PERSON-CENTERED PLANNING FOR DISABILITY SERVICES

Kelly Kulzer
Taft College

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Person-Centered Planning for Disability Services

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1: Person-Centered Practice Foundation

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What we will learn

- Background of person-centered practice within the disability community context
- John O'Brien's role in the person-centered planning movement

Person-centered practices within the disability context gained popularity in the United States as people with disabilities moved from institutions to the community in the 1970s and 80s. As the culture began to shift from a medical model of disability to a more inclusive social model of disability, the way of planning for people's wants and needs needed to evolve, as well.

John O'Brien is considered one of the original thought leaders on person-centered planning with people with developmental disabilities. There are many others who contributed to the field, but O'Brien's contributions should be recognized and celebrated by people focused on self-directed services, like people who support the Self Determination Program.

In John O'Brien's, "A Genealogy of Person-Centered Planning With People With Developmental Disabilities", the author provides a brief history of the original purpose and evolution of person-centered planning. His points are important to anyone supporting and upholding human rights with people with disabilities as a foundation for what we are doing.

O'Brien states, "From its origin person-centered planning was inseparable from the work of discovering community opportunities and developing new ways to organize support" (p. 5). A deep emphasis on person-centered planning requires us to commit to locate and encourage community support. Without a commitment to community inclusion, this work will remain incomplete.

Person-centered planning was not originally intended to help coordinate services and focus systems. Its original purpose was deeply rooted in civil rights. Today, we are focusing this strategy to help drive a system, but the focus on civil rights remains.

O'Brien's genealogy of person-centered planning follows on the next few pages.

1.1: John O'Brien- A Genealogy of Person-Centered Planning With People With Developmental Disabilities

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By a variety of names, person-centered planning is an element in social care reform, as in these examples. The US Department of Health and Human Services set person-centered planning at the center of disbursement for the nation's main source of social care funding (DHHS, 2014; NQF, 2020). The Act that establishes publicly funded services for people with developmental disabilities in the Canadian Province of Ontario established person-directed planning as the forum for selecting and coordinating services (S.O., 2008). *Valuing People*, an initiative to transform supports to people with learning disabilities* in England, identified person-centered planning as a necessary tool for changing systems of support (Routledge, Sanderson, and Greig, 2002).

These mainstream instances of person-centered planning happen as elements in centrally managed public service reforms. In contrast, this genealogy traces the origin of a person-centered planning lineage that emerged at the edge of social care systems, among a network of activists aligned with people with developmental disabilities and their families in Canada, the US, and the UK from about 1970 through about 1986. Approaches to person-centered planning which emerged then influenced the design of other methods. Some are still practiced in evolved forms. These approaches, along with many others, have had some influence on the mainstream practices adopted by systems (for a description of these early approaches, their commonalities, differences, and offspring see O'Brien *et al.* 2014). Retrieving the origins of this tradition highlights sources of social innovation that can contribute to social care system reform, if those engineering the reforms choose to learn from them and make room for such conditions to flourish.

This genealogy is constructed from my current reflections on memories of active participation in this network, aided by review of materials from that time and more systematic inquiries compiled from interviews with a number of person-centered planning innovators (Lyle O'Brien and O'Brien, 2002; O'Brien and Blessing, 2011).

1.2: Mainstream Person-Centered Planning Practice

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From the early 1970s requirements for individual service plans played a part in social care reforms as attention to individual skill development overcame professional pessimism about the educability of people with developmental disabilities. Over about thirty years, approaches to individual planning developed, sometimes into the mainstream forms of person-centered planning in use today.

In the context of mainstream service delivery, person-centered planning usually has characteristics like these. The stated purpose is to improve measurable service outcomes that advance system policy. The process addresses the person as a service user: consumer, client, recipient, patient. A system authorized service coordinator facilitates or oversees the process. It seeks the benefits of active service user involvement in care by clarifying goals and specifying available services that will cost-effectively assist goal attainment. The process promotes informed choice among available, cost-effective services and treatments a person is eligible to receive. It refers service users to services funded from other sources. It sees family members as carers who may also be eligible for services. The process aims for a good balance between what matters to a person and what matters for a person, where what matters for the person is judged from the perspective of managing organizational risk. It pursues a good fit between personal preferences and the way available services are delivered.

Mainstream applications of person-centered planning function as tools in social care reform and are managed bureaucratically. Under administrative authority and with advice from stakeholders, social care systems typically define a form of person-centered planning, promulgate rules to govern its practice, tie the chosen form of planning into resource allocation and service coordination processes, set the tempo for planning events, incorporate planning into audited record-keeping routines, provide technical assistance, develop curricula, and require courses of training (e.g., NQF, 2020). Academic research centers and consulting firms usually play important roles in definition and implementation (e.g. HSRI, 2020).

*Terms are contested and changing. Since 1950 the diagnostic label mental deficiency has been succeeded in turn by mental handicap, mental retardation, learning difficulty and learning disability (in the UK), and intellectual disability. I chose developmental disability to aggregate the human service labels assigned to the people who collaborated in producing the forms of person-centered planning discussed here. A North American administrative coinage, it identifies people with different diagnoses who share a life long need for coordinated services that originates before age 22. Intellectual disability, autism, cerebral palsy, epilepsy, and other conditions that produce needs for similar services are commonly grouped under this label. Social Care” is a common term for what the US knows as “Long-Term Care.”

1.3: A Network of Innovators

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Implementation of mainstream person-centered planning practices are engineered by system logic. Senior authorities define specifications in consultation with interested constituents, their agents plan and implement the means to meet those expectations. Outside that logic, just at the outer edges of the social care system, there is another source of creative energy for improving the life chances of people who rely on social care. Beginning about forty-five years ago, in a decade of rapid service system growth, innovative practices, including person-centered planning, began to emerge at this edge. Emergence can't be commanded and controlled as engineering can, but it gives birth to unexpected possibilities.

Reaction to institutional scandals and skilled and tenacious advocacy by influential family voices and professional leaders brought cautious and qualified legislative and judicial statements of rights for people with developmental disabilities. Driven by court decisions, inquiries, and legislative action, public investment expanded. The service sector grew rapidly as money flowed to reduce the institutional census.* There were positive changes: residential services were smaller and located on ordinary streets, physical environments were upgraded, staff ratios increased, health care improved, there was more attention to developing skills, observing typical routines, and exposing people to local settings and activities. Interdisciplinary teams of professionals wrote individualized service plans and set goals that addressed their judgments of individual potential. When the team judged it appropriate, people with developmental disabilities and family members had seats at the table where plans were made for them and a say in goal setting.

Rapid growth also brought in new workers who carried seeds of further change. Demand for staff and front line managers attracted many from outside the professional identities typical of the field. Even in direct support positions more people held degrees in outlying fields of study than ever before or since. Many new workers were active in moments for civil rights and peace and had done terms of voluntary service in community development or were discharging their obligation as conscientious objectors to military service. Hope that activism would bring positive social and cultural change shaped their consciousness. Fans of Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962; film in 1975), these young people were ill-fit to take subordinate places in the established social care hierarchy and unquestioningly follow orders and protocols. Everything was open to question and typical staff client boundaries often melted in shared life experiences.

Across organizational boundaries and outside of formal roles, networks formed among those who did not find a way to the future they desired in mainstream waves of local service growth. Informal networks brought together families with high expectations for support to community living, people with developmental disabilities seeking opportunities to live their lives in ways they valued, and dissident service workers, Those who created these self-organized networks saw themselves working for social justice. They spoke of walking with developmentally disabled people and their families who sought to experience life as citizens with publicly recognized dignity, agency, and capacity to contribute.

Different interests shaped loose and changing networks. Lawyers and their expert witnesses connected, researchers who assisted people with developmental disabilities to blow up professional underestimations of their capacity for learning and performing meaningful work connected, people committed to those whose behavior challenged existing community supports beyond the breaking point connected, family members and educators committed to creating inclusive schools connected. Multiple interests energized connectors among networks. Networks offered mutual assistance in attracting resources and shaped formal conference agendas and informal life in conference hotel bars.

The self-organized network that generated early approaches to person-centered planning took shape around the work of Wolf Wolfensberger. His thinking and the example of his unrelenting advocacy against the segregation of people with disabilities framed and provided a vocabulary for our inquiries into practical support for social integration. Wolfensberger deconstructed the thinking that produced institutionalization, articulated a corrective in his interpretation of the principle of normalization, and framed a range of implementing concepts, including locally governed comprehensive systems of community services, citizen advocacy, and new roles for parent organizations as social inventors (Race, 2003).

Early in the 1970's, The Canadian National Institute on Mental Retardation (NIMR), founded to strengthen the family voice in policy and practice, adopted and promoted Wolfensberger's ideas through demonstration projects, policy development exercises, multiple educational events, and publications. Wolfensberger maintained strong ties with NIMR when he moved to Syracuse University in 1973 to establish The Training Institute for Human Service Planning, Leadership and Change Agentry. Both NIMR and the Training Institute were explicitly committed to advocacy for social justice and the development of services that would play a part in shifting the social status of people with developmental disabilities by relentlessly promoting social integration. Syracuse University was also home to The Center on Human Policy a setting where organizers collaborated with sociologists to campaign for

community supports based on qualitative research that revealed the dark side of institutionalization and documented the benefits and workings of community alternatives (Ware & Story Sauer, 2021). These initiatives, and a number of innovative agencies and regions, provided multiple opportunities to strengthen our network by working on these organizations' agendas and strengthening relationships among their leaders.

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* In the US neither the move from institutions nor the mandate foe special education have ever approached full funding. The leading deinstitutionalization case, *Olmstead v L.C.*, instructs states to implement alternatives at "a reasonable place."

1.4: Ground Level Innovation

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Those who produced early person-centered planning approaches did not set out to engineer individual planning processes for systems. In fact, naming person-centered planning as a distinct form of practice came very late in the 1970s and early 1980s. Identified practices, such as Personal Futures Planning (Mount, 1984), emerged from assemblage of ad hoc practices to identify desirable changes in the organization of services.

Our network participants felt personal responsibility to accompany known people in their quest for a good life in a particular place. Some were members of families of people with disabilities. At work, some network members were responsible for developing and managing local day or residential services. Others assisted institution inmates to resettle. Others organized families and young people seeking a path from (usually segregated) special education into adult life in their community. Others offered support in crisis. A few were responsible for developing regional systems of social care services. A few were disabled leaders of early efforts to encourage people with developmental disabilities to speak for themselves. All wanted publicly funded services to offer better assistance than they currently did.

While we were by no means the only people to develop a critique of existing services, our network provided a platform from which we could observe ourselves as actors in a system we increasingly felt called to change. A powerful instrument for self-observation came in the unexpected form of a service evaluation instrument, *PASS* (Wolfensberger and Glenn, 1973), which operationalized 34 dimensions of the principle of normalization. While very few authorities ever used *PASS* to score the quality of the services they commissioned, investments in teaching *PASS* and applying it in consultations offered us multiple, intense opportunities to observe and reflect on snapshots of the day-to-day experience of people in services. The process of team debate produced knowledge that stimulated innovation. We named many ways that current service practices –our practices– reproduced social exclusion and restrictions of human rights and analyzed their causes. We noted the costs and limits that established service structures imposed. Most important our practical imaginations were lit.

Growing commitment to change in our own practices and structures introduced ambiguity into the roles of those of us who worked in social care. We felt responsibility to change the system that we worked inside and depended on. Very few of us had job descriptions that authorized us to be change makers. A growing number of us discovered openings for innovation at the edges of our formal responsibilities. Some found enough space to create individualized alternatives to group living, develop integrated employment and other supports to community participation, prevent social isolation and promote belonging, and discover strategies for accommodating differences rather than focusing exclusively on fixing diagnosed deficiencies. Many times these were one

person innovations developed to interrupt a pattern of service failure that threatened a person with exclusion or to support a person and family with a strong vision and assets to invest in action. (For a variety of examples of such ground level innovations, see Meissner, 2013; O'Brien & Mount, 1991; O'Brien & Mount, 2015).

Our purpose, individualization of support for meaningful community roles, demanded a guiding and motivating narrative that expressed each person's identity, capacities, requirements for assistance, and personal images of a desirable community future.

Otherwise we risked reproducing the institutional practice of classifying and managing people in groups. Identified approaches to person-centered planning emerged to invite people with different perspectives to come to a shared understanding of a desirable future that was strong enough to motivate and guide action. From its origin person-centered planning was inseparable from the work of discovering community opportunities and developing new ways to organize support.

The context of ground level innovation shaped these forms of person-centered planning differently than mainstream reforms would have done. Through years of development these enduring qualities of person-centered planning at the edge took shape. At their initiative or with their permission, innovators join a person in an effort to improve life chances for themselves and other people with developmental disabilities. The person is addressed as a citizen seeking more opportunity to live a community life that they value. Those involved recognize themselves as engaged in an action learning process. They explore new ways to push back limits on what is possible, rather than following established practices to produce more of the same. They will meet resistance, both in the world outside and within themselves. The purpose of meetings is to organize action and learning by all those involved, not to write orders, wishes, or demands for others to fill. Family, friends and other citizens are seen as allies and agents of change as are direct support workers. The number of people involved will change: a bigger circle of people will be involved in big changes; fewer when things are stable. Social care ser-vices are means to support citizenship. It is right that the person is in effective control of supports, though this can be complex in practice. The person's desired future defines the context and limits for applying clinical expertise, technologies, and strategies that increase a person's capacities to perform desired community roles. Because the social innovator's

effort is grounded in responsibility to a person they know, feedback on what is working and what is not is rapid, situated, and open to quick response and real time revision.

From its earliest days person-centered planning has contributed to ground level social innovation in two ways. It brings a person and their allies together to form a circle that collectively holds and updates an understanding of the person's identity and images of a desirable future that are powerful enough to activate, focus, and sustain each circle member's contribution to positive change in the person's experience of community.

And, it builds habits of conversation that encourage deep listening, creative imagination, and courageous action when obstacles, failures, conflicts, and breakdowns of trust threaten the person.

1.5: Different Patterns of Thinking

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The era of deinstitutionalization shifted large numbers of people with developmental disabilities into a growing inventory of local services. Most of this growth transferred dominant patterns of thinking and established forms of power along with the people. True to the facts and their professional perspective, expert voices convinced judges and legislators that institutional deficiencies resulted from failure to implement known good practice. They diagnosed the cause as woefully insufficient public investment resulting in overcrowding, substandard professional and care staff ratios, and impoverished physical environments. They persuasively recommended substantial staff increases, new buildings, rapid increase in the number of service providers, and higher standards of care.

Our network developed a different, more disruptive perspective. As we learned to listen better to people with developmental disabilities and their families and observed our own practice more critically it became clear that the services we operated were not organized to support desired futures in community life outside service settings. As trust grew, more of the people we served voiced desires for a job, a home where they were not one of a client group, intimate relationships, and opportunities to pursue personal interests. These ordinary desires far too often ran aground on the structures of our group based, professionally controlled services, especially when people required more than a little assistance. Other people with developmental disabilities communicated inadequacies in the support we provided by harming themselves or others, actions that pushed us into increasingly restrictive practices including retreat to institutionalization. We realized that these were not just problems with implementing known, technical solutions. Along with the people we served, we were trapped in an insufficient pattern of thinking.

Many of our organizations could be said to take for granted a professionally distanced view of people as isolated, embodied deficiencies to be objectively classified and systematically managed. This perspective cast people with developmental disabilities in passive roles as objects of professional assessment, surveillance, and prescribed intervention. Assessment sorted people into group program models for treatment and supervision. Services were delivered in environments designed to facilitate staff surveillance and implementation of prescribed routines. When compliance with treatment regimens mitigated deficiencies, and a person better matched a professional template of normalcy, that person earned a greater measure of supervised independence. Failure to progress consigned a person to a lifetime of social exclusion in a group of people with similar status, and very few made enough progress to achieve discharge from supervision. This distanced way of knowing and resulting structures of exclusion and control too often persisted as people with different qualifications and titles moved to the head of the individual service planning table and the executive offices of organizations.

We wanted a richer pattern of thought, one that took direction and inspiration from the voices of people with developmental disabilities, their families, and their allies among service staff. Wolfensberger was an important source of vocabulary and critical practices that opened up better ways of thinking. In the late 1960s he turned from the form of clinical psychology that focused on testing and treating individual deficiencies and adopted a social psychological and sociological perspective. This turn informed his work as one of the leaders in the creation of a comprehensive system of services in

Eastern Nebraska that became an international model of a local service system that was sufficient to make institutions unnecessary (Casey, 1985). He focused on discovering practical means to create systems of services that would, over generations, shift the social status of people with developmental disabilities by promoting social integration. In Wolfensberger's vision of a desirable long term future, differences would remain, assistance in various forms would remain, but social devaluation of those differences would diminish significantly and reduce the risk of social exclusion. This vision stretched our network's horizons and motivated us to work for changes in people's community roles and relationships far beyond those measured by an increase in positive checks on a skill inventory.

We were inspired and informed by other creative resisters to the dominant pattern of thinking. Early in the 1970s physically disabled activists labeled the medical model of disability; theorized a replacement social model that names discriminatory practices, enforced inequality, and inaccessible environments as primary causes of disability; or-ganized politically to demand physical and social accessibility; and offered one another practical assistance and advice to control their own services (Heumann, 2020).

Burton Blatt and Seymour Sarason engaged the emerging field of Community Psychol-ogy to shift the focus of inquiry from treating individual pathology in service settings to creating social settings that enable flourishing lives in diverse communities (Sarason, 1972). Their work reinforced the application of aesthetics, story, and politics in our efforts to think better about our work. Their colleagues at Syracuse University's Center on Human Policy introduced us to qualitative research methodologies and a perspective on disability as a social construction and the development of a sociology of acceptance grounded in their careful listening to people with disabilities and close observation of service and community settings (Bogdan & Taylor, 1975).

Network members reached outside human service fields for ideas and planning practices. Connections between the Canadian National Institute on Mental Retardation and the Environmental Studies Program at nearby York University linked us to Eric Trist and his colleague David Morley We explored the search process, a participatory planning method that supports diverse voices to develop images of a desirable future strong enough to guide sustained efforts to learn new ways in a complex, changing, and unpredictable environments (Emery and Emery, 1976). In the search process, an image of a desirable future is not a fixed goal to be analyzed into targets to hit. It is a tentative, narrative synthesis of differing expressions of human purposes that correlates action in a common direction of travel. The shared image is reshaped and renewed to adapt action to rapid and unpredictable environmental changes.

Learning the socio-ecological systems theory behind the search conference clarified an-other pattern of thinking that limited our work (Ackoff, 1974). Individual planning in social care was commonly built on mechanistic assumptions. Based on their diagnoses, professionals predicted attainable goals for an individual, set objectives, and prescribed procedures. We came to see that this (attempt to) predict and control approach had four defects. First, the assumption of predictability was false to our experience: unpredicted skills and interests showed up in unexpected ways as people had access to new opportunities, and so did unexpected problems. Underestimation of a person's capacities was far and away our most common error. Second, it reinforced institutional power relationships by setting the professional voice above others and subordinating the person to staff assigned to implement the plan. A person's access to desirable experiences, like a visit with family, might be made contingent on compliance with staff orders.

Third, it closed off discovery of new possibilities. It confined attention to the person in service settings when attention to the person in community settings produced better questions and liberated new ways of knowing and acting. Fourth, it divorced the work from a principle source of meaning: learning to move, however haltingly, toward the ideal of a more just and inclusive community. Experience showed that goal setting by people with developmental disabilities themselves and family members could also be entangled by these limitations.

Approaches to person-centered planning took shape as our network gained experience of social innovation and developed new ways of thinking. Methods grew through adap-tation of procedures developed while teaching and applying Wolfensberger's thinking and applying the qualitative methods in use at The Center on Human Policy. Windows into people's current and desired lives opened as oriented ourselves to supporting valued human experiences: being respected, belonging, choosing, contributing, participat-ing. An empathic reconstruction of personal history could highlight both the burdens imposed by social exclusion and restricted freedom and the forms of resilience the person employed. The concept of Model Coherency – aiming to harmonize an account of the most important human needs of people an organization served with the way ser-vices are conceived, organized, and delivered– formed the core of thinking about how to support movement toward a person's desirable future. The idea of modeling methods on those valued outside the human service world took us to adapt techniques sources like Richard Bolles' *What color is your parachute?* (Bolles, 1970), an approach initially designed to reveal hidden interests and capacities of engineers changing jobs.

Methods took shape as we folded in practices from other fields. The search process framed collaborative effort to visualize a desirable future. Group Graphics (Sibbet, 1977) introduced visual methods to energize the dance between imagination and action by setting forth graphic templates to guide thinking and capture emerging ideas and images. Interactive planning (Ackoff, 1974) specified methods for generating idealized designs that surfaced and challenged limiting assumptions. Organizational develop-ment provided new maps of change (Weick, 1979). New approaches to community development (Kretzmann and McKnight, 1993) expanded our tactics for discovering community opportunities and strengthened our focus on planning as an active process of revealing people's gifts and potential opportunities through community exploration.

1.6: Conclusion

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The network chronicled here has expanded, divided, contracted and reformed over the decades since early forms of person-centered planning emerged. Some of us original participants are still at work, glad to be joined by new generations. Wolfensberger's legacy remains, transmitted by a loyal group of teachers and woven into our thinking. Many more ideas and practices have been incorporated to enrich our thinking and shape our action. The voices of people with developmental disabilities have grown stronger and better organize. Experienced families invite others into leadership. The network's core endures in a shared commitment to carry on the unfinished work of social inclusion, particularly by creating practical supports that resist unjust structures. The work remains at the social care system's edge where boundaries are fluid.

The edge can contribute modestly to the center. Person-centered planning situated in self-organizing networks of ground level innovators whose purpose is to join with people with developmental disabilities to work for social justice can never scale to meet the demand for mainstream planning practices that aims to increase the benefits that thousands of people experience from social care. Current conditions make it very hard to make the changes necessary to realize the promise of stated values, such as those expressed in *The UN Convention on the Rights of Persons with Disabilities*. Those who shape mainstream person-centered planning can adapt techniques from ground level innovators, recognizing that they will have different effects. More fruitfully, those responsible for operating the social care system can learn from and find non-intrusive was to support self-organizing innovators. The most benefit to the whole social care system will come through expanding mindful engagement with the patterns of thinking and relationship that emerge from individual and organizational innovations. As net-work learning about more liberating patterns of thinking becomes the subject of serious conversation in wider circles, available perspectives on what is possible will expand and large scale changes will be better grounded.

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2: Person-Centered Practices

Background

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Person-centered practices are at the core of everything in the Self Determination Program (SDP). Person-centered thinking and planning ensure the person served by the regional center is the focus of all programs and services. This person, the individual served by the regional center, is also in charge of all decision-making.

Some people will run their SDP plan with minimal support. Others will choose trusted supporters to help them manage their Self Determination Program. Still others will depend more heavily on their circle of support for a successful SDP experience.

Regardless of ability or interest in running their own program, the person served by the regional center, often referred to as the “participant”, “person served” or the “individual served”, is the center and main focus of the program. The SDP participant is the person in control of their goals, their staff, and their lives.

SDP Participants are experts on their own lives and are key in making improvements, choices, and changes to their daily schedules, participation in the community, and short and long-term goals. These participants have ultimate decision power over their programs — not the participant’s family, not their circle of support, not the regional center, and not the vendored agencies that provide services. Ultimately, the decisions about a participant’s daily life – along with all supports and services they want and need– belong to the person in the program: the SDP participant.

The PCP drives the budget and spending plan

Use the information gathered in the person-centered plan to create an aligned budget and spending plan.

Person-centered planning always focuses on what the person served wants and needs to live a meaningful life.

A person-centered plan identifies a participant's goals and dreams. The PCP facilitator and participant with the circle of support then ask the question, "What needs to happen to meet this goal?" This is how we identify needed services and supports, always focused on the goals and desires of the person at the center of the plan. These identified needs do not have to reside within the PCP if the participant does not want them there, but they are needed to help the regional center know what services and supports will be needed in the budget. That is how the independent facilitator and the regional center’s SDP team begin the conversation about what services exist in the traditional system to meet the PCP identified needs.

Once the goals are identified, the connected services and plans to work towards the goals are represented in the spending plan.

The person-centered plan (PCP) also is a strengths-based approach, unlike the medical model of disability often used by agencies and systems to determine what types of services and supports an SDP participant qualifies to receive.

It is important to always focus on the life and voice of the person served by the regional center when using the Self Determination Program to meet a person’s support needs. Person-centered direct supports and effective independent facilitation elevate the wants and needs of the person served above those of their circles of support. These desires and needed supports are the center of California’s Self Determination Program.

2.1: Why Person-Centered Practices Matter

Page ID 65715

DDS on Person-Centered Planning

The Department of Developmental Services (DDS) explains why person-centered planning matters in self determination. In the SDP FAQ area of the DDS

Person-centered planning is about the individual's future and reaching their goals. The process should be driven by the individual and reflect what is important to and for that person. Person-centered planning can include other people, such as family or friends, only if the individual chooses to include them in the process. Once the individual has made choices about what he or she wants and needs, an individual program plan (IPP) is written based on the individual's decisions. The IPP lays out the individual's goals and what is needed to reach those goals, including necessary services and supports.

Without the SDP participant, there is no self direction. Being self determined is the core of this program. That means that as the independent facilitator, your role is to ensure the voice of the individual served is the focus of everything connected to the SDP planning process.

To be clear, individuals served by the regional center are in charge of their lives, plans, and desires — not their family nor the people who work for them.

This means the voice of the individual served by the regional center is heard and accurately reflected in all SDP planning. The person at the center of the program is the boss. They are the authority on their own lives, and as an independent facilitator, it is an honor and a privilege to support them in the ways they see fit.

Circles of Support

This does not mean that family members are not a part of the circle of support if the SDP participant chooses to include them. An SDP participant can include any person willing to provide support and input on their planning. Using the circle of support tools available through the inclusion.com website, explore the tools available.

If a participant does not wish to invite someone to participate in their circle of support, they should not be compelled to do so. Even if the participant is conserved. This may sound problematic, and it certainly could be. However, the participant's wishes are fundamental to the validity of the Plan. The independent facilitator may need to have some awkward or challenging conversations with people who believe they are integral to the participant's success.

As the parent of a regional center client myself, I cannot imagine how I would react if my daughter did not want me to be part of her planning team. However, if she asked me to step back and not participate, there would be a reason. Everything she does has purpose even when I struggle to see it. Hopefully I will continue to value and respect her autonomy long into the future. Hopefully I will have the confidence in how my husband and I raised her to know she is equipped to choose people she trusts to support her. And hopefully we will maintain a wonderful relationship throughout our lives. If at some point she wants me to step back, I hope I take a deep breath and do as she asks gracefully.

As an independent facilitator and a parent of a minor, this line might be blurred today. However, if in adulthood, a participant does not want their parent to play an active role, it is likely there is a reason why. Successfully navigating these relationship dynamics could be key to understanding why SDP is the best fit for the participant. Listen with more than your ears to these conversations and interactions. Listen to what a parent says when their loved one is not in the room.

Using the PCP to identify services and supports

In conversations with service coordinators, the participant and their circle of support will explain situations and allow the service coordinator to make suggestions of possible services in the traditional system. By describing the goals and what needs to happen to meet the goals, service coordinators can think of traditional system services that would be authorized to meet those goals and needs.

Here are some common traditional system services:

- Adaptive Skills Training
- Independent living skills/supported living skills (depending on where the adult lives)
- Individual training and education
- Parent Education
- Respite

- Social Skills Training
- Social/Recreational Services

There are many more listed on the Regional Centers Services and Descriptions page of the DDS website.

Additionally, California's State Council on Developmental Disabilities recently unveiled a tool to better understand services available through the regional center system. The page, entitled, "Types of Regional Center Services" can help people better understand the role of the regional center system in the lives of people who qualify for services.

Because we strive to ensure person-centered practices are embraced, independent facilitators know that not all participants will have the same services that their friends have. One area of constant struggle in this program is the focus on what others have.

For example, a family served by an IF wants to increase their budget. The parent of a person served by a regional center tells their IF, “My friend’s son got _____ from her regional center. I want my son to have the same thing.”

When confronted with a “keeping up with the Joneses” request, there are important things to keep in mind:

1. Person-centered plans show what the goals are and provide ideas of how to meet those goals.
2. No two people served by the regional center system have identical needs.
3. Other people served by the regional center system may have different needs than your client.

As a professional in this field, help the people you serve understand the beauty of this program. Choice, freedom, and authority are all key principles of self determination. However, responsibility and support are equally important. We are stewards of an amazing, tax-payer funded program. For it to be sustainable, we must all work together to use these funds wisely. Keeping up with the Joneses is not our mantra. Getting more “stuff” is not our mantra.

> Our mantra is “when my needs are met, I am content.” If needs are not met, then the program is not working, yet.

To ensure the needs are met, it is vital to document them in the Individual Program Plan (IPP). Once needs are documented in the IPP within the traditional system, the budget creation process becomes much easier.

Recently, the Department implemented a statewide person-centered IPP template. Consider this new IPP process to be a framework moving towards the ideal of person-centered practice. It is a skeleton. The bones of the plan are present, and there is a huge opportunity to use the framework in positive ways to meet people’s needs.

This change from planning by filling in blanks and checking boxes to open-ended narratives about a person’s life has allowed service coordinators to lead conversations that get to the heart of people’s needs, desires, and hopes for their own futures. Use these opportunities to add information from person-centered planning activities into the official, and legally binding, Individual Program Plan.

One of the regional center’s main jobs is to ask questions about needs, circumstances and possible resources when a participant or an independent facilitator shares needs that are new to the regional center. This is a huge part of case management.

Ideally, the regional center service coordinators you work with are already highly skilled at talking with families about disability, explaining kinds of services regional centers provide, and finding services to support individuals served by regional centers. However, sometimes the participant and their circle of support have no idea what a regional center can or should be providing. At times, the regional center uses specific language, or jargon, focused on the disability-connected supports and services. This creates a wide gap in understanding between the regional center and those they serve.

As an independent facilitator, you have the opportunity to bridge that knowledge gap and help people navigate California’s unnecessarily complicated service-delivery system.

> **Quick Recap:**
>
> Person-Centered Planning matters because:
>
> - It can show what a person wants to be doing in their life.
> - It can provide insight about how to work effectively with a person.
> - It can elevate and center the voice of the person at the center of the plan.
> - It can focus the planning team on aspects of life that might be challenging and provide a starting point for collaboration.

2.2: Person-Centered Thinking Resources

Page ID 65716

Resource Links for Person-Centered Practices

- Inclusion Press: Circles of Support page
- Person-Centered Thinking Tools: Helen Sanderson and Associates
- Charting the Life Course, UMKC
- Inclusion: Person-Centered Planning: PATH, MAPS, and Circles of Support
- National Center on Advancing Person-Centered Practices and Systems Report in PDF format: Person-Centered Planning: Choosing the Approach that Works for the Person
- Citizen Network's Library Page

Person Centered Planning & Advocacy

by Tracy Love

Edited by Tracy Love and alisonloach

This text has wonderful interactive PCP tools. Use it to practice person-centered thinking activities and to solidify foundational knowledge.

If the button does not work, or if you are accessing this text in a print version, search for the text on the Pressbooks website using "person centered advocacy" in the search.

Networkecampusontario.pressbooks.pub | eCampusOntario Open Authoring Platform

Person Centered Planning & Advocacy

Author(s): Tracy Love

Editor(s): Tracy Love, alisonloach

Subject(s): The Arts

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Institution(s): Cambrian College

Language: English (Canada)

Common Person-Centered Thinking Activities

Helen Sanderson and Associates has instructions and downloadable tools to use.

- **4 plus 1 questions**
- **Communication Chart**
- **Decision making agreement**
- **Decision making profile**
- **Good day/Bad day**
- **Learning Log**
- **Matching Support**
- **Perfect week**
- **Presence to contribution**
- **Relationship circle**
- **Sorting important to/for**
- **The doughnut**
- **What's working/not working**

3: Person-Centered Communication and Plain Language

Page ID 44202

What we will learn

- How to use plain language
- About language around disability
- To identify and use strategies to improve interpersonal communication

Why Language Matters

As an independent facilitator, you have the opportunity to support people with developmental disabilities from all walks of life. California is a beautifully diverse place with people from all corners of the earth. Communicating with people effectively includes developing strategies to work with people in disability communities, as well as from diverse language and cultural backgrounds.

To ensure understanding of the Self Determination Program, you may find you need to explain California's systems to your clients and their circles of support. Doing this will undoubtedly include discussions about ableism and plain language. These explanations may be with individuals whose dominant language is English or one of the many other languages spoken in our state. It is vital to remember that these systems are baffling to English-dominant and English-learning people, alike. Using plain language, checking for understanding often, and comfort with discomfort are all key in communicating clearly.

Working with people from different cultures can enrich our lives and improve our empathy. Doing so with humility and grace can improve everyone's experience.

The next sections were written by Disability Studies faculty around the United States. The information in each section is important to have as a foundation in person-centered communication. Language around disability, using plain language effectively, and

Remember to always listen more than speak. The 80/20 rule is especially important in person-centered practice.

80/20 Rule

80% of the time, I listen.

20% of the time, I speak.

When the person-centered planner is speaking more than listening, it might be difficult to truly hear what the participant wants.

Deeper thinking about language in person-centered planning

In the next sections of this text, there is important foundational information about communication. Think of one person or one group of people you know you struggle to communicate with effectively. Perhaps it is a family member whose beliefs differ vastly from your own; maybe it is a person who uses AAC -- augmentative and alternative communication -- to communicate. Whomever you pick, think about communicating with this individual as you read about the various sections of this text. Reflect on strategies you might try to communicate more effectively and respectfully with this person.

3.1: Language and Developmental Disability

Page ID 44230

People with developmental disability, like people with any impairment, have diverse experiences and views on their own disabilities. Comedian and actor Zach Anner, who writes about his cerebral palsy, made a video with the Cerebral Palsy Foundation for their "Just Say Hi" campaign (2015), which urged strangers to greet people with cerebral palsy and other disabilities. In response to the Cerebral Palsy Foundation's "Just Say Hi" campaign, disability rights scholar Kim Sauder, who has cerebral palsy, noted, "rather than telling people to 'just say hi' a more appropriate lesson would be to make it clear that disabled people should have the right to exist in public without comment" (2015, para. 13). None of us can assume that we know which terms a person with a specific impairment prefers. Even two people with the same impairment might want to be called different terms.

Just because somebody has a diagnosis does not mean that they will identify with the diagnosis, or even identify as disabled at all! The same label might mean vastly different things to two people. Rebecca Monteleone and Rachel Forrester-Jones (2017) interviewed fifteen British people labeled with intellectual disability. Some research participants had created their own definition of intellectual disability related in part to how others had treated them, and affirmed stigma surrounding intellectual disability. Monteleone and Forrester-Jones explained, "Identification of disability primarily relied on physical or tangible experiences of disability. The experience of disability in oneself was often accompanied by self-degradation or feelings of injustice, and the judgement of others played a role in perceptions" (Monteleone & Forrester-Jones, 2017, p. 308). They also found that some people with intellectual disability were unfamiliar with common disability terminology and uncomfortable talking about disability. The authors called for more accessible language access.

Dan Barry investigated a group of mistreated men. The men had intellectual disabilities. They worked in a meat processing plant in Iowa. Barry wrote about what he found in the *New York Times.* He also talked about words surrounding intellectual disability in the United States. Barry explained that language about intellectual disability has shifted over time. He wrote,

> *By the 1950s, the accepted term had become mental retardation. … But no matter how well-intentioned, this term also devolved into a pejorative, posing a problem for groups and government agencies whose names included the r-word. And as people with intellectual disability moved out of institutions and took their rightful place in the community, they began to advocate for themselves—and to express their loathing for the word "retarded." (Barry, 2016, paras. 16-17)*

Disability language continues to change over time. What is acceptable in one era is frowned upon in the next. Lawrence Carter-Long explained that over the course of his life, from the late 1960s to the present, "while my condition hasn't changed, I've been called handicapped, handi-capable, disabled, differently-abled, and a person with a disability — the latter being an understandable attempt primarily by parents of disabled children to separate the disability from the person" (King, 2016). Despite the numerous different labels applied to his life, Carter-Long emphasizes that "my condition hasn't changed" (King, 2016). What he means by this statement is that the view of him as a person, the view of his impairment, and the "proper" way to talk about disability changed rapidly. But the whole time that he was referred to by differing labels, Carter-Long still had the same impairment, cerebral palsy. He didn't change, though the disability terminology changed, and in some ways, society's view of him and his disability changed, too. Terms fluctuated from the offensive to the euphemism, from identity-first to person-first.


Advocacy and self-advocacy helped shut down Pennhurst State School and Hospital, a Pennsylvania institution known for abuse and violence against people with developmental disability. One crumbling and abandoned campus building is shown here in 2014. No Admittance. Photograph. *Thomas James Caldwell*. *CC BY*

3.2: Accessibility

Page ID 44227

Summary: Accessibility

- Accessibility is the quality of being able to be used, reached, entered, engaged with, or obtained
- Reasonable accommodations are modifications made to a person's environment to make something accessible to someone with a disability
- For something to be accessible, it needs to be able to be physically, cognitively, and socially reachable
- Universal design makes things accessible to everyone, but care must be taken to address conflicting access needs

This book frequently discusses "accessibility." Accessibility will come up in the context of civil rights and equitability, and in the context of history and policy. Accessibility is woven into disability culture itself, and is made explicit in the tenets of critical frameworks such as disability justice.

Awareness of accessibility is part of thinking critically about disability, including how lack of access relates to structural ableism. Exercises [ADD LISTING AND LINKS] give you an opportunity to practice your own awareness of accessibility in the world around you. This textbook also aims to demonstrate some key aspects of accessibility.

This introductory section provides some foundational information about what accessibility means and how it can be implemented.

What Is Accessibility?

"Accessibility" is the quality of being able to be used, reached, entered, engaged with, or obtained. If that seems very broad, it is. Accessibility can apply in many ways to many settings; for example "is that activity accessible to people without disposable income?" or "please do not make that accessible to the toddler." Here we focus on accessibility in the context of disability. In other words, can people with disabilities use, reach, enter, engage with or obtain something.

Reasonable Accommodations

Unlike the broad concept of accessibility, "reasonable accommodations" only exist in the context of disability. Reasonable accommodations are modifications that are made to a person's environment in order to make something accessible to someone with a disability. The term is connected to the Americans with Disabilities Act (ADA), a disability policy and law that is discussed in more detail in Chapters 4 – 7.

Reasonable accommodations do not make things easier for disabled people. They make things possible.

Types of Accessibility

Accessibility is a large, interdisciplinary topic. It is of interest to engineers who design doors, designers who create user interfaces for software, special educators who work with students in classrooms, occupational therapists who work with patients in hospitals, stage managers who coordinate theater spaces, and countless others. There is more than one framework (Chapter 2) for understanding accessibility. For our purposes we will use the Information Worlds framework [REF].

Physical accessibility – Can people use it?

Physical accessibility relates to being able to manipulate, employ, or otherwise make use of something. For example, can people see the picture? Can they see visual formatting such as bold text or line breaks? Can they hear a recording or a sound that indicates a warning? Can they pick up the tool and use it? Can they enter the building?

Examples of strategies to improve physical accessibility might be image descriptions or descriptive text for movies, tags that indicate the meaning behind visual formatting, subtitles for films or transcripts for podcasts, a light that displays along with a warning sound, specialized grips on tools, wheelchair ramps, lower counters, or sign language interpreters.

? Try It: Image Descriptions for Physical Accessibility

There isn't a single right way to describe images for people who cannot view them. Some people think it's best to be very precise and literal; others think it's best to capture the essence of the image. There's even a group turning image descriptions into poetry (Chapter 8).

In deciding how to describe an image, it may be helpful to consider the context in which the image is being used. Is it purely decorative? If not, what is the critical information it is providing? Is that information very specific, like a technical diagram, or is it more for the image's emotional impact, or maybe to show what a speaker looks like? Another thing that may be helpful is to ask yourself, "If I was talking to someone on the phone and couldn't text them this image, how would I describe it to them?" In any case, the image description should be short and pithy.

Imagine that the first image is included on a web site about disability-related discrimination. What text would you use to describe it for someone who could not view it?

Imagine that the second image is used by a family reading app to introduce the two hosts of the program. What text would you use to describe it to someone who could not view it?

Cognitive accessibility – Can people understand it?

Cognitive accessibility relates to being able to comprehend something. Do the words make sense? Are the sentences clear? Was the necessary background included? Were acronyms defined? Is it possible to figure out where to go, where to look, or what to focus on? Is it clear what the images or diagrams mean?

Examples of strategies to improve cognitive accessibility might be using plain language (optimizing writing for a specific audience); providing easy-read versions of materials; presenting the same information in more than one way or multiple types of media; or using summaries, bullets, or highlights to emphasize key information.

Plain language is language that enables people to find what they need, understand it on the first try, and use it to meet their needs (https://www.plainlanguage.gov/about/definitions/). Using plain language does not mean "dumbing down;" all of the key information needs to be retained, just delivered in a more accessible way. Plain language also does not always mean using simple words; indeed, sometimes removing technical terms or acronyms makes things harder to understand or removes key information. One example of this is that patients may not understand when healthcare providers ask, "would you like us to push on your chest and put a tube down your throat," but they may be able to understand asked, "would you like us to give you CPR?" However, the technical terms may need to be defined or explained.

? Try It: Plain Language for Cognitive Accessibility

Consider the following statement of rights from the American's with Disability Act Subpart C:

No qualified individual with a disability shall, on the basis of disability, be subjected to discrimination in employment under any service, program, or activity conducted by a public entity.

How might you rewrite the text in language that's accessible to a disabled adult with a middle-school reading level who needs to know their rights?

Social Accessibility – Can people reach it economically / culturally?

Social accessibility relates to being able to reach or engage with something from a socio-economic, geographic, or cultural perspective. People in general—and that includes people with disabilities—have a variety of lived experiences and come from many different regional or cultural backgrounds. Disabled people also may intersect with disability cultures and bring those backgrounds with them as well.

Examples of strategies to improve social accessibility are being mindful of assumptions regarding lived experience or material access (for example, not assuming everyone has been able to travel abroad, or that everyone can pay for a coffee if someone in your group wants to meet up at a coffee shop); avoiding language that is derogatory or offensive; and using symbols that the community values.

Social accessibility can be particularly difficult to achieve, in part because of the way that ableism is engrained in our culture. It can also be difficult for outsiders who may not understand the history and culture of specific disability communities. One example of this is the use of the puzzle piece symbol to represent autism. Outsiders to the Autistic community who have little insight into how the symbol has been used as a means to oppress autistic people may think it's appropriate to use; however it is likely to turn off—or outright offend—most autistic people. To make materials more socially acceptable, instead use one of the community's own symbols such as the rainbow-colored infinity symbol. Like the nuances surrounding respectful language, if you don't know the socio-political landscape of a disability community, ask insiders before taking action.

Universal Design

Universal design is about creating things to be accessible for everyone. Universal design posits that making something more accessible to disabled people also makes it more accessible to everyone else. For example, the multi-use of wheelchair ramps for baby carriages, shopping carts, rolling suitcases, people who use other types of mobility devices, and anything else with wheels or difficulty climbing that needs to get up the stairs.

While in theory universal design is a way to improve life for everyone, in practice it can meet with barriers when accessibility needs conflict. For example, making a piece of writing cognitively accessible to someone who requires a lot of specificity and technical jargon to accommodate their language pragmatics or social disability may make it inaccessible to someone who requires simple words and short sentences to accommodate their learning disability. In these cases, it may be necessary to compromise or to provide multiple ways of doing something to cover everyone's access needs.

Further Reading and Resources on Accessibility

Plain Language Resources

- https://www.plainlanguage.gov
- https://centerforplainlanguage.org/learning-training/

Resources for Audio and Visual Accessibility

- Ways your native operating systems and common programs can help create transcripts
- How to write good image alt text, with examples

General Accessibility Resources

- Really comprehensive, practical "How To" resource from Harvard that focuses on accessibility for people creating content (that would be you in this class!).
- Web Accessibility Laws and Policy
- Small intro to Universal Design

3.3: The Language of Disability

Page ID 44226

Summary: The Language of Disability

- Language matters because it shapes our mental models
- The language of disability is evolving, context-dependent, and not absolute
- A good rule is to use the preferred language of individuals and communities, and ask when uncertain

How we talk about something shapes how we, and others, feel about it. Language creates narratives, or the stories we tell. It influences discourse, or the conversations we have. Language can be empowering or marginalizing. Cultures and communities often have their own words for things; indeed shared language is one of the characteristics that defines a community. The words a person uses can reveal their values and their world views.

Throughout this text, we will trouble at the language and definitions of disability, unpack disability narratives, and encounter a variety of ways that disability communities use language. The following definitions provide a starting place for this further exploration.

Starter Definitions

Disability – Very loosely, something that makes it harder for someone to do things than people who don't have that same characteristic or circumstance. However, the definition of disability is very complicated and depends on which mental model a person is using to represent disability. Chapter 2 will unpack the definition and meaning of "disability" further and introduce multiple models of disability.

Ableism – Discrimination and prejudice against people with disabilities or people who are perceived as disabled. That is, treating someone differently on the basis of disability or perceived disability.

Structural / systemic / institutionalized ableism – Ableist narratives, practices, and world views that are so much a part of what people accept as normal that they typically go unnoticed or are presumed as facts of reality.

Referring to Disability: Choosing the "Right" Language

The language used to refer to disability and disabled people has changed significantly over time, and continues to evolve. Some terms may be more obviously offensive, such as the outdated euphemism of "differently abled," or "the 'R' word" which people find so offensive the US government passed legislation to remove it from federal documents (Rosa's Law). However, knowing how to respectfully refer to disability and disabled people after that quickly becomes context dependent and complex.

Person First vs. Identity First Language

"Person first" language is intended to literally "put the person first before the disability." Examples of person first language are "person with a disability," "woman with intellectual disability," and "artist with cerebral palsy." The movement toward person first language grew out of protest to the dehumanization of being treated like a health condition and not like a person.

"Identity first" is intended to treat disability as an identity. Examples of identity first language are "disabled person," "Deaf woman," "autistic artist." The movement toward identity first language also grew out of protest to dehumanization; however, it uses a different mental model (see Chapter 2) that views disability as an important and integrated part of one's identity.

While both person first and identity first language emerged as ways to refer to disability in a more humanizing and respectful way, they are grounded in very different views of disability. Person first language treats disability as a medical condition, and seeks to decouple the person from that condition—"I am seen as a person instead of a condition." Especially for highly stigmatized medical conditions (e.g., person with HIV) this can be an important distinction.

Identity first language treats disability as just another aspect of a person's identity such as gender, nation of origin, or religion. It seeks to integrate disability as one aspect of a whole person. Proponents of identity first language feel that disability should not be separated from the person, because, although it may be marginalized, it is not undesirable. In other words, it should not be stigmatized but instead celebrated.

Regional Differences

To further complicate the question of how to refer to disability, these are rationales are specific to disability in the United States. In other countries where disabled people have similarly fought for increased rights and respect, use of respectful language evolved in different ways. So what is respectful in one country or culture may be disrespectful in another.

Insider Language

Recall that shared language is a part of what makes community and culture. Disability communities also include insider language to refer to disability or to themselves. Some examples of insider language are “crip” (a reclaiming of the work “cripple” by the cross-disability community) and “autie” (a “nounification” of autistic used within the autistic community).

Some insider language may be acceptable for people outside the community to use, particularly when people with disabilities have explicitly used it to name to something outside of community spaces. For example, “crip lit” as a literary genre. However, insider language can often be disrespectful when used by people outside of the community

> *Characteristics that are recognized as central to a person’s identity are appropriately stated as adjectives, and may even be used as nouns to describe people: We talk about “male” and “female” people…not about “people with maleness” and “people with femaleness.” We describe people’s cultural and religious identifications in terms such as “Russian” or “Catholic,” not as “person with Russianity” or “person with Catholicism.” We describe important aspects of people’s social roles in terms such as “parent” or “worker,” not as “person with offspring” or “person who has a job.” We describe important aspects of people’s personalities in terms such as “generous” or “outgoing,” not person first language as “person with generosity” or “person with extroversion.” Yet autism goes deeper than culture and learned belief systems. It affects how we relate to others and how we find places in society. It even affects how we relate to our own bodies. If I did not have an autistic brain, the person t’hat I am would not exist. I am autistic because autism is an essential feature of me as a person.’*
>
> – Jim Sinclair, Why I dislike “Person First” language

So What Language Do I Use?

Some readers may come to this text having been taught that they must use person first language to be respectful. However, not only is there no hard rule, but many people find identity first language more respectful.

Some communities have strong opinions about which language to use. For example, the intellectual disability community generally prefers person first language, while the Autistic community generally prefers identify first language. Use the language the community prefers when speaking generally about the community or population, or when you have no other way to determine a preference. For example, if you’re talking about the population of people who have been diagnosed with an autism spectrum condition, use “autistic people” (identity first language) to reflect community preferences.

On an individual level, you can use a strategy called “person-centered language.” That means, literally, to center the person’s own preferences for how they would like to be called. In other words, ask them what terms they would like you to use. For example, “What language do you use to describe yourself? Would you like me to use that language too?”

This textbook defaults to community and individual preferences with respect to language where known, and otherwise uses both identity first and person first language interchangeably.

? Try It Out: Unconscious Use of Language

Which “sounds right” to you?

- Deaf person or person with deafness
- Downs Syndrome person or person with Downs Syndrome

- Blind person or person with blindness

Did the answer surprise you?

These communities have worked hard to instill their language preferences into U.S. culture. Deaf communities and Blind communities have a cultural preference for identity first language so most people will feel like Deaf person and Blind person "sounds right," whereas Down Syndrome communities have a cultural preference for person first language so most people will feel like "person with Downs Syndrome" "sounds right." The point of this exercise is not to get the answer "right" but to show how when language preferences become part of a broader society, they can become unconscious. We use them without being aware of what we've done. Critical disability provides tools to increase our awareness of this kind of phenomen.

Further Reading on Language

- Emily Ladau on disability language https://www.thinkinclusive.us/post/why-person-first-language-doesnt-always-put-the-person-first
- Avoiding anti-ableist language in autism research (and elsewhere): https://www.liebertpub.com/doi/10.1089/aut.2020.0014
- Insider language: cripping – https://crippingthecon.com/more-on-what-cripping-means/

3.3.1: Notes on "The Language of Disability" (Raymaker)

Page ID 65765

Observations from a parent of a person with Down syndrome

In Raymaker's discussion of person-first language, she uses Down syndrome as an example within the Identity First (IFL) and Person First language (PFL) model. She asks people to think about these examples:

Try It Out: Unconscious Use of Language

Which “sounds right” to you?

- Deaf person or person with deafness
- Downs Syndrome person or person with Downs Syndrome
- Blind person or person with blindness

In the United States, there is no "s" at the end of Down. John Langdon Down, the person for who the syndrome is named, did not have Down syndrome. He described it. Thus is it not a possessive "Down's" nor is his last name "Downs". Down syndrome -- capital "D" for Down, lower case "s" for syndrome.

The example should read:

- Down syndrome person or person with Down syndrome

While I am grateful, Raymaker used the entire medical condition, instead of the offensive, "Downs" reference, independent facilitators should be aware of this language.

Further, in recent years, referring to a person as "Downs" has become less acceptable to younger generations. This has likely been influenced by the medical community's use of "Downs" as an excuse to not treat medical questions that parents/advocates address. Instead of digging deeper into a medical condition, we often hear, "That's a 'Downs' thing" when the condition may or may not be connected to the triplication of the 21st chromosome.

Down syndrome is a diagnosis that, for better or worse, brings to mind certain stereotypes. Grammatically speaking, it is a noun that has not been accepted as an adjective, so using "people with Down syndrome" makes a lot of sense. There is no need for a nickname for medical conditions.

3.4: Community

Page ID
44228

Summary: Community

- A community is a mutually-supportive group of people who share a common culture, language, and purpose
  - There are multiple, diverse disability communities
- The individuals who make up disability communities are also diverse, and members of multiple other communities
- This book seeks to incorporate as many disability communities and disabled voices as possible; however the impossibility of full representation is one of its limits

A population is a group of people who share some characteristic, for example the population of people who have a hearing loss, or the population of people with brown eyes. When this text uses the word “population” it is in this way.

A community may include members of a population, but it is defined differently. A community is a group of people with shared history, values, culture, language, and symbols which provides members with mutual support and a sense of belonging. When this book refers to disability communities or to a specific disability community, like the Deaf community, it is in this way.

The use of plural (disability communities) and singular (Deaf community) in the previous paragraph is very deliberate. For people who have not spent a lot of time connected to disability culture, it might seem like there is—or would be—a single “disability community.” However, disability is a huge domain with many different populations and disability communities are many, diverse, and sometimes overlapping.
Disability communities may form around type of disability, use of specific types of assistive technology, common goals or priorities, intersecting identities, a particular shared history, specific interests or vocations—anything that a community could form around. Disability culture is rich, diverse, and continuously evolving, even when it is marginalized or left out of mainstream discourses. Disability studies focuses on that richness and brings it into the center.

While this text includes history, quotes, perspectives, and contributions from as wide range of disability communities as possible, there are as many and more communities not represented here. As with the other limitations in this textbook, I enthusiastically encourage readers to seek beyond the boundaries to other communities and their contributions to the world. Disability culture is rich and rewarding, and worth taking a place at center.

3.4.1: Evolving Language- Language and the Self-Advocacy Movement

Page ID 44229

Nowadays, there are many types of advocacy and self-advocacy. Advocates do everything from fight for individual inclusion in the workplace and blog about disability rights to lobby for law changes and educate family members and professionals to participate in protests and civil disobedience. Social media sites, like Facebook and Twitter, have changed activism. People can connect with disability communities through the internet regardless of access to transportation and participate in social media activism campaigns. Language is the focus of some disability activism.

Eugenicists created language like “moron,” “imbecile,” and “idiot”. These terms were once medical labels for people with intellectual disability based on IQ scores. According to Thomas Armstrong (2010),

> *It was Goddard who first coined the term ‘moron’ (from the Greek word moros, which meant ‘dull’) in 1910, a word that was later applied to people who achieved an IQ score of 51 to 70. Those who scored from 26 to 50 were known as ‘imbeciles,’ and those with an IQ of 0 to 25 were deemed to be ‘idiots.’ These were actual scientific terms used by professionals to describe low-scoring individuals on IQ tests in the first half of the twentieth century. (pp. 141-142)*

Once simply medical labels, words like “mentally retarded” devolved into ableist slurs (Barry, 2016). People with intellectual disability, and allies inside and outside of disability communities, have successfully campaigned against use of the “r-word” (Special Olympics, 2017). As Matthew Williams, who has epilepsy and an intellectual disability, said in his 2015 TEDx Talk,

> *There has been lots of change since Special Olympics began in 1968, but in too many cases, people with intellectual disabilities are invisible to the wider population. People use the r-word in front of me, and they think it doesn’t matter. That’s the word “retard” or “retarded” used in a derogatory manner. They’re not thinking about how much it hurts me and my friends. (Williams, 2015)*

Beyond everyday speech, the advocacy also impacted the way the U.S. government writes disability policy. In 2010, President Obama signed Rosa’s Law, which with the purpose “to change references in Federal law to mental retardation to references to an intellectual disability, and change references to a mentally retarded individual to references to an individual with an intellectual disability” (P.L. 111–256, 2010). This legislation amended education, health, and disability rights laws, removing the outdated and offending language and replacing it with preferred language of “intellectual disability.” Rosa’s Law is one example of how language used around disability is important, and why some advocacy focuses on shifting disability terminology.

Language around developmental disability has changed over time, but offensive terminology remains

New York State Institute: a group of girls with Down's syndrome, standing on some steps. Photograph. Credit: Wellcome Collection. CC BY

More language advocacy must still be done at other levels of government. People with developmental disability have higher rates of abuse than nondisabled people. NPR investigated and found that "unpublished Justice Department data on sex crimes… show that people with intellectual disabilities — women and men — are the victims of sexual assaults at rates more than seven times those for people without disabilities" (Shapiro, 2018). Meanwhile, some states still use offensive disability terms from eras when eugenics was considered a legitimate science, especially in legal proceedings. For instance, in court proceedings surrounding sexual assault, the State of New Jersey uses the terms "physically helpless," "mentally defective," and "mentally incapacitated" to describe people with developmental, mental health, and/or physical disabilities who are victims/survivors of sexual assault (N.J.S.A. 2C:14-3a [2C:14-2a(7)]). Court proceedings around consent should not dehumanize abuse victims with disabilities and survivors with disabilities through old-fashioned language.

Erasing **euphemisms** in favor of clear-cut words is another facet of disability language advocacy. Euphemisms are ways of not saying things straightforwardly. So rather than saying somebody has a disability, using a euphemism might mean saying somebody has "special needs." Lawrence Carter-Long began a social media campaign, #SayTheWord, with this goal in mind, and other disability rights advocates enthusiastically jumped in. Jamie Davis Smith for the *Washington Post* reported that Carter-Long advocates for "disability" over "special needs": "'A need isn't special if other people get to take the same thing for granted,' he says, arguing that using terms like 'special needs' can obscure access to having those needs met, because they can make ordinary needs seem extraordinary" (Smith, 2017).

Morton Ann Gernsbacher, Adam R. Raimond, M. Theresa Balinghasay, and Jilana S. Boston (2016) agree that euphemisms like "special needs" detract from disability discussions. After the authors created stories about characters, who they either labeled with "special needs," "a disability," a specific impairment, or no impairment, they surveyed adults with and without connections to disability, asking them to rank the characters in terms of preference and to complete a free-association task around the words "special needs" and "disability" (p. 6). **Free association** is when people think of every word that comes to mind about a particular topic. So the researchers would ask their participants to brainstorm about the phrase "special needs," and the word "disability." The researchers categorized and analyzed the lists of words associated with "special needs" and "disability." They concluded that the term "special needs" was vaguer, more negative, and more associated with "special rights" and "segregation" than the word "disability" (p. 9). Interestingly, "Participants were significantly more likely to associate developmental disability with the euphemism *special needs* than with the term *disability*" (p. 8). When general public hears "special needs," they may think of people with developmental disability, but they also link "special needs" to negative words, segregated settings, and the idea that accommodations are going above and beyond. This free association may speak to the stigma and ableism surrounding people with developmental disability in particular. Gernsbacher, Raimond, Balinghasay, and Boston argue against using the euphemism "special needs" for these reasons.

Disability rights advocates are fighting to use the language they choose to define themselves. People in some disability communities overwhelmingly prefer identity-first language ("disabled person") or person-first language ("person with a disability"). For instance, many autistic people prefer identity-first language ("autistic person") (Kenny et al., 2015). Communities may collectively prefer one over the other for historical and advocacy-related reasons. In 1999, Jim Sinclair, an autistic advocate and community-builder and co-founder of Autism Network International, argued for identity-first language ("autistic person") and against person-first language ("person with autism.") Sinclair's reasoning was three-fold: One, separation versus integration of identity; two, importance versus lack of importance of identity; and three, moral values attached to identity. Sinclair's first reason for preferring "autistic person" is that "saying person with autism suggests that the autism can be separated from the person. … Autism is hard-wired into the ways my brain works. I am autistic because I cannot be separated from how my brain works" (Sinclair, 2013). So one argument for identity-first language is integration of disability into a person's identity, rather than separating disability.

Sinclair's second reason for preferring identity-first language is that "saying person with autism suggests that even if autism is part of the person, it isn't a very important part. … We talk about male and female people, and even about men and women and boys and girls, not about people with maleness and people with femaleness" (Sinclair, 2013). In a similar sense, Sinclair argues that "person with autism" makes autism appear incidental, or like something that could be removed or not mentioned without changing the person underneath. Yet Sinclair and many other autistic adults view autism as a core aspect of identity that affects everything else about their experience as a human being. This argument for identity-first language is that disability is an important identity that shapes lives.

Sinclair's third reason for disliking person-first language is the message it might send about the value of autism, or autistic lives. Sinclair writes:

> *Saying person with autism suggests that autism is something bad—so bad that is isn't even consistent with being a person. Nobody objects to using adjectives to refer to characteristics of a person that are considered positive or neutral. …It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person. I know that autism is not a terrible thing, and that it does not make me any less a person. (Sinclair, 2013)*

Disability is too often seen as negative. Sinclair resists this negative definition of disability by putting autism at the center, and that autism is a part of or one way of being a person.

Just as Jim Sinclair argues for identity-first language, other people with disabilities argue for person-first language. Some early self-advocates with developmental disability favored "people with disabilities" over "disabled person" due to focusing on personhood rather than impairment. One large self-advocate group got its name because of this very reason. After attending a Canadian self-advocacy conference in 1973, people with developmental disability in Oregon gathered to plan their own the following year (The Minnesota Governor's Council on Developmental Disabilities, 2019): "At this planning meeting, one man talked about being labeled 'mentally retarded' and said, 'I want to be known as a person first!' People First was later chosen as the name for a new self-advocacy organization" (The Minnesota Governor's Council on Developmental Disabilities, 2019). As an act of empowerment, some disabled people seek to reclaim ableist slurs and repurpose these terms for their own use. It's important to recognize that reclaiming offensive language is only something that members of the marginalized group can do, not people without disabilities. For instance, some people with disabilities choose to refer to themselves as "crips." Disability studies scholar Simi Linton says, "*Cripple*, *gimp*, and *freak* as used by the disability community have transgressive potential. They are personally and politically useful as a means to comment on oppression because they assert our right to name experience" (Linton, 1998, p. 17). It's OK for people with disabilities to call themselves words that society recognizes as offensive. It's best to ask each individual person with developmental disability what language they prefer to be called if they can communicate this information. Otherwise, it's best to make sure you use respectful, up-to-date language to talk about any person and their disability.

Language can be used to help or hurt, and the words used to describe people can be used to justify discrimination. As the R-Word: Spread the Word to End the Word campaign website puts it, "Language affects attitudes and attitudes affect actions" (Special Olympics, 2017). Why focus on language? Words hold great power.

4: Creating a Person-Centered Spending Plan

Page ID 64808

What we will learn

- What will be included in a spending plan
- How to make sure the spending plan reflects the person-centered plan
- How to identify services that support a participant's goals and desires.

Guide participants through the spending plan process

As you create a spending plan, make sure you explain how the spending connects to the person-centered plan. Much like in an IEP, each staff person, activity, and purchase in the person-centered spending plan should refer to a goal in the PCP. If there is not a direct connection between the goal and the proposed spending, it should not be there.

Verify spending is connected to PCP goals

Much like people in school have an **Individualized Education Plan (IEP)**, people served by California's regional center system have an **Individualized Program Plan,** widely referred to as an IPP. The IPP should reflect the needs and wants of the person served. If the IPP does not reflect a person's needs and wants effectively, the participant can ask the service coordinator to improve the plan to make it more accurate and reflect the individual's real life.

An individual's authorized services and supports are reflected in the IPP. This is a legal document that is required by the Lanterman Act.

Many people served by the regional centers and their circle of support fail to realize the importance of the IPP. If an IPP is accurate and contains all needs, this can make the budget authorization process in the Self Determination Program process easier. Each regional center has its own procedures for this, of course, but an inaccurate or vague IPP can be problematic for budget creation.

If the IPP does not reflect a person's reality, the budget creation process can be very difficult. It seems this is where many struggles between the regional center and the SDP participant begin. One way to reduce conflict in this area is to make sure the IPP is accurate, up to date, and includes what life currently looks like for the individual served by the regional center.

The person-centered plan should be the place where all of a person's strengths and passions are shared, and it can also focus on how the individual would like to be spending their time. Some people want to be working. Others volunteer. Still others want to participate in activities in the community. Once this is known, the regional center should offer a service that meets the individual's needs. When the service is provided in the traditional system, the individual will participate in the service provided by a vendor of the regional center. However, in the Self Determination Program, the funds that are approved for the traditional service can be used creatively to meet the needs in many different ways. Those different ways of using the funds are the line items of the spending plan

What spending plans include

Spending plans include detailed information about the supports and services an SDP participant will use over the course of a year. This includes staff, worker's compensation (in the sole employer model), and all anticipated supports for the year.

Sounds hard, right? How are we supposed to know exactly what will be needed for twelve whole months. Thankfully, independent facilitators often carry a crystal ball in their pockets. For those of you who have either forgotten to carry one or have not yet gotten a crystal ball, there are ways to plan for a year-long plan focused on the PCP.

Teachers call this "beginning with the end in mind". Other professional fields likely have their own catchy phrases. The idea is start at the end of the year. Where does the participant want to "go" in SDP? Then, break down the steps and create a plan to get to a *part* of the goal. Some goals are long-term; others are shorter term. It is important to plan for reasonable steps towards a goal.

The services and supports in the spending plan are the disability-related supports and services to help meet the PCP goals.

In the spending plan, the IF or the participant will include as much detail as is available. This will help minimize mid-year edits and changes, which, by all accounts, are no fun.

- Staff
- Services
- Names of businesses that provide the service
- The cost of the service

- Duration and Frequency
- IPP/PCP goals (adding the PCP goals into the IPP helps ensure the PCP goals are reflected in the spending plan)

Additionally, AB 143 changed statute to require regional centers to certify spending plans.

The DDS SDP Directive released on November 25, 2025 includes clarification of what should be in a spending plan.

Services and supports in the spending plan:

- Address the goals in the individual's IPP.
- Are not available from generic services, including but not limited to, Medi-Cal, InHome Supportive Services, services from other state departments such as the Department of Rehabilitation, and services provided by local school districts or private insurance.
- Are eligible for federal financial participation, which means the services or supports are eligible for federal funding and that the services have been approved by the federal Centers for Medicare and Medicaid Services.

4.1: Representing goals in the spending plan

Page ID 65719

Writing employment into a spending plan

To show you how the spending plan would address an employment goal, there are various supports an individual might need. Here is a sample goal:

Sample Employment Goal

Kelly will work at a job she chooses with the support she needs to succeed.

In the case of working at a great job, an individual might need someone to support them. This is referred to as a “job coach” in the traditional system. However in SDP, participants can write the job description creatively, hire someone specific to work with as a job coaching support provider, or even hire a support provider for different hours than the traditional system allows. This is one area of creativity in SDP.

To work at a job, Kelly, the person with the goal above, might need support in some of the following areas:

- Career coach: person to support Kelly find a job, write a resume, develop career and professional skills
- Transportation: Kelly rides a bike, but her job is far from the bike path. She needs help to learn how to mount her bike on the public bus’s bike rack.
- Transportation: The bus might not run at the times Kelly needs on Sundays. She might need to hire a driver, like Uber or Lyft, for occasional transportation needs.
- Schedule: Kelly uses a paper calendar well, but her employer uses an app to schedule her shifts. She wants to be at work on time, and she wants to use the same technology as he5: Person-Centered Services and Supportsr workmates.
- Professional appearance at work: Kelly might need support with laundry, fragrance, hygiene, or creating routines that support her success.

If there is an employment goal, but the participant doesn't quite know how to get to their dream job, yet, create a career development coach position and include it in the spending plan.

Be mindful of the service code definitions. If in the traditional system there is a need for a progress report for continued funding, the same progress report will likely be required in SDP. Prepare for that as you are creating the spending plan.

Deeper thinking about representing an employment goal in a spending plan

Take five minutes to create a list of everything that needs to go right for you to get to work, stay at work, and work at work.

- What are additional needs that Kelly might have to meet her employment goal?
- Are any of those things missing for Kelly?
- Is the Department of Rehabilitation an option for the supports needed?
- How will Kelly get to work on time?
- What kind of schedule (time of day/length of shift) will help facilitate success?

The spending plan can include a career coach, a transportation coach, and a technology coach so that Kelly can succeed at attaining and maintaining her desired job. These could be funded with various traditional service codes, depending on what your regional center provides. Consider describing all of the employment needs, hopes, and desires to your service coordinator. Work collaboratively with them to find creative ways to meet needs.

When an individual has a goal of being active and included in their community, it is important to remember that answering questions about that activity will help shape the spending plan and reveal needs that might lead to funding based on the traditional system.

5: Person-Centered Services and Supports

Page ID 58864

Person-Centered Services and Supports: Job Descriptions, Finding Employees, and Being a Boss

Identifying Person-Centered Services and Supports

One of the challenges people receiving regional center services face is feeling like they do not know what to request. Often this is where trust falters, and people feel overwhelmed. Using the service coordinator's expertise can help the SDP participant improve their lives, but understanding what the regional center can provide, based on the Lanterman Act services, can help all parties.

Helping Participants Find What They Need: Understanding Purchase of Services (POS) guidelines from regional centers

Here is a summary of Central Valley Regional Center's Purchase of Services policy document from 2024. Each regional center should have their own POS guidelines posted on their website. Take a minute to find the regional center that serves your community now.

The original document is from Central Valley Regional Center (CVRC). The CVRC Purchase of Services (POS) policy outlines how the regional center determines, authorizes, and funds services for individuals with developmental disabilities. All purchased services must align with the Lanterman Act, be based on the individual's needs and preferences, and be documented in an Individual Program Plan (IPP) or Individual Family Service Plan (IFSP). Keep in mind that purchases and services in SDP must also follow the Centers for Medicaid and Medicare services guidelines.

Independent Facilitators can use this structure to guide planning, help individuals advocate for services, prepare for IPP meetings, and ensure that requests meet regulatory requirements.

The policy emphasizes:

- Person-centered planning
- Use of generic resources first (e.g., Medi-Cal, schools, IHSS)
- Least-restrictive and cost-effective services
- Evidence-based supports only
- Service effectiveness and progress monitoring

Understanding these principles helps Independent Facilitators prepare strong, compliant justifications for service requests and support individuals in navigating denials, appeals, and exceptions.

Noncredit Community College Opportunities

California Community Colleges offer noncredit classes to the community. There are classes that are geared towards people with disabilities. And, there are short term business development certificates. One category of classes is the "Career Development and College Preparation" or CDCP certificates. These certificates are built to retrain, enhance skills, and lead to employment.

Noncredit course availability varies by college. MiraCosta and Mount San Antonio College has huge noncredit programs. Other colleges may have fewer course offerings, but they might be exactly what you are looking for.

Deeper thinking about person-centered services and supports

Here's an analysis activity to dig deeply into a PCP goal:

1. Consider the connections between the person-centered plan and the services and supports a participant needs to meet their PCP goals.
2. Choose one PCP goal.
3. Brainstorm all the things that need to happen for the goal to be met
4. Create a pathway to achieve the goal.
5. Now list every service or support that will be needed to achieve that goal.
    - Who/which organizations or agencies can provide the service/support?
    - How much will it likely cost?
    - What will success/goal achievement look like?

6. Prioritize -- which parts of the goal will be addressed in this year's spending plan?

6: Funding a Person-Centered Life

Page ID 64453

What we will learn

- What can be funded with SDP monies
- What cannot be funded with SDP
- Other ways to fund the unallowable costs of life with disability in California

The Self Determination Program is amazing! And many people who want to enter it have an incomplete understanding of the rules about funding. To best support our community, it is vital that independent facilitators understand the Centers for Medicaid and Medicare Services regulations so they can make recommendations and explain limitations of programs funded with tax-payer money.

This does not mean that a person-centered plan should not include dreams and goals that are not allowed under SDP. It simply means that SDP funds are ONE way to meet the needs, desires, goals, and planning in the life of the person served by the regional center system.

Unlike in the traditional system, cost savings strategies actually help extend budgets, allowing SDP participants to focus their funding allocation on the life-changing supports and services that thinking outside the box with SDP can provide.

A meaningful life filled with choice, control, and autonomy makes complete. Without these basic human rights, people can be marginalized and unfulfilled.

The next sections will focus on cost saving strategies that can help maximize budgets.

- Generic Resources
- Low Cost and No Cost Community Resources
- Innovation Highlight: Grassroots Tech Swap
- ABLE Accounts
- Gifts
- Nonprofits dedicated to specific support
- Self Determination Program Funding

6.1: Generic Resources

Page ID 65721

Note: If you are using the electronic/online version of this text, the **bold text** is meant to be a hyperlink to the generic resource.

The California Community Living Network (CCLN) has a generic resources help page.

From **the CCLN webpage on generic resources:**

Now more than ever, we are being asked to do more with less, including assisting our consumers to access ever shrinking generic resources. Here are some useful sites that other providers have found helpful.

- **In Home Support Services County Offices** - "IHSS" provides homemaker and personal care assistance to persons receiving Supplemental Security Income or who have a low income and need aid in the home to remain independent."
- **Disability Benefits 101 (DB101)** - Helps workers, job seekers, and service providers understand the connections between work and benefits: health coverage and benefit programs for workers and job seekers - descriptions of state, federal and private benefit programs, articles, guides to health and benefit programs, access to local resources, search engine, site map, tutorial, newsletter.
- **Disability Information on Government Resources** - Federal website committed to helping people with disabilities learn and develop skills, find meaningful work, and realize the promises of the Americans with Disabilities Act.
- **DRI – Disability Research Institute** - partnership between the Social Security Administration, Office of Policy, Disability Programs, and the College of Applied Life Studies at the University of Illinois, Urbana-Champaign (UIUC)—focuses on understanding the reality and impact of SSA income programs—SSI and SSDI—on applicants and recipients. Offers research, information, training and education, and data usage.
- **Government Benefits** - Asks questions about your status and offers suggestions about whether you might qualify for government benefits and from which programs; a coalition of federal agencies maintains the site.
- **GPO Access** - the Superintendent of Documents, U.S. Government Printing Office, has searchable databases to find government information, federal bulletin boards, Federal Register, Congressional Record, Congressional bills, United States Code, Economic Indicators, General Accounting Office Reports.
- **Social Security Disability Benefits:** A Primer (PDF, 168 KB) - For most U.S. workers and their families, Social Security Disability Insurance provides protection against loss of earnings due to disability. This primer provides an overview of the SSDI program, including who is covered, what benefits they receive, how the program is administered, and how it is financed.
- **Social Security Administration** - Has searchable information on benefits, how to apply, PASS, publications, ABA hotline numbers for children appealing SSI terminations.
- **Social Security - Frequently Asked Questions** - Questions, answers, and blanks to choose topics, request information, find more links.
- **Social Security - Disability Publications and Information** - Benefits for people with disabilities, with how-to, planners, publications, other languages, and more.
- **Social Security information** - English, Spanish and other languages.
- **Social Security - Supplemental Security Income (SSI)** - Questions and answers about SSI.
- **Seguro Social - Publicaciones en Español** - Información y publicaciones en Español.
- **Social Security - Regulations** - Social Security Program Rules home page.
- **U.S. Department of Housing and Urban Development**
- **Department of Fair Employment and Housing** - Protecting Californians from employment, housing and public accommodation discrimination, and hate violence.

6.2: Low Cost and No Cost Community Resources

Page ID 65722

There are many resources available in communities throughout California. The local recreation department or YMCA might have opportunities that would help meet some PCP goals.

Here are examples of no cost and low cost activities in the Bakersfield area.

ChatGPT and other gen-AI tools can help with ideas for community connections.

Below is what ChatGPT produced, with some editing and updates, when prompted to, "Create a list of low cost or no cost resources in Bakersfield to build community and increase happiness."

Here's a curated list of **low-cost and free resources in Bakersfield** that can help people build community, improve well-being, reduce isolation, and increase happiness. I've organized them by the research-backed factors that contribute to happiness: connection, purpose, movement, learning, creativity, nature, and service.

🤝 Community & Social Connection

Libraries (FREE)

Kern County Library

- Book clubs
- Craft nights
- Adult education
- Movie nights
- Technology classes
- Language conversation groups
- Family events
- Volunteer opportunities

Branches throughout Bakersfield and the surrounding communities.

Shafter Learning Center

The best, most welcoming library and community learning space... at least in Kern County.

Community Recreation Centers

City of Bakersfield Recreation and Parks Department

Offers:

- Pickleball
- Walking clubs
- Senior activities
- Fitness classes
- Community events
- Holiday celebrations

Many programs are free or under $20.

Farmers Markets

Great place for social interaction without needing to purchase much.

Examples include:

- Kaiser Farmers Market
- Haggin Oaks Farmers Market

Coffee Meetups

Local coffee shops often host:

- Open mic nights
- Bible studies
- Business networking
- Game nights

Examples include independent cafés around downtown and southwest Bakersfield.

🌳 Nature & Outdoor Activities

River Walk Park

The Park at River Walk

FREE

- Walking
- Sunset watching
- Bird watching
- Community events
- Outdoor concerts

Panorama Park

Panorama Park

- Scenic overlooks
- Walking paths
- Picnics
- Frisbee
- Photography

Kern River Parkway Trail

Kern River Parkway Trail

Miles of paved trail for

- Walking
- Running
- Cycling

Wind Wolves Preserve

Wind Wolves Preserve

FREE

Excellent for

- Hiking
- Wildlife viewing
- Wildflowers
- Photography
- Guided hikes

Hart Memorial Park

Hart Memorial Park

Great for

- Picnics
- Fishing
- Walking
- Family gatherings

🚶 Walking Groups

Many neighborhoods organize informal walking groups through:

- Facebook
- Meetup
- Nextdoor

Walking with others is one of the easiest ways to build friendships.

🚴 Active Living

Pickleball

Several public courts offer free play.

Popular locations:

- Jastro Park
- Greenacres Park
- Silver Creek Park

Disc Golf

FREE after purchasing discs.

Courses include:

- Truxtun Park
- Hart Park
- Silver Creek Park

Cycling Clubs

Local recreational rides welcome beginners.

🎨 Creativity

Bakersfield Museum of Art

Bakersfield Museum of Art

- Low-cost admission
- Free family days
- Workshops
- Community exhibits

Paint Nights

Often held at:

- Libraries
- Churches
- Recreation centers

Many are free.

Community Theater

Stars Theatre Restaurant

Volunteer opportunities:

- Ushers
- Stage crew
- Set construction
- Acting

🎵 Music

Free concerts:

- River Walk
- Downtown events
- Church performances
- School concerts

Join a community choir or church music group.

📚 Learning

Community Colleges in Kern County

Bakersfield, Taft, Cerro Coso, Porterville, and all their satellites

Low-cost and no cost options

- Community education
- Personal enrichment
- Lectures
- Cultural events

Adult School

Kern Adult Education

Offers:

- Languages
- Computer skills
- GED
- Career exploration
- Citizenship

Many classes are free.

💕 Volunteering

Research consistently shows volunteering increases happiness.

Opportunities include:

CAPK

- Food distribution
- Community events

Habitat for Humanity Golden Empire

- Build homes
- Retail store volunteering

Animal Shelters

Volunteer to:

- Walk dogs
- Socialize cats
- Adoption events

Faith Communities

Many churches, temples, mosques, and synagogues host:

- Support groups
- Potluck dinners
- Hiking groups
- Young adult groups
- Senior lunches
- Choirs

Most activities are free.

❤️ Disability-Inclusive Community Opportunities

Many organizations welcome people with intellectual and developmental disabilities and their families:

- The Arc of Bakersfield
- Kern Regional Center community events
- Special Olympics Southern California local programs
- Self-Advocacy groups
- Parent support groups
- Inclusive recreation programs

🧘 Wellness

Free or low-cost options include:

- Community yoga in the park
- Meditation groups
- Walking meditation
- Library mindfulness classes

🎲 Games & Hobbies

Look for groups featuring:

- Board games
- Chess
- Dungeons & Dragons
- Photography
- Gardening
- Quilting
- Knitting

Many meet at libraries or community centers.

🎉 Annual Free Events

Examples include:

- Christmas Parade
- Downtown street fairs

- Cultural festivals
- Art walks
- Fourth of July celebrations
- Holiday tree lighting
- Outdoor movie nights

🌱 Simple Daily Happiness Habits (Free)

Research suggests these habits can have a meaningful impact on well-being:

- Walk 20–30 minutes outside.
- Call or text a friend.
- Visit a local park.
- Read at the library.
- Write down three things you're grateful for.
- Listen to live music.
- Volunteer for an hour.
- Attend a free community event.
- Learn something new.
- Eat lunch with someone instead of alone.

Add a A "Happiness Challenge" in Bakersfield (or your town)

- A community living coach or community integrator could help facilitate these weekly activities to explore the community.
- A participant could use a schedule like this to coordinate a weekly social group
- A participant could practice transportation to safely arrive at each community event.

There are countless ways community participation can address people goals.

Try one activity each week:

Week	Activity	Cost
1	Walk at River Walk Park	Free
2	Attend a library event	Free
3	Visit a farmers market	Free to browse
4	Volunteer at a local nonprofit	Free
5	Explore Wind Wolves Preserve	Free
6	Play pickleball at a public court	Free (if you have equipment)
7	Attend a community concert	Free
8	Join a book club or hobby group	Free

This mix of outdoor activity, social connection, learning, creativity, and volunteering aligns well with what positive psychology research has found to be the strongest contributors to long-term happiness.

**Tech hint: This is where generative artifical intelligence tools, like ChatGPT, can help with planning.

6.3: Innovation Highlight- Grassroots Tech Swap

Page ID 65723

One brilliant IF, Cindy Cox in the KRC catchment, created a grassroots technology swap opportunity. To ensure all staff under 320 Community Living Supports could check in and out for shifts with the Electronic Visit Verification (EVV) tool, iPads and tablets were gathered, wiped clean, and re-purposed into staff tools. This helps participants avoid paying a cell phone stipend to staff, maximizing their SDP budgets.

6.4: ABLE Accounts

Page ID 65724

ABLE Accounts are not generic resources. No regional center should be instructing a participant to use their ABLE funds for regional center provided services.

One way to save for bigger financial needs is to open an ABLE account. The CalABLE program allows people with disabilities to save their own money in 529A accounts. These accounts are similar to college savings accounts, and the funds saved (and earned within the account) can be used on disability-related expenses.

There are some things that SDP funds simply cannot fund. Consider saving in a CalABLE account for expenses like those.

According to the CalABLE webpage,

ABLE accounts are a life-changing tool for millions of people of all ages. Adults who developed a disability later in life, veterans and guardians planning future financial stability for adult children with disabilities can take advantage of these accounts.

To be eligible for an ABLE account, the beneficiary must:

- Have a disability or qualifying medical condition that began before age 46
- Have a U.S. permanent address that is not a Post Office Box
- Have a social security number or a tax identification number
- Confirm one of the following:
- Is eligible for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) because of a disability
- Have a condition that:
    - Is expected to last 12 months or longer or result in death, and
    - Causes a marked and severe functional limitation, and
    - Has been diagnosed by a licensed doctor; *or*
    - Have a condition listed on the Social Security Administration's "Listing of Impairments"
    - or the "List of Compassionate Allowances Conditions"

To open a CalABLE account, go to the CalABLE website. If you are the beneficiary and are over the age of 18 and can manage your own account, go ahead, and get started.

6.5: Gifts, with caution

Page ID 65731

Please be very careful with gifts. If the participant is connected to means-tested benefits, gifts could be construed as "in-kind support". This could be devastating for someone who relies on those programs. Currently there could be a conflict with Social Security asset tests and in-kind supports. Advocates are working really hard to improve systems, but check to make sure you have the most updated information possible. Working with a trained Works Incentives Planning and Assistance (WIPA) professional can help navigate the complicated aspects of benefits management.

7: Regional Center Resources and SDP Guides

Regional Center Links and SDP Guides

Page ID 58867

The following list contains links to SDP Resource Pages at the 21 Regional Centers

- Alta California Regional Center SDP Resource Page
- Central Valley Regional Center SDP Resource Page
- Eastern Los Angeles Regional Center SDP Resource Page
- Far Northern Regional Center SDP Resource Page
- Frank D. Lanterman Regional Center SDP Resource Page
- Golden Gate Regional Center SDP Resource Page
- Harbor Regional Center SDP Resource Page
- Inland Regional Center SDP Resource Page
- Kern Regional Center SDP Resource Page
- North Bay Regional Center SDP Resource Page
- North Los Angeles County Regional Center SDP Resource Page
- Redwood Coast Regional Center SDP Resource Page
- Regional Center of the East Bay SDP Resource Page
- Regional Center of Orange County SDP Resource Page
- San Andreas Regional Center SDP Resource Page
- San Diego Regional Center SDP Resource Page
- San Gabriel/Pomona Regional Center SDP Resource Page
- South Central Los Angeles Regional Center SDP Resource Page
- Tri Counties Regional Center SDP Resource Page
- Valley Mountain Regional Center SDP Resource Page
- Westside Regional Center SDP Resource Page

Index

Page ID
44209

Glossary

Plain Language Glossary

Page ID
44210

A

Ableism - Discrimination based on someone's perceived or actual disability.

Accessibility - Making sure everyone, including people with disabilities, can use a place, service, or information.

Accommodations - Changes that help people with disabilities do things more easily, like extra time on a test or ramps for wheelchairs.

Advocacy - Speaking up for yourself or others to get what is needed.

Assistive Technology - Tools that help people with disabilities, like screen readers for people who are blind or speech-to-text software.

B

Barrier - Something that makes it hard for someone to do what they need to do, like stairs without an elevator.

C

D

Disability - A physical or mental condition that makes some activities harder for a person.

Discrimination - Treating someone unfairly because of who they are, like not hiring someone because they have a disability.

Department of Rehabilitation (DOR) According to the DOR website, DOR is the California state agency that works with people who have disabilities to secure employment, develop or promote in their current job, and live independently in their community of choice.

E

F

G

H

HIPAA - Health Information Portability and Accountability Act - Protects health information and medical privacy

I

Inclusion - Making sure everyone can take part in activities, jobs, or education, no matter their abilities.

Independent Facilitator- a person, either paid or unpaid, who helps a Self Determination Program participant figure out what they need to be successful in the program

Independent Living - When a person with a disability makes their own choices and controls their own life.

Individual Education Plan -

Individual Program Plan

J

K

L

M

N

O

P

Paid Internship Program (PIP): Employment

Person-Centered Planner: Trusted supporter who leads the PCP process

PCP (Person-Centered Plan): A plan that focuses on what a person wants for their future and how they want to live their life.

PCT (Person-Centered Thinking): A way of thinking that ensures the person receiving services is the focus of all planning and decision-making.

Privacy

Q

R

Reasonable Accommodation - A change that helps a person with a disability do their job or take part in school or activities without being too difficult for others.

S

Self-Advocacy - Speaking up for yourself and your needs.

SDP (Self Determination Program): A program in California that allows participants to direct their own lives by choosing their own goals and the people who support them.

Service Animal - A trained animal, like a guide dog, that helps a person with a disability do daily tasks.

Spending Plan

T

Transition Services - Help for young people with disabilities as they move from school to work or adult life.

U

Universal Design - Creating places, products, or information so that everyone, including people with disabilities, can use them easily.

V

W

Workforce Development - Programs that help people learn skills to get jobs and succeed at work.

X

Y

Z

Detailed Licensing

Page ID 44211

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Overview

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