Charting a Meaningful Life:
Planning Ownership in Person/Family-Centered Planning

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"Ownership of one's life isn't a tangible thing that comes with a guarantee or warranty. It is a physical, mental, spiritual, and responsible connection/reconnection to life for an individual who seeks his/her own destiny." ~Nancy Fudge

Introduction. There is a growing interest in person-centered planning, person-centered care, and individualized service/support planning for adults and children across a variety of human service systems (O'Brien, O'Brien, & Mount, 1997; Walker, Koroloff, & Schutte, 2003). Interest in person-centered planning (PCP) has grown along with the movement to increase self-determination, choice, personal responsibility, and meaningful community lives for adults and children with various disabilities (Nerney, 2004). As envisioned by its originators, a foundational principle of person-centered practices is that human beings define and realize themselves through community connectedness (Blessing & Golden, n.d.). With the belief that a life which is "service defined" is a life not fully lived, John O'Brien and the other early proponents of PCP began to advocate for individualized life planning that would create meaningful community connections and social roles for people with disabilities (O'Brien, 1989). Such planning would no longer isolate people from their communities because of their disabilities, but rather, would involve these people in society while facilitating hope and self-determination (O'Brien & O'Brien, 2000). Individuals would be connected to "everyday lives" that are valued by people with or without disabilities (O'Brien & Lovett, 1992). (For a more detailed review of the definition and principles of PCP, see the accompanying conference paper devoted to this topic by Adams, Grieder, and Nerney.)

In this context, the question of planning ownership -- or "who owns the plan?" -- in person-centered planning is undeniably central. Yet, as we consider this key question, it may be more enlightening to ask ourselves instead, "who owns the person's life?" For indeed, person-centered planning puts the focus on the adult or child and his/her future, rather than on a set of services, programs, or treatments that can be offered to meet various needs and goals (Falvey, Forest, Pearpoint et al., 1994). The plan itself is not the goal, even if it is multifaceted, culturally relevant, and directed by the person or family. Rather, the plan is simply one pathway to a life complete with respect from others, meaningful opportunities and choices, personal responsibility, community/school presence and participation, and self-chosen supports. In this paper, therefore, we consider the question of planning ownership, with an eye towards *life ownership*. We also

discuss the role of the "focus person" (i.e., the adult or child for whom planning is conducted), family members, and formal and informal supporters in creating a person-centered plan designed to facilitate a meaningful life.

Common Elements of the Person-Centered Planning Process. To understand ownership issues in PCP, it is useful to briefly review common approaches to the planning process. There are many ways to conduct PCP including, Planning Alternative Tomorrows with Hope (PATH), Making Action Plans (MAPS), Essential Lifestyle Planning, Personal Futures Planning, and Recovery Planning for adults (O'Brien & O'Brien, 2000), as well as wraparound services or Individualized Service/Support Planning (ISP) teams for children (Walker, Koroloff, & Schutte, 2003). While each approach has its own unique procedures, there are some common elements that define the PCP or ISP process (O'Brien & Lovett, 1992; O'Brien & O'Brien, 2000; Walker, Koroloff, & Schutte, 2003). First, everyday events and activities in which the individual participates (or would like to participate) are the focus of planning. Second, family, peers, and connections within the community/school are key sources of support for the focus person, and are considered prior to a pre-determined set of disability-related services or treatments. Indeed, a central purpose of PCP is to enlist community members (where needed and desired) to help the focus person define and work towards a desirable future. Third, the focus person and supporters who believe in the person's potential are the primary authorities on the person's life direction. Similarly, a fourth element in PCP is that the focus person and his/her family are approached as fully capable human beings, with a unique set of strengths, values, and skills that may have been obscured by dependency, isolation, discrimination, abuse, improper treatment, and so forth. Fifth, because the focus person and/or family lead the process, by definition, planning more naturally reflects their own use of language, cultural and other diverse viewpoints, spiritual beliefs, and unique personal characteristics or ideas. Finally, the focus person and/or family decide who attends planning meetings, as well as where and how often they meet.

Other important elements of the planning process include that plans are written in the individual's own words (avoiding jargon); the strengths and weaknesses of the individual are stated from the person's own perspective; and planning makes use of what the person knows works in her/his own life. In addition, these planning approaches strive to create an opportunity for care providers and other supporters to view things from the person's or family's perspective. Importantly, focus people/families can alter the planning process or plans at any time. For adults and children with mental or emotional difficulties, person-centered or directed planning often includes self-chosen wellness strategies the person/family uses to avoid crises, as well as how the person/family would like crises to be handled, if they occur (Tondora & Wartenberg, 2005).

Respective Roles in Planning. In light of these PCP principles, ideally, focus people and families are much more than "partners" in planning, they have much more than "input" to share. Rather, these individuals are the authorities and leaders of planning because they are the experts on their own lives, even if they need help charting their recovery journey. This implies that the locus of their plan rests with them, and they draw in the family, peers, providers, community supporters, and others they want to support them as they pursue self-chosen life goals (or designate proxies to do so when they are unable). Indeed, within PCP, focus people/families choose how, when, and who will be most effective in assisting and supporting them in achieving a productive and higher quality of life. When given this type of leadership, people tend to choose partners who acknowledge their abilities and potential. As such, planning eliminates the traditional wall of authority and control between the person receiving and those providing. A cooperative foundation is created to help people/families achieve their own goals.

Unlike traditional planning processes, PCP cultivates personal involvement in one's self-improvement and services/treatment because the individual is the plan's main architect. Indeed, most humans are more invested in pursuits they have chosen for themselves. Knowing their own hopes and dreams far better than anyone else can, they set goals that are important to them and solicit the support of family, friends, and professionals in meeting them. Further, their investment in their own recovery is strengthened when planning encompasses their whole life, not just a pre-determined set of services offered by a given agency or system. Experience with PCP in mental health has shown that, as individuals take charge of their plans, they also begin to take greater responsibility for their treatment, services, and lives. With this enhanced sense of responsibility comes increased prudence in decision-making that results in greater levels of self-esteem and self-confidence.

In this process, providers (and other supporters) have an important role to play as listeners, mentors, supporters, community representatives, and services/supports brokers. Their goal is to assist the focus person in understanding what led them to need help (in their own words) and how they feel about it. Rather than simply clinically assessing a person in order to complete required paperwork, the provider/supporter emphasizes his/her interest in learning about the person's history, strengths, limitations, dreams, and goals (Adams & Grieder, 2005; Bambara, Cole, & Koger, 1998; Kennedy, 1994; Pocklington, 2005). As originally envisioned, a key emphasis of planning meetings is on building trusting relationships between the focus person/family and the supporters who might be able to meet their needs (Bambara, Cole, & Koger, 1998). Supporters also bring to meetings comprehensive knowledge about various system and non-system resources available to the person/family to help them build upon their strengths

and/or resolve their current problems (Walker, Koroloff, & Schutte, 2003). Providers and supporters help to educate the focus person and family about the options available to them and how to access them. They also anticipate barriers, delays, and other obstacles to planned goals/pursuits in order to allow alternative solutions to be generated, if necessary (Connecticut Department of Mental Health and Addiction Services, n.d.). Supporters are expected to respectfully handle the inevitable conflicts that will arise when focus people suggest a course of action that concerns or contradicts others on the planning team (Bambara, Cole, & Koger, 1998).

<u>Barriers to Planning Ownership for Adults and Children in Mental Health Recovery.</u> There are a number of barriers that adults and children with mental/emotional difficulties might face when assuming leadership or ownership of their life/services planning. Given space limitations, we are unable to provide an exhaustive list of concerns, or comprehensive explanations of them, but strive to highlight several of the major issues.

Among the most significant barriers to personal/family planning ownership are those at the regulatory level (Holburn & Vietze, 1999), which is fraught with mandates mired in medically oriented rather than recovery oriented approaches to care (Pocklington, 2005). Certainly, the rules and regulations dictating eligibility for Medicaid and other public supports on which many adults and children/families with emotional/mental health difficulties rely also pose major challenges to implementing PCP and personal planning ownership (Nerney, 2004). These important issues are addressed in detail in the accompanying conference papers on regulatory (by Selleck and colleagues) and implementation (by Tondora and colleagues) issues in person/family-centered care.

Another set of barriers to personal ownership of the planning process occurs at the provider and program levels. Many providers and administrators are uninformed about the purpose and procedures of person-centered planning to increase self-determination and personal responsibility for one's own life. Still others are openly ambivalent or outright opposed to the values and principles of self-determination and PCP (Cook & Jonikas, 2002; Holburn & Vietze, 1999; Schaefer, Justice, & Horvath, 2004). Many providers express concerns that they do not have sufficient time to facilitate true person-centered planning, that they will have to intervene or "pick up the pieces" if someone makes a mistake or poor choice (rather than providing options and alternatives to the person, so s/he can remedy the mistake) (Cook, Terrell, & Jonikas, 2004), or that at best PCP is another passing fad and, at worst it will ill-serve many clients/families (especially those who are most affected by their distress/disability). Providers often indicate they "already are doing person-centered care" even when they are not (Holburn & Vietze, 1999; Smull, 1998), that many of their clients "can't do" or "failed at" PCP (O'Brien, O'Brien, &

Mount, 1997), and that PCP is something only for people with developmental disabilities. Further, given the current configuration and financing of mental health systems, it is likely that planning will be located within service programs that have their own regulations and interests such as maintaining cost effectiveness, completing required paperwork for billing, monitoring quality of programming, and so forth. These concerns often do not prioritize placing individuals/families at the center of their own planning, making it difficult to foster planning ownership.

Concerns at the provider and program level also revolve around how providers will change roles to become coaches and advisors during planning rather than "leaders" and "experts" (Smull, 1998). Many professionals receive training that reinforces their role as experts who must "manage" their clients' "chaotic" lives, since clients are "irreversibly ill." Shifts away from this type of thinking, and learning how to function as a member of a PCP team, take time, commitment, strong leadership, and widespread sharing of personal recovery stories as a result of PCP.

A related and very common concern in PCP circles is whether, once a system or program adopts person-centered planning, the process remains person-centered or whether it inevitably becomes system-centered (Holburn & Vietze, 1999; O'Brien, O'Brien, & Mount, 1997; Wehmeyer, 1998). This barrier begs the question of how a system or program "stays true" to the PCP planning process, ensuring that the focus person/family maintains ownership of planning and related action steps. Indeed, as first envisioned by some of the founders of the approach, person-centered planning was meant to be done "one person at a time" (Mount, 1994; O'Brien, 1987). The energy and resources needed to accomplish a truly person-directed planning process, along with the steps to bring it to fruition, can be intense and, by definition, economies of scale may not be possible since the process is highly individualized and personal (O'Brien & Lovett, 1992; O'Brien, O'Brien, & Mount, 1997). This can pose a significant barrier to promulgation of person-centered planning as it was originally conceived.

Another set of barriers to planning ownership may lie with focus individuals and their families. While in no way blaming focus people for the failures of human service systems, it is important to acknowledge that adults and children with mental/emotional difficulties and their families may experience reluctance, fears, and mistrust when told they can take control of the planning process, and indeed, their own lives. There are many possible reasons for this; some of them include: a lack of trust that human service systems or various care providers will cede control, due to past experiences that would indicate otherwise; service eligibility criteria that require an emphasis on illness and crises in order to receive assistance; learned helplessness

consequent from years of dependency (especially for those in nursing homes and other institutional settings); lack of motivation and isolation due to the symptoms of one's illness or from side effects/improper use of medications; and common misperceptions among focus people (and their supporters) that mistakes or poor judgment indicate incompetence to be in control of planning (Stefan, 2004). Additionally, many people and families worry that they must "get it right the first time," rather than recognizing that planning is a *process* with starts and stops along the way (Anderson, Duerscheidt, & McLean, 2004). Individuals and families also may have a difficult time communicating or articulating their ideas (Anderson, Duerscheidt, & McLean, 2004; Walker, Koroloff, & Schutte, 2003), or may too distressed, frightened, or defeated to lead planning (Adams & Grieder, 2005). Finally, in some cultures the idea of sharing problems and enlisting help outside of the family, especially to cope with mental or emotional distress, cause great discomfort (Alvidrez, 1999; Wynaden, Chapman, Orb et al., 2005; Zhang, Snowden, & Sue, 1998).

Another internal barrier to planning ownership can come from focus people/families' lack of education about self-determination and person-centered planning. People who have received mental health services may worry that this is another attempt to make them "pull themselves up by their bootstraps," to abandon them, or to leave them without adequate treatment and services. Others may worry that this type of planning means that formal services and treatment are no longer sought or used, which is often not the case. Further, as has been seen in the Florida Self-Directed Care Program, lack of literacy or learning disabilities can be a barrier to planning ownership. Fearful of gaining yet another label ("illiterate"), some individuals may choose instead to relinquish their power to care providers rather than reveal their difficulties with reading and writing.

Finally, a major impediment to personal/family ownership of the planning process at the legal level grows out of ongoing concerns in behavioral health and society at large about the "competence" of adults with psychiatric diagnoses to make their own treatment and life decisions (Wong, Clare, Gunn et al., 1999); clearly, this issue is different for minors, who do not have legal rights to make certain decisions by virtue of their age. As stated previously, there is much confusion about the difference between lack of experience to make decisions and the physical/mental incapacity to do so (Stefan, 2004). One could speculate that this ongoing issue also is a result of the conflict between the newly emerging recovery paradigm and the traditional medically oriented one which casts people who seek behavioral healthcare as persistently ill and incapable (Pocklington, 2005).

A related issue often voiced by care providers pertains to liabilities and risks they shoulder in maintaining the health and safety of the people/families they serve, and those with whom their clients come into contact. This concern partly grows out of misperceptions that person/family-centered or directed planning means that "anything goes," when in fact accountability for choices is an important element of PCP (Nerney, 2004; Wehmeyer, 1998), as is protecting the person/family when at risk of harming self or others through already-existing mechanisms within the system. Along these lines are concerns providers surface about how person-centered planning can be achieved for people who are mandated to treatment or are served in forensic settings, important issues that are discussed in an accompanying conference paper by Singh and Van Tosh.

Recommendations to Support PCP for Adults and Children in Mental Health Recovery. With these many barriers in mind, there is an understandable tendency to assume that public and private behavioral health care systems are too entrenched in traditional methods to achieve the promise of person-centered planning. However, there are a series of small and large goals that can be pursued to foster planning ownership. Certainly, equally ingrained human service systems and federal financing agencies have made similarly fundamental changes during the past 15 years that are instructive for our field (Nerney, 2004). (Details for how we can learn from other communities are detailed in an accompanying conference paper by Blessing and colleagues.) Additionally, several states already are leading the way in promoting self-determination, person-centered planning, and self-directed care as avenues to mental health recovery for adults, including Connecticut, Florida, Michigan, Ohio, and Oregon (Connecticut Department of Mental Health and Addiction Services, n.d.; Cook, Terrell, & Jonikas, 2004; Nerney, 2004; Schaefer, Justice, & Horvath, 2004). Therefore, one major recommendation to address planning ownership barriers is for SAMHSA to continue to coordinate and fund efforts that allow states to widely share their experiences in turning ownership over to focus individuals, and to train other states on how to accomplish this at the regulatory, provider, person, family, and other supporter levels. Along these lines, another strategy to overcome barriers to planning ownership would be for SAMHSA and other relevant federal/state agencies to fund and coordinate local, statewide, and national events for people to come together for the purpose of sharing the successes of PCP, and to discuss barriers and solutions.

Certainly, widespread education and skills training for administrators and providers will be necessary to help them understand how to recognize and foster true personal ownership of the life/services planning process. To be effective, this effort must include sensitivity training about using the language of recovery rather than illness when supporting people with emotional/mental

health difficulties, and effective and culturally sensitive communication with adults and children in distress or crisis. Education also is needed on providers' roles in planning meetings, identifying and accessing non-system resources for people who request them, cultural competence in planning and leadership, working with focus people to balance desires, risks, and resources, and how to work effectively with focus people who are inexperienced with planning ownership in order to transfer the reins over time (there is some literature addressing this issue; see Anderson, Duerscheidt, & McLean, 2004 and Bambara, Cole, & Koger, 1998). One effective educational strategy may be using a combination of literature, outcomes/efficacy data, and personal accounts such as recovery dialogues to help providers learn the new roles of advisor, mentor, or supports broker. Further, those involved in educating providers about self-determination and PCP have found that acknowledging staff's fears and doubts about PCP, rather than dismissing or shaming them, is more likely to lead them to accept a new role in their clients' lives (Holburn & Vietze, 1999). A longer-term goal in this area is to include concepts about recovery, self-determination, and PCP in pre-service training programs at both the undergraduate and graduate levels. Reaching students with concepts of personal planning ownership could set the stage for innovative, more effective ways of helping adults and youth to recover their lives.

To overcome internal barriers to personal/family planning ownership, funding and coordinating peer-led education and ongoing support/mentoring for people in the pre- and active planning stages also would be effective. Learning from peers the principles, values, and mechanics of owning one's own planning process can serve not only to increase skills, but also people's understanding of their right to life ownership. Some training topics could include: an overview of the principles and practices of PCP; leadership and self-advocacy skills; reviews of human and civil rights; the role of the focus person and others in PCP; strategies for identifying and inviting relevant supporters to join a PCP team; and how to effectively communicate within a PCP team. The consumer-run technical assistance centers currently funded by the Center for Mental Health Services would be an excellent resource for such training, as would state Offices of Consumer Affairs, national adult and children's mental health advocacy organizations, and peer-run programs or networks found in each state.

Education also will be needed for all people involved in planning teams about the importance of flexibility, patience, clearly defining shared goals and responsibilities throughout the planning process, respectful conflict resolution, how to stick with the process for the long-term, and allowing one another to take risks and make mistakes. Experienced programs have found that planning meetings are less productive when focus persons and providers are afraid of offending each other or saying the wrong thing (Holburn & Vietze, 1999). Indeed, planning teams

will need to work on building trust in one another, even when tough or challenging questions need to be posed. Often times, understanding and practicing the art of "agreeing to disagree" allows people to move forward to discover alternatives to the problems under consideration.

Another critical aspect of planning ownership education would be to help states and programs learn the various regulations regarding how to bill for planning meetings (and subsequent action steps by the team), which is discussed in a separate conference paper by Selleck and colleagues. As has been witnessed many times when introducing new approaches and models into state systems, PCP needs both to be adopted as policy and to be adequately funded or there will be little responsibility or accountability for continuing with it over time (Goldman, Ganju, Drake et al., 2001; Rosenheck, 2001; Schaefer, Justice, & Horvath, 2004). At the same time, unfortunately, there are many powerful stakeholders within behavioral health who will feel their interests are not served by PCP and self-directed care for people with psychiatric disabilities. Mandates and money alone will not solve this problem. As such, active leadership at the federal and state levels will be required for several decades to come to ensure the long-term viability of PCP and personal ownership of life planning.

In order to address the issue of how systems or programs maintain the practice of personal ownership of planning over time, processes for continual quality assurance and *independent* audits by peers/families trained in PCP will need to be funded and coordinated. Assessment of quality should not focus solely on the rating of services/supports, but on whether the choices people make are personally meaningful and whether planning ownership leads to a valued community life (Nerney, 2004). A simple PCP fidelity scale (which includes open-ended items that encourage people to reflect in their own words on their PCP experiences) developed for these purposes would ensure standardized ratings across programs and states. If these audits reveal that ownership is slipping away from the focus person, these individuals should be offered access to impartial, external mediation or grievance procedures, as well as additional education about maintaining personal leadership.

A final major recommendation in this area is for SAMHSA, CMS, and other public and private organizations to fund PCP demonstration projects specifically within behavioral health, modeled after the self-determination grants awarded by the Robert Wood Johnson Foundation in the 1990s and the federally-funded Cash & Counseling Demonstration Projects. Supporting this type of initiative could move the field from the talking phase to the acting phase, and promote the development of knowledge about what facilitates and what hinders PCP ownership.

Model Planning Programs in Mental Health Settings. Finally, the planning processes of three model programs for adults with mental illnesses are highlighted here because they

successfully have put the focus person at the center of the planning process. Through the FY 2001 Real Choice Systems Change Grant, Oregon conducted three demonstration projects involving PCP: Essential Lifestyle Planning (ELP) in service coordination; Employment for Life (EFL); and the Empowerment Initiatives Brokerage (EIB). The EIB project is seen as one of the most successful in this demonstration. It employed elements of the previously-mentioned MAP and PATH planning approaches, which are collaborative, team-oriented tools to assist the focus person (called customers) and their self-chosen supporters (family, friends, professionals) to gather information about the person's history, strengths, dreams, needs, and best plan of action to help reach goals and avoid pitfalls. In order to gather this information, the program's resource broker offered customers the opportunity to participate in a series of meetings (A. Young, personal communication, 10/24/05). The first meeting was one-on-one, and was used to discuss the customer's history. The second meeting in which people could choose to participate was a group planning session to learn how to use the MAP approach and practice it with other customers. The final meeting offered was to conduct additional planning using MAP, PATH, PFP, or another approach suggested by the customer. Customers were encouraged to invite supportive others of their choosing to planning meetings; most chose to have a friend or family member present. An EIB broker assisted 25 customers in writing PCPs that translated each major goal into a corresponding Action Plan that listed the services and supports to be purchased through the brokerage to help the customer achieve that goal. When the customer wanted to change the plan, s/he would contact the resource broker who would make the exact change requested and submit it to the state office for approval.

In the Florida Self-Directed Care program, person-centered planning begins once a participant self-enrolls in the program. A Life Coach is available to assist in reviewing the policy and purchasing guidelines of the program, and also to provide educational and resource materials to guide participants in the planning process. The participant decides who should be involved in planning, which may vary at different stages of planning and by the goals being pursued. Life Coaches and participants communicate by phone and electronically, or during in-person visits in the home or community. To further support planning, program participants also are encouraged to exchange information and develop friendships with each other through a newsletter, warm-line, and web site. It is important to note that some people choose to plan independently, without assistance from a Life Coach. Planning in this program offers three different types of services, called traditional, non-traditional (service substitutions), and recovery enhancement supports. These choices provide opportunities to receive services in least restrictive environments, practice cost effectiveness, and seek a healthier holistic recovery. The participant decides who will

provide a service, how many times s/he needs the service within a specified time frame, and what his/her projected outcome will be. After choosing their goals, participants create Life Action Plans that detail the budget accompanying each of their specific recovery goals. Planning continues to evolve as individuals experience self-awareness, reach their goals, or decide to change them. An annual Life Analysis and quarterly assessments provide meaningful insights into the participants' progress and/or set-backs.

Person-centered planning also is a central feature of the Georgia consumer-operated Peer Centers. The purpose of these Peer Centers is to provide people with the opportunity to direct their own recovery and learn self-advocacy, while teaching and supporting each other to manage their distress and access community resources (Riefer, 2003). In this context, planning is conducted with the belief that one's personal goals determine his/her satisfaction with services and ability to embrace recovery (Riefer, 2003). All Certified Peer Specialists receive training on person-centered planning and its role in recovery. Within Peer Centers, goals are set by assisting the person to explore strengths and needs in his/her living, learning, social, and working environments, along with system and non-system resources s/he may wish to access. A strong emphasis is placed on utilizing peer support as a major resource for recovery. Life goals and specific steps to reach them are detailed in each person's Individual Service Plans, which are reviewed (and modified, as needed) on a regular basis.

Conclusion. With the release of the Surgeon General's Report on Mental Health (1999) and the Report of the New Freedom Commission on Mental Health (2003), we are at a crossroads in the transformation of public behavioral health care systems in our country. It is our belief that systems transformation begins with a transformation of the life/services planning process, such that focus people and those who believe in their potential are truly at the helm of defining and achieving self-chosen pursuits for a meaningful and valued community life.

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