The Power of Person-Centered Planning

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Abstract

The purpose of this article is to awaken the reader to the possibilities which exist when working on Person-Centered Planning and the individual with intellectual disabilities, specifically, Down syndrome. Although Person-Centered Planning has been in existence for more than two decades, it is viewed in a new way through the experiences documented in this article by individuals, and the use of a new format which includes photography, the computer, and a guide for what questions to ask and how to ask them. The central question of what caregivers can do once the Person-Centered Plan is enacted is posed as well. The Person-Centered Plan is seen as not disability-specific, but a capacity-building process in which the personnel involved are key to linking the individual to the community in order for dreams and personal goals to be realized.

Keywords
person-centered planning, self determination, self advocacy

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Concept Versus Reality

The concept of Person-Centered Planning has been in existence since the 1980s, the era in which self-determination, self-advocacy and "people-first" language was born. It is basically a template for assisting the individual with disabilities to express and document a living portfolio and plan for meaningful action toward one's lifelong goals and desires.

I was first introduced to person-first planning as a special education administrator by a parent of a child diagnosed with Asperger's syndrome who wanted an opportunity for her eighth grader to create a life plan as an expression of self-advocacy. Perhaps in the late nineties one did not pay attention to all of the criteria for facilitating such a process, but the spirit was certainly there. Through a Person-Centered Planning process with this student, I witnessed a person who had never before communicated his dreams and desires, transformed into someone who was able to express very clearly his personal goals for high school. Though there might have been ten or so people at this session, the student commanded the attention of each and every participant and together this group of parents, teachers, and support staff were guided towards the development of a transition plan that would propel this student to a successful high school experience. The planning was conducted in an atmosphere that conveyed respect for the student's thoughts and ideas and dignified his choices. We saw the student stretch toward challenges in course work selection that might have otherwise been overlooked.

As professionals, we know there are times when the individuals may put forth requests or express goals that appear to be a bit unrealistic. Nevertheless, it is up to the support team to craft a plan with the person that can suspend judgment about what is or is not a realistic aspiration. Together, a plan for action is created that has relevance and purpose between the goal and the steps that will be taken to move forward. Students with disabilities who express the desire to be a writer or an artist and wish to take classes in printing or in painting, must be encouraged and supported to cultivate an interest in ways that are meaningful to the person. It becomes necessary for the professional staff to help find the pathways that provide experiences that move the person closer to the goal so that he or she may use these experiences as a means for making informed decisions about where to go next.

Developing plans that encourage and honor positive aspects embedded in a person's dreams and hopes send a message to the person that his or her thoughts and ideas are important. This, in turn, connects the person to the plan at deep levels that result in commitment and motivation to do the work.

Person-Centered Planning is really a facilitated conversation between the focus person and important people who know and care about the person. A skilled facilitator who has been trained in orchestrating a planning method will guide the group through a series of questions, stories, and listening opportunities that serve to bring forth the essence of the person and to understand what it is that makes him or her "tick."

Ownership and Empowerment

Now, later in my career, I have the pleasure of observing the involvement of person-centered support teams more intensely than in my earlier experiences. Pathfinder Village (www.pathfinder.org) in Edmeston, NY, is the home to more than eighty individu-

als who have Down syndrome ranging in age from 11 through 61. Most of the individuals at Pathfinder Village have lived in this community for a significant portion of their lives. They require levels of support ranging from moderate to intensive. Many of these individuals attend day programs while others are employed in the community. A small percentage of the individuals spend their day in the Village itself due to health-related reasons. Recently, an initiative at Pathfinder Village was launched that incorporated training and a new format for Person-Centered Planning into our service system. What began as an opportunity for school-aged individuals to begin thinking about their lives spread rapidly to an initiative in which a large number of post-school age individuals were interested in participating.

There is a great deal of empowerment and ownership behind the development of a person-centered plan. There are many different approaches to developing a plan that is person-centered. One method for planning, *A Framework for Planning* © (Blessing & Ferrell, 2003), was developed by Carol Blessing, LMSW, a faculty member of the Cornell University Employment and Disability Institute, School of Industrial and Labor Relations and owner of Carol Blessing Consulting. Pathfinder Village adopted this particular method for implementing the person-centered initiative. The *Framework for Planning* provides a template and companion workbooks to guide and to record the process. The Village is using the student workbook entitled, "Preparing for Transition: Person-Centered Thinking for Students and the People Who Care About Them" (Blessing, 2004). The intent behind this particular workbook is to initiate conversation with students, (and as adapted for other Village residents), about how to see their lives as they prepare to leave the academic setting or prepare for transition from one type of support to another. This workbook has a pictorial outline that can guide the person and the people who are working with the person to develop a unique plan using the type of communication approaches that are necessary for conveying the information that is significant to the individual. It is a method for shifting the point of view of planning with people from a disability focus (what are we trying to fix) to a capacity view (what are the strengths that we can mobilize) of the person. The individual sets the direction and his or her support team become allies, advocates, and reinforcements.

Residents who participated in the early stages of the person-centered initiative spread the word about the value these meetings held for them. The meetings were referred to as "my" meeting; and some residents made statements like, "I have a book, would you like to see it?" The "book" was, of course, the pictorial compilation of various photographs pertinent to the person as he or she developed and reviewed his or her life goals. It is a reflection of the person's individual story.

Systemically, the sessions for Person-Centered Planning have become preparatory meetings to set the stage for much larger Individualized Support Plan (ISP) meetings as required by regulations. Thanks to Person-Centered Planning sessions, the person and other participants come to the ISP meeting prepared, informed, and ready to be contributing members of the larger planning team. The ISP meetings have moved away from sessions in which the person was "talked at" to sessions in which the individual is "conversed with." The usual anxiety-provoking standard meeting format has been replaced with one that encourages the individual to feel

confident and be a major part in his or her support network.

Photography and Language

Dyches, Cichella, Olsen, and Mandleco (2004) recently published a detailed study conducted with 15 school-aged individuals who have disabilities. The study suggests that people might better express themselves with photographs of what they feel are important in their lives as a means to elicit alternatives to traditional communication and expressive language. The opportunity to take photographs or to choose photographs to incorporate in the person-centered plan affords the individual an opportunity to understand, enhance, evaluate, and reflect upon those things that matter in their lives. Pictures also serve to provide supporters the guidance that will be needed to keep moving forward towards the goal. For example, we might come to understand that the person values a picture of a best friend; now what do we do with that information? It may become apparent that it is necessary to look for or develop opportunities for these two people to spend time together. This kind of awareness surfaces the circumstances and new experiences that create the conditions for essential changes in the quality of an individual's life. Additionally, there are occasions in which the person may require a sounding board and the photograph, accompanied with a few words, may accomplish this.

The Story of "Joe"

Perhaps what is most important in the development of the person-centered plan is the finding of potential connections between the individual and the community at large. Carol Blessing relates a story of a man named Joe, who deeply valued spending time with large groups of people to talk, laugh, and have fun with. However, for the time that Joe spent working at a sheltered workshop, he was virtually alone. He lived alone in a supported apartment. He walked the streets alone, ate alone, went fishing alone, and spent evenings, weekends, and holidays alone. For years Joe had no one that he could call "friend" in his life and lacking reading, writing, and other basic skills, he had no idea how to change this picture. When Person-Centered Planning was used as a way to think about where Joe might find places in the community in which he could be with people who liked to do the same things as he did, several important connections were developed. A big coffee drinker and lover of cigarettes, coupled with a strong sense of humor and his interest in being in large, friendly crowds served as the basis for scouring the community for social outlets that catered to these interests. It didn't take long to find a potential match. Bingo! In no time at all and with minimal support from Blessing, Joe became an avid Bingo player (Joe could match to sample and thus fill up Bingo cards along with everyone else). More importantly, Joe became a "regular" in a group of people who played every week at the same Bingo halls. They missed him if he failed to show up. They called to find out how he was. They invited him to other events. Joe was nearly 60 years old before he had made his first real friend.

In every sense, Joe's real disability had been that he was lonely. He wanted and needed friends and safe places to spend his time. At the end of Joe's life, he had become a vital member of his community, and continues to be missed and remembered since his passing away. How would anyone know this unless time had been spent listening to Joe, getting to know what mattered to him, and trying to understand his interests and preferences? Sometimes as practitioners we tend to

forget that the individual who has an intellectual disability may not be able to express that, although employed or part of a day program, they are not satisfied with where they are spending time and/or with whom. In many cases, people who live with intellectual disabilities are often surrounded only by people who are paid to be in their life or with people who attend the same program but with whom they have not chosen to be friends. This is particularly true of adults with intellectual disabilities once they leave the school system.

According to Blessing (2003), integrating person-centered practices into the transition planning process for students with developmental disabilities can lead to a decrease in the dropout rate of students involved in special education. The School to Employment Project (S.T.E.P), developed by Blessing and implemented in a city school in Troy, NY, used Person-Centered Planning to surface goals and objectives to be used in the development of the student's Individualized Education Program (IEP) in all of the major transition areas. Supports were tailored to individual learning styles and preferences using the theories of multiple intelligence and experiential learning. All students participating in the project earned high school credit for their work and whenever possible, activities were adapted to the NYS learning standards. S.T.E.P. focused on helping students leave school with paid employment of at least a part-time status that was reflective of his or her interests, skills, and abilities. It also connected students to needed services and supports without requiring the student to attend a program before gaining access to community living, learning, and earning.

Making the Connection Beyond Pathfinder Village

Here in Pathfinder Village, we believe that people who have Down syndrome, like all human beings, have a need for connection and belonging. Person-Centered Planning helps to surface what is the essence of these connections with people. This is consistently reinforced through the photo choices that individuals make in the process of completing their person-centered plan. Individuals have the opportunity to choose pictures from personal collections or take photographs of events, places, and people in their lives. What really needs to occur is ensuring that the process serves as a move away from complete reliance on the Village as the only source for meeting a person's needs to a process through which the Village becomes a conduit between the individual and authentic community roles. We need to ask the questions of when, where, and with whom might this person form real relationships and share experiences? How would it make sense for us to bring the community into the person's life and the person into the heart of the community? What can the people from the community contribute to the Person-Centered Planning process? Are there any individuals who share similar interests with our focus person (Joe)?

The real work is taking the information from the person-centered plan and crafting the support that is needed in making the connections between the disability community and the general community. Present caregivers need to ask themselves where they have the internal capacity and the external resources necessary to make these connections. Then, there develops a natural extension of community and belonging when the two worlds merge, creating a social impetus for change.

When developing the initial person-centered plan, it is important to be well-equipped with the necessary visual prompts

that will engage, inspire, and excite the individual and the other participants to communicate. The atmosphere must be conducive to holding natural and authentic conversation. The Person-Centered Planning process is a model for life goals and as such, is always a work in progress.

Preparing for the Person-Centered Planning Meeting

Key points to reflect upon when working to develop a first draft of a person-centered plan in preparation for the Individualized Support Team meeting include:

1. Be familiar with using whichever person-centered method or process is selected. For a review of prevalent methods currently being used in the field, visit the Person-Centered Education Site developed by Carol Blessing www.ilr.cornell.edu/ped/tsal/pcp (note: this site includes *A Framework for Planning*).
2. Ask the individual to list the people he or she would like to have contribute to the development of a positive profile embedded in the planning process.
3. Make time to take time. Try not to make the individual feel that there is a specified time frame in which all questions must be answered or that there is a checklist of information that must be gotten through.
4. Explain that if some questions cannot be answered at this time because they require additional thought or process time from the individual that no decision will be made until the person has been able to contribute to the process.
5. Convey the message that whatever is discussed is confidential and will be kept that way unless the individual wishes to share the information with others. Negotiate with the person prior to convening a session the information that is to be private (that is, not discussed at this time in a public forum) and that which is public (open for group involvement/awareness).
6. Consider having a scribe or recorder available to organize the conversation on a computer that has the template of the planning process on file. If the computer image can be projected in a way that all of the participants can easily see what is being transcribed, then no other recording devices are necessary. However, if the computer screen is not large enough for all to see, it is strongly urged that large newsprint paper is posted and used to keep the public record.
7. Consider giving the computer disc or CD ROM, as well as a hard copy of the template and meeting notes, to the individual at the meeting.
8. Allow the individual to tell his or her own "story" to get the sense of who and what the individual is about, inside and out. Solicit stories from family and friends that reinforce or help to surface major themes. Remember that this is about capacity-seeking so the stories need to be focused on the positive!
9. Initiate the conversation with a discussion of the person's interests, skills, and natural talents. We all enjoy talking about ourselves and this will establish a level of familiarity and comfort with the individual.
10. Center the meeting on the core of uniqueness that the person brings: gifts, strengths, and capacities.
11. Assure the individual that the team is a source of support during the meeting and after the meeting ends. The person should be encouraged to return to any member of the team for assistance whenever needed.
12. When developing the plan, remember to build on the existing strengths that the individual and the support team already have in place. Take into account the person's resources, family ties, experience, and any other relevant factors that will help increase the "do-ability" of the plan.
13. The end of the meeting should be a time to consider the connection between the individual and those people who are already part of his or her life to surface ideas and strategies for forming a bridge to meeting new people and sharing in different experiences. Remember that the object is to expand the concept of team from members who are on the team as part of their paid job or family responsibility to include others who are not yet part of the person's life.
14. Remember that the whole experience is a metacognitive one for all involved. Everyone will learn things about the person, and themselves, throughout the process.

In the actual experience of the conversation, the facilitators must keep in mind that this is not their meeting nor is it their agenda. Therefore, it becomes critical that the individual is allowed to express him or herself without others putting words, answers, thoughts, or feelings into their mouth for them. If the individual does not use words with which to communicate or if he or she needs extra time to process questions and information, then non-traditional methods for self-expression and ample time for processing should be used. It is also important to create questions that are germane to the individual who is, in essence, in the spotlight and to use appropriate functional methods for ensuring that it is the individual's "voice" that is being heard. If sign language or communication boards are the vehicles of expression, then these should be present and used throughout the conversation. Experience has shown that there are times when it is necessary to give the individual various options or choices in order to obtain a response. The choices and options that are provided should be familiar ones to the individual in order to ensure accuracy in the response and to enable the person to make reasonable choices. Shevin and Klein (1984, 2004) discuss the preparation for individuals in the art of choice-making and how important it is for the adult with developmental disabilities to be taught appropriate choices throughout the school curriculum, prior to the adult seeking independence in later life experiences. Of course, family members, close friends, and paid supporters may provide some guidelines in these areas, but should never override the voice of the focus person. Questions posed to the focus person must take into account the person's sense of realism. As professionals, we need to exercise our innate understanding or intuition when seeking to comprehend what someone is trying to say, as in the case of Chris.

The Story of Chris

I can always count on Maureen.

Chris, one of the residents at Pathfinder Village, was asked to describe his favorite place to spend time and he identified a donut shop. Upon further exploration, the team learned that it was not the donuts and coffee that the individual enjoyed so much, but the time he spent in the donut shop with his dad. He liked walking to the shop with his father and the company that they shared together during the trip. This is the art of listening to the message behind the up-front statement.

It has been interesting to see the reaction of this resident who first engaged in Person-Centered Planning utilizing the new format and approach at Pathfinder Village. Chris conveyed his experience throughout the Village community regarding his "special meeting" quickly and enthusiastically. He was very proud that he had this meeting and that his thoughts were important enough to be heard, that they were worth listening to. He felt validated and knowledgeable about his own life. Interestingly enough, he chose to use a photograph of his home for the cover of his plan and to entitle the document "My Life is Important." During the planning process, he was asked whom were the people most important to his life. He identified that they were his caretakers and his girlfriend. He also expressed the reason that these people were so important to him was that they could be

counted on. They could be told things that no one else could be told or would understand. When he was asked in another question to reflect on something that was important to him, he identified a picture of the beach at Cape Cod, which came from the Internet.

Unadilla House

Chris's home at Pathfinder Village

The beach picture was important, he explained, because "this is where my family and my home is." His aspiration for the future included becoming a sports writer or a car mechanic. He likes to be around machines and enjoys using his hands.

Keeping in mind this person's interests, it became the work of the team to find opportunities through the ISP for assisting the individual in having opportunities that reflected his life goals. Chris is involved in a sheltered workshop setting that has little to do with the dream he holds of working with tools and machines. He generally is involved in contract work and assists in the assembly of seasonal kits (egg-dying and make-up kits) or the packaging of hospital gowns. This is perhaps the most critical component of engaging in Person-Centered Planning. It is necessary that the goals that surface during the process be acted upon. Support team members have listened to what Chris has said matters to him but now must begin to forge the link between the goal and the opportunities that he experiences. One suggestion that surfaced for Chris in his desire to work with tools and machines was to utilize the support of a job coach to spend time at a local gas station where he could learn the names of different tools and practice applying them in specific situations by handing the appropriate tool to the mechanic as requested. Though seemingly a small step toward realizing his ultimate goal of being a mechanic, Chris may potentially see his dream realized. In reality, there may not be a job coach available, but instead a volunteer, college intern, or a community member willing to take Chris under his wing. In this case, Chris' MSC (Medicaid Service Coordinator) will approach a community gas station, amenable to this concept, where Chris has visited with his buddies. A request will be made that he assist the willing mechanic for one hour per week. Imagine the reaction on the part of Chris, as he travels down the right path for certain. Another option would be to pursue an adult evening class, which would expose him to working with small engines and machinery as well as other individuals with similar interests.

At work I prefer to use my hands

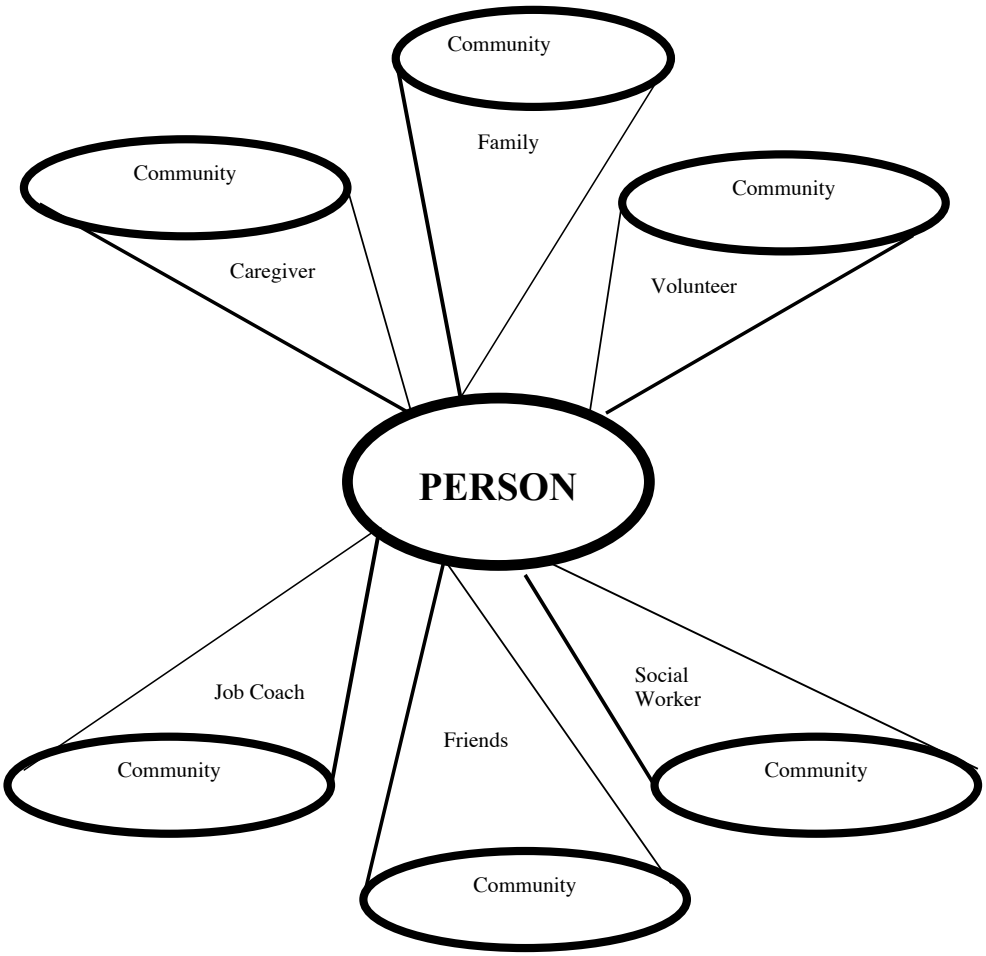
Another man has expressed an interest in theater with a local theater group. The ISP team learned of this because of the person-centered plan, and made arrangements to have the individual join in and work with ticket sales in addition to assigning him a small part in a local community theater performance. This is only the beginning for this individual. The research states that when a person gains control over his or her life choices and this power has shifted, the quality of life im-

proves. This is all due to the individual becoming most involved in the Person-Centered Planning process (Conroy, 2005).

Finding the "Path" at Pathfinder Village

One must keep in mind that all people, including people with Down syndrome, continue to learn and grow with every experience. Providing opportunities for people that recognize and honor the person's dream paves the way for using today and yesterday's experience as a vehicle for making the informed decision and taking the next step into tomorrow where new opportunities and experiences await. Although created as a means in finding better ways to listen to people with disabilities than traditional approaches offered, Person-Centered Planning is not disability-specific. Person-Centered Planning is also not location- or environment-specific. This type of approach, format, guidelines, and the use of photography can be employed in various settings such as the natural family environment, supervised living, supported, or even independent living. It is the beginning of many life lessons for anyone who is willing to begin a lifelong journey finding one's path here in the Pathfinder Village community and in all communities serving those with developmental disabilities.

Graphic Organizer Reflecting the Person-Centered Planning Process



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