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FOREWORD & ACKNOWLEDGEMENTS

The Department of Developmental Services has adopted a value-based vision for the future of our system. These values embody an approach centered on the person and family. Our values also embrace cultural and individual differences, and support the role of families in the lives of their children with developmental disabilities. The values are intended to provide the underpinnings of a system that respects the choices made by individuals and families and assures a cost-effective use of public resources.

This manual is the product of extensive input from individuals with developmental disabilities, families and organizations who represent important components of the service delivery system. Due to popular demand and to new statutes, which revised the IPP process, the Department of Developmental Services is updating the manual, with thanks to the contributors providing updated information for this revision.

The Department also extends special thanks to the artists who graciously consented to the inclusion of their photographs and drawings in this manual.

INTRODUCTION

Purpose

The 1992 amendments to the Lanterman Developmental Disabilities Services Act¹ (Lanterman Act) require a person-centered approach to Individual Program Plans (IPPs) for individuals with developmental disabilities (consumers). The basic requirements related to IPPs in the 1992 amendments to the Lanterman Act are:

- 1) *IPPs will be centered on the person and family.*²
- 2) *The Department of Developmental Services (the Department) will prepare a standard format for IPPs, with instructions. The format and instructions will embody an approach centered on the person and family.*³
- 3) *The Department will prepare training materials to implement the person-centered approach to IPPs.*⁴
- 4) *To insure a person-centered approach to IPPs, each regional center shall use the standard format, instructions, and training materials prepared by the Department.*⁵
- 5) *All public or private agencies receiving state funds for the purpose of providing the services and supports selected through the IPP process shall respect the choices made by consumers including, but not limited to, where and with whom they live, their relationships, the way they spend their time (including education, employment and leisure*

1. Welfare & Institutions Code Section 4500 et. seq.
2. Welfare & Institutions Code Sections 4646(a) & 4646.5(c)
3. Welfare & Institutions Code Section 4646.5(c)(1)
4. Welfare & Institutions Code Section 4646.5(c)(1)
5. Welfare & Institutions Code Section 4646.5(c)(2)

*activities) the pursuit of their personal future, and program planning and implementation.*⁶

*6) Information needed by consumers and families to exercise their right to make the choices necessary for person-centered IPPs will be provided in an understandable form.*⁷

*7) The activities of employees of the regional centers and service providers related to person-centered IPPs, shall reflect awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and family.*⁸

*8) Decisions concerning the consumer's goals, objectives, and services and supports that will be included in the IPP and purchased by the regional center, or obtained from generic agencies, shall be made jointly by the planning team at the program plan meeting.*⁹

*9) The consumer or, where appropriate, their parents, legal guardian, or conservator; and a regional center representative shall sign the individual program plan prior to its implementation.*¹⁰

*10) The IPP shall specify the approximate start dates for services and supports and shall contain timelines for actions necessary to begin services and supports, including generic services.*¹¹

*11) The Department will monitor regional centers so that consumers will receive services and supports that have been identified in the IPP.*¹²

6. Welfare & Institutions Code Sections 4502(j) & 4502.1

7. Welfare & Institutions Code Sections 4502(j) & 4502.1

8. Welfare & Institutions Code Section 4646.5(a)(1)

9. Welfare & Institutions Code Section 4646(d)

10. Welfare & Institutions Code Section 4646(g)

11. Welfare & Institutions Code Section 4646.5(a)(4)

12. Welfare & Institutions Code Section 4646.5(c)(3) & 4648.1

This resource manual is designed to fulfill the requirements of the Lanterman Act, and to facilitate the adoption of the values that lead to person-centered individual program planning. It is intended for use by all those who participate in person-centered planning. It was developed with extensive input from consumers, families, advocates and providers of service and support.

Summary

The introduction presents an overview of the person-centered approach to planning for a preferred future. The values that are essential to a person-centered approach are explained in the second section. A description of the roles and responsibilities of those involved in person-centered planning is also included in the second section. The third section contains the standard format for written IPPs, with instructions and explanations.

The fourth and fifth sections of the manual contain examples of person-centered approaches to IPPs, and stories that illustrate how person-centered planning has been done in specific instances. These sections provide useful ideas for those engaged in person-centered planning.

Training guidelines are found in the sixth section. These training guidelines are intended for use by teams of trainers that may include consumers, families, service coordinators and providers of service and support.

A pocket guide to person-centered planning is available separately. The pocket guide is a paraphrased version of the material from the first three sections of this manual. The purpose of the pocket guide is to provide a brief overview of the person-centered IPP process. This guide was prepared by Bill Allen, of Allen, Shea & Associates, and is written in a

style that is easy to read.

A glossary of the acronyms and terms, and a list of references are found at the end of the manual.

How to tell what is mandatory from what is being proposed as "best practice"

Italics are used throughout the manual when something mandatory is being described or referred to. The words "shall", "will" or "must" also indicate mandatory language. Mandatory means it is required by the Lanter-man Act or other law or regulation. The reference in law or regulation that makes something mandatory is found in the footnotes.

Instructions or other text in normal type represents current best practice. These best practices are consistent with and supplement what is mandatory. The words "may", "can" or "should" indicate best practice, as opposed to mandatory action.

If you have questions . . .

If you have questions or comments about this material, please contact:

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Person-Centered Planning

Person-centered planning, for the purposes of this manual, is an approach to determining, planning for, and working toward the preferred future of a person with developmental disabilities (a consumer¹³) and her or his family. The preferred future is what the person and family want to do in the future based on their strengths, capabilities, preferences, lifestyle and cultural background. Person-centered planning is a framework for planning and making decisions. It is not a collection of methods or procedures. Person-centered planning is based on an *awareness of, and sensitivity to the lifestyle and cultural background of the consumer and family.*¹⁴



Person-centered planning is an approach to determining, planning for and working toward the preferred future.

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13. For the remainder of this manual, the term consumer will include the consumer, and where appropriate, the authorized representatives of the consumer. "Authorized representative" means the conservator of an adult, the guardian, conservator, or parent or person having legal custody of a consumer who is a minor, or person or agency authorized in writing by the claimant or by the legal guardian, conservator, or parent or person having legal custody of a minor claimant to act for or represent the consumer (Welfare & Institutions Code Section 4701.6).
14. Welfare & Institutions Code Section 4646.5(a)(1)

The preferred future

The preferred future of consumers and their families is determined by finding out what their *life goals, capabilities and strengths, preferences, barriers, and concerns or problems* are.¹⁵ When consumers describe *where and with whom they want to live, who they want to socialize with, how they would like to spend their time, what jobs they want to have, and other aspects of their daily lives,*¹⁶ they are describing their preferred future. Observing those who have difficulty with language will provide an indication of their capabilities, strengths, preferences and concerns or problems. Asking those who know a consumer well can also provide the necessary information.

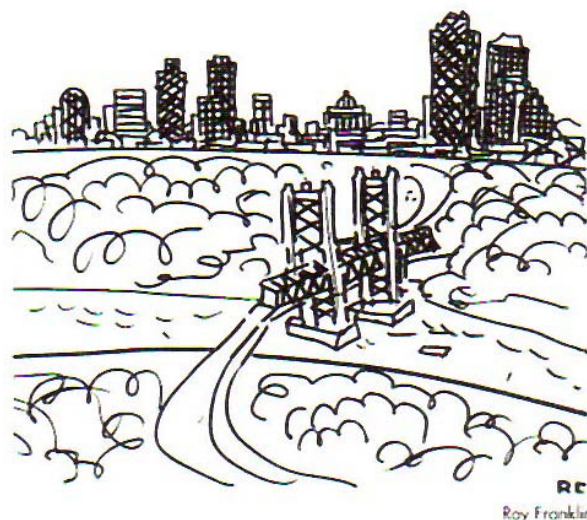
The needs, barriers, concerns and problems experienced by a consumer are identified in this person-centered process, but only as they relate to the goals, capabilities, strengths and preferences of the consumer and family. Procedures, such as diagnosing the consumer and listing the deficits and needs that led to that diagnosis, and prescription of activities intended to remedy the condition described by the diagnosis, do not fill the requirement for providing a planning process that is centered on the person and family.

When consumers describe where and with whom they want to live, whom they want to socialize with, how they would like to spend their time, what jobs they want to have, and other aspects of their daily lives, they are describing their preferred future.

¹⁵ Welfare & Institutions Code Section 4646.5(a)(1)

¹⁶ Welfare & Institutions Code Section 4502(j)

Although knowledge and expertise are respected and valued, planning that is prescribed and controlled by others without respect for the choices made by consumers and families is not person-centered. In an approach to planning that is focused on the consumer and family, members of the planning team adopt the role of consultants or advisors who help the consumer and family achieve their preferred future.



Ongoing planning

Person-centered planning assists consumers and their families to build their capacities and capabilities. This planning effort is not a single event or meeting, but a series of discussions or interactions

among the consumer, family, service coordinator¹⁷ and others. This group of people is called a planning team.

Person-centered planning assists consumers and their families to build their capacities and capabilities.

17. The service coordinator may be an employee of the regional center or may be a qualified individual or employee of an agency with whom the regional center has contracted to provide service coordination services (Welfare & Institutions Code Section 4647[b]). Where appropriate, a consumer or the consumer's parents or other family members, legal guardian, or conservator, may perform all or part of the duties of the service coordinator . . . if the regional center director agrees and it is feasible (Welfare & Institutions Code Section 4647[c]).

The planning team must include the consumer (and family when the consumer is a minor child¹⁸), and the service coordinator: In addition to the service coordinator, other representatives of the regional center may also function as planning team members. When invited by the consumer, others may join the planning team.¹⁹

Consumers and families must be able to communicate effectively with other members of the planning team. For consumers who experience difficulty in communication, that may mean that a facilitator of the consumer's choosing should also be a member of the planning team.²⁰ *If all of the members of the planning team do not share the same language, an interpreter or translator is necessary.²¹* The size and composition of the planning team should be arranged to meet the communication needs and preferences of the consumer and family. The essential feature is that *the information exchanged among the members of the planning team must be exchanged in a form that is understandable to the consumer and family.²²*

Consumers and families must be able to communicate effectively with other members of the planning team.

Whenever possible, relevant information should be exchanged among members of the planning team before planning conferences are held. For example, written reports of professional assessments should be given to the consumer and family prior to the planning conference where the assessments will be discussed.

18. Welfare & Institutions Code Sections 4646(b) & 4685

19. Welfare & Institutions Code Section 4646(d)

20. Welfare & Institutions Code Section 4648(a)(12)

21. California Code of Regulations, Title 22, Sections 98210(a) & 98211(c)

22. Welfare & Institutions Code Section 4502.1

In some cases, consumers will benefit from tangible forms of information. For example, it may be necessary to assist the consumer to visit other types of work or living environments prior to a planning conference where a change in these areas will be discussed. It is important for planning team members to identify the issues that may need to be addressed in a planning conference before the conference so that there are no "surprises" during the conference.

The planning conference

The planning team will periodically review the consumer's IPP in a manner agreed to by the planning team. This review will include discussion of the consumer's achievements and needs, approximate scheduled start date and time lines for actions necessary to begin services and supports, and determining whether previously scheduled services and supports have been delivered as planned.²³ Services and supports are expected to be effective in meeting the goals stated in the IPP, reflect the needs, preferences and choices of the consumer, and reflect the cost-effective use of public resources.²⁴ As defined in regulation, cost-effectiveness means obtaining the optimum results for the expenditure.²⁵

These reviews are scheduled often enough to meet the needs of the consumer and family, but not less often than once every three years.²⁶ These meetings are called planning conferences. Planning conferences provide a snapshot of the planning process at a point in time. They allow the planning team to evaluate the effects of the scheduled services and supports in moving the consumer (and family, as appropriate) toward the preferred future, and to decide what modifications to the IPP are needed.

23. Welfare & Institutions Code Section 4646.5(a)(4), (5) & (b)

24. Welfare & Institutions Code Section 4646(a)

25. California Code of Regulations, Title 17, section 58501(a)(6)

26. Welfare & Institutions Code Section 4646.5(b)

The decisions made by the planning team during planning conferences are made jointly. Decisions concerning the consumer's services and supports purchased by the regional center shall be made by agreement between the regional center representative and the consumer; or where appropriate, the parents, legal guardian, conservator or authorized representative at the program plan meeting.²⁷ The plan must be signed by the consumer; or where appropriate, his or her parents, legal guardian, or conservator; and a regional center representative prior to the plan's implementation.²⁸ This means that team members share information freely with each other, and attempt to agree among themselves as to the best course of action to achieve the preferred future for the consumer and family. Collaboration, cooperation and mutual respect among the members of the team are essential to this joint decision-making process. In those instances where agreement cannot be reached, another meeting shall be held within 15 days.²⁹ The consumer and family shall be informed verbally, and shall be notified within five days,³⁰ in writing, in a language, which they comprehend, of their right to a fair hearing.³¹

The decisions made by the planning team during planning conferences are made jointly. Collaboration, cooperation and mutual respect among the members of the team are essential to this joint decision-making process.

Planning conferences provided a snapshot of the planning process at a point in time.

27. Welfare & Institutions Code Section 4646(d)

28. Welfare & Institutions Code Section 4646(g)

29. Welfare & Institutions Code Section 4646(f)

30. Welfare & Institutions Code Section 4646(b)

31. Welfare & Institutions Code Section 4705(d)

*Disagreement shall not prohibit implementation of the agreed upon services and supports.*³²

*At intake, the regional center shall also inform the consumer and family of the advocacy services available through the local area board and the nearest office of Protection & Advocacy, and shall provide the addresses and telephone numbers of those agencies.*³³

The written IPP

The planning conference results in a written IPP that documents the choices and decisions made by the team using person-centered methods. Completion of a written IPP, however, is not the outcome of person-centered planning. While the planning team is responsive to the needs of funding and service agencies for complete and accurate information, the needs of these agencies should not prevent the team from centering their attention and activities on the consumer and family.



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*The written IPP contains goals and objectives based on the needs, preferences, and life choices of the consumer and family.*³⁴

It also contains a approximate scheduled start dates and time lines for actions necessary to begin services and supports, a scheduled of the type

32 . Welfare & Institutions Code Section 4646(g)

33 . Welfare & Institutions Code Section 4646(c)

34 . Welfare & Institutions Code Section 4646.5(a)(2) & (3)

*and amount of services and supports to be purchased by the regional center or obtained from generic resources or other resources in order to achieve those goals and objectives, and a list of those responsible for providing the services and supports. The consumer and family shall have input to the selection of these providers.*³⁵

During the planning conference, the service coordinator will keep notes to ensure that what was agreed to is reflected in the written IPP. At the end of the planning conference the team will review and agree upon what was decided, and who is responsible for the next steps.

There may be some issues remaining at the end of the review that require further consideration or investigation before they are jointly agreed to. Those remaining issues will be considered by the planning team as a whole after the necessary information is available. This may result in additional review by the planning team. *If agreement cannot be reached at the meeting, a second meeting must be scheduled within 15 days. Additional meetings may be held if the team agrees*³⁶. The team may also agree to a range of alternative solutions to some remaining issues and delegate the choice among those agreed-upon alternatives to the service coordinator.

While handwritten IPPs are permitted, they are usually typed some time after the planning conference to make them easier to read. When the written IPP is typed after the planning conference, the typed IPP should be distributed to the members of the planning conference within 45 days after the planning conference.

Whether handwritten or typed, *the final IPP must be prepared in a form that is understandable to the consumer and family.*³⁷ *If the consumer or family needs interpretation or translation services to fully participate in*

35. Welfare & Institutions Code Section 4646.5(a)(4)

36. Welfare & Institutions Code Section 4646.5(a)(4)

37. Welfare & Institutions Code Section 4502.1 and California Code of Regulations, Sections 98210(a) & 98211(c)

the development of the IPP, or to understand the written IPP, the regional center shall provide translation or interpretation services as appropriate.³⁸ The consumer; and/or family, shall sign the IPP prior to its implementation.³⁹

Whether handwritten or typed, the final IPP must be prepared in a form that is understandable to the consumer and family.

Those portions of the final written IPP that require specific services should also be given to the appropriate service providers. The entire IPP may be distributed to each service provider involved, with the permission of the consumer.

Working toward the preferred future

Planning does not stop when the planning conference is completed. Members of the planning team continue to have informal discussions and interactions. These provide opportunities to monitor progress, and make minor adjustments to planned activities that are consistent with the selected goals and objectives. Providers of service and support engage in the activities they have agreed to, and keep the planning team members informed.

³⁸ California Code of Regulations, Title 22, Sections 98210(a), (c), (d) & 98211(c)

³⁹ Welfare & Institutions Code Section 4646.5(a)(4)

Values, Roles & Responsibilities

Values

The Department's efforts to design and implement a system of individual program planning that embodies an approach centered on the person and family are based on the following values:¹



Empowerment and choice

- The developmental services system supports rather than controls individuals and families, entering into partnerships that promote self-determination and interdependence.
- *Opportunities are provided to consumers to make choices in their own lives, including where and with whom they live, their relationships, the way they spend their time, the pursuit of their personal future and program planning and implementation.*^{2,3}

The developmental services system supports rather than controls individuals and families, entering into partnerships that promote self-determination and interdependence.

1. Adapted from *Building partnerships, supporting choices: A Vision for a Preferred Future for Persons with Developmental disabilities* (1994). California Department of Developmental Services, with additions from the Lanterman Act.

2. Welfare & Institutions Code Section 4502(j)

3. Note: It may be necessary to provide several different opportunities, options and experiences for consumers and families to reach a point of true choice.

- Adult consumers have a choice of lifestyle options, and are supported in reaching their own future with the least amount of control by others.

- *All public and private agencies receiving state funds for the purpose of serving persons with developmental disabilities provide consumers with opportunities to exercise decision-making skills in any aspect of day-to-day living and provide consumers with relevant information in an understandable form to aid the consumer in making his or her choice.*⁴

- Consumers and families express their opinions, desires and disappointments without fear of reprisal.

Diversity

- *Information is provided to consumers and families in a form or language they understand to facilitate their decision-making.*⁵
- Professionals join in partnership with consumers and families to engage in the person-centered IPP process.
- *Professional performance reflects sensitivity to the cultural preferences, values and lifestyles of consumers and families.*⁶



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4. Welfare & Institutions Code Section 4502.1
5. *Welfare & Institutions Code Section 4502.1 & 4641*
6. Welfare & Institutions Code Section 4646.5(a)(1)

Family support

- *Families are respected and supported in their role of primary decision makers on behalf of their minor children.⁷ They make choices, which determine what services are given, where and by whom. Services and supports provided build on family strengths, natural supports and existing community resources.*
- *Children with developmental disabilities most often have greater opportunities for educational and social growth when they live with their families.⁸*
- *When a minor child must live out of the family home, the regional center will make every effort to place the child in a living situation as near to the family home as possible.⁹*
- *If appropriate, the regional center will take the steps to develop services and supports necessary to return the child to, or in a living situation near, the family home.¹⁰*



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7. Welfare & Institutions Code Section 4685(a)(1)
 8. Welfare & Institutions Code Section 4685(a)
 9. Welfare & Institutions Code Section 4685.1 (a)
 10. Welfare & Institutions Code Section 4685.1 (b)

Community integration

- Consumers will participate in valued ways with their friends, neighbors and co-workers in all areas of community life, with services and supports being provided which enable them to have real choices in where they live, work and socialize.
- Adult consumers are supported in natural settings in their local communities, with opportunities to live in their own homes, to be involved in meaningful activities, and to participate in the life of their communities.
- Consumers who are minor children live and grow up within a natural or surrogate family, attend their neighborhood schools and play with non-disabled children of their own age.



Virginia Rathbun

Teamwork

- The process of planning for a preferred future is a team effort, which is completed with a high degree of cooperation and a sense of partnership among all the participants.

The consumer and family are full participants in this effort. Their choices are given the full attention and respect of all the members of the team.

- *The consumer and family are full participants in this effort. Their choices are given the full attention and respect of all the members of the team.*¹¹

Accountability

- *Measurement of progress toward a preferred future is made in terms of desirable outcomes as they are expressed by the consumer.*¹²
- *Services and supports provided to consumers and their families reflect the cost-effective use of public resources.*¹³
- While written records of the decisions and choices made by the planning team at planning conferences are made in the prescribed format, completion of these records is not treated as an end in itself.
- Members of the planning team complete the activities they agreed to do within the times agreed to.

Measurement of progress toward a preferred future is made in terms of desirable outcomes as they are expressed by the consumer.

Roles and responsibilities

The developmental services delivery system in California affects hundreds of thousands of children and adults directly. The system has an important impact on the lives of consumers, their families, their neighbors, and whole communities. The complexities of providing services and supports to consumers and families require coordination and cooperation between governmental and community agencies to ensure that no gaps occur in communication or provision of services and supports.¹⁴ Each

11. Welfare & Institutions Code Sections 4502(j), 4502.1 & 4646(d)

12. Welfare & Institutions Code Section 4648(a)(7)

13. Welfare & Institutions Code Section 4646(a)

14. Welfare & Institutions Code Section 4501

participant in this system has an important role, and every role carries with it certain responsibilities.

Consumers and families

*Consumers and families have the central role in the system, and have been given leadership in the design of services and supports.*¹⁵

Consumers and families have the central role in the system, and have been given leadership in the design of services and supports.

Consumers and families are responsible for: taking the time to think about what they want, expressing their hopes, dreams, desires and needs as clearly as possible, and working as team members.¹⁶

Circles of support and natural supports

A circle of support is a group of community members that meets with an individual with developmental disabilities in order to share experiences, promote autonomy and community involvement, and assist the individual in establishing and maintaining natural supports. A circle of support generally includes a majority of people who neither receive nor provide services or supports for persons with developmental disabilities, and who do not receive payment for participation in the circle of support.¹⁷

15. Welfare & Institutions Code Section 4501

16. Capitol People First and Protection & Advocacy, Inc., (1994). *Your IPP: It's not just a piece of paper*. Sacramento, CA.

17. Welfare & Institutions Code Section 4512(f)

Natural supports are personal associations and relationships typically developed in the community that enhance the quality and security of life for the consumer. Natural supports include, but are not limited to, friendships reflecting the diversity of the neighborhood and the community; associations with fellow students or employees in regular classrooms and workplaces; and associations developed through participation in clubs, organizations, and other civic activities.¹⁸

A circle of support is a group of community members that meets with an individual with developmental disabilities in order to share experiences, promote autonomy and community involvement, and assist the individual in establishing and maintaining natural supports.

Both circles of support and natural supports can be of great use to a consumer. Their roles and responsibilities are defined by the consumer. Consumers decide whether they want a circle of support and the extent of involvement of natural supports.

Providers of services and supports

Providers are an essential element of the service delivery system. Their role is to provide the services and supports that *assist consumers and families in achieving the greatest self-sufficiency possible and in exercising personal choices.*¹⁹ They assist consumers and families in working toward their preferred futures as identified during the IPP process. Providers do

18. Welfare & Institutions Code Sections 4512(e)

19. Welfare & Institutions Code Sections 4648(a)(1) & 4685

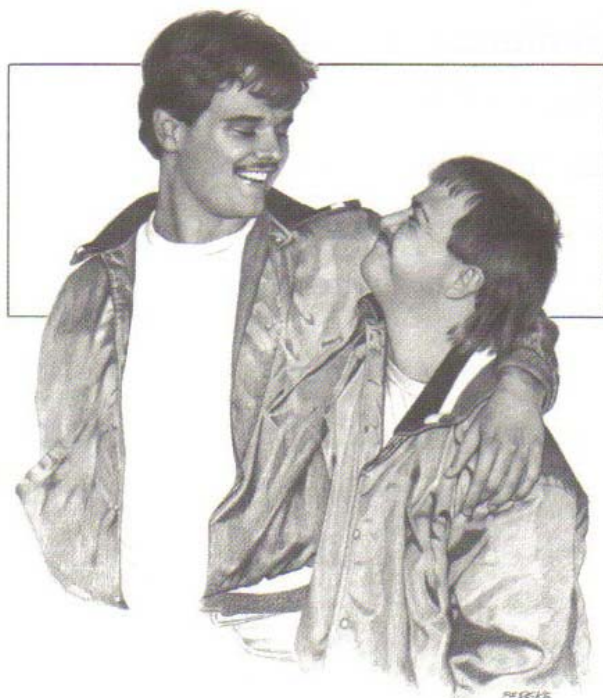
not prescribe preferred futures, but *respect the choices of the consumers and families they serve.*²⁰ The services and supports they provide are consistent with the preferred lifestyle and cultural background of the consumers and families they serve.

Providers help consumers and families advocate for themselves and make their own choices, and avoid making choices on behalf of consumers and families unless they are unable or unwilling to make their own choices.

*Providers are responsible for delivering the services and supports as they are scheduled in the consumer's IPP. They are also responsible for achieving the outcomes defined in the consumer's IPP.*²¹

Providers are also responsible for providing consumers and families with the information they need to make informed choices. *This information must be presented in a form that is understood by the consumer and family.*²²

Providers assist consumers and families in achieving the greatest self-sufficiency possible and in exercising personal choices.



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20. Welfare & Institutions Code Section 4503(i)

21. Welfare & Institutions Code Section 4501 & 4648(a)(6)(A)

22. Welfare & Institutions Code Section 4502.1

Regional centers

The primary role of the regional centers is to provide fixed points of contact in the community for consumers and their families so that consumers may have access to the services and supports best suited to them throughout their lifetimes.²³ *Regional centers are responsible for providing each consumer with a service coordinator.*²⁴ *The service coordinator coordinates the activities necessary to develop and implement the consumer's Individual Program Plan. Those activities include participating in the individual program planning process and obtaining necessary services and supports from generic agencies, private agencies or by purchasing them.*²⁵ *The regional center conducts a variety of activities to achieve the stated objectives of a consumer's IPP.*²⁶

The primary role of the regional centers is to provide fixed points of contact in the community for consumers and their families so that consumers may have access to the services and supports best suited to them throughout their lifetimes.



Edward Bell

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- 23. Welfare & Institutions Code Section 4620
 - 24. Welfare & Institutions Code Section 4640.7(b) & 4647
 - 25. Welfare & Institutions Code Section 4647(b)
 - 26. Welfare & Institutions Code Section 4648

Regional centers are responsible for ensuring that the standard format for person-centered IPPs prepared by the State is followed in the individual program planning process.²⁷ Regional centers are also responsible for ensuring that the purchase of services and supports reflects the cost-effective use of public resources.²⁸

The State

The State of California has accepted a responsibility to establish and maintain a service delivery system that assists and supports eligible individuals with developmental disabilities (consumers) and their families.²⁹ The State Department of Developmental Services (the Department) provides leadership, oversight, coordination and technical assistance to the other participants in the system. The Department is responsible for providing a standard format, instructions, and training guidelines for IPPs, which ensure that IPPs are centered on consumers and families.³⁰ Annually, the Department will review a random sample of individual program plans at each regional center to make sure they conform with statute.³¹

27. Welfare & Institutions Code Section 4646.5(c)(2)

28. Welfare & Institutions Code Sections 4646(a) & 4648(a)(6)(D)

29. Welfare & Institutions Code Section 4501

30. Welfare & Institutions Code Section 4646.5(c)

31. Welfare & Institutions Code Section 4646.5(c) (3)

FORMAT & INSTRUCTIONS

Introduction

In the two previous sections, person-centered planning in California was described as a mandatory and value-based planning system. This section describes the components of the standard process and format for person-centered individual program planning. This section also contains instructions for conducting person-centered individual program planning. *All regional centers must use this format in compliance with these instructions.*¹ *The person-centered approach to assessment and individual program planning described below will be used when developing IPPs for all regional center consumers, and all residents of state developmental centers.*²

Every consumer over the age of three will have a person-centered IPP that contains all of the components shown in this section. Some consumers may have other individual plans in addition to the person-centered IPP.

These additional plans are sometimes necessary to comply with the statutes or regulations of funding or monitoring agencies other than the Department of Developmental Services. For example:

- Consumers in some health licensed facilities will also have Individual Habilitation Plans;³

1. Welfare & Institutions Code Section 4646.5(c)(2)
2. Welfare & Institutions Code Sections 4646(c) & 4646.5(c)(2), and William Coffelt, et al., v. Department of Developmental Services, et al., Final Settlement, pages 26 & 27.
3. While these plans are called Individual Habilitation Plans in California, to differentiate them from our IPPs, they are called Individual Program Plans in the Federal regulations governing Intermediate Care Facilities for individuals with mental retardation (Title 42, Code of Federal Regulations, Section 483.440(c)(1) Standard: Individual Program Plan)

- consumers involved in some work programs will also have a work-related plan;⁴
- some children with serious medical problems, who are living in community care facilities, will also have a separate plan that addresses their medical problems.⁵
- Children below the age of three years old are required to have Individualized Family Service Plans (IFSPs), instead of IPPs.⁶ These family-centered plans that are focused both on the needs of infants and toddlers with developmental disabilities, and the corresponding needs of their families. When toddlers with developmental disabilities reach the age of three, they (and their families) are transitioned into the person-centered IPP process.

The person-centered IPP that is described below is focused on beneficial outcomes for the consumer and family. The additional, or supplementary, plans that some consumers must have to receive certain types of services are usually focused on procedures and serve as detailed instructions for professional service providers.

Because each effort to engage in person-centered planning is as unique as the consumer that is the focus of the plan, this process and format and its instructions are intentionally designed to be very flexible. There are currently more than 125,000 consumers in the developmental services system in California. Each consumer is entitled to a person-centered approach to planning for her or his preferred future.

4. These are called "Individualized Written Rehabilitation Programs" (IWRPs) and are required by Title 29, United States Code, Section 102

5. These are called "Individual Health Care Plans" (IHCPs) and are required by Welfare & Institutions Code Section 17710(d) & 17731(c)(1)

6. Welfare & Institutions Code Section 95020(a)

The headings in *bold italic type* at the left margin in the subsection entitled "IPP Development" represent the mandatory components, which each regional center's planning process must include. The headings in *bold italic type* in the subsection entitled "Content of the written IPP" is the information required to be in the written IPP document.

The text under each heading constitutes the instructions and considerations for engaging in a person-centered planning process, and completing written IPPs in a manner that conforms to statute. As in the previous two sections, *text in italics* denote the mandatory features of the instructions. Use of the words shall, will or must also indicate mandatory language. References to the statutory authority for these instructions are found in the footnotes.

IPP Development

Person-centered IPPs

*An IPP describes the needs, preferences and choices of the individual and family. It is developed through a process of individualized needs determination, and embodies an approach centered on the person and family.*⁷ Any person who is eligible for regional center services shall have an IPP.⁸ The IPP process uses person-centered methods⁹ to assist individuals with developmental disabilities and their families to obtain the services and supports needed to build their capacities and capabilities. Person-centered methods provide individuals with developmental disabilities and their families with opportunities to choose where and with whom they live, with whom they socialize, how they spend their time, what jobs they have, and other aspects of their daily lives.

7. Welfare & Institutions Code Sections 4646(b)& 4646.5 (c)(1)

8. Welfare & Institutions Code Section 4646(c)

9. Welfare & Institutions Code Section 4646(a)

After all appropriate options for meeting each individual program plan objective have been considered by the planning team, the IPP should describe the specific responsibilities and timelines, by which future changes will be made. This should be done for each objective. The IPP is not static, but changes as new opportunities or obstacles arise.

Consumer choice

Consumers must be informed of their right to make the choices recorded in their IPPs.¹⁰ Those choices include, but are not limited to, where and with whom they live, their relationships with people in the community, the way they spend their time, including education, employment, leisure, and the pursuit of their personal futures. All public or private agencies receiving state funds for the purpose of serving persons with developmental disabilities, including, but not limited to, regional centers, shall respect the choices made by consumers.¹¹

Everyone needs to know what the options are before they can make a meaningful choice. *To aid consumers and families in making the choices related to their IPPs, all publicly funded agencies shall provide relevant information in an understandable form.¹²* For example, information can be provided in consumer forums on specific topics or areas of interest. Visual and experiential information can also be provided by facilitating consumer visits to different types of living arrangements or job possibilities.

10. As specified in Section 1 of this manual, the term consumer includes the consumer, and where appropriate the authorized representatives of the consumer, including the consumer's parents, guardian or conservator. Conservators generally have limitations on their authority to make decisions and choices on behalf of the consumer. For more information on the role of conservators, get the pamphlet by Sterling L. Ross Jr., *Guardianship, Conservatorship, Trusts and Wills for Families with Mentally Retarded or Other Disabled Family Members*, available through Protection & Advocacy, (800)952-5746.

11. Welfare & Institutions Code Sections 4502(j) & 4502.1

12. Welfare & Institutions Code Sections 4502(j) & 4502.1

Making choices among several attractive options is a learned skill. Some consumers will be able to do this more easily than others. When making or expressing choices is difficult, facilitation and/or self-advocacy training may be necessary to ensure meaningful participation in the person-centered planning process.

Choosing between attractive and undesirable options is not difficult for most consumers. Even for those consumers who have difficulty articulating their choices verbally, repeated attempts to avoid an option when it is presented can provide a clear indication that the option is not attractive to them.

Personal preferences and cultural background can also affect the ability of some consumers and families to express their choices in a manner that is easily understood. *Those who present options for consumers and families to choose among, must present them in a way that reflects awareness of, and sensitivity to, their lifestyle and cultural background.*¹³

In a few instances, consumers and families will insist on making choices that other members of the planning team consider to be unsafe or harmful. If these choices would constitute criminal conduct, or would present an immediate threat of serious bodily injury, team members will take the same steps available to any citizen in similar circumstances, take those actions required of professionals by law or regulation, or other actions consistent with professional ethics.

13. Welfare & Institutions Code Section 4646.5(a)(1)

Michael Smull, in his book entitled *Supporting People with Severe Reputations in the Community* (1992) has this to say about the role of consumer choice in a person-centered planning system:

"In the current system of service, complete control over all essential choices is in the hands of professionals. The outcome of this planning process is to rebalance the locus of control. The service system must continue to assure reasonable protection of the individual while supporting substantial freedom. Control is shared through collaboration. People who cannot articulate where they would wish to live or who they wish to live with can tell us of their preferences through their behavior. Those who tell us what they think we want to hear can learn to put forward their own wishes. We will need to assist these individuals to discover what their informed choices are. They will need encouragement and careful exposure to relevant life experiences. We have found that as people gain power over their lives, they often need less control or protection.

Neither the process nor the outcome eliminates the need for skilled professionals. People will still need support for their behavioral, psychiatric, and medical needs. People will still want to learn new skills and will need good teachers. We are not discarding all of our professional skills, we are simply putting them in their proper position. Our skills should be used to help people in achieving the lifestyles of their own choosing. They (our skills or influence) should not determine that lifestyle.

The greatest challenge for all of us in supporting people with disabilities is finding the balance for each individual. A balance is needed between:

- Freedom of choice and the safety and health of the individual;
- Personal liberty and the expectations of society to conform to social norms; and
- Encouraging individuals while avoiding coercion.

Because the balance achieved needs to take into account the circumstances, the core values, and the complexities of each individual, it is different for each individual. These are the same issues that we wrestle with for ourselves and our loved ones. This is why we focus on the ambiguous issues of lifestyle choices. This is why we do not stop with the traditional information such as deficits in adaptive behavior, cognitive disabilities, psychiatric diagnosis, medical issues, and behavioral problems." (Part I, Pages 3 & 4)

There are a small number of consumers who have little or no capacity to make these choices, and who have no legally authorized representative to make them on their behalf. The director of a regional center (or designee) may give consent on behalf of the consumer where it is necessary to authorize essential medical, dental, or surgical treatment.¹⁴

The Planning Team

Person-centered planning is done by a planning team. A planning team is a group of individuals who are focusing their attention and efforts on building a preferred future for one member of the team, the consumer. The consumer is an equal with the other members of this team. This team is involved with the life of the consumer and family on an ongoing basis. It should not be thought of as a team that meets only when a written IPP is due.

This team meets to share what they know about the life patterns, interests, and preferences of the person and family. The informal discussions of a planning team identify the strengths and abilities of the individual and family, as well as the problems and challenges they experience. Where the individual or family needs help in solving problems, or overcoming challenges, the team chooses a course of action that will promote the desired outcome.

The planning team (at a minimum) consists of the parents or legally appointed guardian of a minor consumer or the legally appointed conservator of an adult consumer, and one or more regional center representatives.^{15 16 17} Planning teams conducting person-centered individual program plan reviews within the state developmental centers shall include a regional center representative who must participate in these reviews at least once every three years.¹⁸ When invited by the consumer the planning team may also include other persons, including service providers.¹⁹

15. Welfare & Institutions Code Section 4512(j)

16. The planning teams for minor children with special health care needs who are living in licensed community care facilities will also include those members required by Welfare & Institutions Code sections 17710(d) & 17731 (c)(1)

17. Planning for infants and toddlers under the age of three will include those participants required by Welfare & Institutions Code Section 95001.

18. Welfare & Institutions Code Section 4646.5(b) State developmental centers are licensed health facilities. As noted earlier (page 3-2), they are also required to engage in a different, but compatible, individual planning process by Title 42, Code of Federal Regulations, Section 486.440. This process results in Individual Habilitation Plans. These plans must be prepared at more frequent intervals, and do not require the participation of a regional center representative.

19. Welfare & Institutions Code Section 4646(e) & 4512 (j)

*The consumer shall have the opportunity to actively participate in the development of the IPP.*²⁰ Planning conferences are conducted in the primary language of the consumer. For participants whose primary language is other than that used by the consumer, active participation will require that a translator or interpreter is available.

Ethnic and cultural preferences may also influence the selection of planning team members. *The planning team must include those who can ensure that relevant information is provided in an understandable form.*²¹

Consumers may invite any interested person to participate on the planning team. Friends, neighbors and advocates can provide invaluable information to the team. They can also be productive participants on the planning team.

It may help to facilitate the consumer identifying a list of individuals that she or he may want to join the planning team. This list may include parents, providers, pastors, counselors, friends, neighbors, and others.

Providers of services and supports can also be members of the planning team. Those providers who have daily contact with the consumer can provide information that is particularly valuable. These providers may facilitate, but should avoid dominating or controlling the discussions of the planning team. The decisions of the planning team are to be made jointly with the consumer.

The preferences, communication style, primary language and cultural background of the consumer and family are important considerations for deciding who will be on the planning team. The team should be designed to promote the free flow of communication. *Decisions must be made jointly.*²² Many consumers can learn to facilitate this process, others will

20. Welfare & Institutions Code Section 4646(b)

21. Welfare & Institutions Code Section 4502.1

22. Welfare & Institutions Code Section 4646(d)

need to have people on the team who can facilitate the process.

The regional center is responsible for sending written invitations to the members of the planning team to attend planning conferences, if the consumer requests written notice.²³ These notices, or invitations, must be mailed at least 30 days before the date scheduled for the conference.

The location, time, date, duration and type of team discussions should be consistent with the preferences of the consumer and family, and promote the free flow of communication. For example, some consumers may have a limited tolerance for sitting in meetings, and may need a series of shorter meetings to promote full discussion. Others may prefer phone conferences. Informal settings, such as a restaurant, barbecue, or picnic, may be preferred by others.

Time and duration requirements

A planning team must be assembled, and a person-centered IPP completed within 60 days of the completion of an intake and assessment process that results in a finding that a consumer is eligible for regional center services.²⁴ At the request of the consumer, a parent or other family member (or other authorized representative) designated by the consumer, will receive written notice from the regional center, at least 30 days in advance, of all meetings to develop or revise the consumer's IPP.²⁵ The planning team will review and modify the IPP as necessary in response to the consumer's achievements or changing needs, but not less often than once every three years.^{26 27} If the consumer requests an IPP review, the review shall be conducted within 30 days after the request is submitted.²⁸

23. Welfare & Institutions Code Section 4646(e)

24. Welfare & Institutions Code Section 4646(c)

25. Welfare & Institutions Code Sections 4646(e) & 4710

26. Welfare & Institutions Code Section 4646.5(b)

27. For consumers living in licensed health facilities, IPPs must be scheduled by the facility at least annually (Title 42, Code of Federal Regulations, Section 483.440[f] Standard: Program Monitoring and Change, W258[2]).

28. Welfare & Institutions Code Section 4646.5(b)

As discussed earlier, it may be necessary to conduct more than one meeting to complete a planning conference. This may be necessary when more information is needed for the consumer or family to make an informed choice.

A series of brief meetings may also be necessary to keep the length of any one meeting within the limits of tolerance of a consumer. Finally, a planning team may not be able to reach a joint decision on one or more issues without seeking further information or review. *If an agreement cannot be reached at the first meeting, a second meeting must be held within 15 days of the first meeting. Disagreement with portions of the IPP shall not prohibit implementation of agreed upon services and supports. In the case of a disagreement, the consumer or family shall be provided a written notice of fair hearing rights within five days.*²⁹

Preparing for a planning conference

The following information will help the team set a positive tone for the planning conference. Participants may also find it helpful to refer to sections four and five of this manual, which contain examples of, and stories illustrating, person-centered planning.

- Be positive. Every individual is unique, valuable and deserving of your respect.
- Develop a team spirit. A team works better when its members are able to trust everyone to be loyal and committed.
- Talk with each other frequently between planning conferences. The planning conference is a time to present ideas that have already been discussed.

29. Welfare & Institutional Code Section 4646 (f) & 4710(b)

- Encourage consumers to come to the planning conference with well-prepared statements of hopes, dreams and preferences. Some people bring a written statement, others bring audio or video tapes that illustrate their hopes dreams, and preferences.³⁰
- Some consumers find rehearsing what they want to say at the planning conference helpful.³¹
- Make sure that everyone on the team has had a chance to read and understand any professional assessments that may influence the choices and decisions that are going to be made during the conference.
- Encourage each other to speak freely. There should be no penalty for saying what you think.
- Be specific about the changes and actions you feel are necessary. Explore several different ways to solve the identified problems.
- Build trust with each other. Do not intrude while others are talking. Do not try to control each other. Do not force your needs and insights into the foreground.³²

Assessment

*Assessment is a required part of the person-centered planning process.*³³
The purpose of assessments is to help the team understand the needs, preferences and choices of the consumer and family. Assessments provide information that helps the consumer and family to define a preferred

30. Capitol People First and Protection & Advocacy, Inc.(1994). *Your IPP: It's not just a piece of paper*. Sacramento, CA.

31. Capitol People First and Protection & Advocacy, Inc.(1994). *Your IPP: It's not just a piece of paper*. Sacramento, CA.

32. Adapted from Heider, 1985.

33. Welfare & Institutions Code Section 4646.5(a)

future, and to choose the best way to get there. In a person-centered planning system, assessments are not used to determine how "disabled" a consumer is or to determine whether the preferred future defined by the consumer and family is appropriate.

Assessment is an ongoing process. When the planning team shares what they know about the life patterns, interests, and preferences of the person and family, they are conducting an assessment. The informal discussions of the planning team which identify the strengths and abilities of the individual and family, as well as the problems and challenges they experience, are the primary form of assessment in the person-centered process.

When the planning team decides it is necessary, professional assessments will be conducted.³⁴ Professional assessments shall be conducted by qualified individuals and performed in natural environments whenever possible.^{35 36} If the consumer, or the family of a minor, agrees, the team will review the consumer's general health status. This includes a discussion of current medications, their side effects, and the date of the last medication review.³⁷ Assessments should be conducted in the primary language of the consumer if feasible, and if not, then an interpreter must be present to assist in the assessment process.

34. If the consumer or family believes that a professional assessment is necessary, and a regional center representative on the planning team refuses to have the assessment completed, the consumer or family may appeal the refusal using the procedures in Welfare & Institutions Code Section 4700 et seq.

35. Welfare & Institutions Code Section 4646.5(a)(1)

36. Consumers living in licensed health facilities must have a comprehensive functional assessment prior to their admissions conferences (Title 42, Code of Federal Regulations Section 483.440[c] Standard: Individual Program Plan, W210 & W211)

37. Welfare & Institutions Code Section 4646.5(a)(5)

Assessments shall reflect awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and the family.³⁸ Assessment is a required part of the person-centered planning process.³⁹

Assessments shall determine⁴⁰ the consumer's:

- *life goals*
- *strengths and capabilities*
- *preferences, including preferred*
 - ◆ *persons and groups to relate to*
 - ◆ *community activities*
 - ◆ *living arrangement*
 - ◆ *employment or school placement*
 - ◆ *leisure activities*
- *needs for supported living and other supports⁴¹*
- *barriers to fulfillment of life goals or preferences*
- *concerns or problems*

For children with developmental disabilities, the assessment should include a review of the strengths, preferences and needs of the child and family unit as a whole.⁴² When children with developmental disabilities live with their families, the assessment shall include a determination of the family's current needs and the supports necessary to maintain the child in the home.^{43 44 45}

38. Welfare & Institutions Code Section 4646.5(a)(1)

39. Welfare & Institutions Code Section 4646.5(a)

40. Welfare & Institutions Code Sections 4646.5(a)(1) & 4512(b)

41. Welfare & Institutions Code Section 4689(c)

42. Welfare & Institutions Code Section 4646.5(a)(1)

43. Welfare & Institutions Code Section 4685(c)(2)

44. Assessments for children with special health needs who live in a licensed community care facility will be conducted in compliance with Welfare & Institutions Code Sections 11710 & 11731(c)(1)

45. Assessments for infants and toddlers below the age of three will be conducted in compliance with Welfare & Institutions Code Sections 95014(a)(1) & 95016(a)

Conducting a planning conference

Planning conferences

Planning conferences are meetings of the planning team. One of the purposes of these meetings is to bring all the members of the planning team together in the same room for face-to-face discussions. *Since person-centered IPPs are the product of joint decisions made (at a minimum) by the consumer and service coordinator, both the consumer and service coordinator must be present at these conferences*, unless the consumer refuses to attend.⁴⁶ If the consumer refuses to attend the planning conference prior to the conference, the service coordinator should review, with the consumer, the issues to be discussed in a manner the consumer finds acceptable.

Planning conferences are generally held as face-to-face meetings, but may be conducted by phone, or through a series of interviews with the members of the planning team, with the agreement of all members of the planning team.

Another purpose of planning conferences is to compile and record the information necessary for achieving the preferred future of the consumer and family. The written record of the information exchanged at a planning conference and the decisions and choices that were made at the conference is the written form of the IPP.

A planning conference and the written IPP that is produced from it provide a picture of the progress that has been made toward achieving the preferred future (and what remains to be achieved) at a given point in time. While planning conferences and written IPPs are important, person-centered planning is more than a series of meetings that produce documents.

Risk Assessment (Revised July 1, 2001)

During the individual program plan meetings, the planning team considers the goals of the consumer and the services and supports needed to achieve those goals. During these discussions, the team should consider whether there are any current or potential health and safety risks to the individual that would affect their desired life and living arrangement. Focusing on the individual's goals, resources, and desires, the planning team can decide how to best manage these risks—in a manner consistent with the individual's desired lifestyle and best interests.

To help planning teams assess risks, and develop strategies to manage them, the service coordinator should review all special incident reports, and other pertinent records, since the last planning team meeting. The Department will make available a special incident database that will help planning teams identify trends or patterns that should be reviewed and discussed during the meeting. The Department will also provide information about best practices for reducing the most common risks. This information will help planning teams identify potential ways to manage risks.

46. Welfare & Institutions Code Section 4646(d)

Scheduling the conference.

- While there is no required time limit for planning conferences, they should be scheduled to allow enough time for thorough discussion of all issues. *If agreement cannot be reached at the first meeting, a second meeting must be held within 15 days.*⁴⁷
- *Planning conferences must be held at least every three years,*^{48 49} but can be requested by the consumer or family at any time. Any major life change should trigger a planning conference. Major life changes include significant changes in health condition, moving from one place to another, loss of a person who is deeply involved in support, loss of a job, change of school, etc.
- The consumer's service coordinator is responsible for scheduling planning conferences, but any member of the team can help with
- scheduling. *When a consumer or family requests a review of the IPP, the consumer's service coordinator is responsible for scheduling the review within 30 days of the request.*⁵⁰
- The date, time and location of the planning conference should be convenient to all team members.
- *If requested by the consumer, a designated representative shall receive written notice of all meetings to develop or revise the IPP.*⁵¹
- The location of the planning conference should be comfortable and easily accessible to all members of the team, with particular attention being paid to the needs of the consumer and family.

47. Welfare & Institutions Code Section 4646.5(f)

48. Welfare & Institutions Code Section 4646.5(b)

49. For consumers living in licensed health facilities, such as the state developmental centers, IHPs must be scheduled by the facility staff, at least annually (Title 42, Code of Federal Regulations, 483.440[f] Standard: Program Monitoring and Change, W258[2]).

50. Welfare & Institutions Code Section 4646.5(b)

51. Welfare & Institutions Code Section 4646(e)

Setting the ground rules

Diversity in culture, language, ethnicity and lifestyle is the norm in California. Productive communication among the members of the planning team requires sensitivity to this diversity. Further, *awareness of, and sensitivity to the lifestyle and cultural background of consumers and families, as well as respect for their right to make choices, is a required feature of person-centered planning.*⁵² Therefore, ground rules for discussion among team members during planning conferences must be established.

These are some suggested ground rules:

- Discussions are positive in tone, focusing on the capacities and capabilities of the consumer and family.
- The decisions and choices made at the planning conference are made by the team as a whole, with deference to the wishes and preferences of the consumer and family.
- Discussions will be non-judgmental and open-ended. Team members agree to share ideas and viewpoints freely, but also agree not to argue. Team members agree to listen to and consider the ideas of everyone on the team.
- The discussions of what the consumer wants to do now, is able to do now, and wants to do in the future, provide the focus of attention and effort for the team.
- There is nothing carved in stone that says that everything that needs to be accomplished at this conference must be accomplished in a single meeting. If further information is needed, or someone has to leave the meeting, the conference can be continued later with another meeting. *If*

52. Welfare & Institutions Code Sections 4502.1 & 4646.5(a)(1)

*agreement cannot be reached at the meeting, a second meeting must be scheduled within 15 days. Additional meeting may be held if the team agrees.*⁵³

- Active involvement and discussion by consumers and families are promoted by creating a comfortable, friendly and encouraging atmosphere during the meeting.

Discussion pattern

Each planning team will adopt a pattern of discussion that suits their needs and preferences. Some things however, need to be discussed at a planning conference. They are shown below in *italics*, within a common pattern of discussion, but they don't necessarily need to be discussed in the order they are listed below.

- It is often useful to have one of the team members keep notes so that later, the planned actions can be related to goals and objectives, which are in turn related to the statement of a preferred future. Many people prefer to have notes taken on a large chart pad so they are easily read by all team members. Others are happy to use note paper and read from the relevant notes when questions rise.
- A general discussion of hopes, dreams (or nightmares) and preferences leads to statements of a preferred future for the consumer. These are statements of what the consumer would do and be under the best possible circumstances.
- With the preferred future in mind, the team discusses the current situation. By encouraging open and frank descriptions of how things are going, and by listening carefully to each other, the team gradually develops a complete picture of what is happening and whether the consumer and family feel they are going in the right direction. These discussions constitute an informal *assessment of the life goals*,

53. Welfare & Institutions Code Sections 4646.5(f)

*capabilities and strengths, preferences, barriers, and concerns or problems of the consumer,*⁵⁴ and how those relate to the consumer's preferred future and desired outcomes.

- A series of goals will emerge from the statements of preferred future and descriptions of the current situation. *Goals are broad statements about where the consumer would like to live, what kind of job the consumer would like to have, what recreational activities the consumer would like to engage in, and so on.*⁵⁵ These are outcome statements. Goals are usually statements of what the consumer would like to change, but can also be statements of what the consumer wants to keep in his or her life. The achievement of some goals may take several years.

The following IPP goals, listed in the Lanterman Act, provide general guidance for this part of the team discussions:

- Increased independence⁵⁶
Example: I will use public transportation.
Example: I will live in my own apartment.
- Increased productivity⁵⁷
Example: I will get a job.
Example: I will get my high school diploma.
- Increased participation in community activities (community integration)⁵⁸
Example: I will join the health club.
Example: I will go to church.

54. Welfare & Institutions Code Section 4646.5(a)(1)

55. Welfare & Institutions Code Sections 4502(j) & 4646.5(a)(2)

56. Welfare & Institutions Code Sections 4646(a) & 4648(a)(1)

57. Welfare & Institutions Code Section 4646(a)

58. Welfare & Institutions Code Sections 4646(a) & 4648(a)(1)

- Achievement of a pattern of daily activities that approximates that available to the non-disabled peers of the consumer⁵⁹
 - Example: I will set my daily schedule.
 - Example: I will handle my own finances.

- Assurance of a stable and healthy living environment in a residence of the consumer's choice⁶⁰
 - Example: John (a minor child) will be supported to live in a foster family home.
 - Example: I will move from the State Developmental Center to an apartment with a paid roommate.

- Increased opportunity for the consumer to develop stable and nurturing interpersonal relationships⁶¹
 - Example: I want to visit my family.
 - Example: I will have more friends.

- Maximized control over choices and decisions that affect daily life^{62 63}
 - Example: I will choose my own toiletries.
 - Example: I will hire my own support staff.

- Development of unpaid natural supports⁶⁴
 - Example: My sister will take me shopping.
 - Example: My neighbor will teach me to ride the bus.

59. Welfare & Institutions Code Section 4501

60. Welfare & Institutions Code Sections 4646(a) & 4689

61. Welfare & Institutions Code Sections 4646.5(a)(2) & 4648(a)(1)

62. Control over these choices and decisions require protection of the civil, legal, and service rights of the person with developmental disabilities. Self-advocacy, or assisted advocacy, is sometimes necessary to protect those rights and thereby ensure maximum control over these choices and decisions. Welfare & Institutions Code Section 4648(b)

63. Welfare & Institutions Code Sections 4503(i), 4646.5(a)(2), 4648(a)(1)

64. Welfare & Institutions Code Section 4648(a)(13)(C)

- Development of a circle of support⁶⁵
Example: I will invite family and friends to a circle of support meeting.
Example: My service coordinator will support me in developing a circle of support.
- Maintenance of a family's ability to care for their child with developmental disability in the family's home⁶⁶
Example: We will receive increased respite hours.
Example: I will go to an after-school program at my school.
- Objectives are milestones on the path to achieving the consumer's goals. Objectives are specific, time-limited activities for implementing goals. Objectives shall be stated in terms that allow measurement of progress toward the desired outcomes, or monitoring of service delivery.⁶⁷

A simple example of the difference between objectives and goals would be that one of the consumer's goals is to have a job in one of several restaurants closer to home. One objective might be to pick-up, fill out and return one job application at a nearby restaurant each week for the next six weeks. Submitting the job applications will not ensure that the goal of getting a job closer to home is achieved, but it is a concrete and understandable step in the process, and is a reasonable objective.

- Additionally, planning team members make commitments to assign or undertake specific activities, within a set time frame, to assist the consumer in moving from one milestone, or objective, to the next. These are commitments made by the members of the planning team, to engage in specific activities within the times agreed to. This is the "who does what by when" information that helps the planning team to maintain its focus and ensure accountability for the agreements made.

65. Welfare & Institutions Code Section 4512(b) & (f)

66. Welfare & Institutions Code Sections 4646.5(a)(3), 4648(a)(1) & 4685

67. Welfare & Institutions Code Section 4646.5(a)(2)

An example of a specific commitment for the objective above might be for one of the other members of the planning team to agree to meet the consumer every Tuesday after work for the next six weeks to walk around the neighborhood with him while he picks up applications and help him fill them out.

- In many instances, the achievement of goals and objectives will require some level of service or support. Some services and supports may be provided by friends, neighbors or a circle of support, at no cost, and as part of a natural relationship. Other services and supports are available through publicly funded agencies that serve all citizens. Services and supports that have been designed specifically to meet the needs of persons with developmental disabilities⁶⁸ are available through the regional center or developmental center.

*When discussing necessary services and supports, the team shall consider all appropriate options for meeting each IPP objective.*⁶⁹ Team members should consider how services and supports can be arranged to achieve the goals and objectives agreed to by the team. Discussion should also include which services and supports can be gained through natural and generic sources, as well as those which can be purchased by the regional center.

These service and support options may include, but are not limited to:⁷⁰

- adaptive equipment and supplies
- advocacy
- advocacy assistance or facilitation
- assessment

68. Welfare & Institutions Code Section 4512(b)

69. Welfare & Institutions Code Section 4512(b)

70. Welfare & Institutions Code Sections 4512(b), 4648, 4685, 4687, 4688 & 4689(c)

- assistance in finding, modifying and maintaining a home
- behavior modification
- behavior training
- camping
- childcare
- community integration services
- community residential placement
- community support facilitation
- counseling for the consumer's family
- counseling for the consumer
- daily living skills training
- day care
- development and provision of a 24-hour emergency response system
- development of unpaid natural supports
- diagnosis
- diapers
- domiciliary care
- education
- emergency and crisis intervention
- emergency housing
- emergency relief for personal care attendants
- evaluation

- facilitated circles of support
- facilitation with a facilitator of the consumer's choosing
- facilitation including outreach and education
- financial assistance
- follow-along services
- foster family placement
- habilitation
- home location assistance
- homemaker services
- identification of circles of support
- infant stimulation programs
- information and referral services
- mental health services
- occupational therapy
- paid neighbors
- paid roommates
- parent training
- peer advocates
- personal care or assistance
- physical therapy
- protection of civil, service and legal rights
- protective services

- provision of circles of support
- recreation
- recruiting, hiring and training personal care attendants
- respite
- respite for personal care attendants
- self-advocacy training
- sexuality training
- sheltered employment
- short term out-of-home care
- social services
- social skills training
- sociolegal services
- special living arrangements
- specialized dental care
- specialized medical care
- speech therapy
- support services for consumers in homes they own or lease
- supported employment
- supported living arrangements
- technical assistance
- training

- transportation services
 - travel training
 - treatment
 - vouchered services
-
- services and supports that are necessary for families to maintain their children with developmental disabilities at home, when living at home is in the best interest of the child⁷¹
 - If a child must live out of the family home, the regional center will make every effort to place the child in a living situation as near to the family home as possible, as well as discuss a plan to reunify the child with the family.⁷²
 - services and supports needed to maintain and strengthen the family unit, where one or both parents is an individual with developmental disabilities⁷³
 - other service and support options which would result in greater self-sufficiency for the consumer and cost-effectiveness to the state.⁷⁴
 - Team discussions are usually concluded with a discussion of when the next conference should be scheduled. While planning conferences must be held at least once every three years, it is up to the team to decide how often they must meet. The preferences and needs of the consumer and family should guide the team's choice of the appropriate time for the next meeting.

71. Welfare & Institutions Code Section 4685(c)(2)

72. Welfare & Institutions Code Section 4685.1(a) & (b)

73. Welfare & Institutions Code Section 4687(f)

74. Welfare & Institutions Code Section 4648(a)(11)

Content of the written IPP

After the team has completed its discussions, a written record of the decisions and choices made is prepared. This is the written form of the IPP that reflects the decisions and choices made during the planning conference. The written IPP should be viewed as a picture of the planning effort at a point in time. At a minimum, each written IPP must contain the ***bold, italicized*** components.

Goals

*A written IPP contains statements of goals based on the required assessment.*⁷⁵

Objectives

*A written IPP also contains objectives for achieving the stated goals.*⁷⁶ IPP objectives must be specific, time-limited, stated in measurable terms, and related to the individual's goals and needs. An objective is measurable if it is written in a way that allows the planning team to determine if every service and/or support specified in the objective has been delivered in a manner that is satisfactory to the consumer⁷⁷.

Objectives must be stated in terms of what benefit the consumer will derive, and not in terms of what procedures service providers will use.

⁷⁵ Welfare & Institutions Code Sections 4646.5(a)(1) & (2)

⁷⁶ Welfare & Institutions Code Section 4646.5(a)(2)

⁷⁷ Welfare & Institutions Code Sections 4646.5(a)(2) & (5)

Family plan component

A written IPP for a consumer who is a minor and is living at home must include a family plan component describing those services and supports necessary to successfully maintain the child with developmental disabilities at home.⁷⁸ Regional centers shall consider every possible way to assist families in maintaining their children at home (when living at home is in the best interest of the child) before considering out-of-home placement.⁷⁹ If an out-of-home placement is necessary, the regional center will make every effort to find a living situation as close to the family home as possible. If this is not possible the regional center will develop a plan to return the minor to, or in a living situation near, the family home.⁸⁰

Schedule of Services and Supports

When the decisions and choices made during the planning conference include provision of services and supports, a summary, called a schedule of services and supports, is prepared.⁸¹ The services and supports that are scheduled must be related to the achievement of the goals and objectives described in the IPP.

The written schedule of services and supports shall identify the provider (or providers) responsible for attaining each objective including, but not limited to⁸²

- natural supports
- generic service agencies
- contracted providers
- regional center vendors

78. Welfare & Institutions Code Section 4685(c)(2)

79. Welfare & Institutions Code Section 4685(c)(2)

80. Welfare & Institutions Code Section 4685(c)(2)

81. Welfare & Institutions Code Section 4646.5(a)(4)

82. Welfare & Institutions Code Section 4646.5(a)(4)

At the end of the planning conference, each member of the planning team should be given an opportunity to review what was agreed to. While handwritten IPPs are permitted, they are usually typed some time after the planning conference to make them easier to read. When the written IPP is typed after the planning conference, the typed IPP should be distributed to the members of the planning conference within 45 days after the planning conference.

Whether handwritten or typed, the final IPP must be prepared in a form that is understandable to the consumer and family.⁸³ If the consumer or family needs interpretation or translation services to fully participate in the development of the IPP, or to understand the written IPP, the regional center shall provide translation or interpretation services as appropriate.⁸⁴

If the regional center administration decides at a later date (and without the consent of the consumer) to reduce, terminate, or change the services (currently being delivered) that are listed in this schedule, the regional center must notify the consumer by certified mail at least 30 days before taking the action.⁸⁵ If the consumer or family files an appeal of this decision within 10 days, the services will be continued during the appeal procedure.⁸⁶

83. Welfare & Institutions Code Section 4502.1 and California Code of Regulations, Title 22, Sections 98210(a) & 98211(c)

84. California Code of Regulations, Title 22, Sections 98210(a), (c), (d) & 98211(c)

85. Welfare & Institutions Code Section 4710(a)

86. Welfare & Institutions Code Section 4715(a)

If the regional center administration decides at a later date (and without the consent of the consumer) to reduce, terminate, or change the services that are listed in this schedule, but have not yet been purchased, the regional center must notify the consumer by certified mail at least 5 days before taking the action.⁸⁷ If the consumer believes that this action is illegal, discriminatory, or not in his or her best interest, the consumer may request a fair hearing.⁸⁸

Review Schedule

The IPP shall contain a schedule of regular periodic review and reevaluation to find out whether planned services have been provided; objectives have been met within the times specified; and consumers and families are satisfied with the IPP and its implementation.⁸⁹

When there is a plan to move a minor child into or near their family's home, the plan will be updated every six months, or as agreed to by the parents or guardians.⁹⁰

87. Welfare & Institutions Code Section 4710(b)

88. Welfare & Institutions Code Section 4710.5

89. Welfare & Institutions Code Sections 4646.5(a)(5) & 4750

90. Welfare & Institutions Code Section 4685.1(b)

IPP Implementation

The scope of services and supports purchased by regional centers

In order to achieve the stated objectives of a consumer's IPP, the regional center shall conduct a variety of activities.⁹¹ These activities may include purchasing services and supports (through vendorization or a contract) for a consumer from any individual or agency which the regional center and consumer agree will best accomplish all or any part of the consumer's IPP.⁹²

A regional center must identify and pursue all possible sources of funding for consumers receiving regional center services including:⁹³

- Governmental or other entities or programs required to provide or pay the cost of providing services, including Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, school districts, and federal supplementary security income and the state supplementary program.⁹⁴*
- Private entities to the maximum extent they are liable for the cost of services, aid, insurance, or medical assistance to the consumer.⁹⁵*

91. Welfare & Institutions Code Section 4648

92. Welfare & Institutions Code Section 4648(a)(3)

93. Welfare & Institutions Code Section 4659(a)

94. Welfare & Institutions Code Section 4659(a)(1)

95. Welfare & Institutions Code Section 4659(a)(2)

- *Parental support - regional centers shall not use purchase of service funds to purchase services for a minor child without first taking into account, when identifying the minor child's service needs, the family's responsibility for providing similar services to a minor child without disabilities.⁹⁶ For example, when purchasing or providing a voucher for day care services for parents who are caring for children at home, the regional center may pay only the cost of the day care services that exceeds the cost of providing services to a child without disabilities unless the family can demonstrate a financial need, or when doing so will enable the child to remain in the family home.⁹⁷*

Regional center funds shall not be used to supplant the budget of any agency which has a legal responsibility to serve all the members of the general public and is receiving public funds for providing those services.⁹⁸ Further, services selected by the regional center must reflect the cost-effective use of public resources.⁹⁹ As defined in regulation, cost-effectiveness means obtaining the optimum results for the expenditure.¹⁰⁰

In implementing IPPs, regional centers shall first consider services and supports in natural community, home, work, and recreational settings. Services and supports shall be flexible and individually tailored to the consumer and, where appropriate, his or her family.¹⁰¹

96. Welfare & Institutions Code Section 4659(c) & California Code of Regulations, Title 17, Section 54326(c)(1). Note that in such instances, the regional center must provide for exceptions, based on family need or hardship.

97. Welfare & Institutions Code Section 4685(c)(6)

98. Welfare & Institutions Code Sections 4648(a)(8)

99. Welfare & Institutions Code Section 4646(a)

100. California Code of Regulations, Title 17, section 58501(a)(6)

101. Welfare & Institutions Code Section 4648(a)(2)

Regional centers are obligated to find innovative and economical methods of achieving the objectives in consumers' IPPs.¹⁰² For example, a regional center may issue a voucher for services and supports provided to a consumer or family.¹⁰³ Community support may also be provided to assist consumers to fully participate in community and civic life. This support may include programs, services, work opportunities, business, and activities available to persons without disabilities. This shall include any of the following:¹⁰⁴

- outreach and education programs and services within the community,¹⁰⁵ including assistance in identifying and building circles of support within the community¹⁰⁶
- supports to consumers to enable them to more fully participate in the community¹⁰⁷
- developing unpaid natural supports when possible¹⁰⁸
- *if facilitation requiring the services of an individual is specified in the IPP, the facilitator shall be of the consumer's choosing*¹⁰⁹

102. Welfare & Institutions Code Section 4651

103. Welfare & Institutions Code Section 4648(a)(4)

104. Welfare & Institutions Code Section 4648(a)(13)

105. Welfare & Institutions Code Section 4648(a)(13)(A)

106. Welfare & Institutions Code Section 4648(c)

107. Welfare & Institutions Code Section 4648(a)(13)(B)

108. Welfare & Institutions Code Section 4648(a)(13)(C)

109. Welfare & Institutions Code Section 4648(a)(12)

Considerations for selecting providers

*The regional center and consumer, and family, when appropriate, shall consider all of the following when selecting a provider of consumer services and supports:*¹¹⁰

- *the consumer's choice of providers*¹¹¹
- *a provider's ability to deliver services and supports that can accomplish all or part of the consumer's IPP*¹¹²
- *a provider's success in achieving the objectives in the IPP*¹¹³
- *where appropriate, possession of a license permitting the provision of the services needed, or accreditation that assures the quality of the services, or professional certification*¹¹⁴
- *the cost of providing the services or supports of comparable quality by different providers, if available*¹¹⁵
- *the eligibility of the consumer for the same, or similar, services and supports from any publicly funded agency that has a legal responsibility to serve all members of the general public*¹¹⁶
- *the cost-effective use of public resources*¹¹⁷
- *the desire of the consumer to receive necessary services and supports without having to move elsewhere*¹¹⁸

110. Welfare & Institutions Code Section 4648(a)(6)

111. Welfare & Institutions Code Section 4648(a)(6)(E)

112. Welfare & Institutions Code Sections 4648(a)(6)(A) & 4512(b)

113. Welfare & Institutions Code Section 4648(a)(6)(B)

114. Welfare & Institutions Code Section 4648(a)(6)(C)

115. Welfare & Institutions Code Section 4648(a)(6)(D)

116. Welfare & Institutions Code Section 4648(a)(8) & 4659

117. Welfare & Institutions Code Section 4646(a)

118. Welfare & Institutions Code Section 4689(a)(2)

- *If the team is considering the appropriateness of having the consumer move to a more restrictive environment, crisis services must be sought in an effort to prevent disrupting a person's living arrangement. If crisis intervention has been unsuccessful, emergency housing in the person's home community must be sought. If dislocation cannot be avoided, the consumer's goals and objectives must reflect that every effort is being made to return the person to the living arrangement he or she chooses, with all necessary supports, as soon as possible.*¹¹⁹
- *When the regional center first becomes aware that a family is considering out-of-home placement, the regional center shall meet with the family to discuss the situation and the family's current needs, solicit from the family what supports would be necessary to maintain the child in the home, and utilize creative and innovative ways of meeting the family's needs and providing adequate supports to keep the family together, if possible.*¹²⁰

*When an existing IPP is being updated, the following shall be determined before a service or support previously selected is renewed or continued:*¹²¹

- *the consumer is satisfied with the service or support,*
- *the planning team agrees that the planned services and supports have been provided, and reasonable progress toward achievement of the planned objectives has been made, and*

119. Welfare & Institutions Code Section 4648(a)(10)

120. Welfare & Institutions Code Section 4685(c)(2)

121. Welfare & Institutions Code Section 4648(a)(7)

- *when there is a plan to move a minor child into or near their family's home, the plan will be updated every six months, or as agreed to by the parents or guardians.*¹²²

Monitoring

*Each consumer shall have a designated service coordinator who is responsible for providing or ensuring that needed services and supports are available to the consumer.*¹²³ *The consumer's service coordinator shall monitor the implementation of the IPP to ascertain that objectives are met.*¹²⁴

122. Welfare & Institutions Code Section 4685.1(b)

123. Welfare & Institutions Code Sections 4640.7(b) & 4689(e)

124. Welfare & Institutions Code Section 4647(a)

EXAMPLES OF PERSON-CENTERED PLANNING

Annotated table of contents

- 1. Personal Profile and Positive Futures Plan Page 3**
Provided by the Institute for Applied Behavior Analysis in Los Angeles, CA, The document is an example of how to develop a personal profile and positive futures plan. The format includes charts and graphics. Background information, current data, choices, dreams and plans are all addressed.

- 2. My Life Page 23**
Provided by NCI Affiliates, Inc. A simple and easy-to-use graphic outline of where a person is in regard to planning for their future. It includes likes and dislikes, important people in your life, preferences, fears, goals, as well as services and supports. Areas addressed include the job, home, health, money, activities and dreams.

- 3. Finding a Way Toward Everyday Lives Page 41**
With the permission of John O'Brien. A thorough examination of person-centered planning, including the foundations and values, limitations, controversies and different approaches.

- 4. Essential Lifestyle Planning Page 69**
With permission of Michael Smull. The document includes planning for the meeting, thinking about choices and supports, meeting preparation, conducting the meeting and development of the plan.

5. Your IPP: It's Not Just a Piece of Paper Page 91

Provided by Capitol People First and Protection & Advocacy, Inc. Part of the Peer Advocacy Project, this guideline to the IPP (Individual Program Plan) is direct and in understandable language. It describes the Lanterman Act and the law, rights, what an IPP is and why it is important, the IPP meeting and how to prepare for it, the appeal process and an IPP planner. This is a consumer-driven and-directed document.

6. Getting There from Here! Page 112

Alien, Shea & Associates developed this guide for Harbor Regional Center. It is directed toward training regional center personnel and provides tips on the person-centered planning process. It is also universally useful for consumers, families, and providers of service. The guide includes what person-centered planning is all about, families of young children, families of students, transitions and adult life. Samples of interviews and plans are included. There is also a section on circles of support.

PERSONAL PROFILE AND POSITIVE FUTURES PLAN

Date of Report:

Locator:

IDENTIFYING INFORMATION

Name:

Date of Birth:

ID#:

Address:

Referral Source:

CPC:

Submitted by:

Cheryl Stroll, M.A./Stacy Daniels, M.A.
Program Manager, SCIP
Social/Community Integration and Participation
Los Angeles/Ventura

Used with permission of
and special thanks to:
Institute for Applied
Behavior Analysis 5777 West
Century Blvd. Suite 590
Los Angeles, CA 90045
(310) 649-0499

Name _____

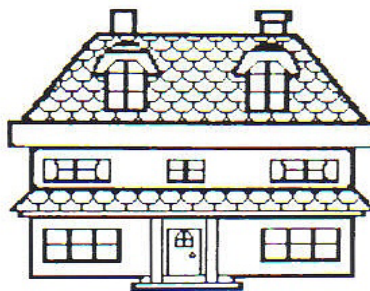
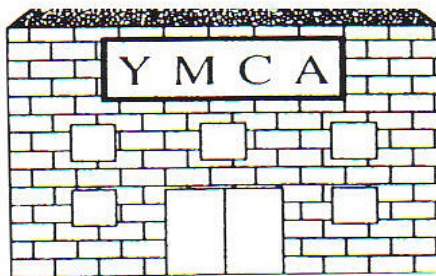
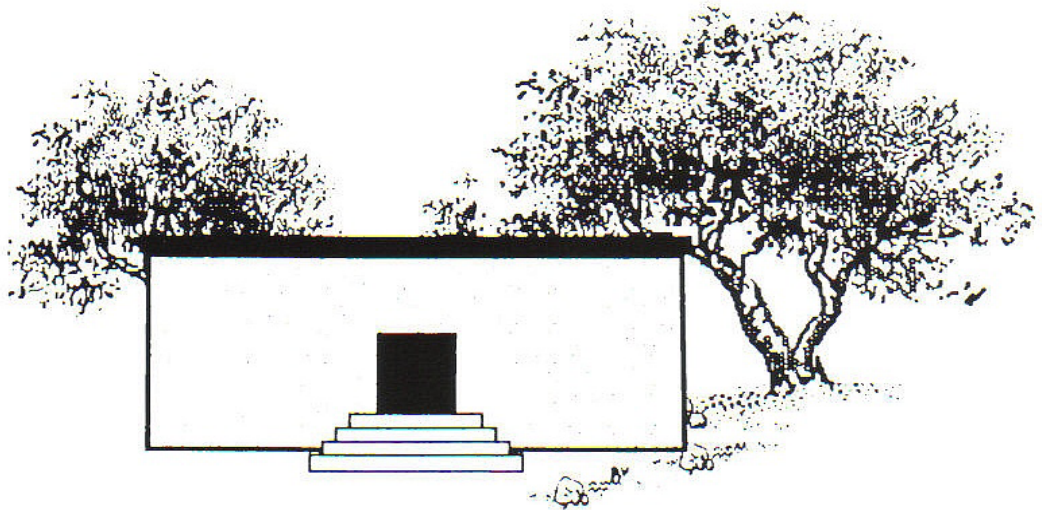
Personal Profile and Positive Futures Plan

A meeting was held on date using person-centered planning processes and group graphs to generate a personal profile. A second meeting was held on date to develop a futures plan. The following information is a transcription of the wall charts generated in those meetings.

Name of Participant	First Meeting	Second Meeting	Title	Goals or Incentives for meetings
Name	Date	Date	Title	<ul style="list-style-type: none">• First goal

Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

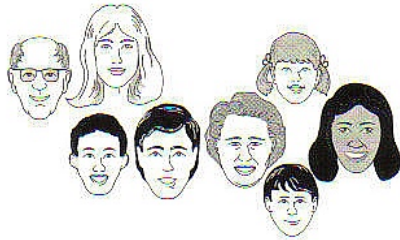
HISTORY



Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

CURRENT SITUATION

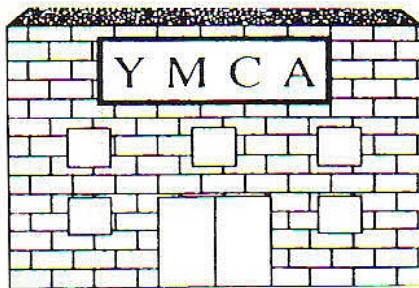
Community



Home



Day Program



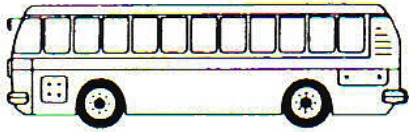
Transportation



Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

PEOPLE IN NAME?'S LIFE

Service Providers

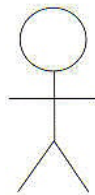
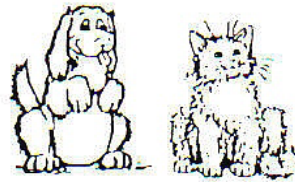


Family



Community

Friends



Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

HEALTH		
Indicators of Good Health	Physical Limitations	Themes and Recommendations
Item	Item	Item

Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

RESPECT AND DIGNITY		
Characteristics Which Gain Respect	Characteristics Which Lose Respect	Themes
Item	Item	Item

Name: _____ Personal Profile and
 Date: _____ Positive Futures Plan

THINGS THAT WORK AND THINGS THAT DON'T WORK		
People, Settings and Activities Which Create Interest, Happiness and Engagement	People, Settings and Activities Which Create Upset, Boredom or Escape	Themes
Item	Item	Item

Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

CHOICES		
Choices Made by Name	Choices Made by Others	Themes
Item	Item	Item

Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

A VISION OF THE FUTURE FOR NAME?

Home

Work

Characteristics

- text



- text

Support Staff

- text

Pay

- text

Neighborhood

- text

Community

Transportation

- text

Recreation/Leisure

- text

Services

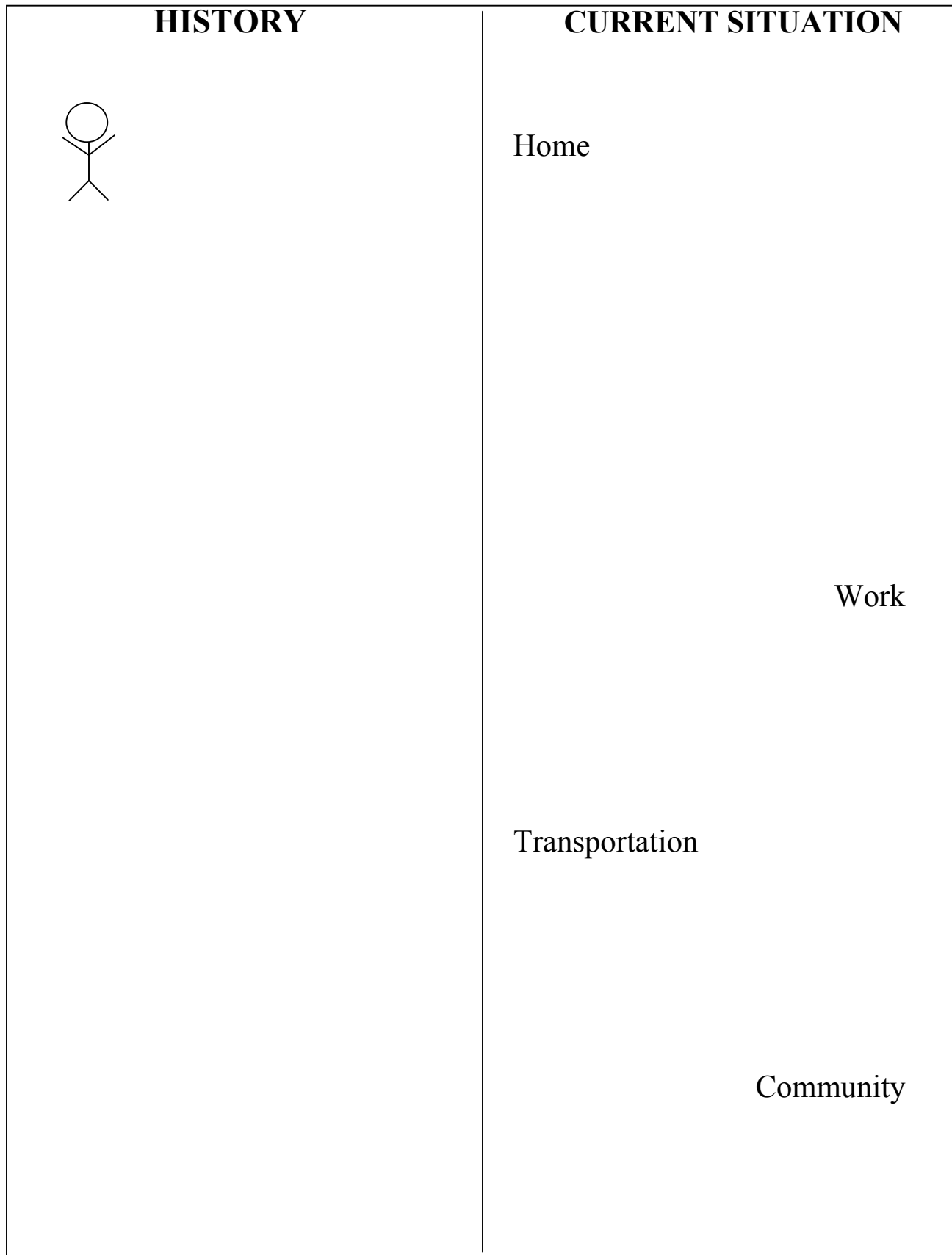
- text

Classes

- text

Name: _____ Personal Profile and
Date: _____ Positive Futures Plan

TASKS		
Task	Person	Date
Item	Item	Item

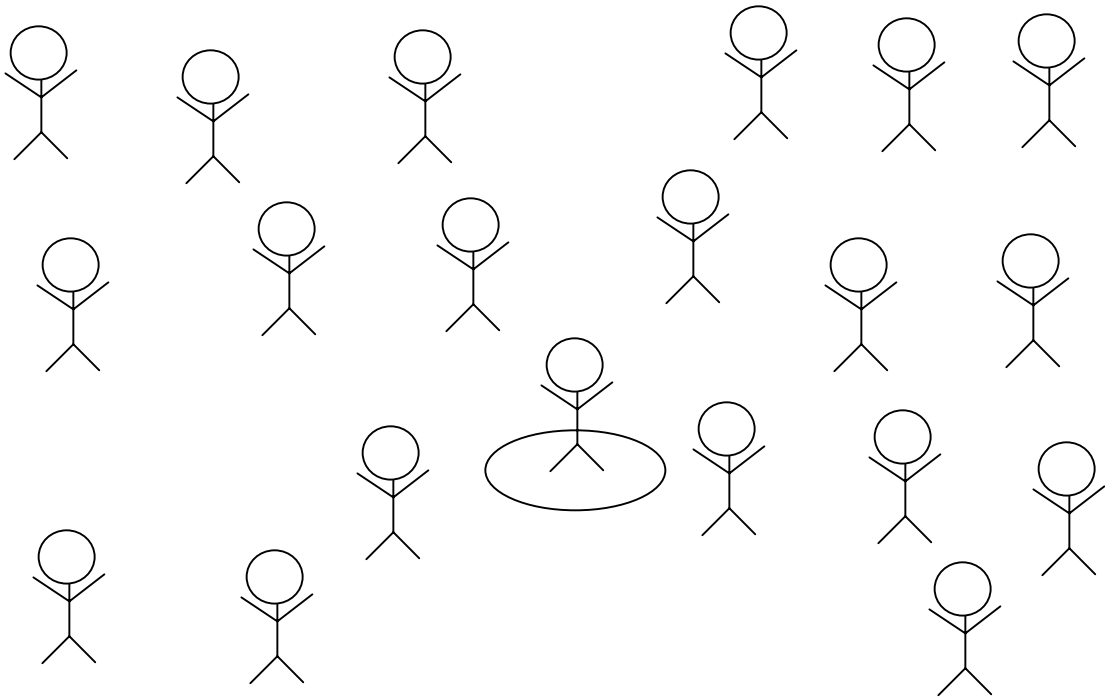


Date: _____

PEOPLE IN NAME'S? LIFE

Service Providers

Family



Community Supports

Friends



Date: _____

HEALTH

Indicators of Good Health	Physical Limitations	Themes and Recommendations
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*

Date: _____

THINGS THAT WORK AND THINGS THAT DON'T WORK

Characteristics Which Gain Respect	Characteristics Which Lose Respect	Themes
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*

Date: _____

A VISION OF THE FUTURE



Neighborhood

Home

Support Staff

Work
Type of Work



Day

Characteristics of Work Place

Supports



Community

Recreation/Leisure

Transportation

Shopping

Community Participation

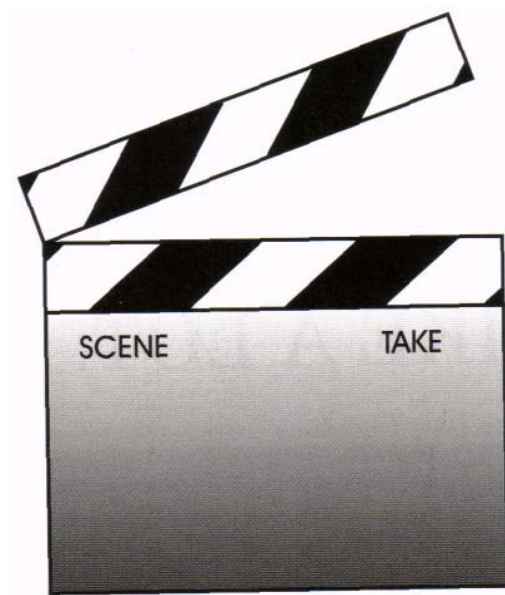
Services

Supports

Date: _____

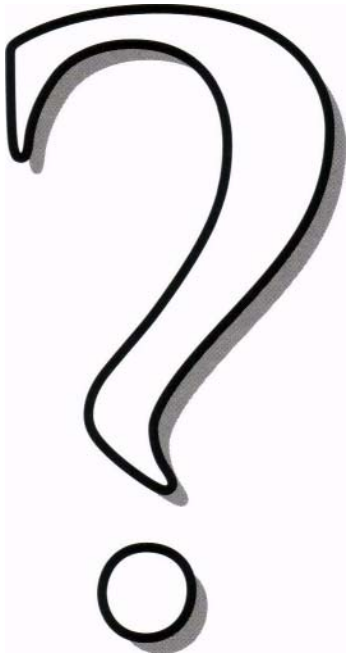
TASKS		
Task	Person	Date
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		

MY LIFE . . .



BY

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Who is

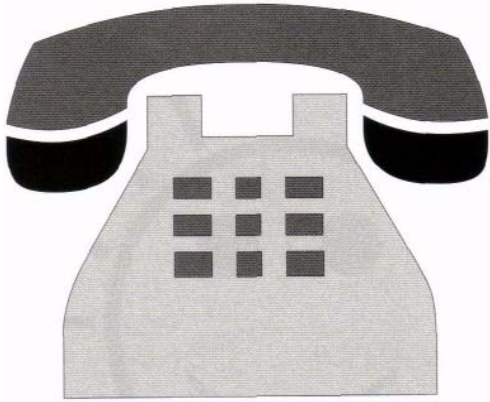
Things I



Things I LIKE A LOT:

Things I DON'T LIKE:

Things I *REALLY* DON'T LIKE:



These people are important to me. I want to invite them to my futures planning meeting:



**Some things make
me
(List)**



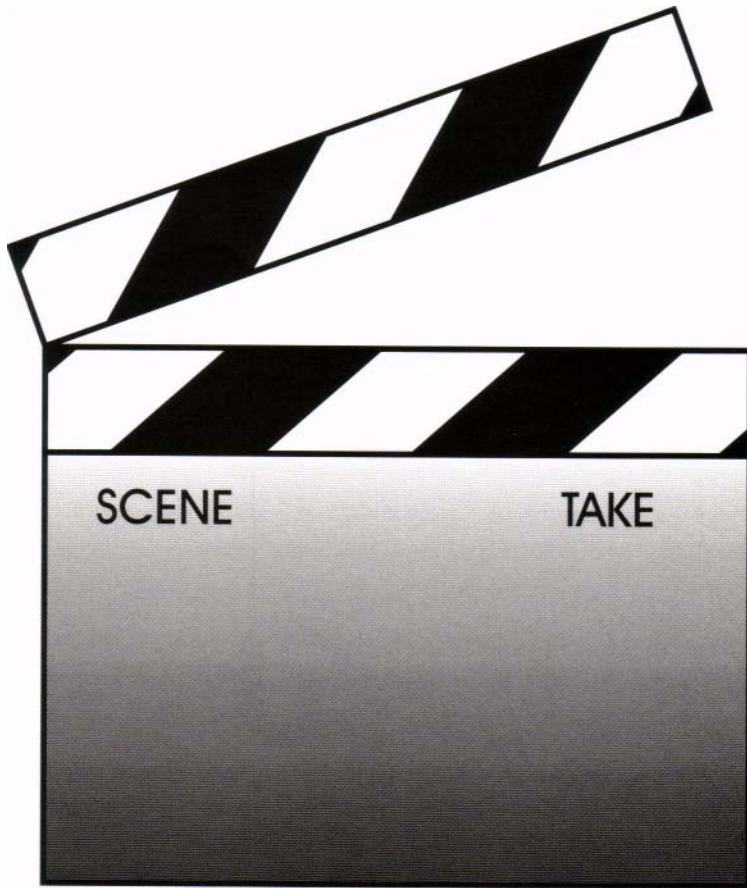
**And sometimes I get sad.
(List)**

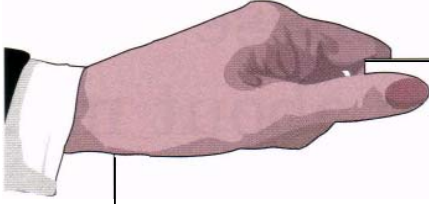


These are my greatest **FEARS!**



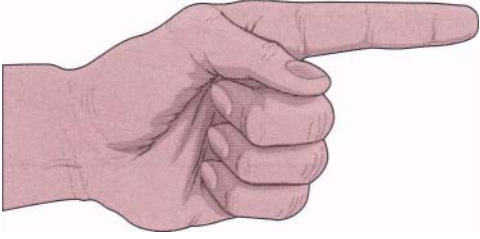
**These are NEW things I
want to do and learn:**



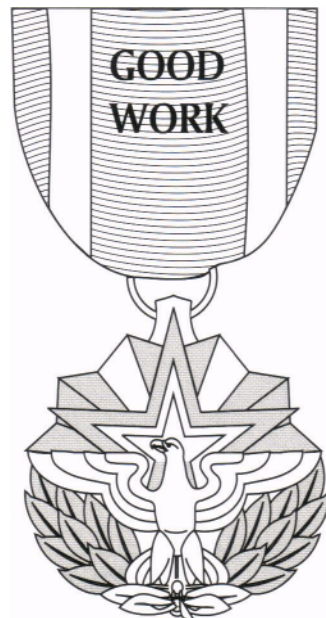


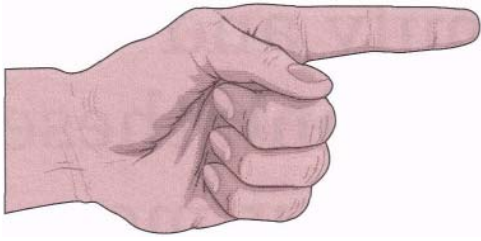
I currently get these services:



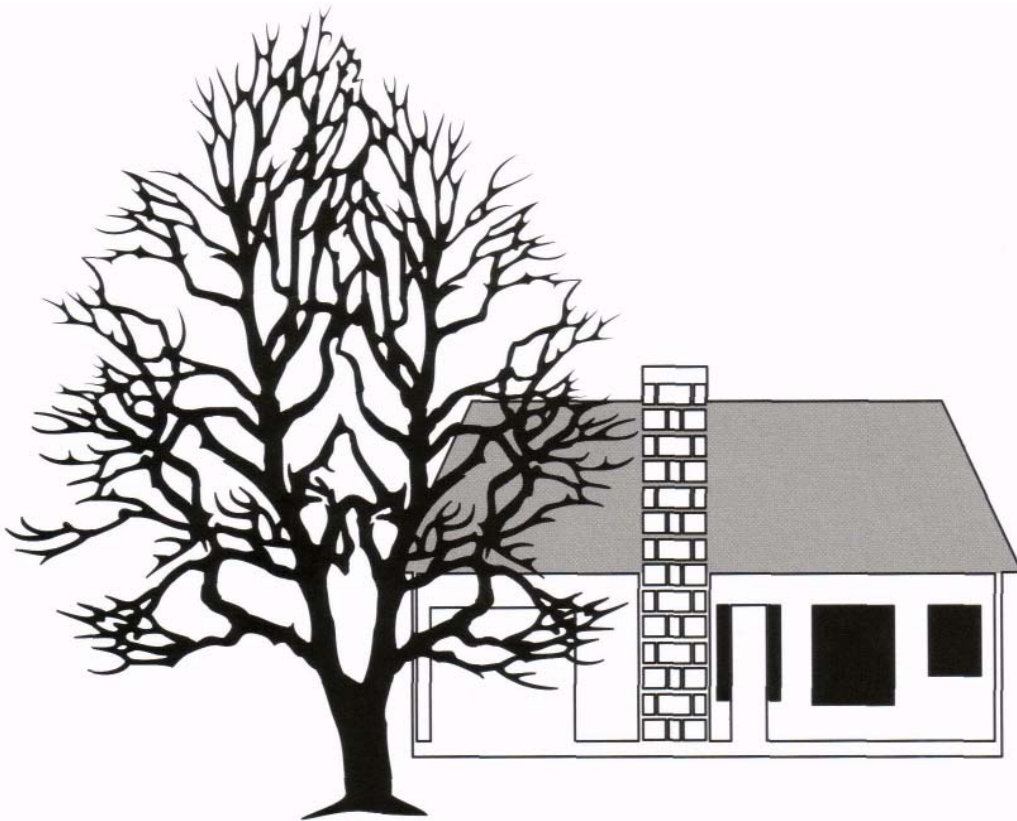


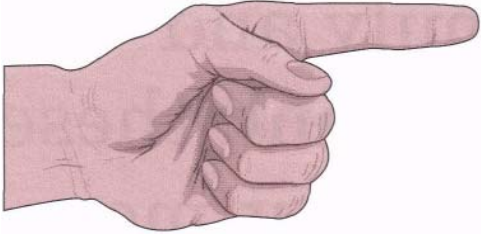
**People at work
think these
things about me**





**People at home
think these
things about me:**





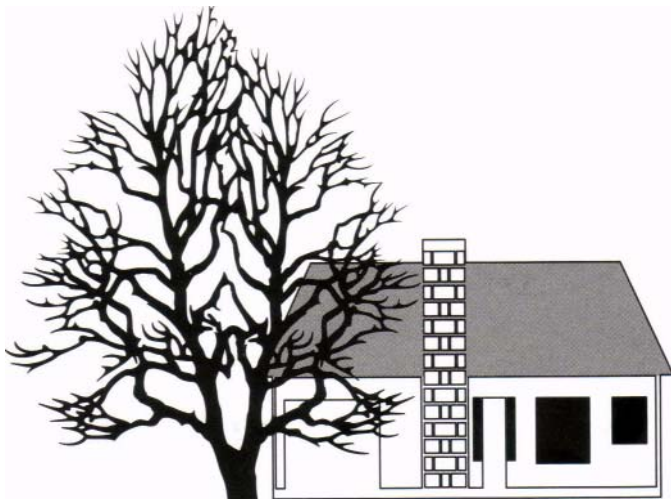
**My family and
friends think these
things about me:**



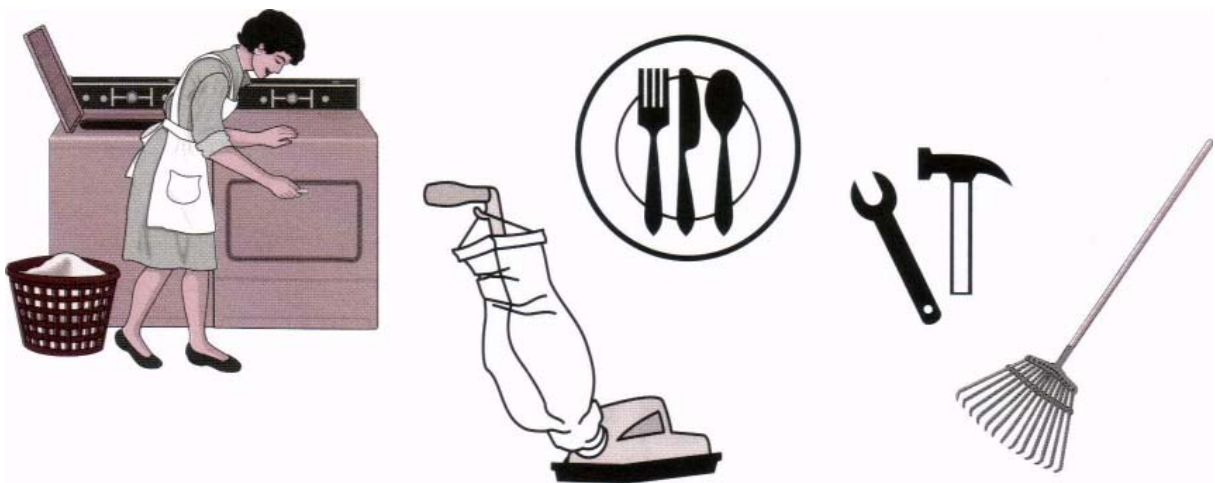
These are the best things about my **JOB**:



About my **HOME**:

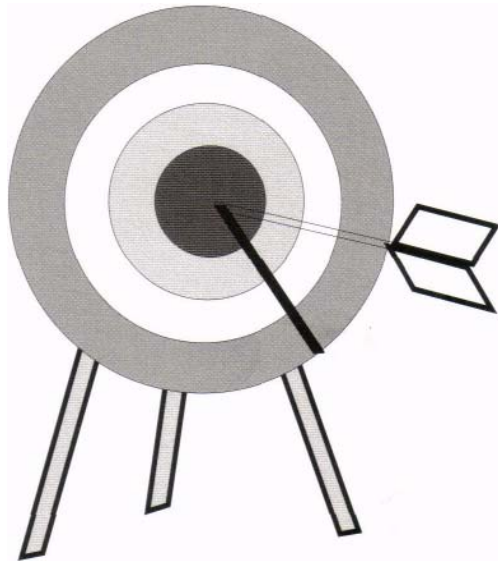


The things I most often need help with at home and work are:

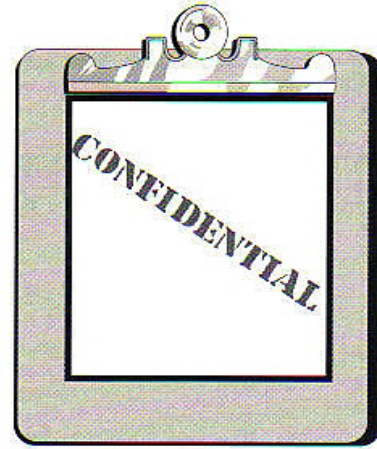


My perfect job would be ...
(explain why)

My perfect home would be .
(explain why)



My health needs:

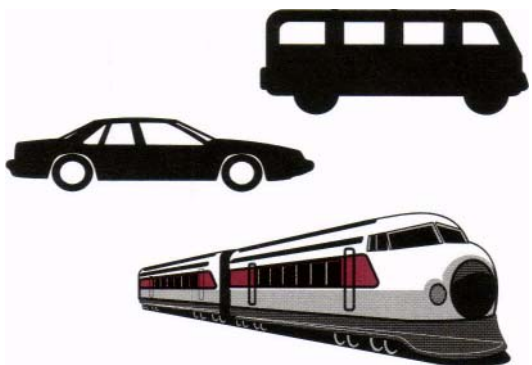
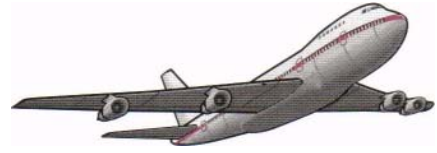




**I need this much
money to live and
this is where it
comes from:**



Places to go ...





If my world were perfect, this is what I'd be doing:

At Home:

At Work:

In the Community:

With My Friends:

FINDING A WAY TOWARD EVERYDAY LIVES

The Contribution of Person-Centered Planning

John O'Brien and Herbert Lovett

Pennsylvania Office of Mental Retardation

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 (P.O. Box 11820, Harrisburg, PA 17108).

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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 every one of us.

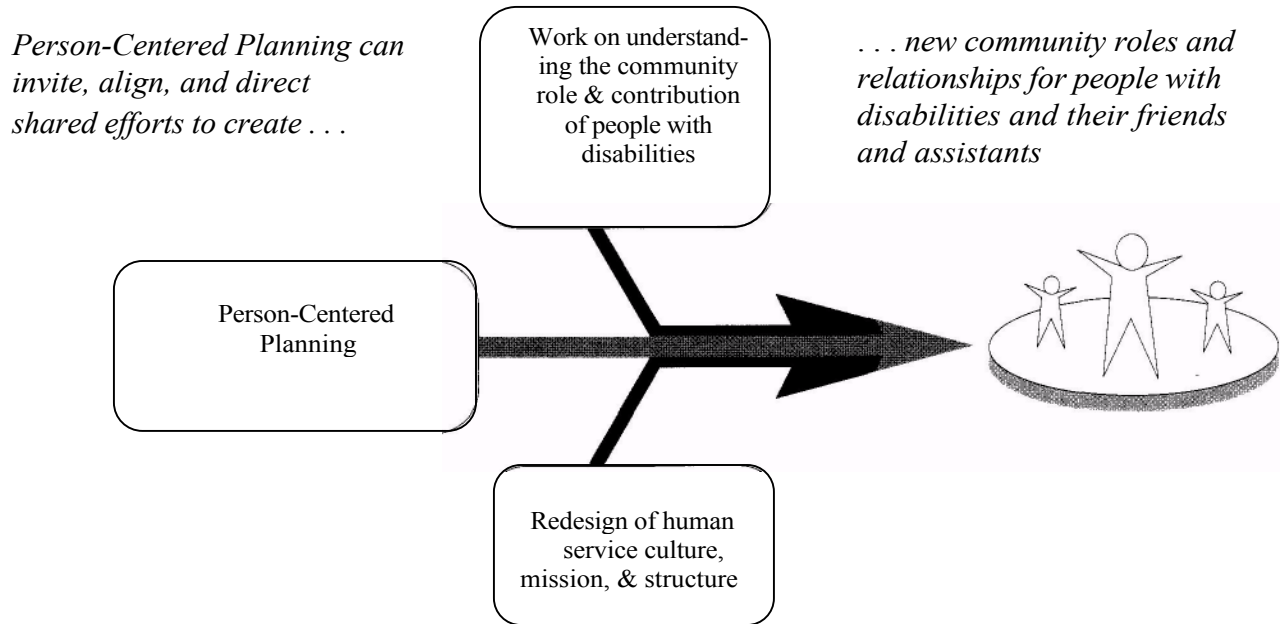
With the insight, advice and cautions of the people whose thoughts are contained in this booklet, let us move forward with our efforts to bring to reality the vision in *Everyday Lives*.

Nancy R. Thaler
Deputy Secretary for Mental Retardation
February, 1993

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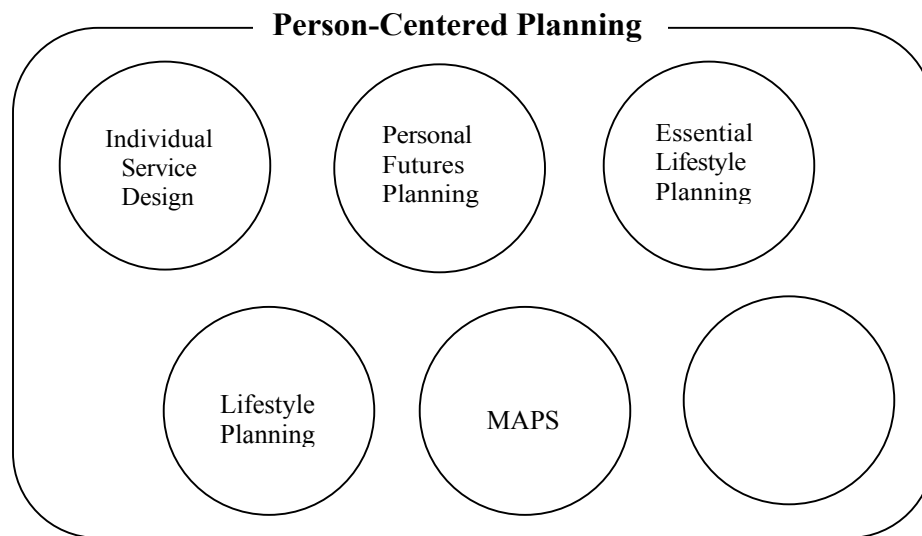
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FINDING A WAY TOWARD EVERYDAY LIVES



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.

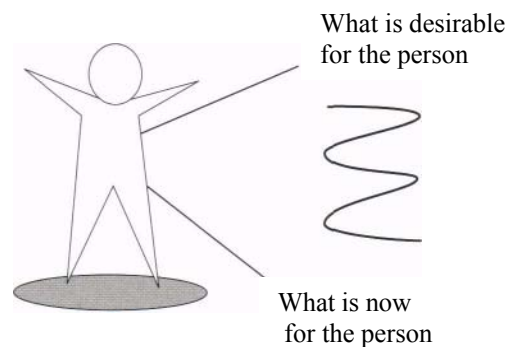
- Assisting people to define and pursue a desirable future tests one's clarity, commitment, and courage. Person-centered planning engages powerful emotional and ethical issues and calls for sustained search for effective ways to deal with difficult barriers and conflicting demands. Those who treat person-centered 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 ...

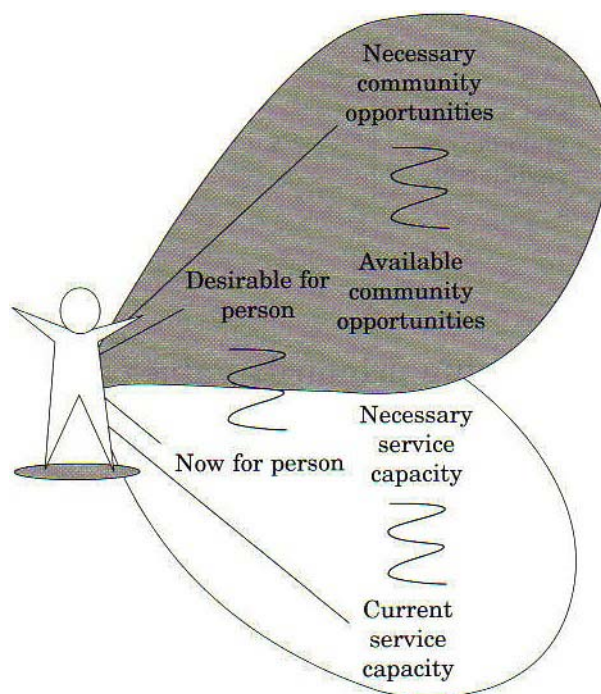
- ... creating a compelling image of a desirable future and inviting people to join with the focus person to make it happen
- ... strengthening personal relationships
- ... helping people plan, act, and learn by reflecting on their successes and failures

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

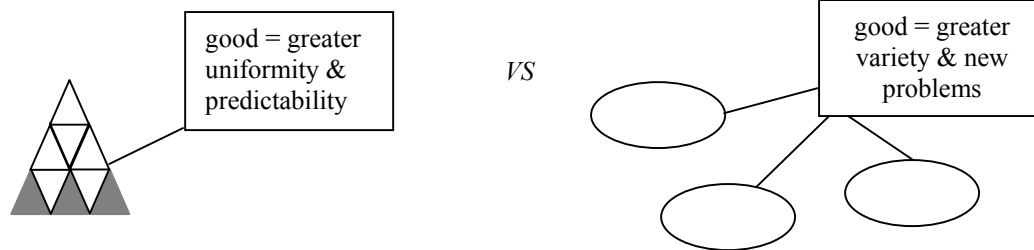
change to happen, community opportunities must be opened and expanded and service systems must develop new capacities, both within themselves and in the wider communities they must be a part of.



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.

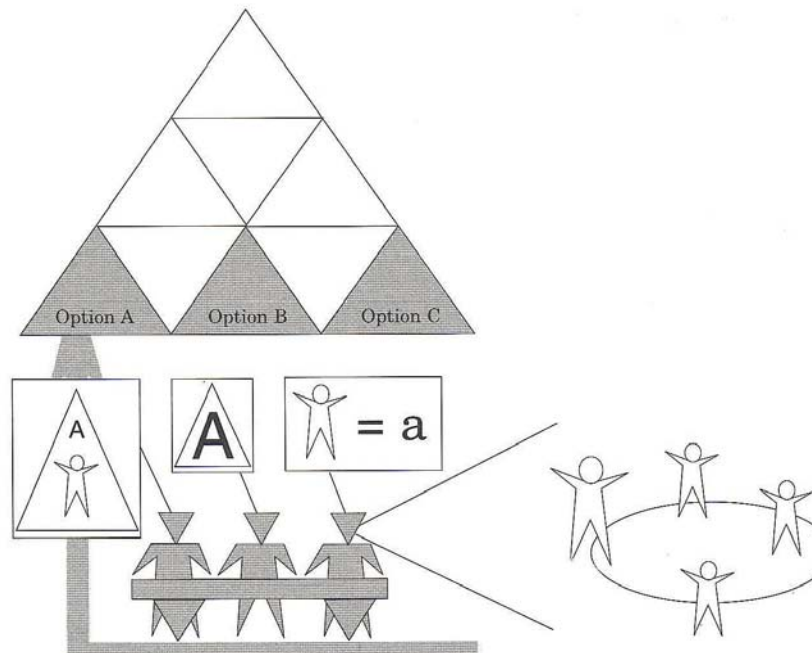
Person-centered planning influences change when people respond to the tension between what a community has to offer now and what the focus person needs to pursue a desirable future. Direct engagement with the focus person and the focus person's allies guides community development. Person-centered planning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



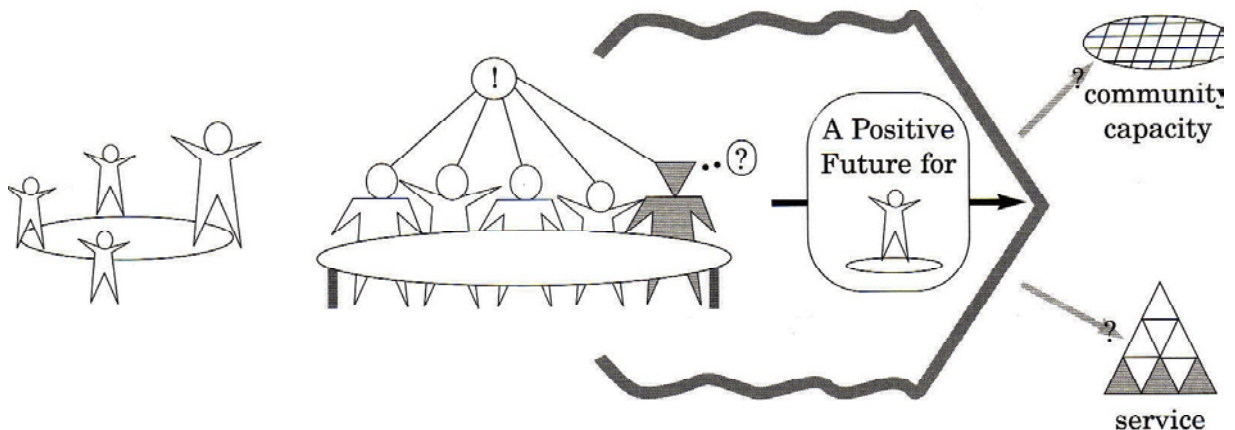
Person-centered planning primarily values accurate individual services. This greatly increases the required variety of service responses.

When uniformity and predictability are primary system values, "individual program planning" functions to decrease uncertainty and variety through a regulated, impersonal ("objective") process of judgment that specific 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 and monitoring treatment



Person-Centered Planning: Increases system uncertainty by . . .

- Strengthening the person's alliances
- Clarifying individual interests and needs
- Energizing new demands on system and 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 destabilizes 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 redrawn 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.

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- 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. 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 cooperative, 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 arrangements.

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 de-institutionalization 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.

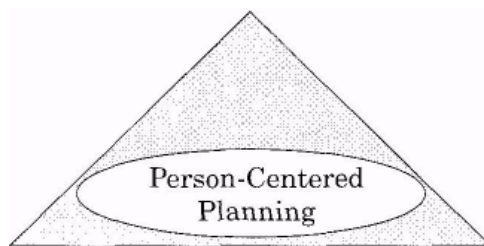
People who facilitate person-centered planning disagree about how much a person's family, friends, neighbors, and co-workers or fellow students can do and should be expected to do. Some believe that natural supports (i.e., unpaid people) should and can be sufficient to assist people and that their contribution 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

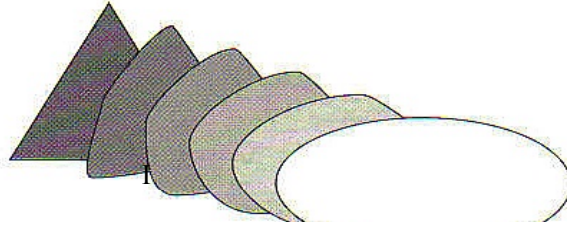
Regardless of these controversies, most people who facilitate person-centered planning worry that a system more interested in fads than in fundamental change will capture person-centered planning.



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 Tightness 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 reallocation 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 and 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

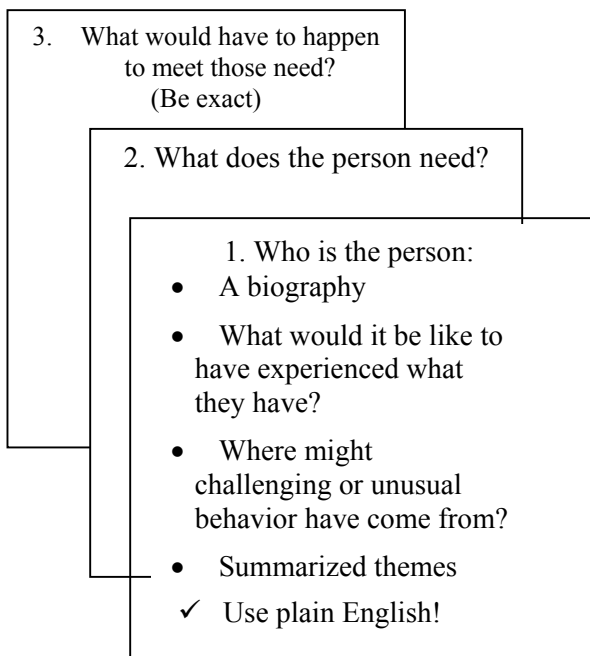
- Start small and grow slowly, perhaps with projects that are specifically resourced as development activities.
- Join and invest in building up a network of facilitators and other involved people who can offer mutual support and criticism. The network will grow as people ask for and give one another 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," emphatically 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.

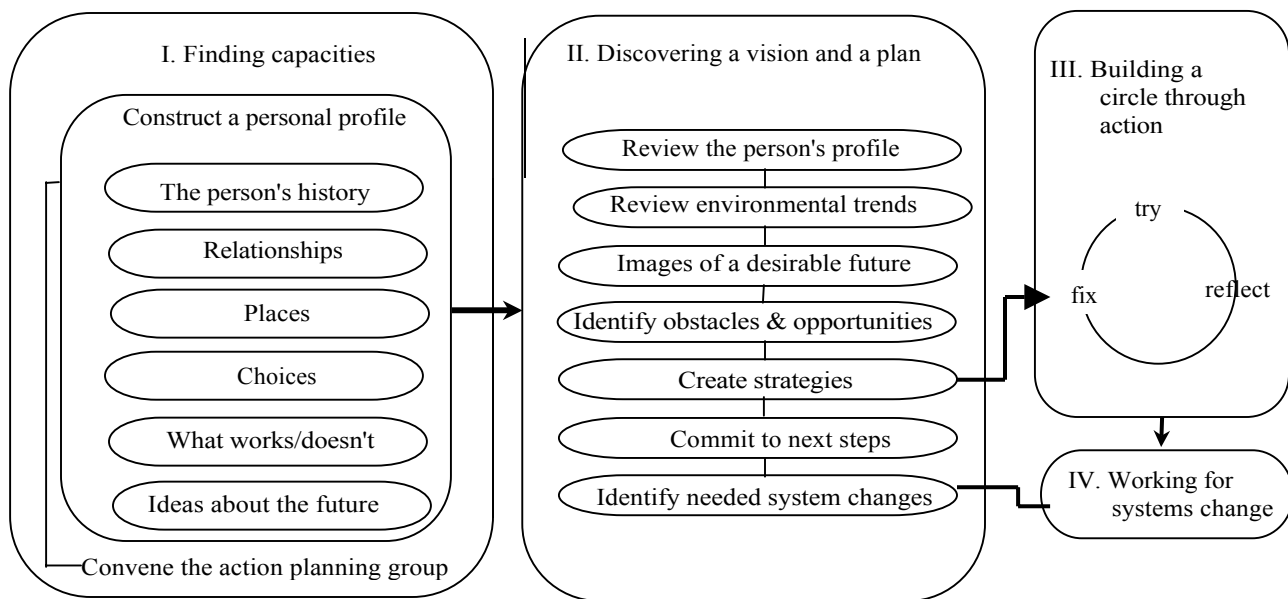
Individualized Service Design

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

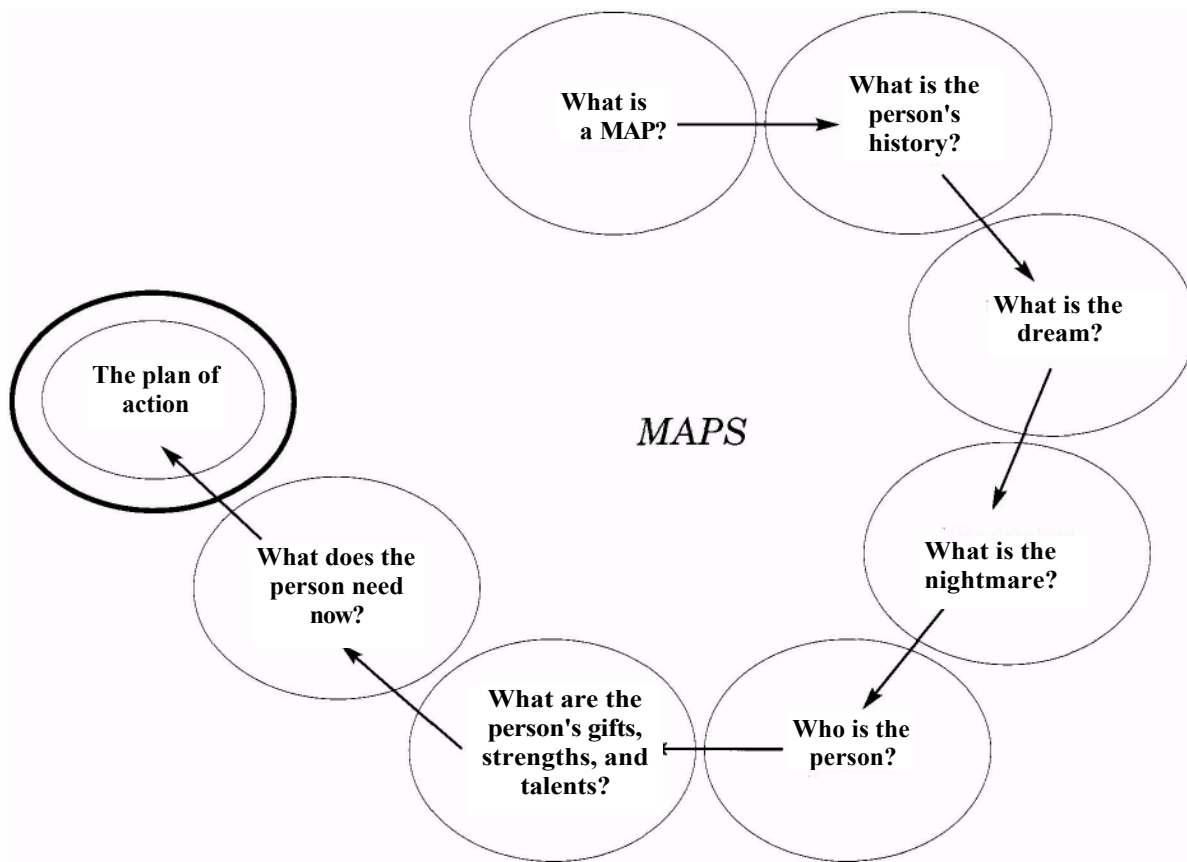


Personal Futures Planning

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

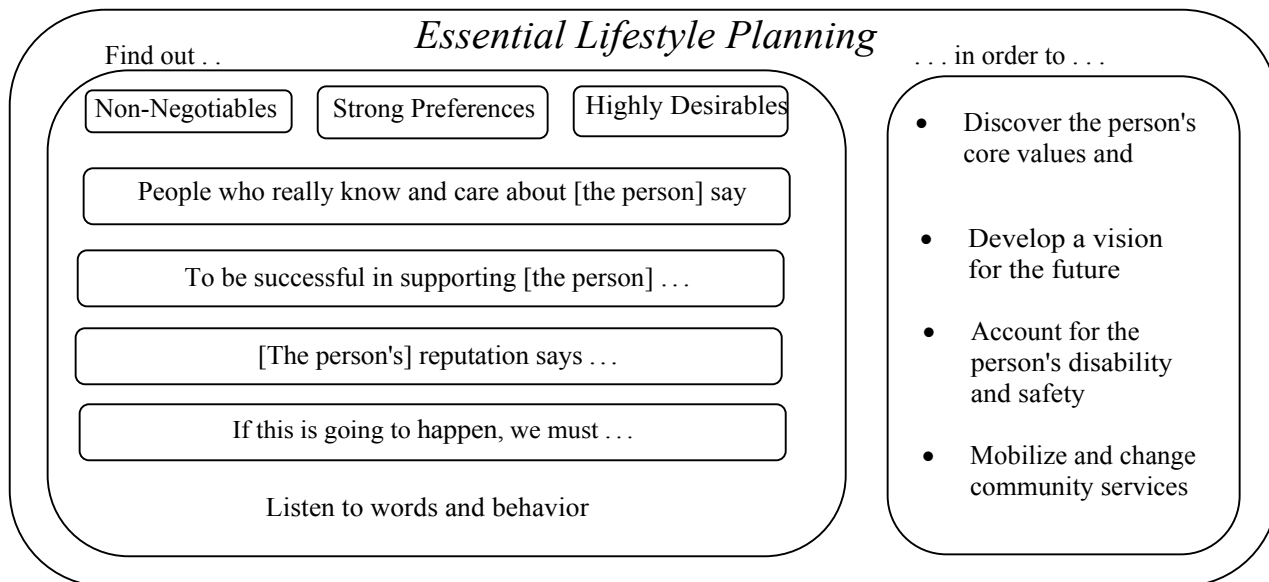
MAPS

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 carry on the day-to-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

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Susannah Joyce (1992). *Gathering together: A collective approach to personal planning with people who have been labeled* (3d edition). London, Ont: Realizations.

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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 renamed lifestyle planning by the book's editors in the context of its application to the activities catalog approach to school curriculum development.

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

Contact: Communitas • Box 374 • Manchester, CT 06040

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

Minneapolis 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, Mass: Author.

Contact: Jack Yates • Ralph Mann Dr • Stoughton, MA 02072

Essential Lifestyle Planning

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

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

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

ESSENTIAL LIFESTYLE PLANNING

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Michael Smull, Baltimore, Maryland

The headings

In "essential lifestyle planning," as in the other forms of person-centered planning, we conduct the meeting using "wall paper." A series of charts are placed on the wall with headings that help organize the information needed to implement community services for the individual. The headings for the charts are:

- Non-negotiables
- Strong preferences
- Highly desirables

People who really know and care about _____ say—

To be successful in supporting _____

_____ 's reputation says—

If this is going to happen we must—

The first three categories—non-negotiables, strong preferences, and highly desirables—ranks what people like and dislike. Keep in mind that while these distinctions can be very helpful they are artificial; good sense should prevail. The next set of headings serves a number of purposes. What people who really know and care say about you is your positive reputation. This begins to counter the reputation found in the record. The heading that says "to be successful in supporting _____" is where the issues of those people who are essential to success and the essential clinical issues are noted. The reputation heading serves two purposes. It gives those who are compelled to recite the past a place to do it, but it also insures that attention will be paid to issues that can be glossed over in the positive focus of the meeting. The last heading on the chart is where action steps are described. The "who, what, and when" are described in order to sustain the momentum of the planning process.

Non-negotiables

Non-negotiables are those lifestyle choices which are essential to a reasonable quality of life for the individual. Positive non-negotiables are essential for a person's life to be tolerable and pleasant. Negative non-negotiables make life so unpleasant and intolerable that their presence will make people act out or withdraw. Non-negotiables represent the core values and characteristics of individuals. Examples of non-negotiables in plans that have been done are:

- not living with smokers
- having lots of friends
- living where I grew up
- living with people who do not mind clutter
- living with people who "love me the best"
- not living in the city
- control over my own space, my own possessions

All of these requests are modest. The non-negotiables we find for people with disabilities are rarely honored and yet readily available to typical citizens in our communities. We refer to these preferences as non-negotiables because they are essential to the individual's well-being. They are the choices that we must honor. Providers who cannot (or will not) meet these are not considered.

Most non-negotiables are stable over time but some of them do change. Where change occurs it typically reflects learning. We find that core values and the choices they reflect evolve over time. As we mature we find that what we value shifts. Often we want more stability and less change. We also make choices that do not have the anticipated results, that do not give us the increase in our quality of life we expected. The

cliche for this is "learning from experience." When ordinary people make a particularly bad choice we call it "learning from the school of hard knocks." In the disability field, when we are angry with someone and "let them fail," we call it "suffering the natural consequences."

Strong preferences

Strong preferences are the middle ground between non-negotiables and highly-desirables. For example, there are people who simply cannot stand to be around cigarette smoke, those who have a strong dislike, and those who simply find it irritating—people with a non-negotiable, a strong preference, or a highly desirable. Strong preferences reflect those choices that make a major contribution to a reasonable quality of life but are not critical to it.

Highly desirables

Choices that are the highly desirables represent those things we would like to have. We are not interested in a Christmas list of things that someone might like. We are seeking to discover those things that people know that they want in their lives. Most of us have lists with a pyramid shape—we have a few non-negotiables, more strong preferences, and lots of highly desirables. Where there is a short list of highly desirables we either do not know the individual very well or the individual is living a very impoverished life. Just as in the other areas, most highly desirables are typically quite modest. We should be able to support people in having many of their highly desirables met.

In thinking about choices and planning

Where services that honor these choices do not exist, we need to plan further. Can we find the setting and then build supports around the individual? How long will it take to develop the setting that meets the

non-negotiables? If the answer is months then we need to see if there are interim efforts that will improve life while the individual waits. We must guard against having interim become permanent. Too often the interim efforts remove the pressure needed to develop the setting that meets the non-negotiables. We must ensure that the non-negotiables will be met.

Where we are planning for others we need to take into account that our understanding is always less than perfect. We are often trying to support people whose disability and circumstances preclude a clear vision of a desired future. Difficulties in speaking for themselves, impoverished life experiences and few connections with people who know and care about them increases our challenge. We need to see all of our lists as representing the understanding that we have at that moment. As our understanding changes we need to change our lists.

Quality of life is interactive and evolves over time. There are synergistic effects. The presence or absence of a reasonable quality of life is made up of a complex of interacting issues. The product of the interaction cannot be easily predicted. We need to pay attention to how people feel about their entire life. We need to continue to learn not only about the effects of single choices but the effects of their interactions. In looking at individuals' perceived quality of life we need to account for their personalities. Edgerton has noted that pessimists and optimists tend to stay that way. Assessments of how people report on their quality of life need to reflect the "baseline" of their personality style.

People who really know and care
about her/him say

How would your mother describe you when bragging to her friends? The stereotype of a mother's description is how this section should be approached. All of the positive attributes of the individual that relate to

human interactions or valued skills would be listed here. Adjectives such as "charming" or "warm"; descriptors such as "loves to help others" or "makes me laugh"; skills such as being an "excellent baker" or plays a "great game of pool"; are all appropriate examples. Clinical descriptors such as "has all his ADLs" or "expresses anger appropriately" are not acceptable.

Few positive descriptors means that you have not invited (or interviewed) the right people or the person needs to move immediately. People who know and care about someone always have reasons why they care. Their stories carry the positive descriptors. If you have sought out these people and have not found them then the individual is living without people who care. Anyone living without people who care needs to leave as quickly as is possible.

To be successful in supporting her/him

If we are to be successful in supporting people with severe reputations we must do more than honor their choices. We need to address their clinical needs. We need to address all of the prerequisites for the individuals to achieve their desired lifestyle in the community. We cannot assume that behavioral issues will simply cease to exist because people are getting the lifestyle that they are asking for. For an individual who throws and breaks things when he gets angry we cannot assume that he will no longer get angry. There need to be reasonable, positive practice behavioral plans to deal with predictable challenging behaviors. Other clinical support issues may be medical, psychiatric, or neurological. Any essential clinical supports needed should be listed.

This is also the area where the issues of other essential people are addressed. In one instance it was critical that an individual's mother be enlisted as an ally before the individual moved. This is an individual who has a close relationship with his mother and she has correctly perceived that we have not done well in supporting her son in the community. For

another individual, whose living arrangements crossed funding jurisdictions, officials from both county services boards had to agree before the individual could move.

His/her reputation says that he/she

Reputation needs to be approached with caution and judgment. When you are planning with people whose reputations are the primary barrier to achieving their desired lifestyle, the reputation must be confronted. But you must also keep in mind how difficult this can be for the individuals who are experiencing this public-parade of past sins. Consider whether this section is needed. It can serve a number of purposes.

First it provides the facilitator a place to consign all of the negative attributes that some people have a compulsion to emphasize. Second, it can be used as a contrast with the positive attributes of the individual and demonstrates how we blame individuals for system problems. Finally, in the process of describing the reputation, we can be alerted to issues that we must account for. Occasionally people feel that the positive emphasis of this planning process precludes raising issues of real concern. For example, someone who has set fires presents a public safety issue that we be adequately prepared for.

The reputation listed in the preliminary plan needs to be shared with the individual and a strategy developed to assist the individual in coping with it. The terms used should be carefully considered to see if they impart the necessary information while they are as respectful of the individual as is possible. Alternatives can be considered as well. Where the planning is being done with people without severe reputations, you need to consider whether this section is needed at all.

If this is to happen we must—

As the planning meeting ends, the momentum that has been created must be sustained. A set of concrete action steps should be developed. They are listed under this heading with the action, the date by which it is to be accomplished, and who is to accomplish it. A list which includes everything up to the move of the individual is unusual. It is more important to establish realistic time frames for moving forward with the plan and to make the planning participants responsible for its execution. The last step is typically a date to get back together to report on progress and continue the planning.

PREPARING FOR THE MEETING

**Disputing the reputation—
understanding the person**

Understanding the person is not a "Pollyanna" process where the difficulties are glossed over by denouncing the service system. Understanding the person suggests that all people are complicated and require more than simple assessments of splinter skills or isolated behaviors. Understanding the person also suggests that people with severe reputations have positive attributes. They have gifts, skills, and potential contributions. Understanding the person requires that we look beyond the reputation to the whole person.

First, we must get to know the whole person. We must move from traditional, deficit-oriented assessments to understanding the person as a real person. We must go beyond simply identifying strengths and needs and discover what the core values are for each person. It is not enough to focus on preferences, we must know each person's dreams and nightmares. We must remember that we can easily make someone's nightmares reality.

It is critical that we know what the values and hassles are for each person. There are few relationships, jobs or situations that are totally hassle-free. We choose to continue in these situations when the values outweigh the hassles. We choose to leave when the hassles outweigh the values. We must recognize that a major difference between ourselves and people with disabilities is that they do not get to "walk" when the hassles outweigh the values. They only get to leave when we allow them to leave.

Meeting the person—not the reputation

We must meet the person rather than the reputation. Find a setting where the individual is comfortable, where the behavioral norms of the setting are not elicited. It can be private space where the individual lives but it might be a hillside where you can sit with a picnic. It might be a restaurant in the neighborhood. It may require that you go along with the person on an outing. We need to keep in mind that the norms of congregate settings are powerful and seek alternatives where the individual is relaxed and comfortable. We also need to keep in mind that many people are shy and will not let you get to know them until they get to know you.

Getting to "know" someone is a social skill more than it is a professional skill. Typical professional skills will elicit social histories or determine mental status but will not help you find out who the whole person is. You need to talk about the good times in the individual's life. When did things go well from the individual's point of view? What are their favorite activities? Who do they feel close to? Who would they like to have involved in their lives? What do they like, what do they really enjoy? What annoys them, what makes them angry?

How much people can share verbally depends on their abilities as well as the relationship you establish. Regardless of the verbal skills there is

much that can be shared and learned. We need to take the time to get to know them as individuals and not rely solely on informants. However, because many people with disabilities are poor historians and because we have given them extensive training in telling us what we want to hear, we also need to interview others.

Selecting "informants"—recruiting allies

We typically find no shortage of professionals who can tell us what is wrong with an individual. To understand the person we need to be able to talk to people who know the person rather than their disabilities. We need to talk to the people who know what is right with the individual, who can tell us why they like the individual.

Find the people who enjoy spending time with the individual. There are no rules about who these allies can or cannot be. For individuals who live in institutions they may be from housekeeping or from the professional/management staff. The only rules for selection are that these people must like the individual and enjoy spending time with him (or her). Look for people who spend extra time with the individual. If there is no one at this moment, start going back in time. Where someone has lived in a facility for years there are almost always people who really know and care about the individual.

Look for family or friends who are available and interested in the individual. They are typically the best historians for the individual's likes and dislikes over time as well as for information about the times when things went well. Unless they appear to be a destructive force in the life of the individual, encourage their involvement in the planning for the person as well as the eventual supports. The key word is encourage. Do not coerce, use guilt, or otherwise manipulate family into promising involvement that they will not be able to sustain.

Ask:

- What do people generally like about the individual?
- What are the individual's gifts; what does he/she do well, what does he/she enjoy doing?
- What makes the individual unique; how is he/she different from other people; if we were to characterize the individual in two or three words what would they be?
- What does the individual find to be a hassle; what doesn't he/she like doing; what makes him/her angry; what does he/she find to be annoying?
- What motivates the individual; what is important to him (e.g., money, praise, personal appearance, family, church, friends)?
- When have things gone fairly well for the individual? Describe the circumstances, speculate on why things went well.
- Who is important to the individual and what is their relationship (e.g., mother, son, sister, friend, special member of the staff)?

The responses can be as short or as long as the informants would like to make them. These are areas to cover as much as they are questions to ask. Just a¹⁵ much of this planning process is adapted from personal futures planning, interviewers should adapt these questions to their own style and circumstances.

**Using professional information—
looking beneath the labels**

We need to look beneath the labels that the individual has acquired to determine if they contain any helpful information. Some labels tell us very little that is useful while others provide critical information. No

label tells us where people live or what work they should do. Where they are accurate, they can tell us where someone should not live or what situations we should avoid.

As many labels are not accurate, we need to start with skepticism. Some people with severe reputations seem to have acquired labels as if they were party favors. They got the labels by simply being at a facility where someone was passing them out. They did not get the label by meeting a set of criteria. They may have exhibited behaviors that were misinterpreted, not examined, or elicited by an atypical institutional environment. Some labels reflect behavior that was present in the past but which is no longer an issue.

People with severe reputations typically have psychiatric or behavioral labels. Some labels give us critical information. If we ignore or dismiss these labels, we can cause the very failures that we are seeking to avoid.

Someone with a bipolar (manic-depressive) disorder must have careful, competent psychiatric care. Someone with a history of severe depressions or psychosis will need careful monitoring so that prompt appropriate treatment is given for recurrences.

We need to be particularly careful with the labels that are "loaded." People with labels of pedophilia or arson are rarely welcomed. Where they do reflect a real condition, we need to take the precautions necessary to assure the safety of the community. Yet, these labels rarely reflect a compulsion on the part of the individual. Typically they were not correctly applied and have no current relevance. A number of people have labels relating to aggression, such as intermittent explosive disorder, whose real histories describe someone who is rarely listened to. Labels that are misapplied, or are no longer relevant, are simply another barrier to life in the community.

Mining the records

While the typical record of an individual with a severe reputation is replete with accusations it can also be the source of significant information. Careful review can yield information about how to help the individual and who else to involve in helping. By reviewing the stories of repeated failures we can prevent errors in our responses to the individual. Reading the record from a "person-centered" orientation will tell us much of what the individual does not like or will not tolerate. There are often clues as to the characteristics of people that the individual does like and what the individual finds to be valued. Current and past social histories should be carefully reviewed for clues regarding family or significant others who may be available to provide supports in the future.

Developing preliminary lists

As you are collecting information about the individual you should be organizing it. Is this a non-negotiable? Is it part of the reputation? Once all of the pre-meeting information has been collected it should be put on charts. Make charts with the various headings and begin to put the information on them. The most difficult part is deciding what is and is not a non-negotiable. Keep in mind that part of the purpose of the meeting is to review, revise, expand the information on the charts. Keep notes of your questions and uncertainties. Sharing your questions about what should go where is an excellent way to initiate and sustain discussion.

Information on the charts should be free of jargon and in everyday English. The only exception is listing clinical labels on the "reputations" chart. Do not worry about having complete information at this point. The purposes of developing preliminary charts are:

- To organize your thoughts;
- To discover what you know, what you do not know, and what you are not sure of; and
- To provide a place for people to start, to give them something to react to.

Inviting the right people—determining who is needed, who is essential

The people who need to be invited are those who know the person the best and those who are essential in the implementation of the plan. People who really know the person can help sort out what is a non-negotiable and what is a highly desirable. You need not invite all who must approve the plan but you need the people who will be responsible for its implementation. They will be educated by the process. Many of them will meet the person (rather than the reputation) for the first time. If you can move the whole person to the foreground and the reputation to the background, skeptics can be changed to allies through their participation in a good planning meeting.

However, this is another area where common sense and good judgment must prevail. People who have profoundly negative feelings about the individual will adversely affect the meeting process and outcome. Do not invite them. Among those who know the individual there may be some whose schedules just do not allow them to come when all of the other key participants can come. You will then have to determine whether to rely on an interview to convey their information and insights or to delay the meeting.

Finally there are the key people who are really needed but are "burned out" on the individual and/or meetings about the individual. The first step

in convincing them that this process is different is to spend time listening to them. Most typically they will agree if they feel that you appreciate all of their past involvement with the individual. You do not need to convert them into enthusiasts prior to the meeting; you just need them to agree to participate in the meeting.

CONDUCTING THE MEETING

Setting the ground rules

Large, interdisciplinary team meetings are a frequent and familiar occurrence in human services. People gather to share their "clinical insights," assessments, and findings in an "objective" setting. Typically, these meetings focus on the individual's deficits (which are labeled as "needs"). The "team's" mission is to "fix" the person. All of the efforts are directed toward moving the individual towards "independence" and "community readiness."

There are several key elements that distinguish an Essential Lifestyle Planning meeting from a typical Interdisciplinary Team Meeting. One of the basic differences is the ground rules that are established and adhered to throughout the meeting. These ground rules should be clearly stated at the beginning of each planning meeting. They are:

1. Use plain English.

Avoid clinical jargon. If we want friends and relatives to participate on an equal footing we all have to use everyday English. Jargon can also serve to distance the individual from the rest of us. Using everyday descriptions, instead of clinical terms, helps to keep the individual's issues in the same realm as our own struggles. It is the job of the meeting facilitator to politely rephrase jargon-laden statements into everyday language.

Whatever is written on the lists at the meeting and incorporated into the final plan should be in language no more sophisticated than that of the local newspaper.

2. The planning meeting should be conducted with, as well as for, the individual with a disability.

The individuals who are the focus of the meeting are always invited to the meeting. If they are absent it should be their choice and not for our comfort or convenience. They should be spoken to directly and never talked about as if they were not at the meeting. The respectful inclusion of the individuals with disabilities during the meeting is a key ingredient to the overall success of the meeting. If people are unable to speak for themselves or if it is not clear what they want, a trusted friend or family member may, through the strength of their relationship, be able to speak on their behalf.

3. Promises for further action are made to the group and not to the team.

As responsibility for the action steps are divided among the participants they must understand that they are undertaking a collaborative process. They are making promises to the person with a disability and the other participants, but not the "team." It is not unusual in "team" plans to set completion dates that conform to expectations rather than reality. If these time lines "slide" the individual will see this as simply another empty exercise. Individuals who trusted the process will be disappointed and may regress in reaction. Realistic timetables and deadlines should be set and those with assignments should be held accountable to the planning group. It is usually more important that an action step be completed thoroughly rather than quickly. Be sure to avoid the seductive trap of over-commitment when setting up the time lines for the steps.

While these three simple ground rules appear to be quite easy to implement, they represent a major shift in "planning behavior." It is hard to break habits and easy to revert to "team meeting" behavior, lapsing

into jargon, ignoring the individual, and making unrealistic promises. The result can be a compromised process which produces a pale imitation of a person-centered plan.

Setting the tone

In this meeting we are to listen to the individual with the disability. The facilitator conducts the meeting on the behalf of the individual with the disability. In this sense, it is the person with the disability who directs and propels the meeting. This is an opportunity for the person's essential lifestyle choices to be identified. Dramatic behavioral incidents of the past must be placed within the context of the person's whole life. Do not allow the meeting to degenerate into a series of professional "war stories." The reputation cannot become the focus of this meeting. Redirect excessive discussion of negative behavioral experiences. For a person with a disability, the negative experiences of the past can become a daily reminder of the most humiliating moments of their lives.

It is equally important that these difficult times not be ignored or glossed over. Rather they should be treated as holding important information for planning. What does the behavior tell us? The key is to learn from each experience and not to place too little or too much emphasis on any incident. One sign of a good facilitator is the capacity to reframe negative accusations into positive statements. A man who "isolates himself may "enjoy being alone." A woman who "resisted doing new and more complex tasks" was discovered to "want to do things that she is good at." Another woman, who was seen as a pest by some staff, was found to "want to have someone who loves me the best." Staff-centered institutions, group homes, and services necessarily cast everything from the perspective of the professional. In a person-centered process we can recast these statements. By seeing them from the view point of the individual we discover behaviors that are not remarkably different from our own.

Keeping it moving and on track

Although the format of the person-centered plan is straightforward and easy to follow, the focus and momentum can be compromised or lost during the meeting. It is easy to become bogged down in excessive detail or psychodynamics. The challenge is to balance process and outcome. We need sufficient discussion to allow people to get past the reputation and focus on the individual. There needs to be enough interaction between the participants so that the synergy of a group process can be tapped. At the same time we need to have a reasonable plan at the end of the meeting and we need to insure that we do not revert to focusing on what is wrong with the individual.

Using the lists as a point of reference will help to keep the meeting focused on the individuals and their lifestyle choices while avoiding the lure of tangential journeys. The facilitator needs to tell people how long the meeting will last and the expected outcomes. Periodically note how the group is doing relative to the remaining time. It is a role of the facilitator to "bring the group back to task" if they get off track. If the group has significant unanswered questions these can be noted and the group can move on. Schedule another meeting to deal with them, where necessary. Typically these questions require additional information as well as additional discussion. The information will need to be collected before there is another meeting.

Building and sustaining momentum

During the meeting the momentum for change and implementation is developed as the individual is seen as a whole person. As the modest requests of the individual are identified, they become the foreground and the reputation moves into the background. This can be exciting! A good planning meeting will energize people to support the individual. They will also need help.

The meeting ends with assignments being made to carry the plan forward as the first step in sustaining the momentum. However, without on-going efforts, implementation will cease. Unlike classical physics (where an object stays in motion unless acted on by an outside force), change in human services only occurs where people keep pushing. One of the goals needs to be to build a "personal network" or "circle of support" for the person. People who have others who care about them in their lives will not have to depend on paid staff to have their choices honored. This is hard to do for most people who have been socially isolated, but for some there are friends or family who only need permission. Where you find that opportunity, give permission.

Collecting additional information

At the end of each planning meeting you need to ask yourself if you feel satisfied in your understanding of the individual. It is not uncommon to find that important questions remain unanswered. Sometimes these reflect the absence of someone that we should have invited or questions we did not ask in an interview. More frequently they reflect the process of discovery that goes on during the meeting. Ending a meeting with unanswered questions is not necessarily a sign of a poor meeting or poor preparation. It can be an indication of how misunderstood the individual has been. The questions arise when we begin to look past the reputation to the individual.

Experience can help the facilitator to have fewer unanswered questions. However, what is immediately at issue is getting the information. Where these questions remain, the first action steps are to find the answers. There are no rules for who is to obtain the information except those of common sense. People who know the individual are logical choices. The facilitator can be the one who gets the information but this may be an indication that there are too few people who are committed to making the plan work.

Writing up the plan

Occasionally writing up the plan is simply a matter of transcribing the lists. More typically, additional information or additional reflection results in changes in the plan. This is the last opportunity to use simple declarative English in describing the individual or the supports. This is also an opportunity to make sure that everything is stated as positively as is possible without misstating who the individual is. This is also an opportunity for reflection. Does the plan capture what we know about the individual? Do the non-negotiables make sense? Include the uncertainties in the written plan. The plan should be seen as a guide rather than revealed wisdom. Remember that it will be implemented by people who were not at the meeting as well as those who were there.

Have the plan typed and distributed within a week of the meeting. If one of the action steps is to get information that is to be included in the plan then the preparation and distribution of the plan becomes an action step with a date by which it is to be accomplished. A key element in sustaining momentum is to put the written plan in the hands of all of the people responsible for its implementation. If they do not get it until several weeks after the meeting it will simply be more paper in an in-basket.

THE PLAN IS AT THE BEGINNING NOT THE END

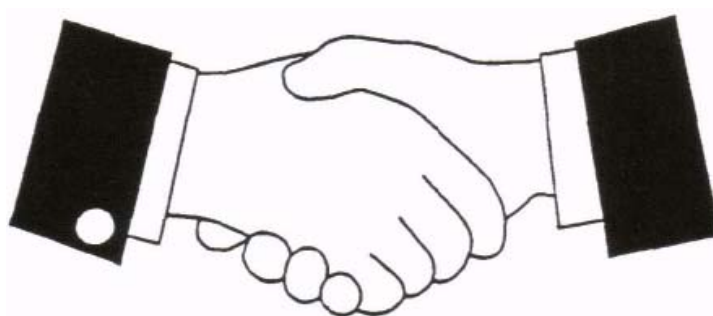
A successful planning meeting can be the beginning of exciting change for the individual. It is when we stop talking and start doing. Putting person-centered plans to work in a program environment is a challenge. It is also an opportunity. System change is easier when done one person at a time. By focusing on the individual's issues you side-step interminable debates over the number of people who should live together and the rules they should abide by. What remains central is meeting the essential lifestyle choices of the individual. Can these choices be met in existing settings? Then the individual should move to that setting. If it requires something new, we need to create it.

It is essential that we not move from trapping people in a program mentality to trapping them in a plan. The plan cannot be frozen in time and never change. Today's plans reflect our present understanding and knowledge. If the plans are accurate, they are a snapshot of what is important now. As the person changes, as our understanding deepens, the plan should change. We need to make certain that we do not tell people that we will plan carefully once and never again. We have to get into the habit of listening to people with disabilities and acting on what they tell us.

YOUR IPP

(Individual Program Plan)

It's Not Just a Piece of Paper!



**A Self-Advocacy Manual for
People Who Get Services from Regional Centers**

**Capitol People First and Protection & Advocacy, Inc.
Peer Advocacy Project
1998**

Used with Permission of and Special Thanks to:
Capitol People First, and Protection & Advocacy, Inc.

THE LAW—THE LANTERMAN ACT



In California, people with developmental disabilities have the right to help and services. The law says that people who get services from regional centers have the right to decide what kind of help they want and need and to make choices about their lives.

The law says that people have the right to make choices about:



Where to live

Where to work



Who to live with

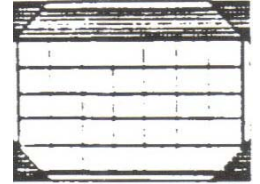
Who to have for friends





What to do for fun

What to do in the years ahead

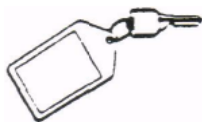


THE LAW SAYS THAT YOU HAVE A RIGHT TO:



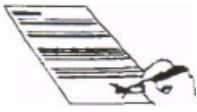
Your own written individual program plan (IPP) that lists your goals and the services you need. This is also called a person centered plan. Sometimes, this Manual will use the term individual program plan (IPP) because that is the phrase the law uses.

Services and help that are provided to you in places that are as normal as possible—not in institutions or places only for people labeled "retarded," but in natural community places, and



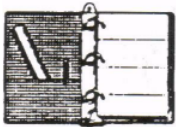
Services that really help you to be a member of your community

The law says that:



Your own written individual program plan (IPP) must list your goals and the services you need to live more independently in the community. ^

You have the right to be a big part of making your plan.



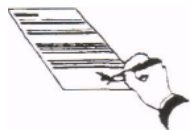
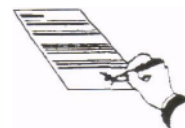
The regional center and other agencies that provide services to you, like group homes and workshops, must help you choose what services you want.

The information you need to choose the services you want must be given to you in a way you understand. This is called "informed choice".



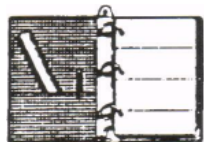
WHAT IS YOUR IPP?

Your IPP is *your* individual program plan. It is *your* own action plan about the *help you need* to live the way you want.



It is a written agreement or contract between *you* and your regional center.

It is made by *you* and your regional center service coordinator (case managers or social workers are now generally called service coordinators) and other people you invite to the meeting. The regional center may also have people it thinks will be helpful to you attend the meeting.



It lists the services that you need and want to be more independent and to live the way you like.

WHY IS YOUR IPP IMPORTANT?



Your IPP is important because it tells about what services and help the regional center will get for you.



Your regional center must provide the services listed in *your* IPP—that is the law (the Lanterman Act).



If something is written in *your* IPP, the regional center must give it to *you*. You are entitled to it. Usually the regional center must buy services for you from another agency.



If something is not written in your IPP, you cannot count on getting it.



Your regional center cannot change what is in your IPP without having a meeting with you. That is in the law too.

WHY IS YOUR IPP *MEETING* IMPORTANT?



Your IPP meeting is important because that is the only time and place where *your* IPP can be officially talked about and written up.



You have a right to be at your IPP meeting and tell people what kind of help and services you need the regional center to get for you.



The regional center cannot write an IPP about you without you being at the meeting.



The regional center must have a person at your IPP meeting who can say yes or no to your requests for services. This may be your service coordinator or it may be a person in addition to your service coordinator. This means that regional centers cannot make decisions outside your IPP meeting about the services you need. The decision must be made in your IPP meeting so that you have a chance to talk with a person who can say yes or no to services you ask for.



If a person who can agree to your request for a service is not at your IPP meeting, the regional center must set up another meeting within 15 days that the right person will be at.



You and the regional center person must agree on and sign the IPP before the services can be given. If you only agree to part of your IPP, you should ask your service coordinator to prepare a statement that says something like: "I agree to the parts of my IPP of (date) Numbered (--,-,--, etc), but not to the part(s) numbered (—,—). Please start or continue the services I agree to right away." If the regional center says no to any of your requests, the regional center must send you a letter within 5 days telling you why they are not giving you the service you want and telling you how to file for a hearing.



The law doesn't require that you have an IPP meeting more than one time every three years. But, if you want to have one sooner to talk about changes in your life, you can ask your service coordinator to set one up. The meeting must be held within 30 days of your request.



You can ask to have your case manager changed.



You can ask to change programs you are in.

WHAT SHOULD YOU DO TO GET READY FOR YOUR IPP MEETING?



Be positive. You are good at lots of things and have good ideas about what you want for your life.

Before the meeting, make sure you take time to think about the dreams or goals you have for the future and the help you need to reach your goals.



Before you go to *your* meeting, talk to people you trust about what you want to say at your meeting. Practice being clear about what *you* want.



There is a special IPP meeting planner at the end of this manual to help you plan for your meeting.

Write down what you want to say about *your* dreams and the services *you* want. If you need help writing it down, ask a friend to help you.



If you have trouble writing or get nervous and forget things at your meeting, you can also make a tape recording of the things you want and bring the tape to play at the meeting.



Before the meeting, if you want, you can ask the regional center to test you—to learn the things you can do and the things you still need help with.



You can invite anyone to *your* IPP meeting. It's *your* meeting so if you want a friend, family member or advocate there to support you, ask them to come.

It is important that you strongly ask for the services you want—but don't get mad. It is always better to try to work together. But, it is *your* IPP and you have a right to ask for the services you think you need. Nobody else can do that as well as you can.



At the meeting, give your case manager or social worker the written list (or the tape) of your dreams and the services and help you want from the regional center. What you have written will help your case manager write your IPP.

WHAT ARE SOME OF THE SERVICES AND HELP YOU CAN ASK TO HAVE IN YOUR IPP?

(At the very end of this booklet, there is a detailed list of services you may request in your IPP. This list is taken from the Lanterman Act, but the law does not limit you simply to the listed services — that is, you may ask for any other services that will help you be more independent or productive.



Help to get a job, including supported employment services.



Help to get into a school or training program.



Transportation and help to learn how to use buses.



Instruction and support so that you can live in your own place.



Training in how to advocate for yourself better.



Help to get involved in fun things going on in the community.



Someone to assist you if you want to be on a committee or a member of a board of directors and need help.



Help to get equipment like wheelchairs or computers that talk.



Other services you need to live a better life.

WHAT DO YOU DO IF THE REGIONAL CENTER SAYS "NO" TO WHAT YOU WANT OR MAKES A CHANGE IN YOUR SERVICES THAT YOU DON'T LIKE?



If you are unhappy about a decision the regional center has made about services you want, you have a right to appeal the regional center's decision.

You should get people to help you with all the things involved with the appeal. It's not easy but it is your right to try to change the regional center's decision. It's in the law.



Within 5 days of making its decision, the regional center must send you a written letter about anything they are changing in your IPP services and tell you why.

If you don't understand the letter, get a friend or advocate to help you.



The regional center is supposed to tell you how to appeal in the letter. If they don't, you will have to ask them. Then you have to fill out a form and send it back.



If you send in a request for appeal within 10 days of the regional center's decision, the regional center cannot stop giving you a service while the appeal is going on. That is the law.

After you send in the appeal form, a meeting will be scheduled so you can again tell the regional center what you want and why you don't like what they decided.



After this meeting, if the regional center still doesn't agree to what you think should be in your IPP, you can ask for a fair hearing. At a fair hearing, you will have a chance to put your case before a hearing officer from the state. The hearing officer will decide if you get the service.

Remember, all this is complicated and everyone should get help with an appeal. Talk with your area board or Protection and Advocacy (telephone 1-800-776-5746) or People First for help.



WHAT ARE YOUR RIGHTS IF YOU LIVE IN A BOARD AND CARE HOME?

**Board and care homes must let you make decisions in your
day-to-day life like:**



When you go to bed



When you eat



Whether you want to have friends over, and



What you do in your free time.

If you live in a board and care home you also have a right to:



Wear your own clothes



Have your own things & use them



Keep and spend a reasonable amount of your own money



See visitors each day



Have a place to keep your own things



Talk on the phone



Mail and receive unopened letters and have letter writing materials including stamps

Rights can be taken away only if you would hurt yourself, another person or the home. Rights cannot be taken away to punish you.



If a right has been taken away, it must be reviewed every 30 days.



You can appeal the fact that a right has been taken away.



You start by calling the regional center's client's rights advocate.



You can also call the area board, Protection and Advocacy (1-800-776-5746) or People First for help.

IPP MEETING PLANNER

This worksheet is to help you plan for the services you want to ask for from the regional center. Use it to help you think about the services you need to help you do all of the things you want to do.

A PLACE TO LIVE

Where do you live now?

- | | |
|--|--|
| <input type="checkbox"/> My own place | <input type="checkbox"/> A group home |
| <input type="checkbox"/> My own place with roommates | <input type="checkbox"/> A large care facility |
| <input type="checkbox"/> My parent's place | <input type="checkbox"/> Other _____ |

Where do you want to live?

- | | |
|--|--|
| <input type="checkbox"/> Stay where I am | <input type="checkbox"/> My parent's place |
| <input type="checkbox"/> My own place | <input type="checkbox"/> A group home |
| <input type="checkbox"/> My own place with roommates | <input type="checkbox"/> A large care facility |
| | <input type="checkbox"/> Other _____ |

What services do you need to help you live where you want?

- | | |
|--|---|
| <input type="checkbox"/> More training | <input type="checkbox"/> More money |
| <input type="checkbox"/> An attendant | <input type="checkbox"/> Help finding a place to live |
| <input type="checkbox"/> Someone to give me regular support and help | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> |

A PLACE TO WORK***Where do you work now?***

- In the community without extra help
- In the community with a trainer or aid
- In a workshop or center
go to school
- Don't work or go to school
- Other _____

Where do you want to work?

- In the community
- In a workshop or center
- I want to go to school
- I don't want to work
- Other _____

What services do you need to help you work?

- A trainer or aid at the job
- Training in a workshop
- Other training
- More education
- Access to workplace—ramps, etc.
- Transportation
- Other _____

Where do you want to work?

- Doctor Services
- Dentist Services
- Counseling

FUN AND LEISURE

What do you do for fun or with your free time?

- | | |
|--|--|
| <input type="checkbox"/> Visit friends | <input type="checkbox"/> Read |
| <input type="checkbox"/> Shop | <input type="checkbox"/> Take classes |
| <input type="checkbox"/> Go to movies or plays | <input type="checkbox"/> Volunteer work |
| <input type="checkbox"/> Play sports | <input type="checkbox"/> Listen to music |
| <input type="checkbox"/> Hobby | <input type="checkbox"/> Dating |
| <input type="checkbox"/> Watch TV | <input type="checkbox"/> Other _____ |

What new things do you want to do?

- | | |
|--|--|
| <input type="checkbox"/> Visit friends | <input type="checkbox"/> Read |
| <input type="checkbox"/> Shop | <input type="checkbox"/> Take classes |
| <input type="checkbox"/> Go to movies or plays | <input type="checkbox"/> Volunteer work |
| <input type="checkbox"/> Play sports | <input type="checkbox"/> Listen to music |
| <input type="checkbox"/> Hobby | <input type="checkbox"/> Dating |
| <input type="checkbox"/> Watch TV | <input type="checkbox"/> Other _____ |

What services do you need to help you do the things you want to do?

- | |
|---|
| <input type="checkbox"/> Training |
| <input type="checkbox"/> Attendant |
| <input type="checkbox"/> Facilitator |
| <input type="checkbox"/> Transportation |
| <input type="checkbox"/> Set up a circle of friends |
| <input type="checkbox"/> Other _____ |

OTHER THINGS

What other things do you think you need help with?

- Cooking for myself
- Shopping for things I need
- Personal care
- Cleaning my place
- Managing my money
- Getting medical care
- Meeting more people/making friends
- Riding the bus or other transportation
- Learning about personal relationships
- Learning about sexual relationships and safe sex
- Self advocacy and knowing my legal rights
- Problems with social security, SSI or other money assistance programs
- Other _____

What other services do you need to help with these things?

- Training (what type ? _____)
- An attendant
- A chore worker
- Just someone to ask questions to
- Help setting up a circle of friends
- An advocate or lawyer
- A service coordinator to help me plan for and get services I need
- Other _____

REGIONAL CENTER SERVICES

Services and supports listed in the individual program plan may include, but are not limited to:

diagnosis;

evaluation;

treatment;

personal care;

day care;

domiciliary care;

special living arrangements;

physical, occupational, and speech therapy;

training;

education;

supported and sheltered employment;

mental health services;

recreation;

counseling of the individual with a developmental disability and of his or her family;

protective and other social and sociolegal services;

information and referral services;

follow-along services;

adaptive equipment and supplies;

advocacy assistance, including self-advocacy training, facilitation and peer advocates;

assessment;

assistance in locating a home;

childcare;

behavior training and behavior modification programs;
camping;
community integration services;
community support;
daily living skills training;
emergency and crisis intervention;
facilitating circles of support;
habilitation;
homemaker services;
infant stimulation programs;
paid roommates;
paid neighbors;
respite;
short term out-of-home care;
social skills training;
specialized medical and dental care;
supported living arrangements;
technical and financial assistance;
travel training;
training for parents of children with developmental disabilities;
training for parents with developmental disabilities;
vouchers;
transportation services necessary to ensure delivery of services to persons with developmental disabilities.

GETTING THERE FROM HERE!

Tips on the Person-Centered
Planning Process
Used by HRC Counselors

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11/92

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Tips on the Person-Centered Planning Process

Introduction

Over the last five years or so, there's been a shift in services for people with developmental disabilities and their families (Bradley & Knoll, 1990). It used to be that services helped separate people from their communities. These days, we're all working hard to find ways to support people in the places where they already live, work and play. This means that as a regional center we need to support people with developmental disabilities and their families in ways that lead to:

- Community membership;
- A person-centered plan;
- Choice and self-determination;
- A commitment to community and family; and,
- Social relationships.

That's what this planning process is all about, helping people look at their hopes and dreams for the future, figuring out the support they need (from family, friends, community and agencies) to get there, and then writing down some first steps to take to move towards that plan right now.

In this guide you'll find some background information on person-centered planning and tips on using all three of the interview formats (*Families of Young Children, Families of Students, Looking at Adult Life*).

Tips on the Person-Centered Planning Process

An Excerpt from *The Challenger* ARC-Napa Newsletter October 1991

Frustrated by traditional IEP or IPP meetings? Concerned with overemphasis on deficiencies? Wonder why many professionals don't want to talk about the things most important to you and your family? Feel there must be a better way?

Well, you're not alone! And, you are right. There is a better way. Person-centered planning involves a new way of thinking about a person with a disability, and helping that person lead a more fulfilling life. Person-centered planning is a variant of personal futures planning (Beth Mount), lifestyle planning (John O'Brien and Connie Lyle), and MAPS (Marsha Forest).

The approach is to develop a vision of a desired future, based on who the person with a disability wants to be and to do, and then to marshal resources to support the person in achieving his or her goals. The circle-of-support or person-centered team seeks to develop community connections, to invent and experiment with novel courses of action, and to stand by the person as any close friend would do.

The traditional way of planning services relies on (1) assessments that look at 'deficits' rather than gifts and strengths; (2) using professional judgment in the place of what the individual and his or her family know about themselves; (3) efforts to 'fix' people, to get ready (often indefinitely) for life; and (4) opportunities, defined by what exists rather than what is wanted. This is service-centered planning, and combined with high case loads, budget constraints, and restricted service menus, often produces mismatches.

Tips on the Person-Centered Planning Process

An analogy may help. Mr. Jones has a leaky faucet, calls a plumber, and she comes to his house to install a water heater. At first, he passes it off as a misunderstanding. The water heater didn't cost him anything, and although he had to fix the faucet himself, he ends up with a sparkling new water heater. Sometime later, Mr. Jones has a leaky toilet, and again calls the plumber. She decides that he really needs another water heater, and installs it. Finally, Mr. Jones throws up his hands, and turns elsewhere for help.

We recently compared the plans generated for a young woman we support. In 1989, Mary's IPP listed four objectives, as follows:

- *With supervision, increase her work skills and productivity;*
- *With monitoring, Mary completes household responsibilities on a regular basis;*
- *Following a budget, Mary pays her bills and buys personal items with money allocated on a weekly basis; and*
- *With support services, Mary socializes in the community with peers at least once a month.*

Mary's person-centered plan, worked out at about the same time, listed Mary's objectives as follows:

- *A job at Mervyns;*
- *Learning communication and problem-solving skills that will help in her relationship with Stan;*
- *The chance to spend time with Stan, so they can find out more about each other as they move towards marriage;*

Tips on the Person-Centered Planning Process

- *Learn about pregnancy and raising a child;*
- *Change her relationship with her mother from adult I child to adult / adult; and*
- *Make sure she keeps her apartment.*

Wouldn't it be more fun to approach life this way¹? And, wouldn't we contribute more to the well-being of those we care about? We think so!

Selected Excerpts from

It's Never Too Early

It's Never Too Late

Written by Beth Mount and Kay Zwernick

New Possibilities

Human services should provide a bridge to the community for people with disabilities. Building on people's capacities and opportunities in networks and communities allows desirable futures to be created and supported. This is the aim of *Personal Futures Planning*.

A New Way to Plan Together

Implementing these new values and accomplishing new outcomes means letting go of service practices that support the old assumptions. For example, the traditional approach to planning for people with disabilities is focused on deficit-finding. This deficit-finding is cumulative as it continues year after year. For each skill a person acquires and each objective a person meets, new deficits are identified and new goals developed. The traditional Individual (Service) Plan process often ends up justifying the continuance of deficit-finding and devaluation in the lives of people with handicaps.

Tips on the Person-Centered Planning Process

There are at least three major problems with the traditional approach to planning:

1. It begins with an assessment process that often highlights the person's deficits. When the person is defined in terms of deficits, then the person is in constant need of services and "fixing." In this situation, the person is never ready for community life.
2. It tends to establish goals that are already part of existing programs. The plan is designed to fit the person into a particular program, even if that program is not exactly what that person needs.
3. It relies solely on professional judgment and decision-making. People with disabilities are prevented from taking initiative or directing action to affect their own lives.

The shortcomings of the ISP can be counterbalanced with a *Personal Futures Plan* developed for the focus person. The ultimate goal of both planning strategies is to improve the quality of life for the person with a disability.

What's person-centered planning all about?

"Personal Futures Planning provides strategies to increase the likelihood that people with disabilities will develop relationships, be part of community life, increase their control over their lives, acquire increasingly positive roles in community life and develop competencies to help them accomplish these goals. Futures planning helps to clarify and implement these ideals, one person at a time."

Beth Mount

Kay Zwernik

It's Never Too Early

It's Never Too Late

Tips on the Person-Centered Planning Process

Person-centered planning (adapted from *Personal Futures Planning*) is a process which complements and enhances traditional service planning.

Traditional approaches and plans are often restricted by:

- The service options that a particular agency offers; and,
- The current bureaucratic categories, laws and/or state politics.

This planning tool, like any other, is only as good as the people who use it to take action. It will have a greater chance for success when:

- The group focuses on strengths, preferences and opportunity;
- The picture of the future is detailed and specific;
- People commit to meet on a regular basis and stick to their commitments of support when they make them;
- Someone agrees to facilitate the meeting to keep the group focused;
- People participating are well connected to their community; and,
- Family members and advocates are in the group.

In using the process, it's important to ask questions in a way that doesn't limit thinking about individual options. This strategy is built on the following assumptions:

1. All things are possible with the right types of support;
2. Support can come from all parts of the community, e.g., parents, family, friends, generic services;
3. Presenting a 'fixed' menu of service options will produce 'fixed' outcomes, not necessarily based on individual preferences;
4. Given lead time, support services can adapt to individual preferences or new support service options can be created; and,

Tips on the Person-Centered Planning Process

5. Most important, that we will not know how to plan for the future unless we ask people with disabilities and their families what it will look like.

The value basis for person-centered planning includes:

- Service options that are based on choices, strengths and needs (rather than a predetermined 'menu');
- Service delivery (type and intensity) that varies from time to time as do strengths and needs (rather than providing more than what is needed or something that is not needed);
- Access to resources that are readily available in the community (not developing new services for persons with disabilities only);
- Services that are coordinated around individual needs (rather than the needs of staff and services); and
- Recognizing the abilities of friends, families, co-workers to teach new skills, participate with, model social behavior and to develop relationships.

The complete set of questions used in Personal Futures Planning (originally developed by Beth Mount and adapted by Alien, Shea & Associates for Harbor Regional Center) is as follows:

Personal Profile:

1. Who is this about?
2. Who helped make this plan?
3. What services do I get now from agencies?
4. How do they describe me?

Tips on the Person-Centered Planning Process

5. What is my health status?
 - A. What health supports do I use now?
6. What are the highlights of my life?
7. Who are the people I know?
8. What do people think of me? (things that are good and bad)
9. What places do I go?
10. What things make me happy and sad?
11. What new people would I like to meet?
12. What things have I learned recently?
13. What new things would I like to do and learn? (What new places would I like to go?)
14. What scares me most about my future?
15. What jobs have I had?
16. What jobs would I like to try?
17. What other things do I know?
18. What is fun about the jobs I have had or would like to try?
19. What would I like about these jobs?

Personal Vision:

20. If I could do anything I wanted, what would my best possible future be?
21. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

Tips on the Person-Centered Planning Process

Person-Centered Plan:

22. Moving toward that vision, what do I want to work on during the next year?
23. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

Families of Young Children

HOW TO GET THERE FROM HERE!
Families of Young Children

1.

What's this all about? This is a chance for families and friends of young children with disabilities to sit down and think about where they're going in the future and the support that they might need to get there. The map will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; or (2) you can work on it with your counselor or case manager. This is not something you have to do, it's voluntary. However, we think that you'll find it useful as well as fun!

1 What is your son's or daughter's name? 2.

3.

2 Who's in your son's or daughter's circle of support? Mom and dad? Family? Others? Who supports you and your son or daughter when you need it?

4.

3 What are some of the great things about your son or daughter? 5.

6.

Adapted from *Personal Futures Planning* (Mount) and *Parent Assessment of Needs* (Chen, Friedman, Calvello) (or R.C.E.B. and H.R.C. by Alien, Shea & Associates; revised 4/92).

Notes and Tips

1. All three of the interview formats have been written in accessible

Families of Young Children

language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.

2. The focus person of the interview.
3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.
4. This will help you get a picture of someone's circle of support.
5. This is an opportunity to set the positive tone for this interview.
6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second.

It's suggested that you use this interview format (*Families of Young Children*) for children under 5 years of age. For families of very young children, especially those who are very new to the service system or for

Families of Young Children

**HOW TO GET THERE FROM HERE!
Families of Young Children**

What kinds of things does your child do on his or her own or with your support? at home? around town? for fun?

7.

5 **What new things would you like your child to learn to do on his or her own or with your support? at home? around town? for fun?**

8.

6 **What makes your son or daughter happy?**

9.

7 **What makes your son or daughter mad or sad or frustrated?**

10.

whom major life crises are occurring, this may not seem to be appropriate. As counselors, you know the families that you work with the best and can make a decision as to when such an interview would be helpful.

7. This is a chance to find out a little more about a child's and family's community boundaries.

Families of Young Children

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.
10. This can help clarify *barriers* in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Families of Young Children

HOW TO GET THERE FROM HERE!

8 What activities do you or other family members like to do with your son or daughter?

11.

9 Are there some things that your child could do to make a difference in your family life?

12.

10 Are there questions or concerns that you have that haven't been answered?

13.

What scares you or other family members the most—right now, and in the future for your son or daughter?

12 What kinds of support does your son or daughter, and your family need?

14.

13 Who can help support you? How?

14 Who helped work on this? 15.

- 11. We're still focusing on preferences and strengths, which will help people think positively about the future.
- 12. Now the interview starts to focus both on planning for the future and thinking about things that will help right now.

Families of Young Children

13. This is a time to find out what worries families about the future. This is very important to know when you're working with persons who are about ready to make a major life change (like from home to preschool).

14. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.

Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

15. Who helped provide the information for this interview.

Families of Young Children

Name of Person:	<i>Harbor Regional Center Brinaina It All Together!</i>	UCI Number:
Moving towards the future, what do you hope will happen next for your son or daughter?	What kinds of support will you need from:	
	Family, friends and community	Support service agencies
16.	17.	
How will you know if your plan has worked? 18.		

16. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.
17. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.
18. Asking families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has a different criteria for success and it's important to find out what that is early on in the planning process.

Families of Young Children

HOW TO GET THERE FROM HERE!
Other Notes

<input type="checkbox"/>	
--------------------------	--

<input type="checkbox"/>	
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<input type="checkbox"/>	
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Notes and Tips
This page can be used as an insert for your additional notes on any one item during the inter

Families of Students

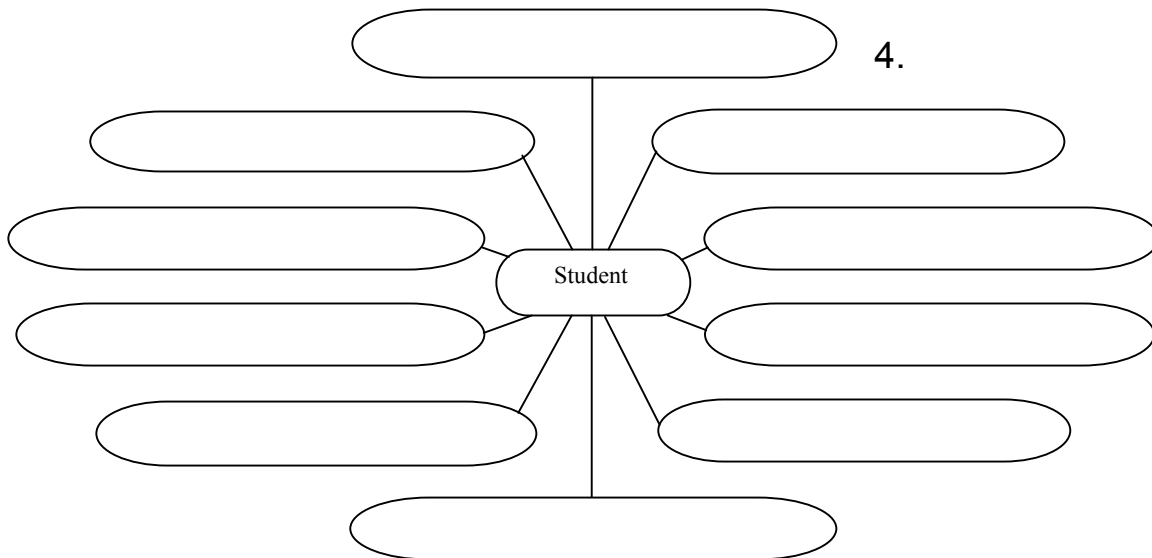
HOW TO GET THERE FROM HERE!

1. **Families of Students**

What's this all about? This is a chance for students with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary*. However, we think that you'll find it useful as well as fun!

- 1 Who is this about? 2. 3.

2 Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?



- 3 What are some of the *great things* about you? 5.
- 6.

Families of Students

Notes and Tips

1. All three of the interview formats have been written in accessible language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.
2. The focus person of the interview.
3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.
4. This will help you get a picture of someone's circle of support.
5. This is an opportunity to set the positive tone for this interview.
6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second.

It's suggested that you use this interview format (*Families of Students*) for children and young adults who are school students.

Families of Students

HOW TO GET THERE FROM HERE!

4 What things do you like to do? at home? around town? for fun?

7.

5 What new things would you like to learn how to do? at home? around town? for fun?

8.

6 What makes you happy?

9

7 What makes you mad or sad or frustrated?

10.

7. This is a chance to find out a little more about someone's community boundaries, likes and dislikes and could help in looking at places to live and work. You might also ask how people get where they go and who goes with them.

If you feel that someone has trouble talking in a group or that it will add to your information base, consider interviewing him/her apart from family, friends or other professionals.

Families of Students

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.
10. This can help clarify *barriers* in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Families of Students

HOW TO GET THERE FROM HERE! At School

8

What new things have you learned at school in the last year?

11.

9

What new things would you like to learn at school?

10

If you're learning about work, what jobs have you had?

12.

11

If you're learning about work, what jobs would you like to try?

12

What's the best part about your Individual Education Plan and your school for you?

13.

13

What could be better about your Individual Education Plan and your school for you?

Families of Students

11. These questions will help you continue building to dreams and hopes for the future. They will also give everyone ideas about future goals and objectives for the Individual Education Plan (IEP). Offer to provide a copy of your notes on this interview to whomever is interested with permission from the person you're interviewing.
12. These two questions could give you some leads about current and future employment preferences, goals and objectives.
13. These two questions can provide a basis for support of the education plan as well as prompts regarding potential areas for educational advocacy.

Families of Students

HOW TO GET THERE FROM HERE!
Looking Ahead

14 What are your dreams and hopes for the future?

14.

15 What scares you the most about your future?

15.

16 What do you see yourself doing in 3-5 years?

16.

17 What support would you need to get there?

17.

18 Who can help you with that support? How?

18.

19 Who helped work on this?

19.

Chapter 4

- 14. What would be the best future? There are no right or wrong answers! You may need to remind people that everything is possible and that this is a chance to dream about what could be!
- 15. This is a time to find out what worries people with disabilities and their families and friends about the future. This is very important to

Families of Students

know when you're working with persons who are about ready to make a major life change (like moving out of their family home).

16. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.
17. Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

You may need to remind people that everything is possible and that this is a chance to dream about what could be! Let this part of the interview go as long as you can! It will provide everyone with a lot of ideas about the future and about what they might just do right now!

18. This helps reinforce everyone working together as a team when support is needed.

If you're working with a circle of support, you might want to suggest that you all get together again soon to start moving towards the best possible future.

19. Who helped provide the information for this interview.

Families of Students

20	Name of Person	<i>Harbor Regional Center Bringing It All Together!</i>	UCI Number
Moving towards your plan for the future, what do you hope will happen next?	What kinds of support will you need from		
	Family, friends and community	Support service agencies	
20.		21.	
How will you know if your plan has worked?			
22.			

20. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.
21. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.
22. Asking people with disabilities and their families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has a different criteria for success and it's important to find out what that is early on in the planning process.

Families of Students

HOW TO GET THERE FROM HERE!

Other Notes

This page can be used as an insert for your additional notes on any one item during the interview.

Families of Students

HOW TO GET THERE FROM HERE! Things About How You Live and Would Like to Live

<p>How do you live now?</p> <p>Alone? <input type="checkbox"/></p> <p>With a roommate? <input type="checkbox"/></p> <p>With your parents? <input type="checkbox"/></p> <p>With other relatives? <input type="checkbox"/></p> <p>In a group home? <input type="checkbox"/></p> <p>Other? <input type="checkbox"/></p>	<p>What do you see as the best <i>things</i> about where you live right now?</p>
<p>What do you see as the <i>biggest</i> challenges of where you live right now</p>	<p>All things possible, where would you like to live and with whom?</p>
<p>Are you living where you want to live and with whom you want to live?</p> <p>If you're living where you want to live for now, please go to question #19.</p>	<p>What kinds of support do you need where you live right now?</p>

This page can be used as insert for individuals who are school-aged and living in other than the home of their parents. These questions will help you to continue building dreams and hopes for the future. They will also give everyone ideas about support needs for living and new options to explore.

Families of Students

**HOW TO GET THERE FROM HERE!
Looking Forward to Your Next Transition**

The questions on these two pages are designed to help you bring together your thoughts about a transition strategy for your son and daughter and some first steps to take towards realizing the *best possible future* after that transition. Remember, this is your plan and it may not be the plan that your son or daughter has in mind so you need to have a family discussion about it as soon as you can. This strategy planning process is built on the following values: 1) all things are possible with the right types of support; 2) support can come from all parts of the community, e.g., parents, family, friends, community services; 3) given lead time, support services can adapt to individual preferences or new support service options can be created; and, 4) most important, that we won't know how to plan for the future unless we ask people with disabilities and their families what it will look like.

4 What kinds of support do you think your son or daughter and family would need to make that transition a smooth one?

1 Who is this about?

2 What's the next transition for your son or daughter and family?

3 All things possible, what would life look like for your son or daughter after that transition?

5 What worries you the most about that next transition?

6 What are some first steps that you could take to start moving your son or daughter and family towards that next transition?

Families of Students

This is a two-page focus interview on transition which can be used as an insert for families of young children and families of students or when talking to adults who will be experiencing some sort of transition within the next year. The transition might be from school to school, from home to home, from school to adult services and so on. It really helps focus activities and information on things that will help make for a smooth transition for everyone involved.

Looking at Adult Life

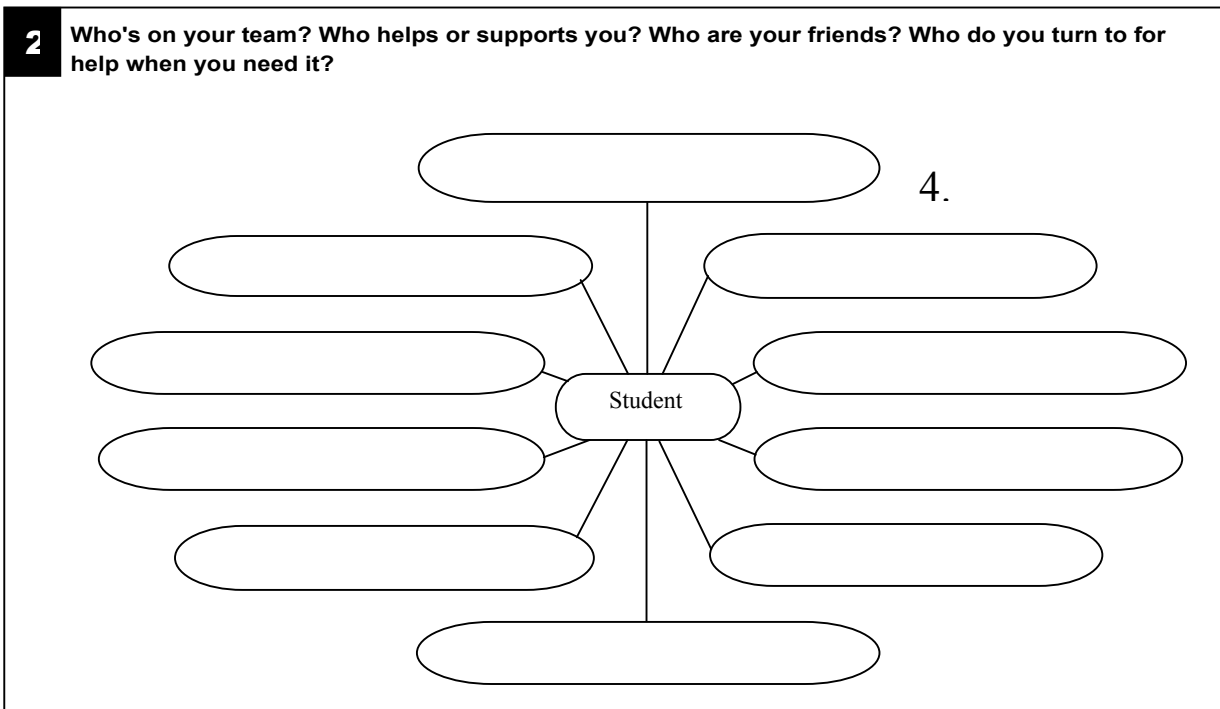
HOW TO GET THERE FROM HERE!

1. Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary*. However, we think that you'll find it useful as well as fun!

1 Who is this about? 2

3.



3 What are some *great things* about you?

5.

6

Adapted from *Personal Futures Planning* (Mount) for R.C.E.B. and H.R.C. by Alien, Shea & Associates; revised 4/92.

Notes and Tips

1. All three of the interview formats have been written in accessible

Looking at Adult Life

language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.

2. The focus person of the interview.
3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.
4. This will help you get a picture of someone's circle of support.
5. This is an opportunity to set the positive tone for this interview.
6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second. It's suggested that you use this interview format (*Looking at Adult Life*) for anyone who is no longer a student.

Looking at Adult Life

HOW TO GET THERE FROM HERE!

4 What things do you like to do? around town? at home? for fun?

7.

5 What new things would you like to do? around town? at home? for fun?

8.

6 What makes you happy?

9

7 What makes you mad or sad or frustrated?

10.

7. This is a chance to find out a little more about someone's community boundaries, likes and dislikes and could help in looking at places to live and work. You might also ask how people get where they go and who goes with them.

If you feel that someone has trouble talking in a group or that it will add to your information base, consider interviewing him/her apart from family, friends or other professionals.

Looking at Adult Life

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.
10. This can help clarify barriers in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Looking at Adult Life

HOW TO GET THERE FROM HERE!
About Work

9 **If you're not working right now, what do you do during the day?**

12.

9 **If you're interested in working, what jobs have you had?**

If you're not interested in working, please turn to the page called *Things About How You Live and Would Like to Live*. If you're already working, please go to question #12.

10 **If you're interested in working, what kinds of jobs interest you?**

11 **Do you need support in getting a job?**

Are you looking for your first job? Yes No

Does it take you a long time to learn a job? Yes No

Do you get social security benefits? Yes No

Do you need support in things like using money or getting to work? Yes No

If you answered yes to any of these questions, you could probably use some support in getting and keeping a job.

Already Working, How's Your Job?

Is it the kind of job you like? Yes No

Are the hours and days okay? Yes No

Do you get the support you need? Yes No

Does the pay cover your bills? Yes No

Do you get benefits? Yes No

How do you get along with people at work?

great
 okay
 not very well

13. When you think about your job (check the one that shows how you feel most of the time)

Are you glad you got it?
 It's okay that you got it
 You're sorry that you got it

Looking at Adult Life

11. These questions will help you continue building dreams and hopes for the future. They will also give everyone ideas about support needs for working and new options to explore.

Offer to provide a copy of your notes on this interview to whomever is interested, with permission from the person you're interviewing.

12. These two questions could give you some leads about supported employment options.
13. If you get some **no** answers, this information could be used to facilitate employment advocacy.

Looking at Adult Life

HOW TO GET THERE FROM HERE! Things About How You Live and Would Like to Live

<div style="background-color: black; color: white; padding: 2px;">13</div> <p>How do you live now?</p> <p style="text-align: center; margin-top: 20px;">14.</p>	<div style="background-color: black; color: white; padding: 2px;">14</div> <p>What do you see as the <i>best things</i> about where you live right now?</p> <p style="text-align: center; margin-top: 20px;">15.</p>
<div style="background-color: black; color: white; padding: 2px;">15</div> <p>What do you see as the <i>biggest challenges</i> of where you live right now?</p>	<div style="background-color: black; color: white; padding: 2px;">16</div> <p>What kinds of support do you need where you live right now?</p>
<div style="background-color: black; color: white; padding: 2px;">17</div> <p>Are you living where you want to live and with whom you want to live?</p> <p style="margin-top: 20px;">If you're living where you want to live for now, please go to question #19.</p>	<div style="background-color: black; color: white; padding: 2px;">18</div> <p>All things possible, where would you like to live and with whom?</p>

14. These questions will help you continue building to dreams and hopes for the future. They will also give everyone ideas about support needs for living and new options to explore.

15. This page is also available with no interview question numbers. In this way, it can be used as an insert for individuals who are school-aged and living in other than the home of their parents.

Looking at Adult Life

HOW TO GET THERE FROM HERE! Looking Ahead

19

What are your dreams and hopes for the future?

16.

20

What scares you the most about your future?

17.

16. What would be the best future? There are no right or wrong answers!

You may need to remind people that everything is possible and that this is a chance to dream about what could be!

Looking at Adult Life

17. This is a time to find out what worries people with disabilities and their families and friends about the future. This is very important to know when you're working with persons who are about ready to make a major life change (like moving out of their family home).

HOW TO GET THERE FROM HERE! Looking Ahead

21 What do you see yourself doing in 3-5 years?

18.

22 What support would you need to get there?

19.

23 Who can help you with that support? How?

20.

24 Who worked on this plan?

21.

Looking at Adult Life

18. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.
19. Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

You may need to remind people that everything is possible and that this is a chance to dream about what could be! Let this part of the interview go as long as you can! It will provide everyone with a lot of ideas about the future and about what they might just do right now!

20. This helps reinforce everyone working together as a team when support is needed.

If you're working with a circle of support, you might want to suggest that you all get together again soon to start moving towards the best possible future.

21. Who helped provide the information for this interview.

Looking at Adult Life

25	Name of Person	Harbor Regional Center Bringing It All Together!	UCI Number
Moving towards your plan for the future, what do you hope will happen next?		What kinds of support will you need from	
		Family, friends and community	Support service agencies
22.		23.	
How will you know if your plan has worked? <div style="text-align: center;">24.</div>			

22. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.

Looking at Adult Life

23. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.
24. Asking people with disabilities and their families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has different criteria for success and it's important to find out what that is early on in the planning process.

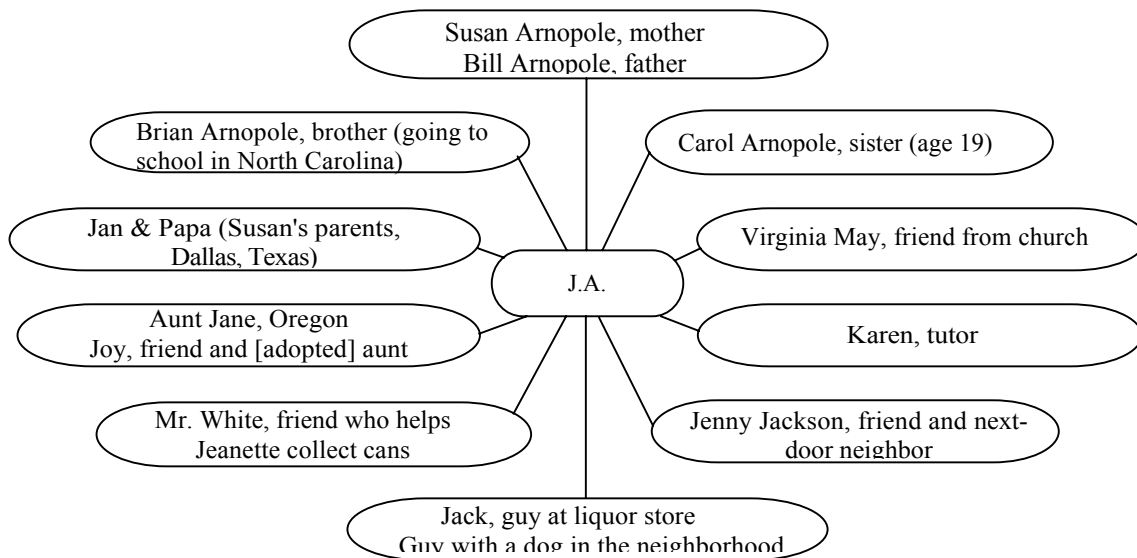
A Sample Interview

HOW TO GET THERE FROM HERE! Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary*. However, we think that you'll find it useful as well as fun!

1 Whose plan is this? *Jeanette Arnopole, age 22*

2 Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?



1 What are some great things about you? *Jeanette mentioned things she does, but not characteristics of her personality. Others, including parents, shared the following observations:*

- Outgoing
- Almost always happy
- Plans ahead/likes to schedule things
- Hard worker
- Very independent
- Concern for others/animals
- Makes people feel comfortable
- Good with John, a neighbor's child (e.g., organized Easter Egg Hunt)

- Honest
- Dependable—If Rebecca says she will do something, she will follow through
- Brave (taken airplane trips on own; learned buses)
- Plans activities
- Talks things through till comfortable
- Thoughtful (e.g., gifts, cards for friends)

A Sample Interview

HOW TO GET THERE FROM HERE! Things About You

4

What things do you like to do? around town? at home? for fun?

Jeanette said:

Crush cans to make money (and later it was learned that this relaxes neck muscles and relieves tension)
Going for walk with dog in neighborhood

Others said:

Going out to eat
Talking with people
Talking with pets, and taking care of them (sister mentioned chasing bird in the bathroom, and getting it back in its cage)

Making pizza and other items
Games, such as parcheesi, Hearts, Jenga
Planning parties and giving them
Holidays (decorating, shopping, etc.)
Using coupons and shopping for groceries

5

What new things would you like to do? around town? at home? for fun?

Jeanette said:

A job, such as handing out coupons at a store

Others said:

Learn how to type/use computer
Doing crafts with sister
Helping at Humane Society as volunteer (this is in the works, currently)

6

What makes you happy?

Jeanette said:

Parties
Listening to music

Others said:

See old friends, etc.
Going out to eat
Jan, Papa, Brian coming to visit
Walking to store on own
Planning trips, parties, etc.

7

What makes you mad or sad or frustrated?

Jeanette said: Sometimes angry with sister
Dad telling her to be quiet, if he's watching TV

Others said: Sometimes loses cool Brother and sister doing things that she cannot do
Seeing a dog in neighborhood chained and not being petted

The family dog (Toby) died When treated like a child
If people say she is 'little'
If things are not ready on time; if people are late
If change is unanticipated, or not scheduled, or not announced
If she doesn't understand directions
If she really wants to do something, and it is interrupted

A Sample Interview

HOW TO GET THERE FROM HERE!

About Work

8

If you're not working right now, what do you do during the day?

Jeanette said:

Crushing cans (about \$8 per week)

Others said:

Takes up offerings at church
Folds bulletins for Lutheran Church (pastor lives up the street)

9

If you're interested in working, what jobs have you had?

Jeanette said: See #8, above

Others said: See #8, above. Red Cross (volunteer couple of hours per week: rolling pennies; tidying paper; labels; ink stamps); Humane Society (volunteer couple hours per week: feeding, groom-ing, etc.); Convalescent Hospital (quit; couldn't understand what was wanted; staff not helping enough); Eden Express in San Pedro (dishes, ironing, folding napkins, etc.); JTPA/ROP job at Vet's Hospital (swept, napkins, towels, aprons, etc.; didn't like yard work); Work experience job (addressing at Special Services); Dollar Saver (delivering papers; stuffing envelopes); and, Pet Store (volunteer work: too confusing; too many different types of birds and of birdseed that needed to be matched, etc.)

10

If you're interested in working, what kinds of jobs interest you?

Jeanette said:

Animal care (feeding, watering, grooming, cleaning cages)

Others said:

In general, Jeanette likes working around people and animals, and her mother feels that Jeanette is best if there are breaks interspersed with more focused work.
Being a greeter at a party
Restaurant work is probably out (doesn't like it)
Messenger (e.g., delivering mail between offices in a complex)

11

Do you need support in getting a job?

Are you looking for your first job? Yes
Does it take you a long time to learn a job? Yes
Do you get social security benefits? Yes
Do you need support in things like using money or getting to work? No

Others said: Making change is sometimes difficult. Jeanette did well rolling pennies and didn't need close supervision. There was a discussion about whether supervisors/co-workers provide accurate, candid feedback as to their experience with Jeanette as a worker/volunteer. Julie, at ARC-Long Beach, is said to see a need for a lot of supervision. Others, including Jeanette's tutor, don't see it this way. Perhaps different supervisors report different things to family and Julie.

12

Already Working, How's Your Job?

Is it the kind of job you like? Yes
Are the hours and days okay? Yes
Do you get the support you need? Yes
Does the pay cover your bills? Yes
Do you get benefits? Yes

How do you get along with people at work?

great okay not very well

No When you think about your job (check the one that
 No shows how you feel most of the time)

Are you glad you got it?
 It's okay that you got it
 You're sorry that you got it

A Sample Interview

HOW TO GET THERE FROM HERE! Things About How You Live and Would Like to Live

13

How do you live now?

Alone?
With a roommate?
With your parents?
With other relatives?
In a group home? Other?

14

What do you see as the best things about where you live right now?

Jeanette said:
Having a tutor to do things with

15

What do you see as the biggest challenges of where you live right now?

Jeanette said:
Cleaning up the house (shares vacuuming, dusting, and other responsibilities with sister)

16

What kinds of support do you need where you live right now?

Others said:
Jeanette is fine at home, without anyone around for substantial periods of time, and can keep herself appropriately occupied. If away for a few days, mother suggests having friend over, and would not be comfortable with either daughter being home alone.

17

Are you living where you want to live and with whom you want to live?

Jeanette said:
Would like to live somewhere else, with a roommate
Doesn't know who or how Would like to live with one or two other people

If you're living where you want to live for now, please go to question #19.

18

All things possible, where would you like to live and with whom?

Jeanette said: A place that is 'affordable'
Jeanette has friend Lee Ann, who stayed over and was 'bossy' and 'nosey'⁵

Others said:
Close to friends/family

A Sample Interview

HOW TO GET THERE FROM HERE! Looking Ahead

19

What are your dreams and hopes for the future?

Jeanette said: Not sure

20

What scares you the most about your future?

Jeanette said:

She can take her own meds (oral, 2x per day)

Others said:

Sister fears that if Jeanette is not more independent, she could come live with her but would likely be disgruntled

Jeanette may fear loss of health/function (e.g., some possible progressive hearing loss, etc.) Jeanette is probably fearful of not having enough money for food, etc., if she moves away from home

A Sample Interview

HOW TO GET THERE FROM HERE! Looking Ahead

21

What do you see yourself doing in 3-5 years?

Jeanette said:

Getting a job

Leaving home

Others said:

These are the two things Jeanette talks about often

22

What support would you need to get there?

Jeanette said:

Need help from Julie at ARC-Alameda County in finding and learning a job

Regarding living on own, I need help cooking (e.g., using the oven, etc.) and how would I shop for groceries? Jeanette can shop for groceries, but would need getting groceries home. There was discussion of getting a cart, and living near a grocery store where there are curb cuts.

Others said:

Is there any way to get information and work with others to help find and develop a job for Jeanette?

Others asked Jeanette if she would need help (training/assistance) in changing sheets, getting oriented to use of public transit, getting to the doctor's office for appointments, going to places not on bus routes, doing own laundry, keeping her place clean? In many of these areas, she may need prompts or assistance.

23

Who can help you with that support? How?

Carol will look into getting Jeanette a cart to haul groceries from the store.

Susan and Karen can help by asking supervisors: "What can Jeanette work on to improve her job performance?" and asking people to be candid.

Family/friends will see about putting marks on oven dial, so that Jeanette can use oven properly. Susan would like information on conservatorship. Carolyn is seeking information/support on special needs trust, and has had person from Los Angeles

(Estate Planning for the Disabled) out to talk about it. John Shea was asked, and agreed to share results of meeting with Julie at ABC-Long Beach, because (a)

there may be ways to collaborate, and (b) some of the ideas/information shared might be useful to Julie.

Looking at alternative living arrangements was identified as a likely area of interest.

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Who worked on this plan?

Susan Arnopole, mother; Carol Arnopole, sister (age 19); Virginia May, friend from church; Joy, friend and (adopted) aunt; Jenny Jackson, friend and next-door neighbor; and Karen, tutor.

Sample Plans

25	Name of Person: Jeanette Arnopole	Harbor Regional Center Bringing It All Together!	UCI Number:
Moving towards the future, what are some first steps that you could take over the next six months to a year?		What kinds of support will you need from:	
		Family, friends and community	Support service agencies
<p><i>For fun:</i></p> <ul style="list-style-type: none"> • Start a crafts project with sister • Learn how to type and use a computer <p><i>For Work:</i> Get a job</p> <p><i>For living:</i></p> <ul style="list-style-type: none"> • Look at different types of places to live • Learn more about living on my own or with others <p><i>For the future:</i> My parents want to learn more about special needs trusts</p>		<ul style="list-style-type: none"> • Go to the hobby store with my sister to see what kind of craft might be interesting • Look at the adult education catalog to see if there are any interesting hobby or craft classes we could take together • Make an appointment at the computer center in Santa Monica • Ask Karen to go with me to try out a computer and if I'm interested in it to see what computer would be best for me • If I can't get a job right away, I'll keep volunteering at the church • Mom can help me apply to be a volunteer at the Humane Society • Ask my sister, mom and dad or Jenny to look at different types of places to live with me • Work on a plan at home with my parents to learn more about things like cooking and shopping for groceries 	<ul style="list-style-type: none"> • Talk with ARC/Long Beach about supported employment • See if they can help me find a job that's about working around people and animals • Ask the regional center for names of people and places I could look at that would give me an idea of what's out there • Ask the regional center for support in learning more about living skills that will help me be more independent, like grocery shopping and cooking • Ask ARC/Long Beach for information about special needs trusts
<p>How will you know if your plan for the next year has worked?</p> <ul style="list-style-type: none"> • I'll be working and doing more things for fun and with my sister 			

Sample Plans

25	Name of Person: John Thompson	Harbor Regional Center Bringing It All Together!	UCI Number:
Moving towards the future, what are some first steps that you could take over the next six months to a year?		What kinds of support will you need from:	
		Family, friends and community	Support service agencies
<ul style="list-style-type: none"> • I'll get a job • I'll be able to buy things for myself at the store 		<ul style="list-style-type: none"> • My dad's got a friend who works at the Marriott who might be able to help me find a job • Mom and dad can help make sure I get to work • My parents can take me to the store • My day program can give me more chances to buy things in the community 	<ul style="list-style-type: none"> • Help in interviewing for a job • Help in learning how to do the job • Help in learning how to get to and from work • Norm can assist me by calling the Department of Rehabilitation and talking to my dad about possible jobs at the Marriott • Learn how to use money at my day program
How will you know if your plan for the next year has worked? <ul style="list-style-type: none"> • I'll be working Monday through Friday and making \$600 a month • I'll be able to take some of my money and buy clothes and a television 			

Sample Plans

25	Name of Person: Jessica Holmes	Harbor Regional Center Bringing It All Together!	UCI Number:
Moving towards the future, what are some first steps that you could take over the next six months to a year?		What kinds of support will you need from:	
		Family, friends and community	Support service agencies
<ul style="list-style-type: none"> • An after-school program • Behavior will improve 		<ul style="list-style-type: none"> • Help from other parents to advocate for an after-school program • Cooperation from schools and child care operators to start a program • Go to a parenting class at the community college 	<ul style="list-style-type: none"> • Advocacy from the regional center • Flexibility in using respite hours in a different way • Respite agency willing to work with a day care center to provide training and supervision • Regional center can provide respite to support our efforts at home • Regional center could provide some extra respite while we attend the college class • Regional center could provide behavior assistance to support what we learn in the class
How will you know if your plan for the next year has worked? <ul style="list-style-type: none"> • We'll have an after-school program that Jessica can go to and I'll feel safe • Her behavior will improve 			

Circles of Support

INTRODUCTION

One of the outcomes of person-centered planning can be a circle of people who are interested in making a positive difference for and with a particular person. This group consists of the focal person and might include neighbors, friends, extended family, employers, service providers, regional center counselors, as well as any other interested persons.

CIRCLES OF SUPPORT

Although regional center counselors will not likely be active members of circles of support (most people feel that you can only fully participate in 1-2 circles), people with disabilities and their families will want more information on how to start and keep a circle going.

What are Circles-of-Support?

Around each person are people who live, work, or play with that person. Some are close relatives; some are neighbors and friends; some are paid service providers. These people—loosely or tightly, formally or informally—constitute what some call a circle-of-support. Others use the term personal team, circle-of-friends, Joshua Committee, or a similar name.

How do Circles come into existence?

There is no one way. Some individuals—because of personality, verbal skills, vulnerability, the efforts of others (e.g., parents), or for yet other reasons—have larger numbers than others of close family members and friends constructively involved in their lives.

Circles of Support

Some Circles—of widely varying sizes and degrees of organization—are put together by the individual, family, or friends, simply because of shared interests, mutual commitments and caring, and the joy of being aligned with each other. Other Circles, especially if the center of attention (often called the focus person) is a youth or adult with severe disabilities, are consciously created in an organized way.

These latter Circles may evolve from a process called personal futures planning—that is, a process known by a variety of names, in which a group of people agree to come together at least once or twice (1) to learn more about the individual and the people in that person's life; (2) to listen to that person's hopes and dreams for the future; and (3) to see what support each person may want to offer to move the focus person in the direction of a 'desired future.'

A personal team seeks to develop community connections, to invent and experiment with novel courses of action, and to stand by the person as any close friend would do. The essence of person-centered planning is having the person with a disability (along with family and friends) create a vision of a desired future, identify the support needed to get there, and determine what steps to take, here and now, in pursuit of that desired future.

Some tips on organizing and nurturing a circle-of-support:

1. Interview the focus person (and family, friends), and get names, addresses, the telephone numbers of people to invite (e.g., parents, siblings, other family, friends, neighbors, teachers or therapists, pastor, physician, etc.). Note: If the purpose of developing a circle-of-support is clear (e.g., helping the person decide where to live and with whom), be sure to invite people who can make a difference.

Circles of Support

2. Set convenient time and place for initial meeting. (This should be the focus person's home or other comfortable, non-agency place.) Suggest that the focus person (or family) prepare or bring cookies, cheese and wine, or whatever.
3. Send a letter inviting people to come to an initial meeting. (See Figure A, for sample letter of invitation to first meeting.) The person with a disability may wish to follow-up by telephone.

Figure A

Friends of Bonnie Jean McLaughlin
 c/o John Shea
 1571 McKinley Road
 Napa, CA 94558
 (707) 255-5871

May 15, 1991

Bill and Gretchen Oertel
 1234 Lawrence Napa, CA
 94559

Dear Friends of Bonnie Jean:

Bonnie Jean has asked me to invite you to her house, 3912 Stover Street, on Monday, June 3rd, at 7:30 pm. You will be joined by several of her other friends, and family, to talk about how we can all support Bonnie. This will be a chance (1) to share with Bonnie the things that make her a friend; (2) to learn what she wants to do (and become) in the future; and (3) to 'brain-storm' how she can move toward her goals. The meeting should last for about two hours.

Bonnie Jean has asked me to help her get a circle-of-support started. No one is under any obligation to offer anything (e.g., advice, assistance, an occasional telephone call). We simply ask that everyone agree to come back at least once to see how Bonnie Jean is doing.

If you have any questions, please feel free to call me, or Bonnie Jean, or her mom and dad.
 Hope to see you soon!

Cordially,

John Shea

4. Typical ground rules are (1) to ask people to come to first and at least one follow-up meeting; (2) no one should feel obligated to offer support (advice, information, personal assistance, etc.); and (3) keep it light and have fun.

Circles of Support

5. A facilitator should be recruited in advance, have an easel, flip-chart, marking pens, and be good at writing things down and keeping the conversation moving along. Note: If possible, someone other than a parent should do this, so that it is a community (rather than an exclusively family) affair.
6. After introductions, you can agree on additional ground rules, which might include:
 - Take turns.
 - Listen to one another, and probe only to clarify.
 - Be respectful of each other's ideas and information.
 - Keep all things [or certain things] in the room.
 - If you say you will do something, follow through.
 - Support one another.
7. Go through a set of questions that will provide information and direction for the future. Ask the focus person first. Then, family. Then, friends. Note what people say. Move to next question. Summarize consensus, and wrap-up with three or four 'bottom-line' questions.
8. Set date (and time) for follow-up meeting (say, in 4 weeks), write up what was learned, vision of what is wanted, steps to get there, and what people offered to do. Send out . . . , perhaps with second letter.

Circles of Support

Some lessons learned

The following factors are often critical or very important in maintaining a personal team, constructively involved in supporting the person:

1. *Communication*—One person agrees to write up the results of get-togethers, and to send out notices of upcoming get-togethers.
2. *Trust*, trying to respond to what the person wants, and consensus—Teams which listen carefully to the focus person and each other, who respect each person's views, and who base offers of assistance on what the person wants or on what the group perceives as in the person's 'best interests,' do best.
3. *Facilitation*—Someone may need to facilitate meetings, keeping track of time, identifying issues and offers of assistance, and seeing that each person has an opportunity to contribute.
4. *Having fun*—Teams whose members enjoy each other and have fun together, often stay together longer, and are eager to continue to be involved with the focus person within the context of a circle-of-support.

Circles of Support

5. *There is no single, best way*—One needs to be adaptable and responsive to the needs and desires of the focus person. One person may not like (or do well) with large, formal get-togethers. If so, try strictly social meetings. One person may wish to keep friends at some distance from one another; let this person direct the group. One person may want a full-blown personal futures plan; another may have a more limited need (e.g., to access disabled and non-disabled peers at school). The circle and its processes should reflect these differences.

STORIES

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This story, by Phylinda Clark and Connie Saverino, describes the experiences of two people moving out of skilled nursing facilities into their own apartments. They talk about some of the difficulties faced by each and the importance of "planning" in person-centered planning.

2. Rock Bottom and In The Corner.....Page 6
Andre Shaw, of Sacramento Vocational Services, sent in this story about the experiences of Jake. Jake once ran with a tough crowd and the story tells how he pulled his life together to gain independence.

3. Doing It On Her OwnPage 8
The story of Joanne was sent in by Nikki Seid of Sacramento Vocational Services. Joanne found her own apartment and supports with the help of her family, who initially did not support her choice to move out on her own.

4. Matt Knows.....Page 10
Scott Donant tells the story of Matt who, through person-centered planning, moved into his own place. This story is an example of how a person who seemingly did not communicate choice, got his point across loud and clear.

5. Making My Own DecisionsPage 12
Orange Redmond shares his experiences planning for his future through supported living.

6. Chairs Are Overrated Page 13

This story, by Diane Turnball at Sacramento Vocational Services, describes Karen and how her circle of support works.

7. It's Just Like Christmas: Making Dreams Come True Through Person-Centered Planning.....Page 15

Christine Dixon, Mary Ellen Sousa and Deborah Tweit-Hull from San Diego outline how one person-centered planning process changed the life of Chris. The process is described as ever changing and requires commitment by all people involved. They stress that the process is individualized and "never looks the same twice".

8. Two Ways To Describe Mary And Two Ways To Provide Services For MaryPage 33

Margaret Kane, of Regional Center of the East Bay, contrasts two ways of providing service--the traditional way and the person-centered way. Examples of what each might look like are also provided.

9. Lauren's StoryPage 35

Susan Ferrell, from Redding, tells "Lauren's Story". This is a story of how Lauren made the sometimes difficult transition from school to adult life. Susan tells the story from a parent's perspective, relating how she became involved in the person-centered planning process as a response to her daughter's needs.

PLANNING: A ROSE BY ANY OTHER NAME

by Phylinda Clark, Connie Saverino

Although Hazel and Dick are neighbors, they barely know each other. Their apartments are a block apart. Age, race, culture, and personalities would suggest that they were different. At first glance they would appear to be a study in contrasts. We met them in much the same way, in similar places - Skilled Nursing Facilities (SNFs). Although they came because of different circumstances, both were placed in SNF as a result of having no one to fight for them.

Over the years, Hazel and Dick have learned a great deal about fighting for themselves. We often wonder what is most important about these two; what they learned or what they have taught? They have taught us about the elusive and unpredictable qualities of person-centered planning. Dick and Hazel are into reality, and their reality has taught us that planning is really hard work. Sometimes it pays off, even when the planning doesn't go as well as we'd hope. It can be textbook, picture-perfect and be worthless.

Dick, age 44, had been in the geriatric skilled nursing home for over 22 years. Planning for Dick met with obstacles. He had friends, fellow patients that he would miss. Plans to continue relationships were met with refusal by staff. Dick would be able to visit them, but they could not visit him. The staff concentrated on readiness skills that Dick had yet to master; they tried getting rid of his guilt, but Dick was a kind and sensitive guy who didn't want to hurt anyone. His actual planning and mapping meeting turned into a three-ringed circus by SNF staff. The social worker looked at the drawings on butcher-paper from felt-tipped markers, and said "this is a very nice guy". In a video, that was taken during a party, she's seen patting Dick's friend on the back to reassure him "no one is coming to rip you away". It was difficult to elicit cooperation, even with the most basic preparations for Dick's move. The

process of finding a roommate and finding a place went quickly, perhaps too quickly. When the "match" between Dick and his first roommate didn't materialize; and the apartment's bathroom wasn't made more accessible to wheelchairs, Dick remained optimistic. Soon we were back to the drawing board, but instead of finding a roommate - two roommates materialized, that are now Dick's closest friends. We located another apartment that was large, roomy, and with only minor alterations to the width of the bathroom door, it became accessible to wheelchairs. To look at, Dick's busy life - filled with friends, hobbies, and outside activities— one would not know that the initial planning for this long awaited move to the community fell through. It all went the way we hoped it would.

Hazel too was anxious to move from a skilled nursing facility. After her mother's death, her supports had slowly fizzled away. We provided support for Hazel for a year, while she lived in a facility. This put us in a position to become acquainted with her, and evaluate what her needs would be once she placed in her own apartment. The recruitment of finding a roommate hit every road block imaginable in spite of picture-perfect planning. When one was found, within days it would fall through, these things would happen even before an apartment search was underway. Cindy came, a roommate for Hazel; the road began to look smooth. We made acquisitions for an electric wheelchair to improve Hazel's mobility. It didn't fit. Hazel didn't want to start over, she was exasperated with the process. Cindy and Hazel got along famously. Hazel was getting out of the apartment, got involved in her church, she took classes in the local recreation center for seniors, and was on the advisory committee at the agency.

Over the next few months events began to occur that gave concern about longevity of this living arrangement. Cindy began to complain of back pain. Hazel's care grew more demanding as her health began to deteriorate. Cindy became engaged; planning gone awry! We were committed to Hazel, so we pieced things together. Cindy transferred to

another job within the agency but lived with Hazel until a roommate could be found. This process was lengthy. Hazel was specific about her personal needs and the qualifications and characteristics her roommate must possess. During all this Hazel's health got worse; she had to be hospitalized. Because she was now had to be placed on a catheter and a oxygen tank, a home nurse was assigned to come in weekly. Still supports were not in place. We continued to have regular, daytime support during the week, but sleep over support was rotated. There was no one to share expenses with Hazel, now that she had no roommate. The agency had to pay the rent. Hazel made a living will, in it she stipulated that no life support, even the ventilator that the doctor had recommended, was to be used. Meeting and planning sessions took a grim turn. Since Hazel was adamant about remaining in her own place, we were committed to helping. Her struggles continue, a fair hearing for additional needs is pending. Never have we planned so much. Planning, listening, and making commitments are all good, but doesn't guarantee anything.

What we do know about planning with people around their own unique capacities and needs is that nothing that makes sense will ever happen. It is elusive and unpredictable because it reflects the hopes and needs of real people; people like Hazel and Dick.

ROCK BOTTOM AND IN THE CORNER

by Andre Shaw, Sacramento Vocational Services

Jake was born with Cerebral Palsy (CP). The CP, however, was only one strike in a life that almost struck out. He had enough money set aside to take care of him for the rest of his life. He had other plans. He was an angry man with a hankering for a rough crowd; a biker crowd. Even though in a wheelchair, he rode a motorcycle (with the assistance of his "friends"). After his recovery from a crash, Jake rented a house. He was "taken care of by the same "friends". "Taking care" of Jake consisted of pumping him full of drugs, stealing his money, and neglecting to feed or dress him. When Jake was rescued by the State, he was found in the corner of the house with no clothes on, and flat broke. With the help of his county conservator, he was able to slowly piece together his shattered life.

After seven years of strict supervision and little control of his life, Jake and his conservator agreed it was time to take another big step forward. He chose and began to receive Supported Living Services, the heart of which is person-centered planning. This gave him the opportunity to begin making choices in a monitored environment. His long-termed goal was to become un-conserved and independent. With the help of his circle of support, in the context of developing a Personal Futures Plan, he talked about his problem with drugs and his bad choice of friends. He talked about his desire to exhibit his artwork. Also, he would like to tutor other disabled adults on how to use communication devices and electric wheelchairs.

He has thought about living in his own apartment; he knows the exact apartment complex he wants to live in, and who he wants to be his roommate. Jake is now seeking help in collecting furniture and utensils. His plans are to attend the community college. In his Individual Support

Plan (a vision-based planning tool), he has made clear the need for adaptations to aid him in his apartment. Jake also knows that if he blows it, the opportunity to live on his own and gain independence, may not come around for a long time.

Jake has a long way to go, but he has begun the journey. With the supports available to him and backed by the belief of his friends, it will be a journey that Jake will accomplish.

DOING IT ON HER OWN

by Nikki Seid, Sacramento Vocational Services

Joanne was living in a skilled nursing facility and was miserable with the living conditions. She felt she had no freedom and little control of her life. Her friends couldn't visit whenever they wanted; they were even asked to leave a few times. Joanne realized that there had to be a better way to live. Her parents wanted to keep her in the nursing home because they knew she would get the care she needed. They may have felt that they were helping her, but they actually were holding her back and making her very unhappy.

Joanne was introduced to Community Supported Living Arrangements (CSLA) and it seemed like a way out. She knew that this was the solution to her misery. She was on the CSLA list and hoped her number would come up soon. Her parents were totally against the idea, and threatened to take her to court to become her conservators. It was hard but Joanne had to go against her own parent's wishes and think of herself first.

Joanne realized that she could get her own apartment, and began thinking about what she needed to do. She talked to friends about roommates and aides; she found them to be a great deal of support. When she began looking for apartments, her parents realized that she was serious. They decided that they were not going to stand in the way of her happiness, and began to support Joanne. The pieces of Joanne's life were now starting to pull together.

Things got so bad with her living arrangements, Joanne decided she would not wait for CSLA. She and her roommate found an apartment and began setting up a thorough system to make the move successful. Her parents even helped to furnish the apartment. They were very impressed with how well planned things were. Joanne knew that one mistake would turn her parents against the whole idea.

Now, Joanne lives in her own apartment. She has hired three aides, and gets support from her roommate. She made some difficult decisions in order to take control of her life. She is now very confident and also proud of her accomplishments. Joanne attends the local community college and wants to share her success story with preschoolers. A person is not limited because of their physical disabilities, and anything can be accomplished if you try hard enough.

MATT KNOWS

by Scott Donant

I first met Matt a little over two years ago. It was at a Interdisciplinary Team meeting, at the Intermediate Care Facility (ICF) that he was living in. He stayed to himself. Matt didn't care about what was going on in the meeting or who I was. He just wanted to spend some time with his dad. After about five minutes of sitting in the meeting, he got up and left. He was the smart one.

The Recreational Therapist did not know what to do, Matt was not interested in playing any games; the Speech Therapist did not know what to do, he did not want to communicate; nor did the ICF staff, because he kept trying to escape. It took about ten minutes before I realized what they meant by "he went for walks whenever he wanted to". The ICF board described Matt as stubborn, lazy, bull-headed, and wanting to do only what he wanted to do. Matt thought of these as pretty admirable qualities.

During the next two years, I heard stories about Matt escaping. One time, he took the lock off the gate, went out of it, and then re-locked it. The staff's concern was that he had left but I was amazed at how creative Matt was. What else was Matt capable of and not showing us?

Matt perceived me as being the person that got him out of ICF meetings. Whenever I arrived, Matt would immediately grab me by the hand and drag me out the front door. If I had to talk to someone else, it would have to get postponed. Once we got outside the door, he would never be specific about what he wanted to do; but it was clear that he didn't want to be there. When our time had ended, Matt didn't want to get out of the car. It seemed as if I had to drag him back inside. The ICF staff often commented that it was obvious I was important to Matt. I was the only person, outside his family, that he was excited to see.

Through the use of person-centered planning, Matt has a completely different life. He did not verbally indicate what his desires were, but to his circle of support, it was clearly obvious what Matt did not want. Instead of trying to plug Matt into available services that were not always appropriate, we started to look for services for what we thought he wanted. Sometimes we were right, but if not, Matt would let us know.

Things are different for Matt now. Matt is living in his own home, he rents with two other people. When he first moved in, staff was concerned that he might leave without letting someone know. We considered putting alarms and bells on the doors, but later decided not to. In the last nine months, Matt has not left his house without taking someone else with him. It appears that he likes where he lives. He no longer pulls me out the door; he pulls me over the threshold of his new home. Unfortunately for me, Matt does not think I am special anymore, there are many people in his life that are special to him now.

MAKING MY OWN DECISIONS

by Orange Redmond

Living at United Cerebral Palsy, 105th Street, wasn't as easy or fun as it is now. I couldn't make any choices, about the food I ate, the places I would go, or how late I stayed up. I didn't have my own money, to pay rent or spend the way I wanted to.

Now, through Supported Living Program, I am involved in planning my own future. I have the freedom to my own decisions about my life. My friends and I have the freedom to do what we want. My life is better because I'm independent and in control of my life.

CHAIRS ARE OVERRATED

by Diane Turnball, Sacramento Vocational Services

Karen has been living in her own apartment for three months now. Prior to that time, she had lived in a Skilled Nursing Facility for approximately 15 years. While she was there she lost contact with her family, became more isolated, and consequently, began to exhibit more "behavior problems". Because Karen communicates mainly through eye contact and moaning, it was difficult for staff at the nursing facility to take the time necessary to figure out what she needed. As a result, she began to slap herself and scream when she needed something. This was clearly "inappropriate behavior", and the people at the nursing facility felt they could no longer serve her. Fortunately, through an innovative independent living program, Karen was given the opportunity to move into her own apartment, with a 24-hour support staff.

Now, Karen always has someone to "talk" to when she needs them and take care of her personal care needs as they happen. She is slowly becoming confident in her support people, and the care they gave her. Karen is much more successful at communicating her needs; through eye contact and positive response. As part of living in her own apartment, her staff conducts a house meeting twice a week. The first couple of weeks, they tried to sit around the table for meetings, but Karen chose not to participate, choosing to retire to her room.

The third week of the house meeting, the staff tried something new. They all sat around on the floor and talked about how things were going. Karen loved the idea that they were all sitting together on the floor. The staff *talked* to Karen, and she enjoyed being the center of attention.

At her first Circle Meeting, in her new apartment, Karen's sister came to take part in the planning process. They had not seen each other in eight years. Cindy, Karen' sister, said she could not bring herself to visit Karen

in the nursing home (because Karen was so unhappy there). It was a beautiful reunion, Karen smiled from ear to ear. Once all the members of the meeting were together, they all sat in the floor of the living room. Karen greeted each person, and the meeting started. It went a little long for Karen and she left to spend more time in her room listening to music. But, the important thing was that she did join the group, and felt like a part of it. Her staff anticipates that the more comfortable she gets with the support gatherings, the more likely she will be to participate in the planning process.

Things may not ever be perfect for Karen. She still gets frustrated when her staff don't understand her, and at times resorts to her old behavior. What's different is that the people consider her preferences, in facilitating her success in her new apartment and her new life. As a result, Karen is more confident and much happier.

"IT'S JUST LIKE CHRISTMAS": MAKING DREAMS COME TRUE THROUGH PERSON-CENTERED PLANNING

Christine Dixon, Mary Ellen Sousa & Deborah Tweit-Hull

Author's Note:

The following story was written for several reasons. Perhaps most importantly, we feel it's critical to take time out to celebrate the "victories" that touch all of us. Secondly, our collective struggles create a need to try to make sense out of the sometimes frustrating maze known as "the system." (In other words, writing this story was therapeutic for the authors!) Thirdly, we believe that sharing stories with others helps us to better understand and continue the work, which enables all of us to fulfill the basic dream of a real home. One final, but important note: Chris is clearly the "star" of this story. True we have formed a partnership and friendship, but without Chris' shared courage and sense of justice, we would still be at the proverbial "Square One." We're still learning, as writers, how to capture Chris' thoughts on paper using her exact words. We struggle with the reality that people who use labor-intensive communication systems learn quickly to speak very succinctly to facilitate conversations. This same skill, however, can make it difficult for the reader to follow the story.

With all of that said, we dedicate this piece to all the dreamers who are willing to do whatever it takes to make those dreams come true.

The Journey Begins

When we met for the first time, forty-six year old Chris was lying in a bed at a local hospital. Too weak to use her communication board, she gazed up to indicate "yes" and down for "no". She appeared frail, having lost more than twenty pounds from her normally petite frame. Extended hospitalization is difficult for anyone, but it becomes even more so when

one has significant cerebral palsy and relies on alternate forms of communication that hospital staff frequently misunderstand.

Approaching her one-month "anniversary" of being admitted via the hospital emergency room, Chris had already endured numerous invasive and frightening medical procedures and a discharge date was nowhere in sight.

We learned that Chris had lived with her family until she was forty-four years old. Following her father's passing and mother's subsequent health problems, Chris had no other choice but to move to a group home to obtain the support she needed.

Chris' understanding of the realities of her situation didn't help her "adjust" to group home living. She expressed this frustration, as well as her continuing grief over loss of her father, through her behavior.

Prior to her sudden hospitalization, Chris had spoken to Tom, her case manager/social worker, about her unhappiness; she wanted to move from the group home. But Chris was scared to make a change and fear of the unknown ran high. She lost her temper frequently and became frustrated easily. Chris and Tom worked out a plan. With Chris' permission, Tom referred her for Regional Center's CSLA "supported living" services. Bureaucracy being slow by definition, months elapsed. Then, Chris was hospitalized. Finally, we were "officially" invited to the hospital to meet Chris.

“Who is this Mary Ellen, anyway?!?” Chris thought to herself.

Our young agency, Creative Support Alternatives, assists people who have disabilities to live in homes of their choosing, secure employment, and establish a valued presence in their neighborhoods and communities.

Pretty basic stuff, really. Definitely not rocket science, as they say. But for people with disabilities and their families who have been surrounded—and sometimes consumed—by "special" services and programs, what we

do can sound somewhat unorthodox. And sometimes scary. So, as we met Chris for that very first time, we were struck by her quiet and gutsy determination.

"I thought I would go back to the group home, anyway. I did not think it would happen. But I was wrong."

We relied on a type of "Twenty Questions" to communicate, with Chris using her eye gaze to respond to yes/no questions. Tom was in the hospital room along with Chris' mother, brother, group home worker, the Regional Center nurse consultant, and of course, Chris. Due to a hospital-acquired infection, Chris was in isolation and we were all required to wear surgical gowns and masks.

Meeting us, two strangers with faces hidden by hospital garb, Chris was assertive despite her obvious pain and discomfort. She wanted to move out of the group home and she wanted our help to do it. (We couldn't help but feel honored. Chris had, in one short meeting, impressed the hell out of us. This was one persistent individual). And the irony didn't escape us; because of a newly implanted gastrostomy tube, Chris couldn't return to the group home even if she had **wanted** to...the home wasn't "licensed" to provide the type of assistance that Chris now required. Yet, she could move to her own (unlicensed) place!

Making Plans

We have learned that "Person-Centered Planning" doesn't—and shouldn't—look the same twice. More than just a different type of meeting, person-centered planning is a continually evolving process because that's what constitutes **life**. In other words, when the process is over, so is life. We know it to be a process of building trust, communication, commitment, and relationships. Person-centered planning represents opportunities to plan together, tackle challenges

head-on, celebrate triumphs, and re-group when necessary. Person-centered planning puts the individual in control, and others supporting versus supplanting that control. On that first day with Chris, we embarked on the journey together.

Over the next month, we visited with Chris at the hospital three or four times each week. We thought of ourselves as "running interference" between Chris and the hospital staff. At every opportunity, we modeled what we were learning about how to communicate with Chris. We explained her yes/no response. We tried to protect her from the day-to-day, unintentional insults that often characterize hospital life. We participated in physical therapy sessions. We assured the nurses that Chris was very much interested in communicating with them. And Chris continued to amaze us with her determined approach to regain what she had lost because of her illness.

We began to piece together a sort of composite picture of what Chris thought she wanted in her new living situation: one or two female housemates, a San Diego location, nearby stores and services and bus line access. We learned a lot about each other. We learned that there is absolutely no replacement for spending time together. Chris shared her fears with us:

"I did not know where I was going to live. I was scared".

Our continuing reliance on Twenty Questions sometimes proved frustrating. We felt uncomfortable knowing Chris' yes/no eye gaze response limited her only to choices we presented to her. She was restricted by our ability to creatively—and consistently—think of the "right" questions to ask. We continued to talk with Tom and Chris' family, asking questions about Chris' preference, experiences, important relationships, anything we could think of. We met with the group home service provider. She seemed genuinely interested in Chris.

She offered lots of practical information about Chris' routines, mealtime support techniques, and the difficulties Chris had with group home "adjustment." (To us, these "adjustment" difficulties served to further confirm her tenacity and sense of self).

Getting Down to Specifics

Together, we devised a housemate flyer: "I'm looking for a person who would like to: share a home (San Diego area, exact location flexible); make a friend (I'm 47, female, enjoy meeting people and going places); earn some money (I use a wheelchair and communication system—I need some help at home and other places, pay negotiable!) Interested? Call Creative Support Alternatives at _____ and they'll connect us!"

Chris chose bright red paper. We began putting the flyers up in several neighborhoods that met Chris' qualifications. Sometimes, we were forced to make what we called "educated guesses." For example, growing up in Chula Vista, Chris was unfamiliar with most of San Diego, yet because she was hospitalized we couldn't tour neighborhoods together. We talked to her about specific neighborhoods, looked at maps, shared insights...and listened. We put an ad in the Reader, a San Diego newspaper with a somewhat "alternative" slant. (The Reader ads also utilized a voice-mail message system, enabling us to explain beyond the actual print ad what Chris was looking for).

We also placed an ad in the San Diego Union-Tribune. The ad read: San Diego Area: Lkg. for F. to jointly rent apt./house, I use a wheelchair, nd. some assistance, pay negotiable. Lv msg. at _____. (The high cost of the ad forced us to be succinct!)

One day, while talking with Chris in her hospital room, she kept glancing at the shelf near her bed. After a few attempts, we understood: she wanted to try to use her communication board again. With her health improving, Chris had the strength to use her board. With a pen as her

"pointer", she slowly spelled out words. After nearly two months of "Twenty Questions", Chris excitedly talked □ via the communication board—for 1 ½ hours! Following the conversation, we said good-bye to an exhausted, but satisfied, Chris. Our spirits soared.

"It was great!! I could express myself!"

Chris' doctor let all of us know she was getting better. The physical therapists continued to help her gain strength and exercise her weakened arms and legs. We pushed the nurses to re-introduce foods to Chris. The doctor's orders said she could begin to try eating again, but the nurses were afraid that Chris would choke easily because of her strong tongue thrust. And their fast-paced schedules didn't allow much time for assisting Chris with eating. We began bringing in yogurt, ice-cream, anything Chris wanted to try (provided it was fattening—she had twenty pounds to gain!) We too were somewhat nervous about helping Chris to eat. Still, we made a point of letting the hospital staff see how we assisted Chris. We shared what we learned and dubbed it "subversive in-service training" for the staff.

Chris' sense of humor and wit increasingly came through via her communication board. The "Discharge Planner" informed us of the hospital's plans to transfer Chris to a county-run rehabilitation hospital (an old geriatric facility, really).

We gently tried to break the news to Chris. We feared that the transfer and additional weeks or months of institutional life would cause Chris' depression to return. After listening to us ramble on for several minutes, Chris used her communication board to interrupt. She had heard the Discharge Planner talking to some of her nurses. "It's a dump!," she said with a smile. So much for breaking it to her gently. (We learned that Chris had a friend who had lived at the facility for 23 years and she was quite familiar with it).

"I thought I might have to stay there. I thought they might keep me there."

Being There

Chris' fierce independence continued to unfold. In her group home, this strength came to be viewed as a behavior problem. In fact, Chris' Individual Program Plan (IPP) contained the following goal:

Chris will communicate her needs appropriately without tantrums by reducing tantrums to one or fewer per month.

Medication had been prescribed by a psychiatrist to decrease her anger and frustration. Everyone knew, however, that the medication merely addressed the symptoms, which Chris' real needs (i.e., a longing for control over her life and living situation) went unfulfilled.

On the day that Chris was transferred to the county facility, we met her at the door as she was taken out of the ambulance and wheeled in. We had promised her that we would be there.

"I was scared. I was glad you were there."

Our mission was clear: make sure the facility staff understood that Chris was there for physical therapy and rehabilitation purposes—in other words, this was a **short-term** admission. It was incredibly important to Chris that this be understood. Within moments, facility staff were taking charge, physically examining Chris, talking about her as if she didn't understand them, asking simultaneous questions without yet learning how she communicated. We had the sense of watching a movie and not being a part of what was happening. We tried to stay close to Chris, answering questions, assuring the staff that Chris was *only* going to be with them for a little while.

Chris' mom and a long-time family friend arrived to visit. We used the opportunity to chat, adding their comments and insights to the ever-

evolving picture of Chris. Facility staff kept coming in and out of the room, asking questions, signing forms. We found ourselves answering the same questions repeatedly. When it was finally time to go, everyone was exhausted. We were frustrated and tired. This was going to be more difficult than we thought.

On the third day after Chris' admission to the facility, we stopped by near dinnertime. A nurse's aide told me Chris would have to eat in her room because "the way she eats upsets the other patients." We flipped...and firmly told the aide that, "Chris eats the best way she can and if anybody has a problem with that, then *they* could eat in *their* room." We stayed through dinner, and it was never mentioned again.

Housemates and Houses

Weeks passed as we helped to screen potential housemates responding to Chris' flyers and ads. If the person calling sounded like she met the criteria set forth by Chris, we arranged to meet her. Generally, we would meet at a coffeehouse or restaurant. During these initial conversations, we shared things we had learned about Chris, what she was interested in, and the types of assistance she needed.

We listened—often between the lines—to learn everything we could about the potential housemate.

We avoided meeting in offices or other "official"-looking places, striving for relaxed and informal conversations. If, at the end of the conversation, the prospective housemate expressed a continuing interest and we felt comfortable with pursuing it further, we helped to set up a meeting with Chris.

Chris' health continued to improve. She made friends with the physical therapists and worked hard to regain her strength. It was tough and demanding work for her. She also resumed her employment program.

While we had mixed feelings about this because of the segregated nature of the program, we knew that the Chris' spirits would be lifted by seeing her old friends. We also knew that the agency was in the process of converting its service delivery to integrated, community employment.

Tom continued to be a helpful and supportive guide. He shared information on resources, advocated for services for Chris, and encouraged all of us by recognizing and reinforcing the progress being made. In turn, we made an extra effort to let Tom know just how much we appreciated him. His presence helped to personalize a large bureaucracy and make it more "user-friendly." We spent a lot of time together with Chris: going out to eat, supporting her involvement in the annual Self-Advocacy Conference, visiting with her family, meeting potential housemates, talking with the staff who worked at her employment program. Spending time together helped us to build a solid foundation for what we hoped would become a long-term relationship with Chris.

We tried to avoid an "us/them" attitude with the facility. Several people at the facility had, in fact, become quite supportive of Chris and her plans to move. Still, others there pushed the limits of our patience by their adherence to facility procedures and policies that made no sense for Chris. We forged ahead anyway, with Chris' sense of humor getting us over the rough spots.

After a number of meetings and conversations, Chris selected a housemate. Unfortunately, the housemate's family personal problems necessitated her backing out several weeks after the decision had been made. While we fretted over this setback, Chris had this to say,

"It's a part of life...it's OK."

We smiled at her philosophical approach and resumed conversations with potential housemates. We were learning a lot from Chris.

Two weeks later, Chris was introduced to another woman who captured her interest. She was a few years older than Chris, with her own business and an Old English Sheepdog. We talked at length about our approach: helping Chris to establish a living situation and housemate relationship based on equality and mutual interest, while identifying her support needs/schedules, what the housemate would like to do in terms of support, available compensation, etc. Simultaneously, we tried to keep the facility staff informed of our progress.

While a seemingly simple task, we were overwhelmed by the facility's inability to comprehend our efforts. We marveled at the collective ineffectiveness of having *too many* professionals. It appeared that they operated in total isolation from one another, even though they all worked at the same facility. The result was a frustrating web of rules and procedures, phone calls and requirements, none of which seemed to have any relevance to Chris or her plans.

In spite of those difficulties, we dove into the time consuming task of identifying an affordable apartment or house that met the requirements set forth by Chris and the prospective housemate. It became apparent that the prospective housemate was a busy woman, with more time commitments than we had initially believed. Still, we thought it would simply be necessary to involve additional supports to accommodate Chris' needs at home.

We used the Union-Tribune and Reader again, this time for available housing. We also tapped into personal connections and put the word out about what we were searching for. We realized one of the most difficult "requirements" was finding a landlord that would allow a friendly and personable Old English Sheepdog!

Finally, we located two strong housing possibilities. We arranged for Chris to see them and called the new housemate so that she might do the same. We were devastated when she informed us that her current living

situation had become unbearable. The previous night, she had made hurried plans and was moving in with a family she had met. The arrangement was cheap and relatively permanent. Chris had just lost housemate #2 and hadn't even moved yet! We wondered how long this was going to take.

"I wondered if it would work out. I thought I still might have to go back to the group home."

We re-grouped again and tried to keep our spirits up. We continued spending time with Chris and kept her family and staff from her employment program updated. They, in turn, encouraged us. They also provided much-needed emotional support for Chris during moments of self-doubt.

There were days when Chris seriously questioned her ability to make it "on her own." We thought it was a healthy and positive sign that Chris was sharing her fears, rather than turning them inward and becoming depressed or angry. We tried to be supportive, sharing our own stories of transitions: changing jobs, leaving home for the first time, moving cross-country.

Unfortunately, Chris later realized that she had made a mistake when she shared her fears with the facility's social worker. Rather than provide emotional support (as one would do for a friend who was questioning her ability to succeed in a new situation) the social worker told Chris that perhaps she really *wasn't* ready to be on her own.

The facility social worker had neither experience with, nor understanding of, supported living. She told other facility staff that Chris was not sure she wanted to move and, therefore, in need of "counseling".

We were furious with the facility social worker's response to Chris. We reasoned that if Chris didn't have what we considered to be very natural concerns over her impending move, we would have wondered if she fully

understood what we were trying to do. And, once again, Tom stepped in with a rational approach. He talked to Chris. He talked to a "neutral person" Chris trusted at her employment program. He asked questions and listened thoughtfully between the lines. And finally, he let us know that he felt confident Chris wanted to move into her own place and needed support to *believe* she could do it.

"I was sure. But I could not go back. I had to go on."

Meeting Mickey

While Chris wondered if she could really make it on her own, we wondered how long it would take to get things in place. We continued the housemate search, this time also looking under ads placed in the "roommates" section, rather than placing an ad. We thought it was somewhat of a long-shot: finding a person who wanted a housemate, who might also like to provide some assistance/support **and** had a reasonably accessible apartment or house.

We left messages with five different people who had placed ads. Of those five, we talked with a woman named Mickey. She sounded interesting and we liked her ad: "Clairmont Area, off I-5, near beach. Quiet college student seeks non-transient housemate. 2BR, 2BA. Laundry, Pool, Call _____."

After a brief phone conversation, we arranged to meet at her apartment. The irony of our "connecting" made us all feel fate was at work. Mickey was living in the same apartment complex where another woman we knew lived. That woman, who utilized the supported living services of another local agency, also had cerebral palsy and used an Epson communicator. Further, we had looked at the same apartment complex two weeks earlier—actually, the apartment right next door to Mickey's—as a possibility for Chris and prospective housemate #2.

The apartment was conveniently located near stores, banks, the bus line, a bowling alley, and even a nightclub called the "Volcano Club" (complete with two life-size dinosaurs perched on the roof!). Chris also had a long-time family friend whose name was, you guessed it, "Mikki." If it wasn't fate at work, perhaps it was at least a good sign! We liked Mickey and thought she met a lot of Chris' preferences.

We met with Chris again and arranged a time to meet with Mickey. We shared what we had learned about Mickey, the apartment, and the neighborhood. Chris anticipated the meeting with reserved excitement.

Several days later, we arrived at Mickey's apartment. She was friendly, a serious student pursuing a new career in animal health. She had a colorful past and her dry sense of humor reminded us of Chris. We talked about what Chris was looking for, as well as what Mickey hoped to find. As the conversation headed towards an end, we suggested that both women think it over and we'd touch base the following day. Mickey said that wasn't necessary from her point of view, she wanted to live with Chris! (Secretly, we were ecstatic. We liked her and thought she'd be a great housemate). Still, we sensed hesitation in Chris.

Via her Epon, Chris said,

"Go for it"

...but then slowly added,

"I'm not sure."

We feared that Chris' self-doubt was returning. But, at the same time, we didn't want to push her into anything. We agreed to talk again with Mickey on the following day. As we drove Chris back to the facility (we always joked that we'd never refer to it as "home"!) we talked about Mickey and the conversation we had just had. We tried to point out important aspects for Chris to think about, such as, compatibility, bus access, the neighborhood.

We dropped Chris off, leaving with a sense of uneasiness. We wondered if Chris would choose Mickey. And if she didn't, would it be because of Mickey, or simply her overall fears of being on her own?

We went to see Chris the following day at the facility. We chatted about a number of things until we couldn't stand it anymore and finally blurted out, "Well??" Chris was not-so-secretly enjoying keeping us in suspense. She then smiled and spelled out the following:

"Let's go for it."

"Are you sure? What *exactly* are you saying?", we asked. Chris' response confirmed that she did, indeed, want to go forward with Mickey. We were excited at the prospect of things moving ahead. To ourselves, we hoped it would all work out for Chris. We were optimistic, but we had been let down twice before.

We proceeded with plans: talking with Mickey and Chris, meeting with Chris' family, relying on Tom for negotiating funding and paperwork details. We joked about Chris' room having a view...of a Tyrannosaurus Rex! We continued to be buoyed by Chris' gusty determination. With the decision finally made and a move-in date set for two weeks away, Chris seemed genuinely happy.

The Final Days

Meanwhile, we learned that the facility had held what they referred to as a team conference. Chris was not invited, nor was Tom or anyone from our supported living agency. Still, the "team" had decided that Chris was not ready to leave and needed to stay at the facility for another month.

Once again, we felt we were watching a movie unfold which we had no control over. We still tried not to adopt an "us/them" attitude, but knew we felt that way in spite of it all. We could hardly believe that they were

making decisions, which greatly affected Chris without her input.

At issue was Chris' weight and gastrostomy tube. We met again with Tom and the nurse consultant from the Regional Center. Their support proved invaluable to Chris, as well as those of us trying to assist her. We reluctantly postponed the move-in for one week.

While we were committed to supporting Chris with or without the gastrostomy tube in place, the facility wanted her to gain more weight. We wanted her to be discharged with the physician's approval versus AMA ("against medical advice"). According to the staff, she had lost two pounds since the supplemental gastrostomy tube feedings were discontinued a week earlier. Chris did her part by eating full meals and snacks three times per day, even when she wasn't really hungry. And we continued planning with Mickey and Chris for the move.

A week passed. Our relationship with the facility social worker and physician became increasingly strained. We resolved to get Chris out of the facility by the targeted date anyway. Simultaneously, we were gathering up Chris' belongings from storage at her mother's house.

Together with Mickey, we helped Chris to set up her new room; we organized the closet and hung pictures on the wall. We looked forward to the Big Move with increasing excitement.

Two days before Chris was to move, we spent nearly five hours on the telephone advocating on her behalf. We were amazed at how many professionals - some who had barely met Chris!—wanted us to "jump through hoops" before officially discharging Chris. We were frustrated because facilities are not designed, sensitive to such issues as the planning and timing involved with a move (e.g., Chris was paying rent and had support people lined up...and waiting).

Finally, the big day arrived. We arrived at the facility. The physician discharged her with the stipulation that Chris be followed up by a to-be-

determined community physician. We had already lined up a home health agency to monitor our support for Chris' gastrostomy tube. We loaded up the car, said good-bye to some of the folks ("residents"), Chris had come to know, filled her prescriptions, and drove away.

We all sighed with relief. It had been a stressful week.

Home Sweet Home

Together with Mickey and Chris, we finished setting up Chris' room. By the time we finished, it was after 10:00 p.m. We helped Chris into bed and pulled the blankets up over her. She was exhausted, but as we said good-night she broke into a huge smile that clearly said, "we did it".

Chris' move was actually the beginning, rather than the end, of the story. We know that every life had many endings and many beginnings. Chris and Mickey have lived together for nearly two months now. They are developing a terrific relationship. Her gastrostomy tube has been removed and the scar has healed. She has gained over ten pounds and, according to her brother, looks healthier than she ever has before.

With our support, Chris has joined a self-advocacy group and is on the steering committee for the annual self advocacy conference. She is attending the monthly Regional Center Board of Directors meetings and has applied for a seat on the Board. Plans for getting a job and taking a community college class are in-the-works. Her relationships with her family members have deepened, along with her new self-confidence. She's meeting her neighbors at the apartment complex and making new friends. Chris has a new life and has taught us many things.

We look forward to continuing the journey together. When asked what it was like to finally have her own place, Chris said, "It's just like Christmas."

Chris

Hello. My name is Chris. I am really happy to be here today. I am going to share some things with you about my living situations. And then, if you like, you can ask me any questions.

I grew up in a home with my mom, dad, my brother Tim and a day-time housekeeper. (A real wholesome Andersons-type family like the one from "Father Knows Best.") After high school Tim moved out on his own. I continued living with my mother and father.

In March of 1989, my mother had a stroke. She continued to live at home but needed assistance with daily living. She lost her speech. (Though, I am happy to say, as time went by, she regained it.)

In October of 1989, my father got ill and passed away. Then I just lived with my mom. Due to my mother's stroke, she needed assistance with living, which made it difficult for her to take care of my needs, too.

I had to leave my home though not by my choice. I was placed into a group home. It was a very uncomfortable situation. I was so used to my lifestyle, with my biological family and my home.

And there I was, living with a houseful of strangers with a whole new set of rules. I was afraid. The way my needs were being met, the expectation of my abilities, my privacy, and the personalities of the people in my home were all different. It was a very rough time. As time passed, I became more accustomed to the routine and adjusted. It was my first taste of being on my own (or so I thought).

Still, I was having a hard time. I was frustrated and very unhappy. I know the people at the group home cared about me. But I felt like I was being worked to death...lots of goals and plans and such. They even had a "class" to teach me how to drink...that made me feel bad. I just wanted a home of my own.

In late 1992, my case manager, Tom, referred me for supported living services (CSLA funding). I was scared but wanted to make a change. But in early February 1993, I became very ill and was hospitalized for 2 1/2 months. I lost 25 pounds and a lot of my strength was gone. I couldn't even use my old communication board. After recovering from my illness, I had to be placed in a nursing home because of medical reasons (with another whole set of rules). Again, this was not by choice. I was afraid when I first went there. Again, I became accustomed. Overall the people there were nice. They really took good care of me, but I knew I didn't want to spend my life there. It was a very old place with lots of old people and it made me sad.

Then a very special person came into my life, Mary Ellen. She reassured me that I wouldn't have to spend my life there. She helped me with the opportunity to live in my own apartment with a roommate. I chose the person that I wanted to live with, we made the rules together, I can go wherever I want, whenever I want. (I can use the elevator to get to my apartment on the third floor by myself!) I eat what I want, when I want. I do my own shopping and banking, and I have my privacy when I want it. I enjoy old movie classics on cable. I have fun with my roommate Mickey's pets -- Pinto, Shakespeare, Aldo, and occasionally, "rescued orphans." I should add something here. I've been on my own for nearly six months. I'm starting community college part-time in late January. I went to visit the people at the group home for the first time last month. It was neat to see that they are proud of me. I'm also getting involved in self-advocacy meetings. And I have interviewed for a seat on the San Diego Regional Center's Board of Directors. I have lots of plans and lots to do.

TWO WAYS TO DESCRIBE MARY AND TWO WAYS TO PROVIDE SERVICES FOR MARY

Margaret Kane

The Traditional Way:

Mary is a 34 year old woman with a diagnosis of moderate mental retardation with moderate neurological deficits, depression and congenital hemiatrophy. Mary has a history of a) "behavioral outbursts" (i.e. yelling, screaming, cursing, self abuse, and threats of physical aggression) occurring at a rate of at least once per month; and b) bossing and threatening peers (in the group home and community) occurring at a rate of 5 times per month. The behaviors identified above can lead to AWOL behavior and/or "physically intrusive behavior" (i.e., hitting, scratching (self and others) and throwing objects). Mary also has a history of crying and screaming several times per day and several hours at night. Mary has tantrumming behavior as well (throwing herself on her bed and throwing objects in her room). The tantrumming occurs at least daily. Mary is on both Mellaril and Klonopin.

Mary tends to move from group home to group home either because she can no longer tolerate the staff and peers, or because neither the group home staff or peers can tolerate her. Mary has also moved from sheltered workshop to sheltered workshop, these moves have been generated by both being demitted for "behavioral outbursts" and by moving out of the area.

Key to Mary's success will be concerted effort to reduce her "behavioral outbursts". Mary will benefit from living in a group home with a staffing ration of 1:3 or possibly 1:2, and with the implementation of a behavioral plan designed to reduce her "outbursts".

Mary will also benefit from working at a day program with a similar staffing ratio, and with a behavioral component. Stabilizing Mary's environment will hopefully create more independence for Mary and will eventually expand her options in the future. A service plan will be developed to reflect Mary's needs.

The Person Centered Way:

I am Mary. I can't remember how old I am. I like people and I like to help people. I want to help handicapped children. I want them to feel loved and not be so lonely. I want a volunteer job at Children's Hospital. I want to live in my own apartment. I don't want to live in a group home all of my life. I am not a baby and I feel bad when I am treated like a baby.

I want to go out whenever I want to and I want to sing in the Church Choir. I don't want to work in a workshop because they make too much noise and everyone is always yelling. I sometimes do bad things and say bad things. I don't want to do that. I should be treated like an adult and not like a baby. I need to learn how to take care of myself. I want to learn how to cook. I want to learn how to wash my own clothes.

Key to Mary's wishes is the opportunity to live much more independently than she currently lives. Mary will be assessed for Independent Living and will either receive ILS Training or will be referred to Supported Living. Possibilities for a volunteer position at either a Hospital or a Child Development Program, with natural supports, will be explored and secured. Supported Work possibilities will be explored and secured. Hopefully, as Mary's wish for independence is encouraged and enhanced, Mary will experience a reduction in her frustration level, and she will be less hampered by "doing and saying 'bad things'". A service plan will be developed to reflect Mary's wishes.

LAUREN'S STORY

Susan Ferrell

At age 22, Lauren faced a major life change. She would no longer be eligible to attend the County Office of Education Special Education program at Shasta College. This was a totally integrated, individualized program in which Lauren worked in the cafeteria and in the laundry, took adaptive physical education and cooking classes, rode the public bus to go on shopping outings and ate lunch with her friends in the college cafeteria. These activities sound fairly run-of-the-mill but, given the extent of Lauren's handicaps, it was anything but ordinary for Lauren to be participating in so many "normal" activities.

Lauren was brain damaged at birth. She has a diagnosis of spastic diplegia (cerebral palsy with no functional use of her legs), severe mental retardation (the last formal test she had put her mental quotient at 18 months) and epilepsy, which is totally controlled with medication three times daily. She does not speak except to say, "hi!, all done, and mom". She appears to have the receptive vocabulary of a 2-3 year old. She is not toilet trained, and she needs assistance with all daily living functions. She is in a manual wheelchair which, when motivated, she can move from point A to point B.

Lauren is also a real charmer. She has a wonderful sense of humor and an infectious laugh. She has a strong sense of self-worth, and she likes being in situations where she can be in control. She has learned over the years how to manipulate people and situations to get her way, and she has learned ways of communicating her basic needs to her care providers.

I am Lauren's mother. Her step-father and I saw a lot of positive changes in Lauren in the two years that she participated in the Shasta College program, and we were anxious for her to continue to grow and develop in the new adult day program that she would be attending. We had par-

anticipated in (in fact, initiated) transition planning meetings with staff of the adult day program with the hopes that her new program could replicate to some degree the community-based model that Lauren would be leaving behind.

Unfortunately, after six months of meetings, phone calls, notes, observations, anger, frustration and tears, it was obvious that Lauren had taken, from our perspective, a giant step backward. She was in a center-based program and only got out into the community for short outings two times a week. She had no job assignment, and her days were filled with activities such as current events discussions and bead stringing. The heartbreaking aspect of this to me was knowing that this was all that Lauren's future would hold.

This was not a transition program or a temporary assignment that was a "filler" before the next exciting opportunity came along. This was the only program in town for low functioning adults, so it appeared that Lauren's future would be a succession of useless strings of beads and non-verbal discussion groups.

It was about this time that I met Ann Turnbull of the Beach Center for Families and Disabilities at the University of Kansas. She spoke at a conference that I attended about how she and her husband and a group that she called an Action Group had turned her autistic son's life around or, in her words, because of the Action Group her son "got a life". In so many ways her son's story paralleled that of Lauren's that when I left the conference I was determined that Lauren too could "get a life" in the community doing meaningful activities.

Within three weeks Lauren's first Action Group meeting was held. There weren't a lot of people, but they were the people who knew Lauren best and could help with planning her future. Those attending included the Director of the County School's program at Shasta College and an aide from that program who had worked with Lauren during her two years at

the College, her Regional Center Service Coordinator who would be instrumental in getting Regional Center funding for this program, a past teach of Lauren's, and a close family friend. Over the past year and a half as Lauren's horizons have expanded, other people have joined her Action Group, but generally the core group has remained consistent.

The Group met every other week for the first two months. Each meeting had a formal agenda, and members left each session with an assignment. In two months, we mapped out what a day program could be for Lauren, got Regional Center approval for funding (I am vendored as a family day care provider), hired staff, and on January 21, 1993, began Lauren's adventure.

What types of things can someone with Lauren's limitations do? She does mobility practice at the mall with the seniors and others who use the mall for exercise before it opens in the morning. Her attendant does not push her but does offer verbal prompts. Initially, she would sit just inside the doorway and complain; now she cruises the mall saying hi to her new friends there and sometimes taking a break with them at the donut shop if she can push herself that far!

She attends Shasta College for adaptive physical education twice a week. She tried adaptive art, but was bored and gave that up before the semester was out. She attends a handicapped horseback riding program in another town. She loves music, so she now takes a private music lesson once a week with a young gal who teaches fiddle.

I must have spoken to ten different music teachers before I came across Tricia, who has never worked with anyone with a handicap before but was willing to give it a try. She has been teaching Lauren basic rhythm (clapping and using a tambourine) and also encouraging her to sing, which she enjoys doing (she now sings "alllll done!"). Once a week Lauren goes bowling with a friend who is also in a wheelchair. They use a ramp to get the ball down the lane, and Lauren has actually broken 100! Todd,

her bowling friend, recently turned 30 and Lauren received the first birthday party invitation in her life for his big 3-0 celebration.

Lauren also shops for all of her own personal items and special food items from the grocery store. Lauren's generally good disposition would often turn sour and she would very loudly tantrum when she went in the grocery store. Now she generally enjoys her short jaunts in the store. She has to carry the items to the check out stand, give the clerk her money and carry the bag to the van. It was wonderful when I went to the store after work one day and was told by the check-out clerk how much improvement he had seen in Lauren's behavior when she's in the store!

Lauren also has a few jobs in the community. At the college, she had learned to hand towels for folding to a co-worker. I approached a local exercise club and even though I was not a member and I didn't know the owner, he was willing to have Lauren do the same thing with the towels that they wash and dry for their clients. Sometimes Lauren has to be removed for a short time-out when she doesn't want to do the job but since it is a job, she must go back in and finish. She is generally there for 15 minutes twice a week, which is about the limit of Lauren's tolerance for that type of activity.

Another job that a member of her Action Group found for Lauren was being an aide in a pre-school class at the YMCA. Lauren went for music and story time (her favorite) and she would do things like hold up a felt board in her lap for the class to see while the teacher attached items depicting the story. The 3 and 4 year olds were told about Lauren by a member of her Action Group who visited the class before Lauren started attending. Although some of the children were a little uncertain about this strange visitor in a wheelchair when she first started attending, she soon became a favorite of the children and they each wanted to be the one that got to sit next to Lauren! I think Lauren wasn't the only one learning something from her being in that classroom! Unfortunately, the

class had to move to a non-wheelchair accessible room, so that assignment came to an end. However, she has been assured of a volunteer slot at a new integrated day care center that will be operated by the Easter Seal Society when it opens in about a month's time.

Lauren's program lasts 6-1/2 hours a day, and they are days that are full of normal activities. At home Lauren is learning to use a duster to wipe her dresser in her room and to operate an adaptive switch to use the blender to make her orange juice. She participates in putting her laundry in the washer and hands it to her attendant for folding. She stirs the pot when they make simple food items like Jell-O or pudding.

I feel I can confidently say that Lauren has a rich and fulfilling life. I do not want to underestimate the work that it takes to keep this type of program operating. One of the major problems in doing our own program has been keeping both attendants (one works three days a week and the other, two). One has been with us since before we started the day program; she was Lauren's after school attendant since 1990. We have had six people in the other slot, however, which has been trying for Lauren as well as her father and me. The current new person seems to be working out great, so we're keeping our fingers crossed!! The other major problem has been back-up on days when an attendant can't make it. It generally falls to her father or me to stay home from work on those occasions. I also now have to handle payroll for the attendants and deal with all of the reporting requirements that go along with being an employer. And finally, there are the constant schedule changes and the challenge involved in finding activities that Lauren can participate in and find meaningful. This however, is one problem that her father and I don't have to deal with alone; her Action Group is there to share that responsibility. Although they do not meet as often as at the beginning of the program, they do come together to help brain storm new activities for Lauren to try. We also, as a group, write her Individual Service Plan and semi-annual reports that I have to submit to the Regional Center. Clearly

this group is instrumental in keeping her program current and adaptable to Lauren's changing needs.

There is no question that, even with all of the negatives that I outlined above, I feel the program is well worth doing. I could not imagine Lauren back at a center with little contact with the "outside world". Lauren has taken on a new air of independence at home which is wonderful to see. Her temper tantrums are much less frequent, and I can take her into a public setting without worrying about how she will behave.

I hope someday I'll be able to turn Lauren's program over to a professional organization that is committed to full inclusion for all people, even those with severe mental retardation. Until that day, we will keep plugging along, doing our own thing, seeing to it that Lauren's life is a good life.

TRAINING GUIDELINES

Person-centered planning is both mandatory and value-based. This training is designed to help planners to strike the delicate balance between doing what is required, and being creative and flexible enough to meet the needs of each individual consumer. For many, this will require rethinking their role in the service delivery system and their approach to services and supports.

The training outlined in this section provides hands-on experience in person-centered planning for all those involved, including: consumers, families, service coordinators, service providers, and advocates. Anyone who is involved in the development of person-centered IPPs should be included in this training. Training should be scheduled in places that are easily accessible and at times that allow for the full participation of everyone.

Facilitators, interpreters, and translators may be necessary to ensure that everyone who wants to participate is able to. Those facilitators, interpreters, and translators who will be directly involved in the person-centered IPP process should attend this training, so that they have an appropriate frame of reference while working with consumers and families. Facilitators, interpreters, and translators should also have basic training in developmental disabilities so that they are familiar with the necessary concepts and vocabulary.

These training guidelines are to be used by the teams of instructors who train those involved in person-centered IPPs. The teams of trainers who conduct this training should reflect the diversity in lifestyle, language, and culture of the groups they are training. The emphasis of the training is on exercises that give experience in person-centered planning. Lecture is kept to a minimum.

Training Objectives

The objectives of this training are to expose participants to:

- person-centered planning values
- a variety of person-centered planning practices
- the requirements related to person-centered planning in the Lanterman Developmental Disabilities Services Act¹¹
- a structured opportunity to apply the values and requirements related to person-centered planning in the California developmental service and support system.

Training Description

This training is conducted as a workshop. The minimum duration for this workshop is one day. The times seen in *italics* under the title of each exercise are the suggested times and durations of the exercises for a one-day workshop. Participants in this workshop will engage in discussion and simulated planning exercises. Participants are arranged in teams of 3-7 members for the simulated planning exercises. Instruction is given by a team consisting of at least one consumer or family member and one person with service coordination experience.

Training Methods

Simulated planning sessions are conducted in stages, with discussion between each stage. Participants are expected to gain hands-on experience in person-centered planning by participating in these simulations. Discussions will cover a variety of topics from how to help consumers make meaningful choices in their lives to barriers to achieving

1. Welfare & Institutions Code Sections 4500, et seq.

the goals and objectives selected at the planning conference. The team discussions result in notes which are compiled into a written IPP by the end of the session.

Training Materials

Each team is provided with an IPP Resource Manual and a presentation easel for note-taking. These teams will also be provided with examples of person-centered planning for the simulation exercises. Each participant is provided with a personal guide to person-centered IPPs. Sample forms and checklists will also be available.

Evaluation Methods

Evaluation is done by groups. If a group engages in productive discussion, completes each exercise, and submits the results of these discussions in the form of a written IPP, the group will have met the objectives of the workshop.

Exercise 1 – Introductions

8:00 AM-8:30 AM

Participants enter the training room, fill out the registration forms, and are seated at tables in groups of 3-7. Instructors distribute copies of the Resource Manual and other training materials and introduce themselves. The workshop objectives are reviewed along with general guidelines for discussion. Break times and location of facilities are discussed.

Participants introduce themselves, giving their names, and their usual roles in developing IPPs. Participants are also asked to discuss their expectations of the workshop. These expectations will be recorded and referred to at the end of the workshop.

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The instructors review introduction, values, and instruction sections of the Resource Manual. Questions and comments are solicited after each major heading within the sections being reviewed.

Exercise 2 - Person-centered planning values and roles

8:30 AM-9:30 AM

The instructors introduce the concepts of person-centered planning by paraphrasing Section 1 of the Resource Manual. Then the instructors review the values and roles from Section 2 of the Resource Manual. Instructors illustrate these values and roles with examples as they review. Instructors solicit questions and comments after presenting each value statement and role.

Exercise 3 - IPP requirements

9:30 AM-10:00 AM

The instructors do a brief review of the required format and instructions for person-centered IPPs from Section 3 of the Resource Manual. Each major heading is discussed briefly with some time provided for questions and comments. The instructors emphasize that this is an introduction to the requirements, and that future exercises will give the participants experience in applying the requirements.

Morning Break

10:00 AM-10:15 AM

Exercise 4 - Introduction to person-centered planning methods

10:15 AM-11:15 AM

The instructors review the examples of person-centered planning methods found in Section 4 of the Resource Manual. Participants are

encouraged to discuss these methods, and relate them to the methods they currently use. The instructors will guide a discussion of the similarities and differences between current practices and person-centered planning.

Instructors then review some of the stories illustrating different aspects of person-centered planning found in Section 5 of the Resource Manual. Participants are then asked to relate some of their own experiences in developing IPPs and how those experiences relate to the values and methods of person-centered planning.

Exercise 5 - Developing a person-centered planning team

11:15 AM-Noon

Each participant in a discussion group will assume a role for the simulation exercises. The roles include:

- the consumer who is the focus of the planning effort
- the service coordinator
- one or more family members (or an authorized representative)
- a friend or neighbor
- a provider of services or supports
- an advocate

The instructors will provide a range of examples from which groups can choose for their simulations. These examples will provide a brief description of a consumer with a cursory history and description of the current situation. Each discussion group will choose an example, and use it to develop complete roles for the simulation. The groups will be encouraged to expand on these examples to meet the needs of the training exercises.

Lunch Hour

Noon-1:00 PM

Exercise 6 - Developing a person-centered IPP

1:00 PM-3.00 PM

Instructors will review Section 3 of the Resource Manual regarding the development of person-centered IPPs. Participants will conduct a simulated planning conference based on the examples they have chosen and the instructions in Section 3. Instructors will circulate from group to group to provide assistance as needed.

Afternoon Break

3:00 PM-3:15 PM

Exercise 7 - Summary and evaluation

3:15 PM-5:00 PM

Each group will present a summary of the simulated conference it has just completed. The instructors will guide these discussions and provide time for a group summary at the end. A written evaluation of the training will be completed by each participant.

Glossary

Area Board

Area boards are independent, regional agencies, which protect and advocate the rights of all persons with developmental disabilities who live in their areas. Area board responsibilities are defined in Sections 4570-4613 of the California Welfare & Institutions Code.

Client Program Coordinator

See Service Coordinator.

Consumer

An individual with developmental disabilities who is eligible for regional center services. The term consumer has replaced the prior term "client".

The term consumer denotes not only the individual, but the individual's authorized representative. Authorized representatives include parents, guardians, and conservators.

CPC

Client Program Coordinator. *See Service Coordinator*

Generic Service

Service or support that is provided by an agency that has a legal responsibility to serve all members of the general public and is receiving public funds for providing those services.

ID Team or Interdisciplinary Team

See Planning Team

Individual Program Plan

A planning document. The Individual Program Plan is prepared in a standard format according to specific instructions. An Individual Program Plan is developed through a process of individualized needs determination and embodies an approach centered on the person and family.

IPP

See Individual Program Plan.

Planning Conference

A planning conference is a meeting of a planning team. The team may be used synonymously with “team meeting”, “ID team meeting”, “program plan meetings”, “IPP meetings, or any other meeting with the purpose a needs assessment centered on the consumer and family, and make the choices and decisions recorded in an Individual Program Plan.

Planning Team

The planning team members are participants in a planning conference that results in an Individual Program Plan. The planning team is defined as the consumer, the parents of a minor or conservator or legally appointed guardian of an adult, one or more regional center representatives, including the regional center representative who has the authority to make decisions on behalf of the regional center, and anyone invited by the consumer or representative, including a service provider. The planning team shall also include developmental center staff knowledgeable about the service and support needs of the consumer when the consumer resides in a developmental center.

Regional Center

A regional center is a private, non-profit, agency that is under contract with the Department of Developmental Services to coordinate services and supports for persons with developmental disabilities. Regional center roles and responsibilities are defined in Sections 4620-4696 of the California Welfare and Institutions Code.

Service Coordinator

An individual who is responsible for implementing, overseeing, and monitoring a consumer's IPP. The service coordinator may be an employee of the regional center or may be a qualified individual or employee of an agency with whom the regional center has contracted to provide service coordination services (Welfare & Institutions Code Section 4647(b)). Where appropriate, a consumer or the consumer's parents or other family members, legal guardian or conservator, may perform all or part of the duties of the service coordinator if the regional center director agrees and it is feasible (Welfare & Institutions Code Section 4647(c)).

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