in many ways from people with developmental disabilities; a key difference is that people with TBI who want to move on after injury have to deal with "who I was" in addition to "who I want to be".

Two basic tools for engaging in person-centered planning were published and disseminated by the RTC in 1998. These materials can either be used within any agency's planning efforts for people with TBI who they are trying to serve, or they can be used by people with TBI who, with a circle of supportive people, want to develop a plan for "Moving On" after TBI. The first tool is a workbook[3] that people with TBI can use to engage in person-centered planning; the second is a manual[4] for any person who takes on the role of facilitating the circle of support. These materials were revised in 2003 and are available now through downloading at no cost at the RTC's website.

What Can I Do to Start Planning My Own Life?

If you are a person with TBI who wants to plan a future for yourself, you can start by obtaining the "Moving On" workbook from the RTC website (or write us requesting a copy). You can review the basic ideas discussed in the workbook about planning for a better future, either alone or with a friend/family member. This review will give you a better sense of what person-centered planning is like and a sense of whether it 'fits' you. If it does, you have two choices:

- Phone your state Brain Injury Association (get the phone number from the national Brain Injury Association's website: www.biausa.org.) Ask them what agencies in your area might work with you in developing a plan. Call the agency or agencies they suggest to see if they will help you with person-centered planning. If they are willing, take the workbook with you when you visit the agency.
- If an agency is not available or is not willing to participate in person-centered planning, you can explore in your family and friend network whether someone will be willing to commit to work with you to develop and carry out your plan. Ask that person to read the "Facilitator's Manual" which can be downloaded from the RTC website or is available from the RTC upon request; this will give him or her a better sense of what you are asking him or her to do.

What Can an Agency Do to Develop PCP?

You should download both the "Moving On" workbook and the "Facilitators Manual" from the website. Review these materials to see if the RTC's approach to person-centered planning 'fits'. If you need additional assistance, contact the RTC for technical assistance, linking through our website. If our materials 'don't fit', a wealth of other approaches to individualized planning is reviewed in a recent article by Donnelly and Carswell[5].

References

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5. Donnelly, C., & Carswell, A. (2002). Individualized outcome measures: a review of the literature. *Canadian Journal of Occupational Therapy, 69* (2), 84-94.

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One Person's Experience with Person-Centered Planning

Claudia is a 55-year-old woman who was injured 10 years ago. She describes herself as spiritual, an optimist and a caring friend. Since injury, she has experienced great fatigue and short-term memory loss. But, from the start of her involvement in Personal Futures Planning (PFP; the type of person-centered planning developed by Dr. Mount) she expressed a strong desire to make life better. In the course of doing PFP, she defined this as being more involved in her community, going back to work, being able to manage her own finances, getting around on her own and becoming better organized.

The first members of Claudia's team were her sister Anne and her life partner Jim, who has been very supportive of her after TBI. As a minister, Anne is well connected in the community. Not surprisingly, it was Anne who helped Claudia with her goal of becoming more involved in the community, by finding a church where she felt "at home" and could actively participate.

Her support team wasn't large, but it was made up of people who loved and respected her. This was critical, as in the three-year period in which she engaged in PFP, Claudia had five different service coordinators coming into and out of her life. Nevertheless, she kept moving on with life and, in fact, has been able to take on most of the tasks typically managed by service coordinators. This skill was strengthened when Gary, a program director from a local service provider, was invited to join the PFP team to help her become better organized. Her growth in organizational skills was supported by her organizing and tracking information about planning, as a shared responsibility in PFP.

Claudia's team meets regularly, creating consistency for her and a continuing opportunity to bring her concerns to the team. One such concern was Claudia's need to find others with TBI who would be willing to share their experiences. A regional TBI resource person was invited to meet with the team, and, through her, Claudia found a support group that has become Claudia's connection to a wider support and resource network.

To assist Claudia in developing her skills in the community, her service provider agency supported cognitive group sessions, during the course of which group leaders noticed that she was adept in facilitating discussions. As a result, Claudia was offered a job working for the agency as a life skills counselor. Because agency policy required that all employees pass a CPR course, they accommodated her by placing her job on hold for several months while she studied for and obtained CPR certification.

Claudia is beginning to see life after injury as worthwhile, as she increasingly is getting the opportunity to, in her words, "use my brain". She had been immersed in a system that held low expectations and saw her in terms of her deficiencies, but now is surrounded by people who have strong but realistic expectations for her. Her upbeat attitude and enthusiasm for life are returning.

"I'm working with a circle of support to plan my future. It's hard work, but I think I can do it."

"With a little help from Your friends!"

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