

Finding A Way Toward Everyday Lives

The Contribution of Person Centered Planning

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Harrisburg, Pennsylvania

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On 29–30 June 1992, the PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE, OFFICE OF MENTAL RETARDATION sponsored a conference that gathered people experienced in various approaches to person centered planning and advocates and administrators interested in learning more about person centered planning. The conference, which was coordinated by Pennsylvania Association of Resources for People with Mental Retardation (PAR), provided background information for this booklet.

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Since the publication of *Everyday Lives*, “the vision for our future,” we have come to realize that each person has his or her own personal image of a desirable future. And so we have been looking for ways to discover what each person’s image of a desirable future is and for the means to make that image a reality.

Person-centered planning in its many and varied forms, if approached in a thoughtful, sincere, and indeed, a moral manner, can help us. It can help us to listen, to understand, and most importantly, to act.

This publication, so thoughtfully prepared by John O’Brien and Herb Lovett, describes the foundation of person-centered planning and its potential for creating a better future for people and for influencing change. It also addresses controversies and fears associated with this new approach.

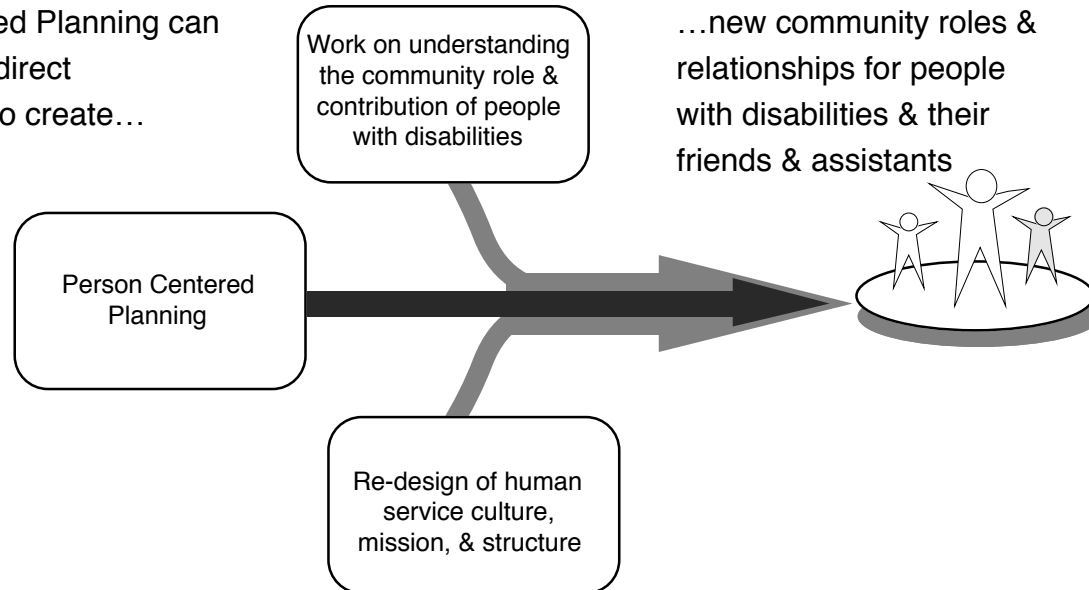
While person-centered planning is regarded as a new idea, it springs from our basic humanity, our eternal capacity for love, and our common desire to create a world that is safe and welcoming for everyone of us.

With the insight, advice and cautions of the people whose thoughts are contained in this booklet, let us move forward with our efforts to bring to reality the vision in *Everyday Lives*.

Nancy R. Thaler
Deputy Secretary for Mental Retardation

February, 1993

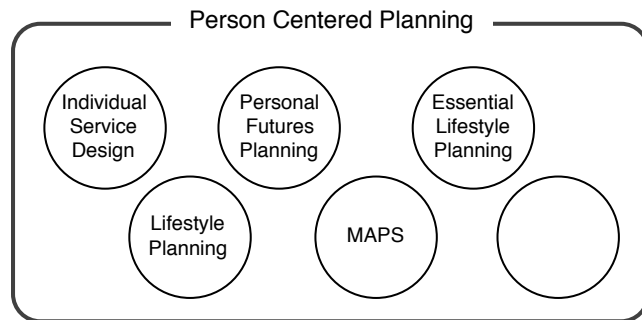
Person Centered Planning can invite, align, & direct shared efforts to create...



...new community roles & relationships for people with disabilities & their friends & assistants

Foundations of Person Centered Planning

The term, person centered planning, refers to a family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends.



Each approach to person centered planning has distinctive practices, but all share a common foundation of beliefs:

- ❑ The person at the focus of planning, and those who love the person, are the primary authorities on the person's life direction. The essential questions are, *Who is this person?* and *What community opportunities will enable this person to pursue his or her interests in a positive way?*
 - Knowledge gained from close, respectful, continuing relationships with the focus person is crucial in answering these questions.
 - Information gained from technical assessments of the person can be helpful, but only in the context of a knowledgeable account of a person's history and desired future. Subordinating professional-technical information to personal knowledge turns the typical agency decision making process on its head.

- ❑ The purpose of person centered planning is learning through shared action. People who engage in person centered planning may produce documentation of their meetings, proposals, contract specifications, or budgets. These are only footprints: the path is made by people walking together.
 - The focus person and those who know the person best may be uncertain about what is possible or desirable for the person. One function of person centered planning is to decrease such uncertainty by encouraging people to try new things together and to learn from them.
 - The focus person and others the focus person relies on may disagree about what is possible or desirable for the person. Disagreements may be explicit and verbal or they may surface in the behavior of all of the people involved. One function of person centered planning is to provide a forum for negotiating such conflicts.
- ❑ Person centered planning aims to change common patterns of community life. Segregation and congregation of people with disabilities are common. Devaluing stereotypes and inappropriately low expectations are common. Denial of opportunity is common. These negative patterns do not necessarily signify mean-spiritedness so much as undesirable habit. If invited to assist a person to pursue a desirable future, some people may remain closed and rejecting, but others will respond generously, based on their sense of justice. Person centered planning stimulates community hospitality and enlists community members in assisting focus people to define and to work toward a desirable future.
- ❑ In order to support the kinds of community changes necessary to improve people's chances for a desirable future, virtually all existing human service policies and agencies will have to change the ways they regard people, the ways they relate to communities, the ways they spend money, the ways they define staff roles and responsibilities, and the ways they exercise authority. Person centered planning requires collaborative action and fundamentally challenges practices that separate people and perpetuate controlling relationships.
- ❑ Honest person centered planning can only come from respect for the dignity and completeness of the focus person. This respect leads those involved in person centered planning to work for...
 - ...equal, non-coercive relationships with the people they plan with
 - ...appreciation and celebration of each person's uniqueness, and constructive ways to understand one another's challenges and failings
 - ...effective ways to communicate the importance of respect and equality to others involved with the focus person.
- ❑ Assisting people to define and pursue a desirable future tests one's clarity, commitment, and courage. Person centered planning engages powerful emotional and ethical issues and calls for sustained search for effective ways to deal with difficult barriers and conflicting demands. Those who treat person centered planning simply as a technique and those who fail to provide for their own development and support will offer little benefit to the people they plan with.

How Does Person Centered Planning Influence Change?

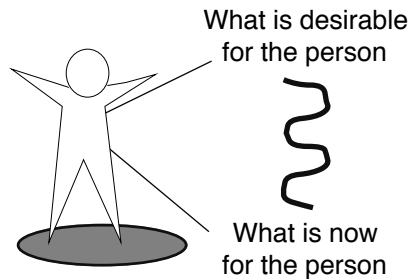
Person centered planning influences change by...

...creating a compelling image of a desirable future and inviting people to join with the focus person to make it happen

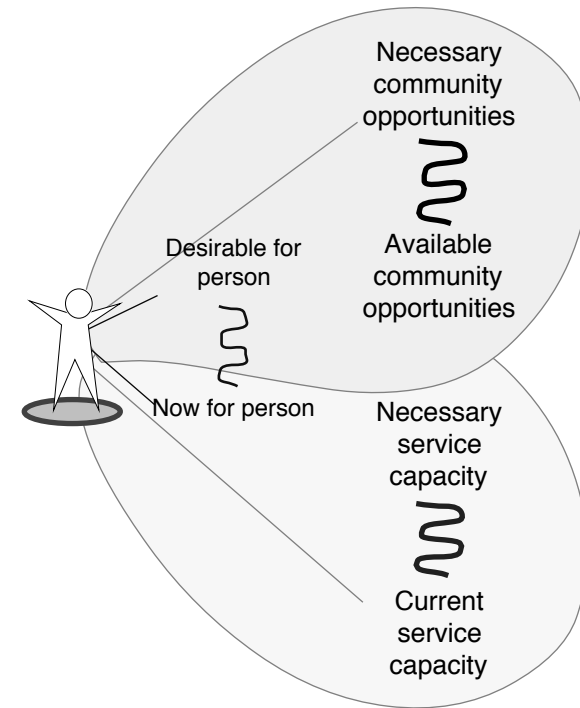
...strengthening personal relationships

...helping people plan, act, and learn by reflecting on their successes and failures

When successful, person centered planning allows its participants to experience tension between what is desirable for a person and what exists now for the person. This tension can energize action for positive change.



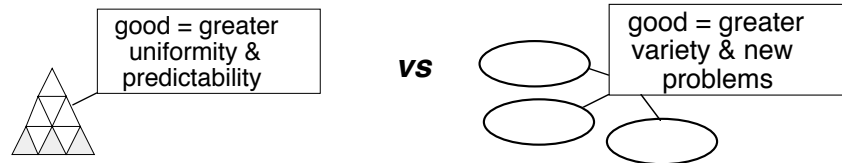
Too often, however, the inertia of service systems couples with prejudice against people with disabilities to stifle hope and opportunity. For change to happen, community opportunities must be opened and expanded and service systems must develop new capacities, both within themselves and in the wider communities they must be a part of.



This development happens through a process of mutual adaptation: first, services change to create new supports for the person and then the person responds to the demands and the rewards of the new situation. This sequence contradicts the tradition that people with disabilities must change themselves as a condition of entry to new opportunities: environments effect change more powerfully than training can.

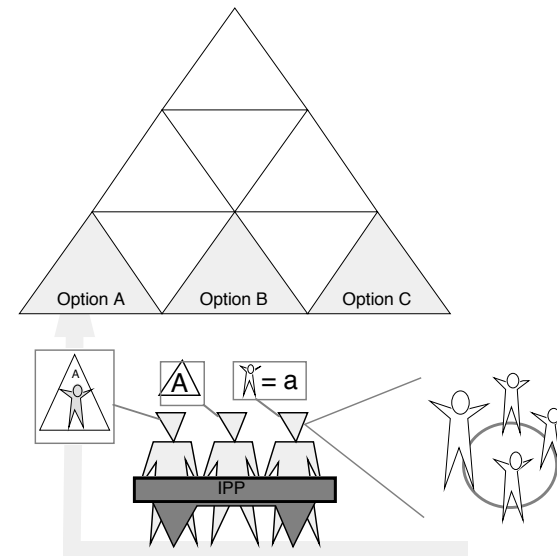
Person centered planning influences change when people respond to the tension between what a community has to offer now and what the focus person needs to pursue a desirable future. Direct engagement with the focus person and the focus person's allies guides community development. Person centered planning is a source of clear invitations to community members.

Person centered planning frequently challenges the culture of most human service agencies. Despite many capable staff who care about what happens to the people they serve, service system culture typically values uniformity and predictability more than the needs of any single individual.



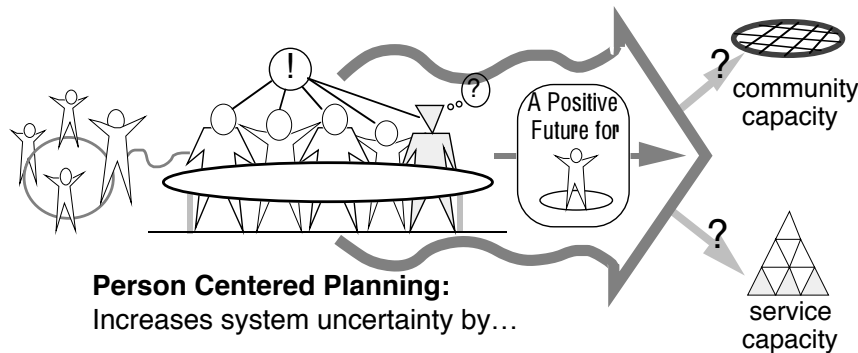
Person centered planning primarily values accurate individual services. This greatly increases the required variety of service responses.

When uniformity and predictability are primary system values, "individual program planning" functions to decrease uncertainty and variety through a regulated, impersonal ("objective") process of judgement that specifies people's daily routines in the pre-existing service option that best matches their disabling condition. The purpose and effect of individual program planning is to make the system more stable by drawing clear boundaries between staff and client and by teaching staff and families and people with disabilities a way to think about people's needs that matches the system's routines.



Individual Program Planning: Reduces system uncertainty by complying with rules governing...

- Measuring the person
- Assigning the person to an available option
- Prescribing & monitoring treatment



Person Centered Planning:

Increases system uncertainty by...

- Strengthening the person's alliances
- Clarifying individual interests & needs
- Energizing new demands on system & community

We have historically been more efficient in providing people for services than services for people. Person centered planning reverses this tradition to create a personalized image of a desirable future and a problem solving process for moving toward that future. In effect, effective person centered planning de-stabilizes a system for individualized schedules and types of assistance. The questions of how best to understand this person and how best to refine this understanding in action are central to the process instead of being the givens of regulations and professional training. Boundaries between professional and client are dissolved in the search for equal, non-coercive relationships. Boundaries between service agency and community are re-drawn as people seek to develop new opportunities. While some people will find these yet-to-be charted areas of work exciting, others, understandably, will find this unsettling and threatening.

Those who want to can find many ways to avoid engaging the tension between current reality and a desirable personal future. They can compare the present to worse past conditions instead of comparing it to desirable future capacities. They can dismiss the image of a desirable future as unrealistic. They can say that they would like to help but that powerful outside forces forbid them. They can stay busy with activities that allow no time to listen to and learn from focus people.

Individual, community, and service development all happen through a learning process which builds on existing capacities and searches for ways to deal constructively with obstacles. Capacities and obstacles come from local relationships among people with disabilities, families, community members, and service agencies as much or more than they are imposed by uncontrollable outside forces. Person centered planning provides a systematic way to learn from sustained action over the months and years necessary for development. If the process is successful, people's sense of a desirable future will evolve. One of the most common misunderstandings of person centered planning is that it is a short series of meetings whose purpose is to produce a static plan. This misunderstanding leads people to underestimate the time, effort, uncertainty, anxiety and surprise necessary to accurately support people's lives over time.

Limitations of Person Centered Planning

Done competently, person centered planning focuses and directs the energy available to the focus person. Each effort uniquely contends with limits on effective action by the focus person and the focus person's allies.

Sometimes limitations come from the service system. Many administrators like to talk about paradigm shifts without investing in the hard work required to make basic change in the way an agency operates. At times one agency or part of an agency will want to make more change than the system that contains it wants to accommodate. Substantive change cannot happen when service workers are unclear in their commitment to change, and administrators offer lukewarm support. Some service systems are so incoherent or inert that person centered planning contributes to good results only for people with very energetic and creative family and friends.

Sometimes limitations come from the focus person.

- ❑ The focus person provides some of the energy necessary for change.
 - Some people's interests and gifts are clear to others and so their ideas about a desirable future offer others definite ways to be involved; others' interests and gifts are more difficult to discern or support. Experience shows that people's apparent level of ability does not relate to the clarity with which they can communicate their interests or enlist other people they know to assist them. However, person centered planning will usually move more slowly and have a narrower reach when a focus person's interests

are not clear. It has also been our invariable experience that people's interests are unclear until they have people in their lives who combine their love with optimism.

- Some focus people welcome other people into their lives; others challenge those who would establish a relationship, sometimes because they have been repeatedly abandoned or abused. Many people with a reputation for being very challenging respond well to the attitudes implicit in person centered planning, but person centered planning often requires hard work to establish, and maintain, relationships when the focus person has a difficult or painful history of relating to others. Person centered planning is not a remedy for people who are difficult to serve, but it can guide dysfunctional services to provide better contexts for people's growth.
- ❑ The focus person's family can make an important contribution, and person centered planning often provides an effective vehicle for families to have the kind of influence they wish.
 - Family members often have connections to community life and can invite their friends to become involved.
 - Family members often hold the stories that define the focus person as a person rather than a "client". Where services often lose a person's history, or narrowly understand it in terms of professional assessments, families can hold the person's individuality in the foreground of discussions.

But family members can lose touch with a focus person, sometimes because of service practices that discourage family involvement.

□ Family members and professionals alike can define people in clinical terms.

- Both family members and professionals can have more influence over than involvement in a person's life. Sometimes professionals have advised family members not to get “over-involved”. Similarly, professionals with the most power in people's lives often do not have much direct contact with them. Psychologists may write influential assessments on the basis of very brief encounters, and administrators can make life defining decisions based on service expediency rather than a compelling sense of the person's identity and needs
- This atmosphere of remote control casts people in a negative light. This focuses planning on people's perceived deficits rather than their capacities; on what could go wrong rather than on what people need for things to go right. When power holders –whether professionals or family members– persist in seeing people in discouraging ways, desirable personal futures become difficult to achieve indeed.

Some limitations on person centered planning come from the amount of learning necessary to create the opportunities and supports a person needs. Even with strong leadership from the focus person and family and commitment to change by service providers, some issues –such as helping people to make friends, or discovering positive daytime roles for people with

high needs for assistance, or finding a constructive way to deal with offenses against the law– are complex and require commitment to the person, often over years.

Person centered planning is not a “quick fix” for people's difficulties. And, when things do work well, the lessons don't necessarily generalize widely. What seems to be one person's dream could easily be another's nightmare. In this sense, person centered planning accurately reflects ordinary life.

Some limitations come from the time it takes for things to happen. One focus person's dream, for example, was to live in a housing co-operative, but organizing the cooperative took several years.

These limitations make responsible facilitators of person centered planning careful not to promise good outcomes from every effort or speedy delivery of personal or organizational change. Responsible policy makers and administrators act cautiously and deliberately when they adopt person centered planning as a means to attain agency objectives on bureaucratic timeliness.

Controversies Among People Engaged in Person Centered Planning

Like any effort that attracts people with a strong desire to contribute to positive social change, person centered planning has its share of controversies. These debates cut across the different approaches and identify critical areas for the development of person centered planning.

- ❑ Involved people differ about the extent to which the focus person should control the direction of the process. Some people, emphasizing the history of services dominating people's lives “for their own good”, want the process only to respond to what the focus person clearly communicates that he or she wants. They say that the process should be “person driven planning”, with the focus person unequivocally in the driver's seat. Others, emphasizing the history of services depriving people of opportunities for experiences and relationships, believe that other people must actively invite the focus person into new experiences and new relationships.
- ❑ Some people who facilitate person centered planning would refuse to assist a person who clearly chooses to seek to live in a congregate, disability segregated setting. Others believe that alliance with the person is primary and believe that the process should serve whatever choice of living and daytime arrangements focus people or their families make.
- ❑ People who facilitate person centered planning differ in the amount and kind of information they use. Some choose to enlist the focus person and others in making a broad profile of the person's history, present experiences, and ideas about desirable futures. Others focus on a particular facet of a

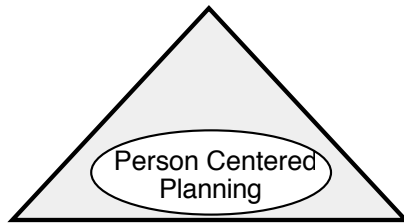
person's life, such as the necessary and desirable specifications for a person's next living arrangement.

- ❑ Some people who facilitate person centered planning are deeply concerned about working within organized service settings. They believe that service systems will inevitably pervert the possibilities of person centered planning and choose to work at the very edge of the service system, encouraging people to get out of, or avoid moving into, the system. Others believe that person centered planning can contribute to reforming services by stimulating, or even requiring, different kinds of service practices. They encourage adaptation of person centered approaches to fit service system agendas like deinstitutionalization or development of new programs.
- ❑ Some people who facilitate person centered planning believe that person centered planning should focus on those people who now get the least service from the system: those living with family members. They see person centered planning as a powerful support to families with disabled members at home and believe that focusing person centered planning on people already in some kind of residential service is another case of ignoring the many people who have only a little share of system resources in favor of the relatively few in high cost, high visibility services. Others believe that person centered planning is a particularly effective way to develop better alternatives for people in costly but restrictive and segregating settings.

- ❑ People who facilitate person centered planning disagree about how much a person's family, friends, neighbors, and co-workers or fellow students can do and should be expected to do. Some believe that natural supports (i.e. unpaid people) should and can be sufficient to assist people and that their contribution is blocked by the presence of human service workers. Others believe that, while natural supports make a vital and irreplaceable contribution, paid help is necessary and desirable. Still others are uncertain about whether unpaid people will respond on a sustained basis.
- ❑ People who facilitate person centered planning differ about the importance of convening an identified, ongoing support group for the focus person. Some see person centered planning as a means to the formation of a circle of support and believe that the circle matters much more than the planning process. Others believe that requiring a defined circle of support is somewhat contrived and could deprive some people who are isolated of the benefits that can come from a good plan. Some debate whether paid service providers can be full, effective members of support circles.

A Common Fear: The Debasement of Person Centered Planning

Regardless of these controversies, most people who facilitate person centered planning worry that a system more interested in fads than in fundamental change will capture person centered planning.

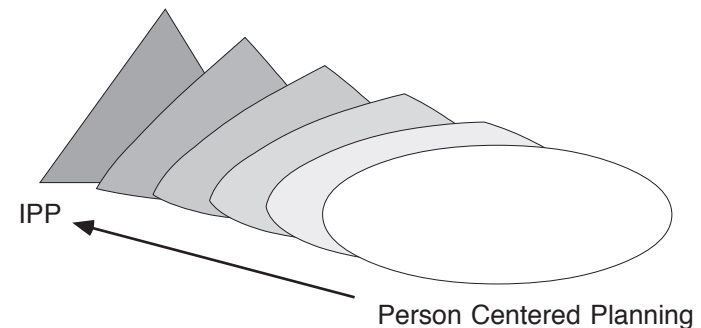


Rather than take on the hard work of learning new ways to assist people, service providers can more easily adopt the vocabulary and some of the techniques of person centered planning. Often this process is not conscious: service providers simply assume that their current beliefs and practices exhaust all of the positive possibilities for the people they serve. It is not so much that they hear people's call for basic change and reject it, as that they listen to people in a way that confirms the rightness of what the system is doing now.

Some signs that person centered planning has become a system fad rather than a tool for change include:

- ❑ System boundaries remain intact. Most of the participants in person centered planning are system workers. There are few efforts to engage community members. There is little re-allocation of agency resources into community settings.

- ❑ Large numbers of people “get” person centered plans, but there is little work on creating new kinds of relationships, new service approaches, and new community opportunities. Often this is justified as fairness because administrators believe it would be inequitable to provide something new for a few of the people they serve. This assumes that the system actually has the capacity to respond to everyone's needs. Otherwise, everyone gets a brightly colored bit of paper that describes a future that no one can assist them to pursue.
- ❑ The system gives people plans and meetings instead of necessary cash or needed paid for assistance.
- ❑ Most talk about person centered planning focuses on how to improve facilitation of planning meetings rather than on how to change the agency's culture and strategy for investing in community opportunities.
- ❑ Administrators require person centered planning without committing any flexible resources and without a procedure for changing regulations and timelines that create real barriers to necessary changes.



- ❑ Administrators, rather than the people involved, tinker with the procedures for person centered planning in order to make it more efficient and more uniform. For example, administrators decide that person centered plans take too long and must therefore be completed in a fixed amount of time.
- ❑ There is limited investment of time for reflection on what people are learning from person centered planning.
- ❑ Person centered planning is expected to produce “good

stories” more than criticisms and questions about the culture and policies of the service system.

Person centered planning can also be defeated by its enthusiasts. Practitioners can paralyze themselves by agonizing over the problems and ambiguities surfaced in the process instead of looking for small positive steps. Practitioners can disempower themselves by looking for high ground from which to observe and criticize rather than looking for common grounds for action.

**Some Possible Safeguards for Person Centered Planning
Which Can Be Initiated By The People Involved**

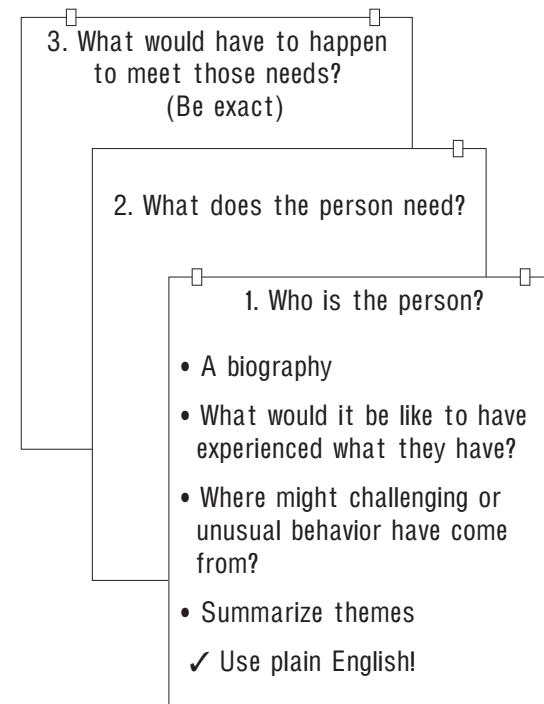
- Start small and grow slowly, perhaps with projects that are specifically resourced as development activities.
- Join and invest in building up a network of facilitators and other involved people who can offer mutual support and criticism. The network will grow as people ask for and give one another help.
- Identify and discuss conflicts, uncertainties, and poor outcomes.
- Take advantage of opportunities to learn such as reading and training related to human service values and group leadership.
- Seek advisors and mentors.

Some Distinctions Between Approaches to Person Centered Planning

From a common foundation of beliefs, each approach to person centered planning builds a distinctive structure to assist people with disabilities and their allies to clarify direction and plan action.

Individual Service Design

Individual service design developed as part of a long-term effort to assist service providers to understand the practical implications of the principle of normalization (social role valorization). It is often used to help service providers develop positive approaches to people who challenge their ability. The process builds understanding of, and identification with, the focus person by carefully reconstructing the focus person's history. The individual service design group attempts to “walk in the person's shoes”, empathically asking what it would be like to experience the events in the person's life. On the basis of key themes derived from reconstructing the focus person's history, the group identifies the person's most important needs and specifies what would be necessary to meet these needs.



Individual Service Design

Personal Futures Planning

Personal futures planning developed from efforts to apply some lessons from the fields of planning and community development to the situation of people with disabilities. Personal futures planning has evolved in two different contexts: support to people with disabilities and their families and friends who begin work with little effective cooperation from the service system; and, assistance to service providers who want to transform the system they work within. The process engages its participants in...

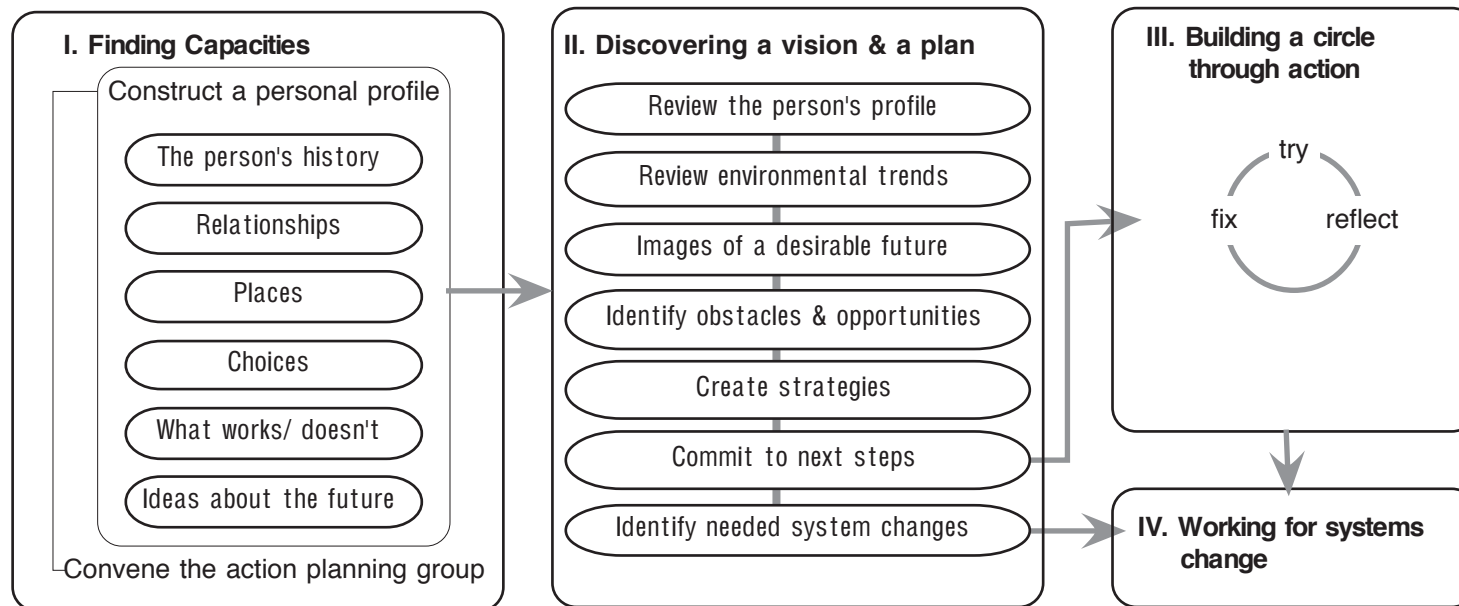
...seeking capacities in the focus person, among those who care about the focus person, and in the focus person's community

...discovering a vision of a desirable future with the focus person and making an action plan

...building stronger and more effective support for the person by joining people in a process of learning through making small positive changes

...specifying and working for changes in the service system which would allow the system to offer more relevant assistance

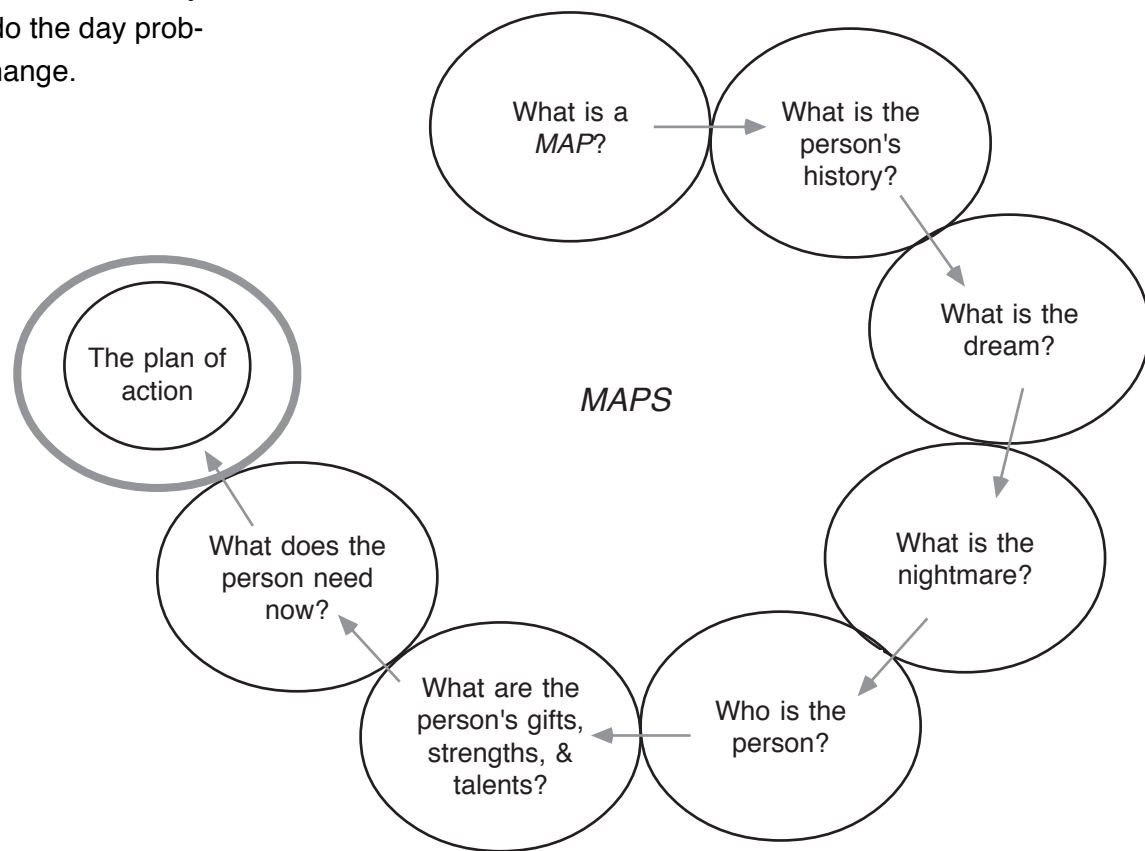
Personal futures planning calls on all of its participants to work creatively together over time as equals across usual organizational and status boundaries.



Personal Futures Planning

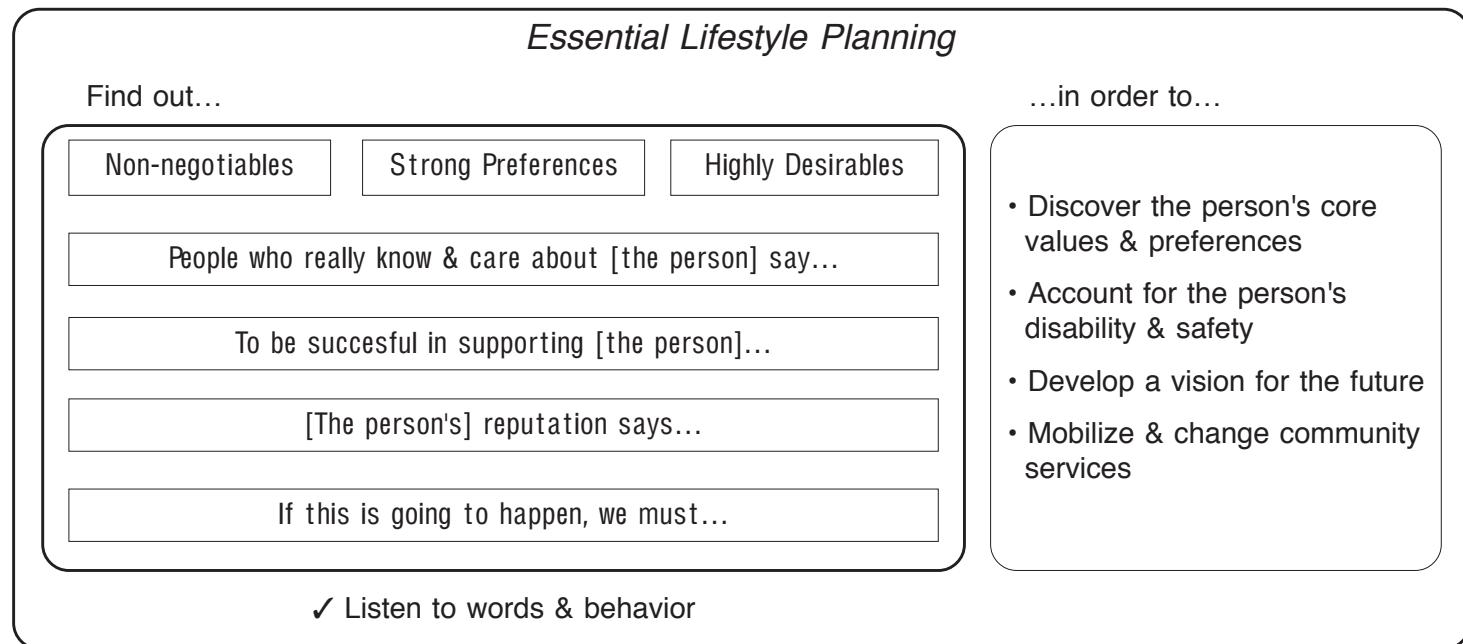
MAPS

MAPS developed from efforts to assist families to include their children with disabilities in ordinary school classrooms. The process brings together students, school staff, and family members to create a shared understanding of the focus person and to clearly identify the focus person's gifts and needs. Based on this shared understanding, participants negotiate modifications to school, family, and individual routines. The *MAPS* process is closely linked to the creation and development of circles of support for the focus person and often for the family and sometimes for the staff involved. Circles do the day problem solving necessary to make and sustain change.



Essential Lifestyle Planning

Essential Lifestyle Planning developed from efforts to assist people to move from institutions into community services. The process focuses on gathering information about the focus person's core values and preferences from the focus person and from those family members, friends, and institution staff who know the focus person well. This information becomes the basis for a request for proposals from service providers and is finally incorporated into a contract between the service system and the service provider who chooses to assist the person. An independent agent typically directs this process. Essential Lifestyle Planning aims to provide the focus person with a secure and effective base of service assistance.



The Future of Person Centered Planning

Person centered planning can invite, align, and direct shared efforts to create positive community roles for people with disabilities. It allows people to exercise their practical wisdom to work for more inclusive, more just communities.

To support their work and its improvement, people involved in person centered planning need to extend their network of relationships across the different approaches to person centered planning, community development, and service reform. The future of person centered planning depends on their willingness and ability to improve their practice through critical reflection on the effects of their work in the lives of people with disabilities and their families.

Resources

*Personal Futures Planning**

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*Note: Some people call this approach "lifestyle planning," probably because copies of O'Brien's chapter by that name (1987) were widely circulated. This chapter was written about personal futures planning, which was re-named lifestyle planning by the book's editors in the context of its application to the activities catalog approach to school curriculum development.

John O'Brien, Beth Mount, & Connie Lyle O'Brien (1990). *The personal profile*. Lithonia, GA: Responsive Systems Associates.

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Jack Pealer & Sandra Landis (1990). *Suggestions for exploring and recording the personal history of someone we're assisting to plan*. Chillicothe, OH: Ohio Safeguards.

CONTACT:

Communitas • Box 374 • Manchester, CT 06040

Graphic Futures • 25 West 81st St, 16-B • New York, NY 10024

MN Governor's Planning Council on Developmental Disabilities • Centennial Office Building • St Paul, MN 55155

Ohio Safeguards • PO Box 1943 • Chillicothe, OH 45601

Realizations • PO Box 1430, Station B • London, ON N6A 5M2

Responsive Systems Associates • 58 Willowick Dr • Lithonia, GA 30038

Individual Service Design

Jack Yates (1980). *Program design sessions*. Stoughton, MA: Author.

CONTACT: Jack Yates • 23 Ralph Mann Dr • Stoughton, MA 02072

Essential Lifestyle Planning

Michael Smull & Susan Burke Harrison (1992). *Supporting people with severe reputations in the community*. Alexandria, VA:NASMRPD.

CONTACT: NASMRPD • 113 Oronoco St • Alexandria, VA 22314

MAPS

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Marsha Forest & Evelyn Lusthaus (1989). Promoting educational equality for all students: Circles and MAPS. In S. Stainback, W. Stainback, & M. Forest. *Educating all students in the mainstream of regular education*. Baltimore, MD: Paul Brookes Publishing Co. pp. 43-57.

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CONTACT: Inclusion Press • 24 Thome Cres. • Toronto, ON M6H 2S5