Personal Futures Planning for Individuals with TBI

FACILITATOR’S MANUAL

2nd Edition

Beth Mount
Margaret Brown
Mary Hibbard

with
John O’Neill
Doug Riggs
The purpose of this Facilitator’s Manual is to introduce you to Personal Futures Planning (PFP). The “you” we have in mind is anyone interested in helping a person who has experienced a traumatic brain injury (TBI) to “move on”: to find a new direction toward a better life and to take the paths required to get there. We call this person a facilitator, meaning that your role is “helping with”, not “doing for”, an individual with TBI. While the person with TBI can serve as her own facilitator, our experience has shown that this role is better filled by someone else, since most people – brain-injured or not – approach something new with greater ease and productivity with a “little help from friends”.

This Facilitator’s Manual is divided into three parts. Part One helps potential facilitators understand what PFP is and whether PFP fits your values, skills and situation. The following questions are explored in Part One:

• What is PFP – the tools used in PFP and the values underlying PFP?
• What are the characteristics of a good facilitator of PFP?
• If you work within an agency, is your work environment likely to facilitate or impede the PFP process?
• Which individuals with TBI are most likely to benefit from engaging in PFP? (We will call this person on whom planning is centered “the focal person”.)

Part Two helps facilitators in the actual “doing” of PFP. This section describes what facilitators do to structure PFP to fit a specific focal person’s situation, techniques to help facilitators carry out their role, goals that facilitators need to keep in mind during the PFP process and steps facilitators can take to keep PFP an on-going process – to keep it directed and engaging for participants. A critical part of keeping the momentum going often includes problem-solving when “breakdowns” occur, such as the focal person’s loss of motivation, or rules and procedures of organizations that act as barriers to meeting the needs of the focal person.

Because such issues are so critical to success, Part Three covers approaches that facilitators have used to address breakdowns that threaten the focal person’s moving forward.

* We will alternate masculine and feminine personal pronouns throughout this text.
PART ONE: What Is PFP and Does It Fit You and Your Situation?

“PFP is an evolving structure for helping you examine where you are now, and to develop a plan or map which shows the way to a self-determined future. It is a design tool for identifying and infusing the positives in our lives and minimizing the negatives. It provides a template for designing a successful life journey. It may make the difference between just existing and real living, depending on our willingness to step out in directions we set for ourselves”. — a person with TBI

A. What Is Personal Futures Planning?

Personal Futures Planning (PFP) is a way of thinking about people with disabilities and about how they can create a better life for themselves. PFP offers procedures and tools for developing and enacting a plan to “get there from here”. In other words, the values underlying PFP have given shape to specific methods discussed in this Manual for assisting people with brain injuries move on. In defining PFP below, the tools and procedures comprising PFP as well as the values behind PFP will be described.

1. What Are the PFP Tools?

The values and assumptions discussed below are essential to PFP, as are the tools and techniques used in the doing of PFP. One tool is the idea of a facilitator to help in the planning process, which is further discussed throughout this Manual. The second tool is the idea of a planning team, including at times a variety of people who can help make things happen for the focal person. The planning team may be as small as two (the focal person and the facilitator) or quite large and may include parents, other family members, the spouse, friends, neighbors, clergy, representatives of community agencies and any other person needed in the process of helping the focal person move on to a better life. Planning teams are discussed further below.

Another key tool, which was developed for doing PFP with individuals with TBI, is a workbook called Moving On. The workbook provides a twelve-step guide, serving as a touchstone for all involved in helping the focal person, including the focal person himself. Moving On was written so that most individuals with TBI can understand it and, thereby, participate as fully as possible in the PFP process. In Part Two of this Manual, the paths in Moving On are explained for the facilitator. Suggestions and strategies are described to help facilitators use Moving On in planning for the focal person’s future.

2. What Are the Values Underlying PFP?

The core value within PFP is that the person with a disability is at the center of all planning efforts involving him. In a growing movement in America toward self-advocacy and self-determination, people with disabilities are changing the way they (and others) think about living life with a disability. People with TBI are becoming more vocal. Their message is clear: They are people, not disabilities, first. They seek re-engagement within the family, community and society. Those who want to support and facilitate this re-engagement have a helpful tool in Personal Futures Planning, because PFP is a person-centered approach to moving on in the world.

If you are a family member or friend of a person with TBI, you may be asking, “Who else would be at the center of planning?” However, if you work in a service agency, you may be
all too aware of the answer. Historically, in most agencies that serve individuals with disabilities, the person served has not been at the center. Instead, the system itself and what it has to offer is central. With PFP, in contrast, what the focal person envisions as a better life and his or her preferences and strengths lie at the center of PFP. The person-centered approach asks, “What do you want to do with your life?” System-centered approaches say, “Here’s what we have to offer (irrespective of what you may want or need)”.

The values that underlie PFP challenge long-held assumptions about people with disabilities. Below, each of four assumptions is discussed in terms of how person-centered thinking differs from traditional thinking, how traumatic brain injury affects each assumption and how these assumptions affect planning for the future.

a. How Is the Person with a Disability Viewed?

The traditional system-centered view of the person with a disability focuses on illness and deficiencies. The first phase in many programs, in fact, is to determine whether or not the person is deficient enough to qualify for services. Thereafter, the nuances of limitations, impairments, illnesses, problems and the like become the focus of evaluation and planning. This over-emphasis on problems and areas of incompetence suggests to the focal person that he or she is a “bundle of problems” or a “brain injury”. People report feeling torn apart by labels and service categories, which often hurt more than help.

In contrast, the person-centered view of the person with a disability focuses on reclaiming and rebuilding the person’s capacities and contributions. The focus remains largely on what the person with a disability can do, not on what he or she cannot do. At the same time, the limitations and complications of disability are not denied. The capacity-based view emphasizes interests, abilities, identities and qualities that the person desires to strengthen. The PFP planning process encourages the expression of these capacities in community living, while acknowledging the challenges associated with disability.

This way of thinking – focusing on capacities and not allowing limitations to define the person – often creates a “tension” when the focal person’s disability is TBI. The “TBI tension” that develops within PFP is that a balance must be achieved between building a capacity view and coming to terms with real limitations consequent to injury. Further, the person with TBI often has a strong attachment to her memory of life before injury. A desire to return to her “old self” may contribute additional tension to the process, in that it conflicts with the need to move on.

b. How Is the Focal Person’s Future Envisioned?

System-centered assumptions relegate the person with a disability to limited options for the future, often embodied in service programs that segregate people with disabilities from mainstream life. Within these settings, usually the only element in common amongst people served is the fact of disability – any disability, but disability only.

In contrast, the person-centered approach assumes immediate movement into the community, with supports as needed. People with TBI go back to work or school, to community participation, to contributing within their homes. They learn new skills and compensation for limitations. They start small, try new things, fail and succeed. In PFP, the future is seen as full of the ups and downs of living life in the mainstream.
The “TBI tension” in terms of envisioning the future is that, in generating ideas about moving on in life, the focal person may feel that the new vision represents downward rather than upward mobility. This tension is handled by seeking in PFP creative benchmarks toward outcomes that the person values, even if the first mark is a downward movement (in the context of who the person used to be). This initial benchmark provides an upward movement toward a life the person seeks. The facilitator emphasizes that going somewhere is better than going nowhere and that creative opportunities for movement can be developed.

c. Who Makes the Decisions? Who Is in Control?

Professionals make the decisions and typically offer limited options in system-centered agencies. The role of the person with a disability is to comply with professional prescriptions. The result is the status quo for the professional, but a loss of power and voice for the person served. The traditional dynamic leads to dependency on paid professionals, which becomes hard to reverse.

Person-centered thinking, in contrast, values the expertise of each person on the planning team, but, at the same time, encourages the person with TBI to make decisions about his life to the full extent possible. The facilitator’s role is not to prescribe the course of action, but instead to encourage cooperative planning and honest dialogue within the planning team, so that each team member can contribute maximally.

The shift in control of the PFP process, toward the individual with TBI and away from professionals, creates a third type of TBI tension. In this case, tension arises when team members are asked to take on new roles: more responsibility, on the one hand, or sharing control, on the other. The facilitator’s job is to help team members through the learning process demanded by their new roles. The person with TBI must achieve a level of insight that supports his centrality in decision making; professionals must learn new ways of contributing and how to share control; family members and friends must learn new ways of nurturing hopes.

d. How Receptive Is the Community?

One of the assumptions underlying system-centered thinking is that communities are rejecting and intolerant of disability. Segregation of people with disabilities is a “logical” reaction to this belief – a way to “protect” them from a “hostile” world.

The person-centered assumption is similar, but critically different. Community members do discriminate against those who are different. Exploitation does occur. Intolerance is a staple of our culture. However, the person-centered view of the community is that through hard effort and community building, parts of the community can become accepting and willing to make accommodations to support people with TBI.

The TBI tension arises in community building due to the fact that, because TBI is not highly visible, the person with TBI may easily enter community settings. However, when the individual’s cognitive or other disabilities emerge within community settings, understanding and accommodation may be more difficult for the community to achieve. The facilitator must manage the tension between creating access to community opportunities while at the same time creating supports for the person with TBI within...
those opportunities. The role is to arrange safety nets, as needed, within the mainstream world.

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In sum, within these values and assumptions, PFP encourages all people involved in planning – including the facilitator – to look beyond medical reports, technical labels, assessments, service categories and funding streams, to see a whole person working to get his life back on track again. The PFP process encourages the person with a brain injury to look beyond the confines of human service programs to imagine life again as a productive citizen in the community, struggling with new and old limitations, with the help of friends, family and supportive human service providers. PFP is the process through which this plan for a more satisfying life is developed and carried out. In the box on the next page, the characteristics of plans developed under PFP and within traditional ways of thinking are compared.

B. What Is the Facilitator’s Role: Who Makes a Good Facilitator?

The facilitator’s role is complex. The role will vary depending on the needs and capabilities of the focal person and of his social network. Sometimes the role includes introducing the idea of PFP to the focal person, deciding whether this person is a good candidate for PFP, helping organize the process so that it works for the focal person, recording “what happens” during PFP to aid the memory of all participating in PFP, encouraging all team members in doing what needs to be done and nurturing their motivation over time.

Facilitators may come from different parts of the focal person’s life. They may be professionals, friends or family members. Potential facilitators should ask themselves two questions. First, are your values compatible with doing PFP? Second, do you have the skills and strengths essential to the PFP process? The remainder of this section covers the values that are critical for PFP facilitators and the skill areas that are important in facilitating PFP. Once a potential facilitator has determined that her values and skills are suitable, specific preparation for the role is accomplished through careful study of the remainder of this Facilitator’s Manual and the Moving On workbook.

1. What Values Underlie the Facilitator’s Role?

The most important requirement for a facilitator is having enough interest in the life of the focal person to be willing to stick with the person and the PFP process over sufficient time to achieve results.

A second requirement is that the facilitator must believe that individuals with TBI can move on. Some people may believe that this is only rarely possible, if at all, for people with TBI. But, good facilitators avoid this negative thinking, giving themselves the freedom to work more freely and optimistically with the focal person and the planning team.

Finally, PFP is based on person-centered views of individuals with disabilities. A good facilitator of PFP is one who after reading pp. 3-6 can agree that person-centered ideas are congruent with her own values and/or experiences.
# CONTRASTING IMAGES OF THE FUTURE

<table>
<thead>
<tr>
<th>CHARACTERISTICS OF A TRADITIONAL PROGRAM PLAN:</th>
<th>CHARACTERISTICS OF A POSITIVE FUTURE WORTH WORKING FOR:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals focus on <strong>decreasing</strong> or changing specific <strong>negative</strong> behaviors of the focal person.</td>
<td>Images of the future contain examples of <strong>increasing</strong> specific <strong>positive</strong> activities, experiences and life situations.</td>
</tr>
<tr>
<td>The plan identifies program categories and <strong>service options</strong> that are often <strong>segregated</strong>.</td>
<td>The plan seeks involvement in <strong>valued roles</strong> in <strong>community settings</strong>.</td>
</tr>
<tr>
<td>Many goals and objectives reflect <strong>minor accomplishments</strong> that can be attained without making substantial changes.</td>
<td>Some ideas will seem unrealistic and impractical, and will require <strong>major changes</strong> in existing patterns of service and funding.</td>
</tr>
<tr>
<td>The plan for one focal person will <strong>look similar</strong> to the plans for other focal people.</td>
<td>These plans reflect the <strong>unique</strong> interests and qualities of the focal person, and the unique characteristics and life of the community.</td>
</tr>
<tr>
<td>These plans will probably not mention <strong>personal relationships</strong> or community life.</td>
<td>The plan <strong>emphasizes</strong> creative ways to focus on the development and deepening of <strong>personal relationships</strong> and community life.</td>
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2. What Skills Do Good Facilitators Have?

The facilitator must display the following skills:

- **Views the team as the primary problem solver**, does not have to have all the answers and encourages each team member to participate fully and appropriately.

- **Does not dominate the planning process**, but instead shapes the process and makes room for different points of view.

- **Listens to people**, actively seeking to hear what others have to say. In other words, he spends less time talking and more time listening.

- **Encourages dreams** and optimistic thinking of the focal person. A good facilitator seeks the seeds of hope in others and supports the growth of such hope. She is prepared to be a role model for living with hope, while keeping her own dreams out of the picture.

- **Validates the focal person’s feelings**, acknowledges the person’s grief and pain, and helps the focal person channel this energy into constructive action.

- **Is sensitive to individual differences** and shapes the PFP process to fit the focal person’s preferences, needs and expectations, as well as the focal person’s cultural background and other factors that affect planning for the future.

- **Provides honest feedback** and encourages the focal person to acknowledge and understand his mistakes and problems, defining this as an important part of moving forward.

- **Encourages the focal person’s taking action, responsibility and risks**. The facilitator helps but does not dominate the focal person. She encourages the view that failure is an opportunity for learning about oneself and possibilities for the future.

- **Is a good resource person**, having good knowledge of the community and relevant service systems.

Few potential facilitators will be highly skilled in all of these respects. But these characteristics are important. If you do not see yourself possessing many of these characteristics, you should probably decline the role of PFP facilitator.

If you are a potential facilitator who is an employee of a service-providing agency, you should read the next section of this Manual. Otherwise, skip now to Section D, “Who Will Most Likely Benefit from PFP?” (page 9).

C. Is Your Agency’s Environment Likely to Impede or Support the PFP Process?

First, PFP will flourish only in agencies that are open to taking **an individualized approach** to the persons they serve. This means paying more than lip service to “individualized plans”. Instead, the agency must view the individuals they serve as varied in their needs and then be open to developing responses that are shaped to fit the individual. It is not enough to explore and assess the strengths, problems and goals of the person being served and then respond only from the “menu” of services the agency has to offer – whether or not any of these services are appropriate to the goals and needs of the focal person.
Second, only agencies with staff who fit within the profile of qualified facilitators and who serve individuals who are ready for PFP (see below) should consider its use.

Finally, PFP is based on person-centered views of individuals with disabilities. As was true of good individual facilitators of PFP, suitable agencies will find that such views (pp. 3-7) are congruent with the agency’s philosophy or at least of the direction in which it is moving. A set-up for failure is trying PFP without sufficient support from those in charge of agency resource allocation.

D. Who Will Most Likely Benefit from PFP?

PFP is a time-consuming process that uses valuable resources, most importantly the time and energy of all involved: the person with TBI, the facilitator and all members of the planning team. A critical role of the facilitator is to decide if PFP is likely to benefit an individual with TBI, either one who expresses an interest in doing PFP or which of several “candidates”, amongst those who receive services from an organization, will most benefit.

Individuals with TBI who have participated in PFP feel that the primary criterion for doing PFP is the focal person’s readiness to plan for the future. Clearly, people experience brain injuries differently and traverse different paths of recovery. However, in general, immediately after injury the person’s priorities are placed on first stabilizing his physical condition and then returning to the community, only then discovering the “meaning” of the injury and its ramifications in day-to-day life. At some later point, PFP becomes relevant as the person feels ready to leave behind the “former self” – to move on to creating a new life.

In exploring a person’s readiness for PFP, the facilitator needs to consider the following:

• Is the person dissatisfied with parts of his life?
• Does he realize that all or some of the goals he once held are less likely to be realized post TBI?
• Is there evidence that the person has begun to identify and acknowledge the effects of TBI in terms of what has been lost, what is “still there” and what others have to say about his strengths and weaknesses?
• Does the person believe that change is possible? Does he believe that life can be better – with effort?
• Is there evidence that the person is willing to assume responsibility for creating and implementing a plan for moving on?
• Is the person willing to accept help from at least one person (the facilitator) now? Is he willing to work with a larger team, at least eventually?
• Is there evidence that the person will commit to “the long haul”, that is meet on a regular basis, participate fully in PFP and take steps in the community to carry out his plan?
In Part One we have presented the information potential facilitators of PFP need to explore in deciding whether PFP fits them and their situation. In Parts Two and Three, the PFP process is reviewed in detail, to give facilitators a clearer picture of how to accomplish their role.
PART TWO: Facilitating Personal Futures Planning

“PFP allows you to figure out where you’ve traveled from and where you wish to go. I look at PFP as a compass and a navigation chart that allows me to travel upon this river of life, rather than trying to navigate it blindly, which most of us normally do through life” – a person with TBI

Personal Futures Planning (PFP) is, in brief, a process in which the focal person and the facilitator meet together over time to develop and implement a plan enabling the focal person to “move on” in life. Often this involves a planning team (important people in the focal person’s social and community networks), using the workbook Moving On as a tool to help in developing the focal person’s plan.

Part Two of this manual comprises a guide for the facilitator. It first describes preparations facilitators need to make before initiating PFP with the focal person. It then explores the goals, strategies and challenges within each of the steps of PFP, to aid the facilitator during the course of doing PFP. An example of an individual with TBI – Charles – who participated in PFP is provided to illustrate the process.

A. Before Beginning PFP…

Structuring the Process

In Part One of this Manual, several questions were raised that must be addressed prior to initiating PFP (see pp. 3-10): Is the focal person ready for PFP? Are you likely to be a skilled facilitator? If you work in an agency, is it likely to be supportive of PFP? Once the facilitator has decided that these pieces are in place, additional issues need to be addressed, primarily who should be involved in the planning process for this focal person and how PFP meetings will be structured. To be noted here is that these decisions are person-specific. That is, the answers for one focal person may differ from those for another. PFP is a flexible process, which is likely to vary from person to person – in its structure, content and pace.

1. The Planning Team – Who Should Be Involved in PFP?

A key ingredient for success in PFP is the involvement of people who know and care about the focal person and who are important to his “moving on”. To the

Charles…

…is an eloquent, bright and compassionate man who had been seeking a focus for his life since his brain injury, which occurred over 25 years ago. Prior to injury, he was a college student headed for graduate or law school and was interested in economics, politics, social justice and teaching. Following a long recovery, periods of unemployment were punctuated for Charles by a variety of jobs that were either menial and unchallenging or required too many information-processing and organizational skills. These jobs ended, leaving Charles with a strong sense of failure. At the same time, Charles assumed a central role in managing his home, raising his children and supporting his wife in her work. He was active in his church and in the TBI self-advocacy community, where he discovered and participated in PFP. We will follow Charles’ progress in PFP throughout Part Two, to illustrate how PFP was structured and implemented for one individual with TBI.
degree that other people are involved, the focal person strengthens and deepens his relationships as well as expands the resources and opportunities available to him. The focal person can afford to be more hopeful with good social support. From others he can find strength and strategies for implementing his plans. The question that remains is, Who and how many other people are to be involved? Outlined below are two strategies or approaches for including others, which might be combined or alternated over time, as appropriate.

In one approach to PFP, autonomy of the focal person is emphasized. Thus, the facilitator and the focal person work together in developing the plan. The focal person then initiates contact with other people in his or her social and community networks to obtain whatever help is needed to implement the plan and find support. The planning team, in effect, is a dyad, who invite others into the process as needed. This is a good strategy when:

- The focal person strongly prefers to discuss her life with one person and seeks the privacy to do so.
- The focal person can ably speak for herself and reflect on her life.
- The focal person can comfortably initiate contact with both paid and unpaid support people, can ask for what she needs and is conscientious in follow-through.
- The focal person has a low dependency on paid human service workers and has a high level of control over her life.

If one or more of these factors is missing, the high-autonomy approach to PFP may fail, typically because key members of the focal person’s support network were needed during the full course of planning but were not incorporated into the process until too late.

In the second approach to PFP, the facilitator and focal person, at the outset, convene a planning team, who agree to meet over time to develop the plan and contribute to solving problems. This approach, with a multi-individual and highly engaged team, is a good option when:

- The focal person needs support in reflecting on her life and in communicating her ideas, preferences and hopes.
- The person needs assistance initiating contact with others, asking for help and following through on her commitments.
- The person depends on others, particularly paid staff, for support, and the quality of her life may be greatly affected by such support.
- Key players in the focal person’s life need help in communicating with each other and in coordinating their efforts, and at least some players can commit to meeting regularly.
- The focal person understands the benefits of people planning together.
- The facilitator is comfortable working with a planning group.

The facilitator and the focal person together decide on the appropriate structure for doing PFP. Making this decision can be based on informal discussions and/or on information obtained through using the first part of Moving On with the focal person. In Map One (pp. 16-18 of Moving On), the facilitator and focal person make a list of the most important
people in the life of the focal person, which may include family, friends and service providers. If the focal person cannot speak easily for himself during this initial step, the facilitator has good evidence that a highly engaged, multi-individual team is more likely to succeed. In such cases, to help identify who should be involved in the planning team, the facilitator needs to then contact those who are closest to the focal person. (“Planning teams” refers throughout this Manual to both the dyadic and the multi-member approaches described above.)

2. PFP Meetings – When and How Often to Meet?

As part of the structuring of PFP, the facilitator and the focal person also decide when to bring the planning team together. They may choose to meet often at first and then less frequently at a later stage. They may find that the pace of meeting feels too slow, so that additional meetings are added. In any case, “how often” to meet and “how much to accomplish” at each meeting must be individualized to fit each situation.

All PFP participants need to be fully aware that developing and implementing a plan takes time – a chunk of time for each meeting as well as for follow-up actions, which may continue for the months (or years) needed to achieve the goals incorporated into the plan. The time commitment will vary greatly, depending primarily on the ability of the focal person to work on her own plan and on the resourcefulness of team members.

3. How to Facilitate Meetings – General Principles

Once the PFP process has been structured to fit the focal person’s and facilitator’s needs, the facilitator should think through his general plans for facilitating each meeting. The following ideas, which largely focus on multi-member teams, provide a start in such strategizing:

• **Use Moving On to provide a “script” for meetings.** Each of the 12 maps of Moving On lists questions that will help planning teams address the objectives of PFP and to complete the respective maps. The facilitator uses these questions to help keep meetings on track. But, as discussed at length in the next section, answering these questions only provides a means for achieving the real goals of PFP. Nevertheless, Moving On should be available to all team members, so that they can see in black and white the primary topics of each meeting.

• **Plan each session in advance**, by meeting with or calling key people, particularly the

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**Structuring PFP for Charles**

Charles asked to be involved in PFP in hopes that it might help him get a better job. He and the facilitator started with a high autonomy approach to PFP, as Charles preferred privacy and was skilled in self-reflection. Charles met with the facilitator every three weeks for about two hours for a period of three months. He left each session with a “to do” list of follow-up activities, which often included reaching out to others. He initiated the involvement of others in a variety of ways. He included his wife by telling her about each session and asking for input. At one point, she wrote a compelling list of his strengths and contributions to the world which he brought into the session. He also included the men in his church in thinking about his life goals. He worked with a college professor to help get information on continuing his education.
focal person, to discuss the agenda for the meeting. Clarify whether others have items to add to the agenda. Also, it is helpful to facilitators to keep a notebook for jotting down ideas and recording important directions emerging during the course of meetings. This notebook should be reviewed prior to each meeting.

- **Design meetings to include the focal person and family members as much as possible.** One way to do this is to select a meeting place and time that is most accommodating to the focal person and key members of the planning team. Suitable settings for team meetings include homes; meeting rooms in libraries, community centers or churches; or even a coffee shop or restaurant. Meeting in a convenient community setting can help optimize participation and create a relaxed atmosphere for exploration. Another inclusion-promoting strategy is to design a clear role for the focal person and provide assistance, as needed, to help her take on this role successfully. Finally, the facilitator might arrange for assistance or support needed to assure participation of key family members.

- **Many facilitators prefer to work with a partner,** as co-facilitators provide mutual support. If this choice is taken, the facilitator should look for someone with whom she can work easily and who complements and enhances her approach to facilitation. Prior to meetings, co-facilitators need to arrange time for pre-planning and post-meeting debriefing. Part of pre-planning is dividing the facilitator’s tasks.

- **Set time limits,** that is, clear boundaries for the beginning and ending of meetings. Effective time management includes beginning each meeting with a clear agenda; calling members together within the first ten minutes of start time; bringing others into the process as they arrive; and setting a clear ending time for the formal meeting (a maximum of two hours), while inviting people to stay afterwards to visit informally if they choose.

- **Make people feel comfortable** by introducing all new team members to the “veterans” at the outset of each meeting. Then review the agenda for the meeting and briefly summarize events that led to this particular meeting. Find personal ways to help each person join into team activities. Finally, providing light refreshments (coffee, soda and snacks) during meetings may help ease communication.

- **Make and keep a record of the meetings.** PFP is not intended to produce paperwork. However, an accurate record is important. Part of this includes the 12 maps that emerge from the Moving On workbook. In a notebook, facilitators should also keep track of any ideas, discussions and actions to be taken that are not part of the maps.

- **Help translate professional jargon** into common language. Ask members to explain any acronym used. And, translate technical words, bureaucratic categories and other labels and phrases that are not commonly used by the general public. Serve as a model for using simple words.

- **Summarize key points,** for example, when changing from one topic to another, before taking a break and at the end of the meeting, to help people stay focused, set priorities and commit to action.

- **Use graphics to facilitate the team’s understanding.** Information collected during PFP meetings can be organized and portrayed using group graphics, a process designed to assist people in groups work together, share goals, remember commitments and solve
problems cooperatively. The facilitator records the comments of the team using colors, symbols and words on large pieces of paper, resulting in “pictures” that illustrate the dynamics in the focal person’s life. One helpful technique is to use at least three colors to code information: positive experiences and opportunities are recorded in green, negative experiences and barriers are recorded in red, and basic information and strategies are recorded in blue. Color-coding helps people identify patterns within the opportunities and barriers depicted and share this recognition within the team. This manner of discovery can help the process of team dialogue and reflection. Color coding and graphics are tools that can help in putting the pieces of a person’s life together to see new patterns and possibilities. However, if these tools get in the way, don’t use them.

B. Facilitating the PFP Process

This section is aimed at helping facilitators use Moving On as a guide in the process of doing PFP. Moving On was designed to be used by the planning team, including the focal person (in fact it was written so that the focal person could read it and initiate the planning process). It is divided into four sections and adopts a theme of taking a journey. Each of the major sections of the journey is referred to as a path, and within each path three maps are to be completed as part of PFP. In this journey, the planning team gathers information about the focal person and uses it creatively to assist in developing a vision of the future and a plan for getting there.

Given the four paths and the task of completing three maps within each path, one could approach PFP as a simple process of completing 12 maps. The questions listed with each map provide an aid to the PFP process: they help frame discussions that lead to completing each map. However, PFP will not fulfill its promise if the goal of each planning team meeting is “to complete a map”. Instead, the facilitator and team need to keep in mind, in completing each map and in attending each planning meeting, what the real goals are.

This section of this Manual is designed to help facilitators go beyond what has already been provided in Moving On. It focuses on the types of information facilitators should be trying to help generate at each path, how to address problems that are likely to arise and, in general, asks facilitators to think “beyond” the completing of each map, to the goals toward which the planning team are working. Thus, completing the maps is simply a visible exercise that helps accomplish basic goals to be achieved within PFP. Below, for each of the four paths of PFP (Beginning My Journey, Expanding and Deepening My Relationships, Redefining Myself, Realizing My Vision), we have described the goals to be accomplished on each path, ideas the facilitator may use in addressing the goals and common stumbling blocks or challenges encountered within each path.

1. THE FIRST PATH: Beginning My Journey

a. Goals of The First Path

At the obvious level, this path – Beginning My Journey – includes three maps that help the focal person and facilitator get an idea of where the process might be going and who can help:
Map 1, “People Willing to Listen and Help”, begins to define the most important people to involve in some way in PFP.

Map 2, “What I Want to Change in My Life”, helps clarify the most urgent problems and issues the focal person wants to change.

Map 3, “My Hopes”, begins the process of creating a positive vision for the future.

As a result of The First Path, the planning team develops a rough sketch of where the person wants to go with his life and the people who may be able to help him get there. The goal is dual: to begin to get to know the focal person and his life situation, as a basis for developing a plan, while at the same time, to affirm the focal person’s hope that he can, indeed, “move on”.

b. Discoveries from and Strategies for The First Path

The maps in the workbook and the task of completing them provide a framework for discussion within the planning team. As noted before, for each map in Moving On, a list of topics and questions are listed, which the facilitator and the planning team will use to organize discussions within the planning meetings. Much will be discovered about the focal person in these task-centered talks, particularly if the facilitator and team keep the goals of this path in mind.

The planning team may be surprised by the many things learned about the focal person by pursuing the questions associated with the three maps of The First Path:

- The large number of people to include at some point in the planning process, on the one hand, or a discouraging absence of people involved with the person.
- The conditions and hardships that the person feels powerless to change or, in contrast, the high level of optimism that the person holds for his future.
- Knowledge of the cognitive and emotional challenges associated with brain injury: problems in memory, information-processing, executive functions and/or mood, which provide a basis for adapting the PFP process to fit the person’s current cognitive problems or, in contrast, residual assets that can be strengthened in PFP.

In the process of carrying out the information-gathering tasks of The First Path, the facilitator needs to remember the second goal of this phase of PFP: validating the focal person’s hope that life can change. The following are a few approaches to providing support that encourages information sharing while reinforcing hope:

- **Affirm the important people.** Facilitators can help the focal person value and appreciate the people she relies on for emotional and instrumental assistance. The focal person may have found that some relationships became stronger after injury or that more meaningful connections with others have been created during the healing process.

- **Explore losses and opportunities to rebuild.** The focal person may feel discouraged by the loss of relationships after injury. Facilitators should offer an accurate description of the losses as well as encouragement, including ideas about new ways to build connections. (The Second Path of PFP reinforces the relationship-building discussion started here in The First Path.)
• **Link the focal person’s experience to the wider disability community.** The focal person may find it helpful to know that rejection, loneliness and social isolation are common experiences for people with disabilities, and yet people with disabilities are changing this condition by becoming valued citizens in community life in a variety of ways. PFP is one way to change patterns of rejection.

• **Reassure the focal person that PFP will help reorganize her life.** Facilitators can help people understand that a brain injury often affects the part of the brain that helps people plan and organize. People can be reassured that PFP serves as an adaptive strategy to help them compensate for impairments in the executive functions. The facilitator acknowledges the confusion the focal person may feel while at the same time offering an adaptive strategy and a clear focus for taking action.

• **Stay focused on things that can change.** Hopes for the future may include concrete personal agendas (e.g., returning to school) as well as hopes that require a change in social policy (e.g., changes in disability benefits programs). The facilitator should validate both immediate and long-term goals by helping people see how they can take immediate action toward the things within their control and join with others to work on social change.

### c. Challenges on The First Path

As the facilitator is clarifying information while affirming the focal person’s hope, she also faces challenges in the process:

• **Managing the balance between real and false hope.** Team members, including the facilitator, may feel overwhelmed by the scope and intensity of the focal person’s hopes, feeling inadequate to respond to dreams that require intensive and/or impossible efforts. The focal person may feel depressed by the gap between where he wants to be in the future and where he is now. Although “grand hopes” may create anxiety of different types, it is best, nevertheless, to begin with idealistic intentions, because ambitions are inevitably diminished by reality. An effective facilitator will both listen to the “big ideas” and help direct realistic action toward implementation. In The First Path, the planning team can affirm hope by letting dreams emerge and by avoiding the unrealistic belief that either the dreams of the focal person are the facilitator’s responsibility or that they are the end points of PFP. The focal person and planning team often benefit

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**The First Path for Charles**

The facilitator began PFP with Charles by discussing the people that he could really count on. Charles identified his wife and children as the most important support people, and his positive involvement in his family was a constant thread of competence and success in his life. He reported a conspicuous absence of service providers in his life, which led to a long discussion of his failure to find a constructive response from most human service agencies. Charles had been offered a steady stream of vocational options that did not reflect his interests or abilities. Vocational evaluations and work trials added insult to his injury by casting him into situations that he experienced as painfully demeaning and dehumanizing. The discussion helped us to focus on his desire to change his long-standing pattern of vocational failure and to clarify his hopes for a job that better matched his interests and abilities, in an environment that offered greater dignity and respect than he had found in the past.
from knowing that PFP begins by generating many ideas and possibilities, and that a clear and feasible pathway for action will ultimately emerge from the process.

• **Managing differing agendas.** Often the hopes and the dreams of the focal person differ from the agendas of others. The facilitator should recognize each team member’s agenda and help get all agendas on the table. The facilitator must work to help the team and focal person find a “middle ground” that brings everyone together with a common focus, otherwise the process will break down. Planning team members often benefit when reminded that different agendas and ideas are okay and that the team will ultimately find a common ground to which they can all contribute. In some situations, the facilitator may need to meet with a team member separately and then bring the team together, as a common path emerges. Sometimes, the facilitator may need to take the lead in suggesting a middle ground.

• **Bringing more people into the process.** In other situations, in which the facilitator feels like the only person on the team who is seeking to stimulate and respond to new possibilities for the focal person, she may need to spend more time supporting others on the team to assume more responsibility.

2. **THE SECOND PATH: Expanding and Deepening My Relationships**

a. **Goal of The Second Path**

Throughout The Second Path, the facilitator seeks to understand, build and **strengthen the focal person’s relationships** so that other people will be there to listen, respond and solve problems over time. The purpose of this path is to continue to get to know the person and to look for opportunities to build relationships:

- **Map 4**, “My Current Relationships”, provides a listing of **all** the people in the focal person’s life.
- **Map 5**, “‘Ins’ and ‘Outs’ of My Relationships”, creates an opportunity for the focal person to reflect on the impact of brain injury on the relationships in her life.
- **Map 6**, “Working on My Relationships”, provides an opportunity to generate strategies for building and strengthening the focal person’s relationships.

b. **Discoveries from and Strategies for The Second Path**

As noted previously, each of the three maps of The Second Path are completed through having the planning team use the questions listed with each map to help frame their discussions. As a result of completing these maps, the team discovers more about who and what really matters to the person, such as ethnic and religious ties and identities, long-standing and significant relationships and possibilities for connections to nurture in the future. The Second Path also often reveals important information necessary in moving ahead in PFP: who else to include in the planning process and how to adapt the process to ensure the participation of essential people. In creating each of the maps of The Second Path, the facilitator actively seeks information about the focal person’s social network that highlights **opportunities** and **obstacles**:

- Which relationships are to be safeguarded, built upon and strengthened?
- What opportunities exist to strengthen immediate or extended family relationships?
• Which professionals are clearly allies and helpers?
• Can professional staff from the focal person’s past become involved in non-paid relationships?
• Do “movers and shakers” exist in the focal person’s network – those who have a good understanding of the local community and get things done?
• Are there people near the outer edge of the social circle with whom the focal person may want to strengthen her involvement?
• Has the focal person made contact with other people with disabilities?
• Which people make things worse?

The discoveries from The Second Path provide a foundation for a deeper discussion of complexities and challenges related to building relationships, asking for and giving personal support and struggling with feelings related to loss in both social life and relationship-building skills. The facilitator can use this path to work on some of the following issues:

• **Opportunities to realize that relationships exist.** As a result of developing the relationship map, the focal person may discover that she has many more people in her life than she thought.

• **Opportunities to improve relationships.** The focal person will see that he can build relationships with people he already knows by working at it and that he can ask people to get involved in his life in a variety of ways.

• **Opportunities to label poor relationships and “let go.”** The focal person may realize that she had relationship troubles before her injury as well as after. Sometimes the injury provides an opportunity to “let go” of problem people and

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**The Second Path for Charles**

Following the first session, Charles asked his wife to make a list of his interests, abilities and strengths. She responded by writing a beautiful letter to him about his contribution to their family and the many other qualities about him that she appreciated. This letter was particularly significant to Charles because he had deeply doubted his ability to contribute to his family as a result of his injury and his poor job history. The letter served as a reminder that he had clearly compensated for his inability to be the primary breadwinner by being a loving and devoted husband and father. His wife had excelled in her work, and his children were equally successful. He was able to see his significant contributions to his family and to value his caring and commitment to them. This insight shed new light on his otherwise dark view of his inadequacies.

In the process of obtaining a detailed picture of his relationships, the facilitator learned that Charles was also an active member of his church, serving in a variety of fellowship and leadership roles and that his religious beliefs and affiliations were highly important to him.

The Second Path helped Charles see the many ways that he was a competent husband, father and community participant. He was able to see that he had “given” as much or more than he had “taken” from his family. To some degree, he was able to make meaning of his job failures when he recognized how valuable his contributions had been within his family. These insights seemed to lay the foundation for “moving on” to the next task: looking hard at job issues and finding some new directions for work.
habits and build more positive connections and activities.

• **Grief over lost relationships.** The focal person may be overwhelmed with significant and diverse losses in his social network. These painful insights can be softened by the promise of building a new life through PFP.

• **Opportunities to balance interactions between people.** As a result of the injury, typical patterns of reciprocity and autonomy may have been disrupted. The injury and consequent dependency may cause the focal person to feel that she is taking more than her share of people’s time, attention and resources. She may be reluctant to ask for more help or may be disappointed and angry about the limits of other people’s good will. These dynamics are important to explore and may lead to new ideas about how to regain a balance in the interactions between people.

• **Opportunities to take constructive action.** The facilitator can help the focal person by focusing on actions to build and strengthen relationships. The facilitator can encourage the person to take risks, to ask more of people and to find ways to “give back”. The focal person can finish The Second Path with a very clear understanding of his current relationships and good ideas about how to change problem situations.

c. Challenges in The Second Path

The facilitator may be challenged to respond to some of the following tensions and difficulties that may arise during this phase of PFP:

• **No one is there for the focal person.** When the focal person is very isolated, the facilitator should take an active and central role in the planning process. The facilitator may choose to pause in PFP at the end of The Second Path to focus solely on relationship-building, before taking on the final two paths of PFP, because of the importance of other people to the focal person’s “moving on”.

• **The focal person is uncomfortable with disclosing his injury to others.** Many people with brain injuries are hesitant to build relationships outside the TBI community because they are not sure how much to disclose about their injury and consequent lifestyle changes. A facilitator can help role-play potential new situations and encounters to help the person find a comfort zone of relating and disclosure. This exploration happens best over time, as people take risks and experiment with new social situations and encounters.

• **The focal person’s social life is highly segregated.** Individuals with TBI often find strength and comfort in relationships with other people with TBI, who may be allies in that they face similar struggles. These relationships can, however, be a hindrance if such ties prevent the person from developing a wider circle of support. The facilitator can directly involve the focal person’s close friends with TBI in PFP, while also urging the focal person to explore new connections and situations.

3. THE THIRD PATH: Redefining My Self

a. Goal of The Third Path

The Third Path is designed to help the focal person clarify who she is now so that she has a better picture of her strengths, interests and capacities as well as the problems and limitations that challenge her:
Map 7, “My Interests and Strengths”, provides an opportunity for the focal person to reflect on her interests and abilities, both in the present and prior to brain injury.

Map 8, “My Challenges and Problems”, helps the focal person name the problems and difficulties she faces both now and prior to TBI.

Map 9, “Who I Am Now”, challenges the focal person to make five to ten statements that best describe the capacities and interests in life that she most wants to build upon and expand.

The goal of The Third Path is to identify “capacity themes”, that is, the themes in the focal person’s life that he will seek to build upon and strengthen as he develops a plan for the future. This path also helps clarify the supports that are needed to help the person compensate for functional losses resulting from the brain injury.

b. Discoveries from and Strategies for The Third Path

Finding capacity themes is the major goal of The Third Path. When describing themes in the focal person’s life, the facilitator seeks to identify patterns, such as the focal person’s skills, ethnic and family traditions, environmental and setting preferences and personal habits that shape the person’s participation and other qualities that are appreciated by others.

In addition to the usual aid of the questions associated with each map, the Skill and Identity Clusters described in the box on p. 22 may help facilitators find capacity themes in the lives of the focal person. These are capacities the planning team will seek to strengthen in building the futures plan.

Opportunities for insight in this path happen as a result of discovering patterns in the information compiled in Maps 7 and 8, which are summarized in Map 9, when the planning team makes a list of statements that best describe the person as she is now. The facilitator uses The Third Path to focus on the following issues.

• Identifying patterns in personal qualities, interests and abilities both before and after brain injury. The Third Path provides an important opportunity to help the focal person see her capacities. The process of listing the focal person’s qualities, interests, skills and abilities from before and after the brain injury leads to a greater understanding of the person and by the person, which is a key to “moving on” after TBI. All involved can better see how the focal person saw himself before brain injury, how he sees himself after TBI and currently. The facilitator plays a key role in helping the focal person see the capacities that have endured. An effective facilitator re-frames these capacities in a way that retains a link to the past while embracing the realities of the present. Summary statements about capacities help a person see that all is not lost and find new hope for the future. An effective facilitator helps restore hope, but not in a way that romanticizes the past or present or minimizes the struggle required to build new options.

• Clarifying that life was not perfect before brain injury and that new opportunities may arise after. The discussion of challenges and problems both before and after TBI help prevent a romantic regression into wishful thinking about the past. During the discussion of life before the injury, the focal person may realize that life then was filled with struggle, and that some of their pre-TBI lifestyle choices were troublesome, if not destructive. Sometimes the focal person realizes that the injury forced a self-evaluation of
Skill and Identity Clusters
That Inform a Capacity Description

Skills, or potential skills and interests
Using one’s hands: assembling, using tools, fixing, repairing, building
Using one’s body: being physically active, outdoor activity
Being helpful: being of service, showing sensitivity to others, drawing out people
Using artistic abilities: singing, fashioning, shaping things, dealing with colors, conveying feelings through body or voice
Using analytical thinking: organizing, classifying, putting things in order, comparing, evaluating, reviewing
Using leadership: selling, promoting, persuading, leading, directing, creating
Using follow-through: using what others have developed, attending to details, recording, filing, classifying

Social identities that are important to the focal person and/or his family
Trade or work identities: being a teacher, a lawyer, a repair person, a beautician, etc.
Ethnic and religious identities: African American, Asian, Hispanic, etc.
Avocational interest identities: sports, music, sewing, singing, politics, bird watching, collecting, etc.
Appearance identities: uniforms, badges, name tags, formality or informality of dress, grooming standards

Environments and settings that resonate with the focal person
Noise and movement levels: quiet vs. busy places
Ethnic places: places where people speak the same language, share similar beliefs
Familiar places: places within walking distance, places where people know you
Standards of efficiency and perfection: perfectionistic vs. “loose”, repetition vs. task variety

Personal habits that affect community participation
Activity levels: morning people vs. night people, high energy vs. sedentary
Health issues: medications, stamina, pain
Disability issues: sensory and physical impairments, adaptations
Structure preferences: high or low structure, fixed or flexible routines

Personal qualities to appreciate and enhance
Being: observant, calm, funny, loving, caring, energizing, kind, “brings out the best in others”, smart, sensitive, effusive, tolerant, wise, spiritual, challenging
Being an: activist, seeker, rebel, peacemaker, protector, teacher, preacher

lifestyle choices that led to a healthier life. If such insight results from this exercise, positive momentum for moving on is increased. The facilitator plays an important part in exploring these lifestyle issues and identifying potential opportunities.

• **Deepening understanding of the frustrations resulting from brain injury and finding additional supportive strategies.** Although a capacity view is emphasized in PFP, an effective facilitator does not deny or gloss over the real limitations and frustrations caused by the injury. The facilitator helps clarify the person's functional difficulties and explore new strategies for support and compensation. An effective facilitator puts the ideas about needs for support together with ideas about the future, so that the focal person sees his strengths, as well as the needs for supportive strategies.

c. **Challenges in The Third Path**

• **A distorted view of the focal person's abilities and challenges.** If the focal person feels hopeless because of past failure and self-doubt, it may be hard for her to accept any positive information about her potential. In contrast, another focal person may only see potential and may be unable to accept the limitations and constraints caused by TBI. The facilitator comes to reflect a balanced view of the focal person by getting to know the person over time in a variety of situations. The facilitator also brings other people into the process to provide additional constructive feedback. A capacity view of the focal person

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**The Third Path for Charles**

The discussion of Charles' interests and strengths helped him focus on his vocational goals. The facilitator helped Charles review his job experiences by helping him build a “green list” of experiences, settings, skills and tasks that were positive and worked for him, as well as a contrasting “red list”, summarizing both his problems and experiences that had not worked for him. Following a general overview of his work and volunteer experiences, the facilitator and Charles reviewed a file of performance reviews from his various jobs and vocational evaluations. Charles was able to reflect on these reports with honesty, humor and insight about his persistent accomplishments and consistent failures. The facilitator listened for information that related not only to the skills and abilities required of each job, but also to clues about his work environment, co-worker relations, job status (or lack thereof), hours and work load.

This reflection led to a list of summary statements describing his consistent strengths and interests and characteristics of jobs that seemed most fitting for him. Thus, the team saw that Charles has a strong sense of social justice and a deep interest in helping other people. One of his most frustrating jobs was processing insurance claims in a hospital setting. While he had great difficulty with the information processing aspect of the job, he loved the opportunity to help patients solve their problems. In fact, in many areas of his life Charles expressed a strong desire to be engaged in a caring role with others. His religious community and faith also served to validate his interest in serving other people in need. Charles had been frustrated in jobs that were either too menial or jobs that required moderately complex information processing. As Charles came to value his desire to work in a helping profession, he began to explore job openings in human service settings and in possibly continuing his education in a social work program. The next phase in the process was finding a focus for his future and organizing and defining the steps to help make it happen.
evolves and changes over time as the focal person learns more about herself, as everyone involved gets to know each other and as the focal person tries out new experiences. An effective facilitator manages the learning process by bringing the right people together over time and integrating their perceptions to form a common understanding of the focal person.

• **Conflicting views of the focal person’s abilities and challenges.** The potential for conflict increases when more people are brought into the planning process. The facilitator is often challenged to mediate the conflicting views and perspectives of the focal person, family and service providers. The facilitator can usually integrate conflicting views as part of the information-gathering process. She reminds the planning team that everyone has a unique perspective and that the planning process helps bring everyone’s ideas together into a common understanding. However, in some situations, the perspectives may be so different or the conflicts may be so heated that the facilitator decides to use other strategies. For example, the facilitator may choose to meet each party separately and then present these views, both similarities and differences, back to the team. An effective facilitator defines a common agenda that is likely to be shared by all parties as a focus for action.

• **Capacity themes before and after the brain injury are hard to find.** Capacity themes may be difficult to identify when, for example, the person may have been injured early in life and has few successful life experiences on which to build. Other focal people may be severely limited because of physical or medical complications or serious, life-defining social problems. Sometimes the facilitator lacks the experience needed to identify capacity themes and consequent areas for development. In any of these more complex situations, the facilitator may be too close to the situation to step back and see other possibilities. In these situations, facilitators may find support they need by working with a partner, a mentor or a person with more experience and a degree of detachment.

4. **THE FOURTH PATH: Realizing My Vision**

“This process has confirmed for me the magic in identifying some goals for yourself and going after them. I’ve noticed that when people identify what they want, the universe seems to provide the resources. When we decide to set some goals and to quit being stuck, then all of a sudden the pieces of life start coming together” – a person with TBI

a. **Goal of The Fourth Path**

During The Fourth Path, the planning team seeks to bring all prior discussions and explorations together into a vision for the future and an action plan with specific strategies and commitments to action over time:

Map 10, “My Vision”, challenges the planning team to record the focal person’s dreams for the future, based on all prior maps and discussions.

Map 11, “My Action Plan”, requires the development of a plan for taking on short-term and long-term goals: the actions to be taken and assignment of responsibility for each.

Map 12, “Keeping Track and Keeping Moving”, is a structured repetition of carrying out the action plan, reporting on progress and developing new strategies to
accomplish the focal person’s vision.

b. Discoveries from and Strategies for The Fourth Path

The focal person’s vision is a summary of the experiences the person wants to increase, making the most of the opportunities and capacities found in:

- The interests and characteristics of the focal person;
- The resources and richness of the person’s family and community;
- The connections and support of family, friends and others; and
- The resources and opportunities in service supports.

Developing a positive vision of the future provides an opportunity for people to use their imagination to generate the most creative ideas possible. These ideas are inevitably shaped by the barriers and obstacles (and unexpected opportunities) of reality, but it is critical to begin the journey of change with the highest vision possible. The initial vision provides a menu of possibilities from which the planning team will choose both immediate priorities and a long-term focus, both of which require a detailed action plan outlining concrete strategies and personal commitments to those strategies.

The planning team helps the focal person focus his ideas and hopes into a vision by integrating the information from the other maps into a coherent set of ideas and actions. The team’s input and values significantly shape the development of the focal person’s dream and provide images of the future that help the focal person:

- Increase his presence in community life,
- Expand/deepen friendships,
- Enhance his dignity and reputation,
- Increase the choices and control that he has in his life, and


The Fourth Path for Charles

Charles obtained a job even before The Fourth Path. Consequently the facilitator used this phase of PFP to critique the new job and brainstorm how to make it even better. Charles began working in an entry level position for a large human service agency that supports people with developmental disabilities. The job offered less than perfect hours and responsibilities, but the long-range prospects of career development in the agency matched his emerging sense of himself. At about this time, Charles was chosen as the Employee of the Month, which affirmed his competence and contribution in his new role. The recognition gave him the confidence to seek another position within the agency with better hours and more training opportunities. As his track record was demonstrated, he realized he could look for better jobs in other human service agencies as well.

As a result of Path Four, Charles developed a long-range vision of where he hoped to be in three years, as well as a short-range plan of how to improve his current job. Charles also explored his options to return to graduate school to work on a social work degree. He decided to wait until his two children were out of college before beginning graduate work. In the meantime, he began to explore programs offered and scholarship options. Charles and the facilitator continued to meet about once a month for four months to continue to review how things were going, to problem-solve and to refine his vision.
• Expand the variety of ways that he can contribute and develop additional competencies and skills.

When a plan is developed with these values and outcomes in mind, the plan will point toward a positive future worth working for. (Facilitators who work in traditional agencies may wish to review the “Characteristics of a Positive Future Worth Working For” [p. 7], to ensure that at this point in plan development the focal person’s plan has avoided the “traps” of traditional plans and instead gives voice to the focal person’s dreams.)

An effective plan will reflect several categories of interests and activities, such as Better Days, Better Living Arrangements, Better Social and Community Lives, and Pursuit of Interests. The choice of categories will largely reflect the priorities of the person.

<table>
<thead>
<tr>
<th>Better Days</th>
<th>Better Social and Community Lives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>Friends and fun</td>
</tr>
<tr>
<td>Transition to work</td>
<td>Community experience</td>
</tr>
<tr>
<td>Work experience</td>
<td>Family life</td>
</tr>
<tr>
<td>School</td>
<td>Community participation</td>
</tr>
<tr>
<td>Adult education</td>
<td>Love life</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Better Living Arrangements</th>
<th>Pursuit of Interests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>Artistic expression</td>
</tr>
<tr>
<td>Home ownership</td>
<td>Spiritual life</td>
</tr>
<tr>
<td>Homemaking</td>
<td>Vacations and travel</td>
</tr>
<tr>
<td>Hospitality</td>
<td>Self-advocacy</td>
</tr>
</tbody>
</table>

After developing ideas relating to several categories, an effective facilitator will help the team prioritize, focusing on a top priority category and developing an action plan for that priority. The team might develop action plans for other categories as well, but plans often begin with a focus on one top priority.

Finally, the time frame for implementing a plan will vary greatly across people – from a few months to several years. Balancing both long-range and short-term priorities helps the team work toward goals that may require years to implement, while working on here-and-now changes that can immediately change the quality of life of the focal person.

c. Challenges in The Fourth Path

If “the proof of the pudding is in the making”, The Fourth Path of PFP truly is the time when the “pudding” may stubbornly refuse to transcend its ingredients to become a finished dish. The challenges to developing a vision, establishing an action plan and then carrying out its steps over time are indeed formidable. Problems that have plagued planning during the first three paths may re-emerge. Stumbling-blocks in the community may sap the enthusiasm of the planning team. Factors totally outside of the planning process, such as an illness of a key member of the team, may sidetrack action. Because of the complex challenges of this step and of the importance of bringing the “pudding” to
the table, Part Three is devoted to discussing strategies to help facilitators and other team members overcome the problems associated with helping the focal person reach his vision.

**In sum...**

...PFP gave Charles the opportunity to examine his past and present interests and dreams, his job successes and failures, and his personal and community involvements. He was able to clarify a new purpose and focus for his life based on his interests in helping and teaching others. In Charles’ own words: “Following my brain injury, society seemed to say to me, ‘Drop out of life, take your medication, and maybe we can find you a job in a file room somewhere.’ PFP helped clear the psychosocial logjam which blocked the flow of my personal development. I was finally ready to move on and the process helped me do so.”

**PART THREE: Supporting PFP Over the Long Haul**

**COMMON BREAKDOWNS and What Facilitators Can Do About Them**

The *Moving On* workbook provides a structure for bringing people together to learn about the focal person, develop a vision for the future and clarify the opportunities and challenges that will affect implementation. But creating the vision is only the beginning of PFP, which the facilitator must lead, encourage, prod, prompt and stick with over time.

Many variables affect the likelihood that a plan will be completed to a point of satisfaction for all involved. Facilitators can work to establish and maintain **four conditions to help ensure that the focal person’s vision becomes a reality**:

- Maintain the involvement of the planning team and their long-term commitment to the focal person.
- Support the focal person in staying engaged in the process and in remaining determined to make changes in his life.
- Find ways to develop your ability as a facilitator to lead the process effectively.
- Develop the organizational supports needed to respond to the goals in the plan.

Effective facilitators often must face the challenge of changing organizations.

Inevitably, breakdowns occur in one or more of these four conditions, and such breakdowns can bring the entire planning process to a grinding halt. The facilitator is challenged to maintain the energy and commitment of the team during these breakdowns. The following section addresses common breakdowns related to each of these four
conditions and suggests strategies for picking up the pieces (yet again) and moving on in spite of difficulties.

A. BREAKDOWN #1: Breakdowns in the Planning Group

Team members are more likely to stay engaged in the planning process when they have a commitment to the person, a clear understanding of their contribution, and support in managing the conflicts that emerge throughout the process. Some of the reasons group members leave the process include:

- Members feel like meetings are a waste of time.
- Members do not have a clear role and consequently don’t know how to contribute.
- People may contribute, but feel that their efforts are unappreciated.
- Members feel that problems related to implementation are too big or that progress toward goals is inadequate.
- People leave when too many conflicts and tensions arise among team members, and are not addressed.

The facilitator plays a critical role in addressing these issues and thereby strengthening the on-going involvement of team members. The facilitator cannot predict or prevent burnout or bailout, but the following strategies may help.

- **The facilitator must run effective meetings.** Follow-along meetings (those associated with Map 12 in *Moving On*) help people maintain their commitment to the focal person as well as learn from the process of implementation. An effective meeting structure enables the team to review their actions, brainstorm new strategies, make new commitments to action and set the next meeting time and date. Part Two of this *Manual* (pp. 11-27) outlines strategies for running effective meetings in general, and Map 12 in *Moving On* provides a useful structure for follow-along meetings. Facilitators need to use this structure to help people solve problems and re-strategize. Follow-along meetings are most productive when the facilitator follows an agenda and structure that helps team members be productive. Groups get stronger when they meet regularly and repeatedly, using this structure.

- **The facilitator must find many ways to encourage participation over time using a variety of renewal strategies.** Reviewing positive actions and outcomes on a regular basis with the planning team is an important renewal strategy, but even the strongest teams run out of energy, get stuck and need to be nurtured and renewed in other ways. Additional renewal strategies include the following:
  - Plan celebrations to recognize important accomplishments, birthdays, holidays and other meaningful events in the lives of team members.
  - Meet in a comfortable place and provide refreshments.
  - Plan an occasion to refocus the team. Take the time to review progress and difficulties and clarify a new focus.
  - Create an occasion to recognize the contributions of each team member. Encourage the focal person to thank people for their efforts.
• Find opportunities for the focal person and team members to tell their story to others: in newsletters, meetings and conferences.

• Help all team members find opportunities for self-development and support.

B. BREAKDOWN #2: Breakdowns in the Involvement of the Focal Person

The focal person is more likely to stay engaged in working toward change when she is involved in steering the process, has a manageable agenda for change, takes clear and focused steps toward that agenda and feels that the team is there for her providing both emotional and instrumental support when needed.

The focal person might lose her commitment to the process for the following reasons:

• The person loses her voice and feels dominated by strong group members.

• The focal person lacks direction and does not know how to move to the next path.

• The person is overwhelmed by her vision and the responsibilities implied by her aspirations.

• The person feels overwhelmed by life in general or suffers from medical, emotional or financial set-backs that take priority over PFP.

• Support the person in gaining a stronger voice in the process. If the focal person seems to be “fading” from the process, then the facilitator should first find ways to help the person hold onto his voice. Some strategies include:

  • Involve the focal person in planning each agenda. In advance of each meeting, clarify an outline for the meeting based on his interests and priorities. Support the focal person in taking a stronger role in directing the meetings, which may include introducing the agenda or facilitating the discussion. Help the focal person not only to clarify his thoughts and feelings prior to meetings but also to prepare statements related to these ideas to use throughout the meeting.

  • The facilitator might ensure that the focal person is addressed directly by others. The facilitator can also support the focal person’s having the time needed to communicate his thoughts.

  • The facilitator can identify and assign a mentor to the focal person who will be an ally during all group meetings and support his speaking up and taking a stand when needed. The mentor might be another team member, another person with a brain injury and/or someone from outside the team who joins to serve as an advocate for the focal person.

• Break “big ideas” into concrete action steps. People with brain injuries often need support to stay focused and to break “big ideas” into organized, concrete and manageable strategies. The facilitator plays a critical role in translating the often abstract hopes and ideals of the person and the team into concrete action steps that everyone can share. If the focal person has trouble staying focused and taking action, then the following strategies may help:
• Pick one priority and stick with it. Help everyone focus on that priority. Break it down into a series of concrete actions, which are assigned to specific team members.

• Be sure that the focal person takes responsibility for some of the action elements. Help her break her tasks down into even smaller steps and support her in taking these actions. For example, if the focal person agrees to make a phone call, be sure that she has access to a phone, has the phone number and can find it when she needs it and knows what she wants to say – perhaps even help her write it down. Don’t underestimate how much support the focal person needs in taking action.

• When and if the vision and the focus fades, help the person revise (re-vision) and create new priorities.

• Support the focal person when change seems too hard. Sometimes a focal person simply cannot deal with the additional demands resulting from having higher expectations of his life. The resulting frustration may be expressed through depression, acting out or fading out of PFP. The facilitator can help by listening to the person and adjusting the demands of the process so that he is not overwhelmed by it. If the focal person is acting as if change is too hard, the facilitator can try the following:
  • Take a break. Back off from all the action elements and planning and give everyone permission to take some time off (summer may be a time for this). Don’t lose sight of the vision and just give up, but instead help everyone acknowledge that it is very human to need a break.
  • Spend more time with the person and in meetings talking about how hard it is. Support everyone talking about how hard life changes are to implement. Help everyone cry and laugh at how hard life is.
  • Break down big agendas even more. Try to find something worth working toward even if it falls short of the ultimate mark.
  • Take time to reflect and specifically recognize all accomplishments to date. Give the focal person time to live with these accomplishments for awhile before taking the next path.
  • Help the focal person visit another person with TBI who has faced similar obstacles that they ultimately overcame. Help the person join a TBI support group if they have not already done so.

• Support the focal person when life gets too hard. People not only struggle with the additional pressures of higher expectations, but they also suffer from setbacks in life which seem to derail all their good intentions to move on. While many people face setbacks related to health, emotional life, relationships, finances, substance abuse, legal problems and other personal problems, people with brain injuries are particularly susceptible to these difficulties. If the focal person is dealing with a setback, the facilitator can try the following:
  • Facilitators can support people through hard times by simply being there and encouraging others to stay connected even through the worst of times. The facilitator
can act as the “guardian of the vision”, holding onto a more positive future for the focal person until she finds renewed energy to move on.

• The facilitator can help the focal person connect with generic supports within the community or to specific groups related to the set-back, such as AA groups, health-related support groups and the like.

C. BREAKDOWN #3: Breakdowns in the Involvement of the Facilitator

Effective facilitators learn and grow from difficult situations that stretch them to develop new abilities and strategies. But, even the best facilitators encounter struggles that may lead to burnout. The whole planning process can stall when and if facilitators get frustrated. A facilitator might abandon the planning process when...

• He gets stuck and doesn’t get help.
• He becomes overwhelmed by the demands and tensions of PFP, which are often added onto an already difficult work load.
• He “moves on”, too, to another job or life option and leaves the focal person and team.

If the facilitator is having trouble maintaining his involvement, the following strategies may help.

• **The facilitator needs to get help.** Throughout PFP the facilitator works hard to get support for everyone else, and so also she might need to get help for herself. Some strategies include:

  • Each facilitator should work with a mentor – someone who has more experience in facilitation and/or responding to the needs of people with brain injuries. An effective mentor has encountered similar problems and issues and can offer good advice and alternative strategies.

  • Invite the mentor or another person from outside the team to help as a consultant, sounding board, mediator or listener.

  • Regain focus. Facilitators lose focus, too, and lose track of where they are headed and how they might get there.

  • The facilitator can learn additional skills related to conflict resolution. A team is often stuck because conflicts have surfaced and are not being addressed. Facilitators play a key role in bringing conflicts to light and then managing their resolution.

  • Facilitators can join networks, associations or participate in conferences with other facilitators. Many networks encourage change agents to exchange ideas and strategies. Effective facilitators find ways to connect with many other people who face similar challenges as they nurture change.

  • When the facilitator leaves... If the facilitator needs to leave, she should consider some of the following strategies to help create continuity and stability for the group in spite of her absence.

    • Facilitators might consider staying involved with the focal person even if they change jobs. For example, she might remain as a facilitator on a voluntary basis or become a
• A facilitator should mentor his replacement as far in advance of his leaving as possible. The facilitator might choose a member of the team to continue in the facilitation role, and not assume that the person who takes over his job is the logical replacement as PFP facilitator.

• If the facilitator is fading out because of competing demands, he might try to renegotiate his job description to make more room for PFP activities, developing a list of activities to decrease and to increase, the latter including the demands of facilitation.

D. BREAKDOWN # 4: Breakdowns in Effecting Organizational Change

An effective PFP process should generate actions from community supports and human service agencies that specifically fit the focal person’s needs. However, the design of individualized supports usually requires organizational change, particularly in human service organizations. Facilitators often become change agents, who must formulate and advocate for needed organizational changes. However, no simple strategy exists for changing the structures that can help or hurt our ability to respond to a focal person’s vision.

Facilitators avoid taking on organizational change when they feel powerless to change systems and/or if they honestly don’t know what would be better. The following strategy may help facilitators develop a constructive approach to organizational change (their own or others).

Organizational change is more likely when important stakeholders – those who have some say over policy – receive clear suggestions regarding what would be better for the focal person and how they can help. The discussion below provides a structure to help facilitators organize themselves in approaching and in meeting with stakeholders.

Change requires your meeting with stakeholders and your presenting a well-developed set of ideas about how “things” under the stakeholder’s control could work better for the focal person. Three actions need to be taken: The facilitator must develop a strategy for gaining access to stakeholders, she may need to do “homework” in preparing a proposal for change and she needs to organize the proposal in a clear, cogent style.

• Gain access to stakeholders. The first question is, Who are the stakeholders you need to talk to? Then, How can you arrange to present your ideas to them? This may be a simple matter of the facilitator walking into his boss’s office and making an appointment for a meeting. If an agency that the facilitator has no connections with is the target, the first step is to use social networks to determine who is the person or persons that hold the keys to policy change. It is wise to determine as much as an outsider can the appropriate level of entry into an agency – finding a person with influence within the agency who may serve as an advocate within the agency may be a better person to contact, in some agencies, than the “top person”.

Once the facilitator has determined who to meet with, she needs to organize the ideas to be presented in a meeting with the stakeholder. These ideas should be in place prior to the first contact, to serve as a firm platform in making contact. Ways of doing one’s “homework” to organize for meeting with agency stakeholders are outlined below.
• **Search for innovations to prepare your proposal. Do your “homework”**. The proposal for change requires facilitators to outline a creative organizational response. Facilitators and planning teams may need to search statewide and nationwide for positive examples of existing ideal solutions. By learning from others, facilitators can propose constructive innovations that are already operating successfully elsewhere. The facilitator can adapt what he learns from others to fit the unique characteristics of his own situation. The following outline can help facilitators build a foundation for a proposal for change.

  • **Describe the gap.** Identify what people need that *cannot* presently be obtained through personal and community networks. Identify what they *can* get through the system. Identify problems with existing supports.

  • **Search for solutions.** Find other people and places that have implemented exemplary supports. Visit settings with creative individualized support designs, learn about funding patterns and explore the details of effective administrative practices. Imagine how this service support might fit the needs of the focal person you represent and how it might be accomplished within the target organization.

  • **Gather and clarify information.** Create a concise way to describe the gap. Produce a short policy document that describes the situation of several people who have similar needs and outlines an innovative organizational response.

  • **Create a proposal for change.** Develop a simple, clear document that describes the problem and policy implications:
    • Summarize the focal person’s vision.
    • Describe what’s going well. In your meeting, use phrases such as, “We really appreciate this agency’s…”
    • Describe what’s wrong. Clarify ONE organizational issue that needs to be addressed to further implementation of the vision.
    • Outline possible approaches to fixing this problem. Provide specific ideas that suggest a better alternative.
    • Clarify what you want from the person with whom you are meeting. Suggest some action steps you would like them to take to help.
    • Describe how the change will affect the outcomes in the focal person’s life and how it might benefit others.
    • Suggest a follow-up meeting, phone call or other appropriate action.

  • **Gain influence by sharing information.** Invent innovative, person-centered ways to share this information with others. Initiate conversations and presentations that enable you to communicate with others and build the influence needed to promote change.

  • **Join with other groups to build coalitions to develop and support similar proposals.**