Chapter 6

Person-Centred Approaches to Services and Supports

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Learning objectives

Readers will be able to:

- 1. Understand the reasons why person-centred approaches were developed
- 2. Identify key elements of a person-centred plan
- 3. Identify two differences between person-centred planning and conventional planning approaches

Introduction

The purpose of this chapter is to outline the underlying principles and key elements of person-centred planning. Differences between person-centred planning and conventional planning approaches will be highlighted. Challenges to implementing person-centred plans will be discussed. Finally, a case example will be used to illustrate some of these points.

History of person-centred planning

In recent years, increasing emphasis has been placed on improving the quality of life for people with developmental dis-

abilities. This growing trend is related to findings that these individuals are treated differently and have fewer opportunities for positive growth and development than people without disabilities. Issues of reduced quality of life are even more problematic among individuals with a dual diagnosis, as their mental health problems further heighten the disparity of their situation. Also, deinstitutionalization has been accompanied by the transfer of institutional patterns of service into community settings (Smull, 1989). For these reasons, an approach to planning individualized services and supports was called for that targeted the very things that most people without disabilities take for granted – a pleasant and safe home environment; enriching and satisfying personal relationships; acceptance by the community; opportunities for work and leisure activities; freedom to make effective choices and decisions; and attainment of hopes and dreams. Person-centred planning approaches were conceptualized as a way to reorganize and reorient the service system to achieve these global, long-range positive outcomes as well as to respond creatively to pressures in relation to dwindling resources and increasing demand. In the words of Todd Risley (1996), the intent of these approaches is to assist the person with a developmental disability to "get a life!"

Elements of person-centred planning

Life plans, lifestyle planning, essential life plans, personal futures planning and functional life planning are all examples of approaches to person-centred planning. Despite some differences, most approaches have several key elements in common. First, they bring together a group consisting of the individual with a dual diagnosis ("focus person") and the people who play an important role in his or her life. For instance, this

group may consist of family members, friends, housemates, co-workers and service providers. The activities of the group are governed by principles that include *community integration*, *normalization*, *increasing competency*, *and empowerment*. Specific goals or outcomes are based on *operationalizing* these principles. For instance, the principle of community integration may be defined in concrete terms as "the person (with a dual diagnosis) will be supported to eat in a restaurant or to take swimming lessons at the local recreational center". The principle of empowerment or self-determination may be translated into goals that "the person will be assisted to make decisions about "little things" (e.g., what to wear or where to go to dinner) and "big things" (e.g., choice of roommates) in his or her life" (Kincaid, 1996).

A general format for person-centred planning

Under the guidance of a facilitator, the planning group typically gathers the following kinds of information:

- People and relationships e.g., who are the most important individuals in the focus person's life and how much time is spent with each person
- Places e.g., where the focus person spends his or her time
- Important life events e.g., home, family and school history; changes in living arrangements; serious illnesses and hospitalizations; service history
- Current health e.g., indicators of good health and poor health; whether the indicators reflect a temporary or permanent situation; current medications and their positive and negative effects on the person's functioning
- Effective choices e.g., whether the focus person makes decisions/choices in day-to-day matters and matters of ma-

jor significance or whether these decisions are controlled by others

- Preferences, hopes and dreams e.g., in regard to people and relationships; things to do or to have; physical, spiritual and emotional health
- Acceptance and respect e.g., aspects of the focus person's behaviour that promote acceptance and inclusion and behaviours that interfere with or prevent these things from happening
- Fears and concerns e.g., in regard to the implications of supporting the focus person to make major life decisions
- Challenges and opportunities e.g., things about the focus person or the system that act to enable or discourage change.

(Adapted from Kincaid, 1996; Smull & Harrison, 1992)

The process of categorizing this information into overall themes which can be used to develop plans to bring about positive lifestyle changes can be enhanced with the use of graphics and diagrams to delineate and explore different factors and outcomes. The group continues to meet to review how much progress has been made toward reaching these goals and to rework the goals and plans as needed. In actuality, the process is never finished since successes fuel new goals and create other opportunities for positive outcomes.

How do you know you are doing person-centred planning?

If there is no commonly accepted approach to person-centred planning, how can you be sure that this is what you are doing? In order to lend some clarity to this issue, Holburn et al. (2000) developed a list of core principles that are integral to the per-

son-centred planning process (see Box 1).

Box 1- Core principles for person-centred planning

- 1. Services and supports are based on the individual's preferences, interests and skills
- 2. The individual and important others are involved in the planning process
- 3. The individual makes real choices and decisions
- 4. Services and supports promote social inclusion
- 5. The plan incorporates natural community supports
- 6. Planning is collaborative and involves a long-term commitment
- 7. Opportunities are created and non-traditional solutions are considered
- 8. The individual is satisfied with the changes in his/her lifestyle

(Adapted from Holburn et al., 2000)

These authors have also identified a number of factors or conditions that result in positive planning outcomes (see below).

Box 2- Examples of factors or conditions that are related to positive outcomes

- 1. The group is lead by a skilled facilitator
- 2. The focus person's positive qualities are emphasized
- The group has members that are skilled at building community relationships and are able to access community resources
- 4. The group has a way to influence decision makers

- 5. There is administrative support for an individualized planning approach
- 6. Supports are flexible and portable
- 7. The group meets regularly to review and refine its plan

(Adapted from Holburn et al., 2000)

How does person-centred planning differ from conventional planning approaches?

Some of the differences between person-centred planning and conventional planning approaches are summarized below:

Elements/	Conventional Approaches	Person-
Factors		Centred Approaches
Language	Clinical/technical	Plain language
Units of Intervention	Micro level (e.g., discrete behaviours)	Macro level (e.g., life ar- rangements)
Options	Limited; usually a fixed menu of services and interventions (fitting the person into pre-existing "slots")	
Membership of Team	Typically professional/paid	Mixture of professional/ paid, nonprofessional and vol- unteer
Roles	Clearly defined roles	Step outside of roles
Time frame	Usually time-limited	Life long
Decision- making process	Top down; driven by systems or organizations	Bottom up or individually driven

Table 1- Key differences between conventional and person-centred planning

Problems with implementing person-centred planning approaches

The acceptance and implementation of person-centered planning approaches may present significant challenges at both a personal and a system level. These difficulties can encompass a range of practical and conceptual issues, such as:

- involving people in the planning process who aren't sufficiently familiar with the focus person or don't play a significant and ongoing role in his or her life
- underestimating the time and resources that are required
- maintaining the group's enthusiasm and commitment
- lack of adequate or portable funds to bring about significant lifestyle changes
- mixed or uncertain feelings due to differences in philosophies and role confusion

Holburn and Vietze (1999) caution that failure to acknowledge and address these factors may undermine the process and its ultimate success.

Bringing it together: A case example

The Case of John

John is a thirty-year-old man who has lived in a residential group home operated by the local Association for Community Living for the past two years. He has a mild developmental disability and a controlled seizure disorder. Before moving to the group home he lived with his mother and younger sister. John's parents are divorced and he has not had contact with

his father for several years. John's move to a group home was prompted by frequent angry outbursts in which he became verbally abusive and damaged property around the home. His mother was unable to cope with these outbursts due to her own declining health. After moving into the group home, John was referred for a comprehensive biopsychosocial assessment. The assessment yielded a diagnosis of bipolar disorder. His angry outbursts were found to be related to sleep and mood disturbances as well as poor strategies for coping with stress. In terms of his strengths and needs, the assessment revealed that John is primarily a visual learner and has a good memory. He has strong interest in people and is mostly pleasant and sociable. He has good money management skills but requires help to plan and cook healthy meals.

In conversations with his family and primary worker, John revealed several wishes regarding his future: (1) to find a job he liked, (2) to live in his own apartment with support, and (3) to find a friend, preferably a female companion.

Steps in the person-centred planning process for John

1. Forming the planning group.

John's primary worker coordinated a meeting to initiate the planning process. John was asked to give input into who the participants should be, and he identified his mother and sister, primary worker, and a long-time friend of the family. The group also decided it would be helpful to invite his social worker to participate. A staff person from John's agency

agreed to facilitate the planning meetings.

2. Developing guidelines for the group process.

With the assistance of the facilitator, the following "ground rules" were worked out.

- The group would work toward assisting John to become an accepted and productive member of his community and support him to develop and maintain social relationships with people from his community.
- They would build upon John's strengths and positive qualities.
- They would commit to long-term involvement in the process.
- They would step outside their traditional or professional roles and be willing to consider a variety of creative options.

3. Identifying goals and priorities.

With the assistance of the group, John decided that his immediate priority was to be able to live in his own apartment with support.

4. Establishing an action plan.

Several "success" factors were identified with respect to supporting John to achieve his goal of living in his own apartment:

- (1) He needed to take his medication regularly to control his seizures and his moods
- (2) He needed to learn and use strategies to better manage his

anger and response to stressful situations

- (3) He needed to get at least 8 hours of sleep at night
- (4) He needed help with meal preparation and shopping

The group developed a detailed plan to address these issues. The plan outlined specific roles, tasks and timeframes.

5. Specifying an evaluation plan.

The group chose to evaluate the success of their plan in relation to three factors: the target goal (i.e., John is able to live in his own apartment with support), John's satisfaction with this lifestyle change (e.g., John is pleased about living in his own apartment), and whether the principle of community integration was met (e.g., John is accepted by the other tenants in his apartment building, and is invited to their monthly social events). They agreed to meet monthly to review John's progress toward achieving these goals, and to problem solve around any difficulties that came up along the way.

Summary of the planning process for John

A planning group was formed that consisted of John, his mother and sister, a close friend of the family, agency staff and mental health professionals. The meetings were facilitated by a staff person from the agency. During lifestyle planning meetings, John revealed three long-range personal goals:

- 1. to find a job he liked,
- 2. to live in his own apartment with support, and
- 3. to find a friend, preferably a female companion.

The case management role was filled by John's primary

worker. She agreed to coordinate services among John's support circle, consisting of his family, family physician, psychiatrist, social worker and job coach.

In the course of working together, the group identified the following obstacles that prevented John from achieving his goals:

- instability of his moods
- noncompliance with medication
- lack of experience with decision making
- need for monitoring of sleep, moods and medication
- need for emotional support and assistance to implement anger management strategies
- lack of familiarity with community transportation
- lack of opportunities for social outings

John's goal of living in his own apartment was prioritized. In addition to the other services he was already receiving, several new elements were added to the support plan:

- responsibility for monitoring his sleep, moods and medication was shared among his primary worker, a staff person from the local mental health agency, and family members
- assistance around meal planning and preparation was provided by his sister and a visiting homemaker
- support to follow through on anger management strategies; also, informal counseling to review and problem solve after an outburst had occurred, provided by his case manager, social worker, job coach and a "buddy" with whom John was paired who lived in the same building

Summary

In this chapter, person-centred approaches to services and supports were presented. The rationale for and context underlying the development of these approaches was discussed. Despite their growing popularity and usage, many issues regarding these approaches remain to be resolved. However, they show great promise and serve to remind us of the critical importance of working toward a positive and inclusive vision for the future of people with a dual diagnosis.

Do You Know?

- 1. The differences between person-centred planning and conventional planning approaches?
- 2. Some of the key principles and concepts underlying these approaches?
- 3. Some of the challenges to implementing these approaches?

General Reading

- Forest, M. & Pearpoint, J. (1992). Commonsense tools: MAPS and circles. In J. Pearpoint, M. Forest & J. Snow, (Eds.) *The inclusion papers: Strategies to make inclusion work* (pp. 52-57). Toronto: Inclusion Press.
- Institute on Community Inclusion (1993). *Whole life planning:* A guide for organizers and facilitators. Boston, MA: Institute on Community Inclusion.
- Mount, B., Ducharme, G., & Beeman, P. (1991). *Person centered development: A journey in learning to listen to people with disabilities.* Manchester, CT: Communitas.

- Mount, B., & Zwernick, K. (1988). It's never too early, it's never too late: An overview of person centered planning. St. Paul, MN: Governor's Council on Developmental Disabilities.
- O'Brien, J. & Forest, M. (1989). *Action for inclusion*. Toronto: Inclusion Press.
- O'Brien, J., Mount B. & O'Brien, C.L. (1990). *The personal profile*. Lithonia, GA: Responsive Systems Associates.

Resources

Circles Network

Website: www.circlesnetwork.org.uk

This is the home page for the Circles Network. It describes the organization's mission, and provides information about build-ing inclusive communities for individuals with disabilities.

Inclusion Press International

Website: www.inclusion.com

This site provides information on material regarding full inclusion in school, work, and community.

Pacer Centre

Website: www.pacer.org

This is the home page for the Pacer Center. It describes the organization's mission and includes links to person-centred planning websites and other planning resources.

References

- Holburn, S., Jacobson, J.W., Vietze, P.M., Schwartz, A.A., & Sersen, E. (2000). Quantifying the process and outcomes of person-centered planning. *American Journal of Mental Retardation*, 105, 402-416.
- Holburn, S., & Vietze, P. (1999). Acknowledging barriers in adopting person-centered planning. *Mental Retardation*, 37, 117-124.
- Kincaid, D. (1996). Person-centered planning. In L.K. Koegel, R.L. Koegel, & G. Dunlap (Eds.), Community, school, family and social inclusion through positive behavioral support (pp. 439-465). Baltimore, MD: Brookes.
- Risley, T. (1996). Get a life! Positive behavioral intervention for challenging behavior through life arrangement and life coaching. In L.K. Koegel, R.L. Koegel, & G. Dunlap (Eds.), *Community, school, family and social inclusion through positive behavioral support* (pp. 425-437). Baltimore, MD: Brookes.
- Smull, M.W. (1989). Crisis in the community. Baltimore, MD: Applied Research and Evaluation Unit, University of Maryland at Baltimore.
- Smull, M.W., & Harrison, S.B. (1992). Supporting people with severe retardation in the community. Alexandria, VA: National Association of State Mental Retardation Program Directors.