# **Title: Take Charge Web Presentation 2013**

# **Slide 1: Take Charge: Person-Driven Planning**

Take Charge: Person-Driven Planning. I’m Dr. Caren Sax, from San Diego State University Interwork Institute. It’s my pleasure to have the opportunity to speak with you to provide background about person-driven planning and offer considerations for individuals with disabilities and their families as they transition from school to adulthood. In addition I will offer examples of how organizations can integrate this model to improve outcomes for the individuals they serve.

# **Slide 2: Person-driven planning**

Person-driven planning must center on the focus person, with an understanding that they must have both the opportunity and the skills to drive their own planning. Building skills in self-determination and self-advocacy are essential to being able to “drive” one’s own plan. Having quality relationships with family, friends, and professionals are critical to providing the context for the focus person to dream and pursue their dreams. None of it is possible without the basic belief of holding high expectations that the focus individual has many options for working, pursuing lifelong learning, and for contributing to their community.

# **Slide 3: PDP at any age**

Here are some examples of plans done with individuals at different ages. We did a plan with Max when he was 17, and was thinking about how to build more skills that could lead to employment. We used a “bus” theme as Max is really into riding the bus. So the graphics and language included bus and transportation themes. Colin did a PATH after graduating from college and feeling a bit overwhelmed as to what to do next. He’s since found a part-time job, is meeting people and finding his own housing. He recently met a girlfriend and is managing his budget pretty well. He’s well on his way to pursuing some of his dreams. Finally, Chris has been using PDP for the past 20 years, as this is a regular practice of the supported living agency that has helped her buy her own home and hire her own support team. Chris often speaks at conferences and talks about her life and how many of her dreams have come true.

# **Slide 4: Outcomes for this presentation**

This presentation will provide information at two levels: 1) for implementing PDP at an individual level; and 2) for integrating the practice at a school or organizational level. First, background information, examples, and stories to promote understanding of PDP with individuals with disabilities are presented. Next, a variety of strategies demonstrate how to meet individuals’ needs that result in their full engagement in the process and promote meaningful action toward their goals. Specific knowledge, attitudes, skills and expectations are required to ensure that outcomes reflect individual’s choices. Skills are required of both the focus individual and the professionals who support the planning. Finally, organizational approaches are described for integrating the practice into transition, education, employment, and community living services.

# **Slide 5: Purpose of PDP**

The purpose of person driven planning is to inform action that makes life better for people with disabilities and the people who know them & love them. It’s pretty simple and straightforward, but an incredibly powerful process.

# **Slide 6: Person-driven, person-centered?**

Person-centered planning grew out of a commitment to inclusion as a social goal, intentionally designed as an inclusive process; person-driven planning is an attempt to ensure that the individual is in charge of their plans, and not just present. There’s a lot of person-centered planning happening, but unfortunately, often in name only. One of the reasons for making the distinction of “person-driven” planning is to put the emphasis on the person who has the most to gain (or lose) from the process.

So to begin, we must ask ourselves, what does it take for people to access an effective way to plan for their futures? Then, what does it take move those plans into action? And, most importantly, how do we help individuals, their families and friends, and the professionals who support the process, to think differently about how planning is carried out?

# **Slide 7: Planning Challenges**

It’s important to look at the continuing cycle depicted in this graphic: first, focusing on an individual’s hopes and dreams, then designing supports and services to make the dreams a reality, while at the same time building on and strengthening skills and capacities, which can then fuel new hopes and dreams and demonstrate the need for new supports and services…..and on it goes. This is a dynamic process that requires some thinking and talking about how our services are structured. Are we willing to look at our approaches to see how person-centered or person-driven they are? Too often, the forms and compliance requirements drive the planning rather than looking at the individual first. Considering these planning challenges may help us examine the way in which we build services and working relationships in order to share control, and accommodate individual needs, choices, and goals. Establishing trust in the process requires that actions match words, and that professional development includes the expectation that individuals will be treated with respect and their choice in goals, directions, and interests will be honored.

# **Slide 8: What’s the difference?**

Most of us are familiar with, and typically more comfortable with a traditional way of planning with individuals with disabilities, especially if we have large schools or organizations. The first concern that I hear raised is that a person-driven approach takes more time. I’ll address that a bit later on when we get into the examples. In the meantime, it’s important to identify the distinctions that using person-driven planning offer as compared with traditional planning. The list of characteristics under traditional planning include: goals tend to be designed to fit within the options that the program already offers; the roles and boundaries are well-defined, including those for the individual, family members, and professionals; the professional, whether it be a teacher, psychologist, case manager, or whoever is the primary person responsible for implementing services, takes the lead. Finally the planning is done according to birth dates, annual review dates, or other scheduled milestones designed for program compliance. Questions and decisions that can impact the path of one’s life need to be discussed at the appropriate time, which don’t always coincide with the mandated meetings. On the other hand, PDP goals reflect individual choices, the roles and boundaries are created according to individual needs and the focus individual takes the lead and/or plays an active role, depending on their age.

# **Slide 9: What it is & What it is not**

As we look more deeply into PDP, we must recognize that it is a reflection of our values about individuals with disabilities and what they bring to our community and our society. By taking an approach to planning that is driven by the individual, then we must think from the perspective that highlights capacities and talents of individuals, that we believe that everyone has something to offer. We have to be willing to think beyond what is currently available so that someone is truly able to reach their dreams. Further, we need to do everything that we can to ensure that individuals develop the self-determination and self-advocacy skills to stand up for their rights and opportunities, so that they are empowered to pursue their goals, including meaningful employment, authentic relationships, and lifelong learning. Too many of the systems that have been designed for individuals with disabilities (vs. with them) are based on “fixing” their perceived deficiencies, trying to force people into existing slots for work programs regardless of their skills and interests, and result in controlling the individual to make things easier. It is widely assumed that meeting compliance regulations is equivalent to offering a quality life, which is not always the case.

# **Slide 10: After Joe’s first meeting**

I had the pleasure to do some work in the Netherlands the past few years, and met several young adults who were part of a pilot program to move out of a group home and into their own places in the community. Each person experienced a PATH or MAP to help set their new directions. After having experienced his first person-driven planning meeting, one 24-year old young adult with Asperger’s made this comment: “it was really different from a 2-hour meeting where everyone else made decisions about my life!” That comment speaks volumes about how previous planning occurred and how disempowered Joe must have felt about his ability to influence the decisions. It’s likely that the professionals had no idea that he felt this way, as I’m sure that they had the best of intentions. Once someone has been in a meeting where others really listen to what they have to say, things change. As Enders and Leech wrote in 1996, **“Independence is defined in terms of how much control a person has over his or her environment, not in the number of tasks that the person can do without assistance.”** Constructing the environment so that individuals can exert as much control and independence as they’d like results in plans that work and outcomes that are meaningful.

# **Slide 11: It takes a change of perspective**

Just as the mindset completely changed for Joe after having the opportunity to direct his own plan and his own future, the mindset of individuals, families, and professionals must be challenged to consider a different perspective. No one likes to feel like they’ve been acting unprofessionally or limiting possibilities for others; and for the most part, I think it’s safe to say that most people in our field are here to make a difference in the lives of the people they serve. The intentions are good, but sometimes the practices aren’t as empowering as they could be. We can all get stuck in the way that we operate everyday – and along those lines, in the expectations that we have for others, and the way in which we design supports and services. It’s easy to make assumptions about what’s best for someone else; it’s not as easy to listen in a different way and to provide an alternate path. The willingness to considering a change in perspective is the first step.

# **Slide 12: Before judging what a family has done or hasn’t done, think about what they may be dealing with!**

As an example of listening differently to a family, I’d like to share this family care map. It was drawn by a mom with a son, Gabe, who has a rare syndrome that requires significant medical, educational, and other supports. Gabe is in the middle circle with a small circle around him to depict his family – Mom, Dad, and sister. The other colored ovals show the network of doctors and other health care professionals, therapists, teachers and educational staff, legal and professional services, recreation and community connections, disability groups including advocacy and other family organizations, and on and on….there are about 70 ovals in all, grouped in 7 categories. The mom began to share the map with the people who were on it. They in turn gained some understanding of all that the family was struggling to understand and balance. The family felt as if they were being treated more respectfully when it was clear how many roles and tasks the family was handling.

# **Slide 13: THE BASICS OF PDP**

To give you some basics about PDP, I’d like to do it by sharing some stories. We’ve been running a small grant project that offers Person-Driven Planning to individuals with disabilities, ages 18-25. We hired and trained 4 of our graduate students in Rehabilitation Counseling to facilitate and record meetings. With the other 2 staff who are on the project, there are 7 of us conducting the meetings. We’ve completed 13 meetings (with pre-meetings) so far, with a goal of completing 18 by the end of September. The photos and stories that I’ll share are from this project.

# **Slide 14: The Flow of the Plan**

A MAP, originally named McGill Action Plan (1989), is a planning process that was designed to further the integration of students with disabilities into the school community, using a team which includes the individual, family members, friends, and school personnel. It is also used to promote the inclusion of adults with disabilities into their communities. A MAP is useful for showing where you are and how to get someplace else. While there isn’t an exact recipe or standard template to use for everyone, the basic components are presented here: 1) Gathering history or telling the story of important milestones of the focus person’s life; 2) finding out what the person’s dreams are (the time frame of the future depends on what the person wants to think about – a year from now or 20 years from now); 3) identifying the person’s nightmares – or the nightmares that the family fears for their son/daughter – it can also focus on what might get in the way of the dream; either way, the outcome of the plan must prevent the worst nightmare from happening; 4) discovering and naming the strengths and gifts that the person offers, the characteristics that make the person unique; 5) understanding what the person wants to do, likes to do, and what the needs are; 6) at this point, an action plan needs to be agreed on, with people identified to do specific follow-up to make sure everyone does what they’ve committed to do; a timeline should be included to note who’s going to what by when. It’s always good to conclude the MAP by celebrating the process, reflecting on what’s been done and what’s coming up. A follow-up meeting to determine progress and possible changes to the plan can be a much shorter process, and typically involves fewer or even different people, depending on the purpose of the meeting.

Here’s a helpful website that walks you through the process: [http://www.inclusion.com/artcommonsensetools.html](http://www.inclusion.com/artcommonsensetools.html%20%20)

# **Slide 15: PATH plans**

Another creative tool used for planning is a PATH – Planning Alternative Tomorrows with Hope, created by Marsha Forest and Jack Pearpoint – which starts with future dreams and then works backward to see where the person is and what needs to happen to help them get closer to their dreams. The steps are numbered in the order that they are discussed in this graphic. Starting with #1 the NORTH STAR, this represents the individual’s long term goals and ideal outcomes for their future. These can be big dreams for someone’s whole life, or they might choose to consider dreams for the next few years, depending on the age of the person and why they’re having the PATH in the first place. The next discussion is listed in the half moon shape of the path, #2 where we list what will have been done by this time next year. It’s important that the language is used in that way, that is, “by next year, I will have accomplished . . .” so that it’s clear that these are actions that one is committed to. We now move back to the left side of the PATH, #3 – NOW, to determine what the current status is of the individual, what’s going well, what might be causing problems or anxiety. #4 – ENROLL, is designed to find out who needs to be recruited to help answer questions, find resources, clarify issues, and help the person move in the right direction; #5 gets more specific as to what needs to be STRONGER to be able to accomplish the 1-year goals which in turn gets them closer to their dreams. This may be stronger in the sense of the person learning new skills or strategies or it might be finding new resources (or better utilizing existing resources) that will support the person and possibly others on the team. Finally, strategies for short term progress may be added as #6, with #7 identifying the first steps that need to be taken right away to build on the energy and momentum that’s typically generated by the PATH meeting. Using graphics and markers to illustrate people’s dreams is inspiring and motivating and are generally used to encourage an interactive process. We’ve been trying some variations on both the MAP and PATH tools, which will be described next.

Here’s a website with recommended books on PATH planning: http://www.inclusion.com/path.html

# **Slide 16: Luke’s adventures**

Luke, who was about to turn 24 when we did his PATH, had just started with an adult agency that’s providing a newly funded service, called “tailored day services.” Services can be used to support job exploration, vocational training, enrollment in postsecondary education, community access, independent living skills and more. If families request services through the regional center system (for individuals with developmental disabilities), they are limited to 15 hours/week although families can pay for more hours on their own. This service offers individual support to adults over age 18 that can be more flexible and customized to meet individual needs.

# **Slide 17: Quick history**

Since Luke had just started with the agency, holding the PATH was an effective way for his new support person to really get to know him. The staff person said that he learned more about Luke and how to help him structure his goals in the 45-minute meeting than he had in the prior two weeks just trying to get to know him. Luke’s mom talked about how she knew that he wanted to move out at some point, but seeing it on the PATH made it more real. It also gave Luke the motivation to begin taking job hunting more seriously. Luke’s very active and is involved in many activities, but work isn’t one of them. He’ll need to make some tough decisions as to what he’ll give up in order to make time for employment. Being able to visually link the job to being able to move out and travel will help him to keep the dreams in sight!

# **Slide 18: Luke’s Adventures**

Here’s the rest of Luke’s PATH – everyone has the option of naming their plan…Luke’s Adventures seemed to fit. This discussion included where he is now, who needs to be on board to help him look for jobs and consider other college and vocational training options, what independent living skills he needs to work on to be successful living on his own, and how he can get more information on his various areas of interest and skills.

# **Slide 19: Luke’s Path under Development**

And here’s Luke, a young man with Down Syndrome, who was ready to finish the PATH after about 45 minutes, as he had a bowling tournament to get to!

# **Slide 20: “For the first time in many years I felt that Felix wanted to look forward into the future.”**

Felix and his mom came to see me after we spoke on the phone about the project we’ve been running related to PDP. Mom felt that Felix was getting stuck – he didn’t seem to be very motivated to work, although he had done a couple of part-time jobs with friends of the family. When we talked, Felix (who is a young man with Aspergers) wasn’t very engaged in the conversation; in fact, at one point, he asked his mom to stop talking as he felt she was either saying too much or he felt that he was being pushed into something he was not sure about. I made it clear that it was totally up to him if he wanted to have a planning meeting or not and to let us know if they wanted to follow up. He ended up having another meeting about a month later to learn more about the process and decided to have it at his house, although he was still not very enthusiastic about it. It was still more Mom’s idea than his, but he was willing to give it a try for an hour. The message we received from his mom afterward sums it all up. She talked about how at the beginning of the PATH, it seemed that Felix wanted to make sure that there were no dreams created that would require much obligation or effort on his part. As the planning continued, Felix became more engaged and felt that the people who were there wanted to help him create something for himself. He soon forgot about the one-hour time limit as he started getting serious about what was being discussed. When his mom contacted us a week later, she said that Felix had already followed up by calling various people, one of the tasks that he committed to doing. He’s much more enthusiastic about working and, as the quote from his mom says on the photo of the PATH planning group: “For the first time in many years I felt that Felix wanted to look forward into the future.”

# **Slide 21: Engaging students in creative ways**

Another family who met with me to explore the idea of doing a PATH for Jack, who is 18, and is moving into his own house this summer, which is located just a few blocks from his parents. This is a big move for Jack, as he has some significant support needs round the clock. When he and his mom met with me, Jack used a timer on his iPad to limit the conversation, as he was ready to go. When the timer was done, he got up to leave. Jack isn’t very verbal, and was more interested in looking at his iPad than in being part of the conversation. But the plan was for his mom and other people in his life to spend some time with Jack to identify images on the internet that he could tape on the PATH to show his dreams. During the PATH meeting, he was engaged the full time (about an hour), and never once picked up his iPad. His mother’s comment that she left for me after the meeting was touching: “Thank you for allowing Jack to reach for dreams as we sat in delight watching him come to terms with something completely new!”  In addition to using internet images and pictures from magazines, we have done other PATHs and MAPs using photos (like the ones used in the DREAMS panel in the slide) of the person’s family and friends, vacations, and other activities to offer another avenue for individuals, especially those who are not verbal or for those who might not otherwise be quite as engaged in the process. It’s helpful to offer a variety of ways to engage the person, including doing the whole plan on a computer, projected for everyone to see, which was done for one of the students.

# **Slide 22: AARON’S MAP: Translating the PDP into required plans/forms**

I’d like to share one more story in order to illustrate how we use MAPs to identify goals and measurable objectives and outcomes. Typically, when a discussion is held at an “official” planning meeting at school, the student (if he attends) doesn’t play much of a role in driving the plan. The parents often feel outnumbered by professionals and may be intimidated or just not confident to ask questions or to question decisions that have been made. With an effective MAP or PATH, the important discussion happens in a this relaxed atmosphere, with people who are there because they care about the individual (and their family), and then they can attend the official meeting to sign the papers. We’ve been focusing on helping to translate what is shared in the PDP meeting into real goals and objectives that can be transferred on to the appropriate forms later.

# **Slide 23: Meeting Aaron**

Having a “pre-meeting” before the plan was essential for Aaron and his mom to fully understand what we were going to do and how it would play out. The family was very frustrated with the transition services that Aaron was receiving at school – goals were very vague, there wasn’t any real direction, and asking for improvement wasn’t helping. They asked me if I would do another assessment – knowing that Aaron had likely had every assessment available, I asked what they hoped to learn from an assessment that they didn’t already know about their son. So, that led to offering to do a PDP, and once they understood what it was all about, they decided to host it at their house. Aaron was turning 18.

# **Slide 24: All about Aaron**

Aaron’s family, friends, neighbors, and some of the folks who had worked with him in after-school programs, plus his current teacher’s aide attended the meeting at their house. The family owns a restaurant so they offered dinner to everyone, as the meeting was held in the early evening. We went through his history, what makes him happy and comfortable, what makes him nervous, anxious and unhappy, and identified his strengths and challenges. The wonderful thing about having a diverse group of participants, is that different people see the focus individual in different environments, with different people, and as a result, may offer very different perspectives and ideas about what’s possible.

# **Slide 25: Future possibilities**

When we got to the part about future possibilities, Aaron had already identified some images of jobs he wanted to explore, activities that could be set up at school, and options for fun after school. He and his mom and another friend had encouraged him to search the internet for images of places, things, and activities that he was interested in. We used those ideas as beginning points to explore.

# **Slide 26: Clarifying goals**

As a result, we were able to identify much more specific goals to include on his transition plan, including the ones listed here:

Identify job sites/environments to visit

Set up opportunities to job shadow (pet stores, animal shelters)

Explore details as to why certain jobs/environments were selected (insulation spraying; repairing slot machines)

Try out various tasks for specific jobs (related to family deli)

Identify options for volunteer work to address interest in helping people (senior center)

Begin training on public transportation

And again, the engagement of Aaron in the whole process was remarkably different from the meetings where we had sat and discussed the overview of the process and the logistics for the meeting. Something different happens when the focus person truly becomes the focus and where others listen to them without judgment and without criticism. We begin to see the self-confidence increase, leading to more interest in taking charge of their lives.

# **Slide 27: Guiding Principles**

We’ve come up with some guiding principles to agree on before setting up a plan with an individual. They must agree to these, as must their family, friends, and the professionals invited to participate. By setting up the ground rules beforehand, we’ve found that the tone of the meeting and the expectations are set before it starts. Here’s the list:

The individual is in charge: they decide who attends the meeting, where it is held, & what goes on their plan.

The meeting must be voluntary for all attendees – and everyone must agree to stay for the whole plan.

A pre-meeting is held to interact with the focus person and family to determine the reason for the meeting and how to best support the individual to be fully engaged.

# **Slide 28: Guiding Principles**

Everyone must attend a meeting with an open mind, allowing for the opportunity to think in new ways, investing in a different way to dream and attain dreams.

**Above all, share ideas that are positive and possible!**

Agreeing to the Guiding Principles and investing the time in a pre-meeting has resulted in effective and relevant meetings for everyone we’ve worked with so far!

# **Slide 29: Changing systems**

For the last part of this presentation, I’ll address how schools and organizations have integrated PDP into their services, mission, and vision.

# **Slide 30: PATH Planning for Organizations**

Just as the PATH can be used to promote thinking about and planning for the future, similarly it is often used to plan with organizations to identify long-term goals. As with other strategic planning approaches, the process offers an opportunity for discussions of core values, shared vision, and builds on everyone’s skills, knowledge, and networks.

# **Slide 31: PATH Plans**

Revisiting the graphic offered earlier for PATH planning, gives us an opportunity to see how a school or organization can use the same sequence to identify long-term goals, short term progress, and specific steps to build skills, knowledge, resources, and motivation to get everyone on board with the plan. Seeing the plan unfold on the wall, helps everyone feel involved in the process. The discussion on one section prompts discussion on other sections, so rather than being a linear process, the recorder must be prepared to jump back and forth as the ideas emerge.

# **Slide 32: Becoming more student-centered**

As my first example: Changes are being implemented in a transition program at a school in San Diego, initiated by the program director and supported by the school director. They were determined to improve their practices toward being more student-centered. With the commitment from the top and the expectations that teachers would be willing to reflect on their practices and change, or at least modify them, the first step was to offer a workshop to the teachers about person-driven planning. I spent some time with the teachers, but the response was underwhelming – some were interested; others felt that they were already doing it; others seemed to feel threatened and were likely to resist making changes in the way they were teaching and supporting students. The plan was to start with one student, with the program director taking the lead on facilitating the plan. They started with a student who was doing well and who had interested family and friends. Nikki, shown in this slide, had an “awesome” meeting, as she described it. Her own talent as an artist was utilized in enhancing the final plan, and her role in inviting the participants, setting up the room and food choices, and determining the focus of the plan, gave her ownership in the both the process and the outcomes. Demonstrating a successful plan makes an easier “sell” to other teachers. Students started to hear about the process from Nikki and began requesting their own meetings. One by one teachers have come on board, willing to try it with one student, then another, then another. PDP meetings are being planned much further in advance now, to ensure that they are held prior to the IEP (Individualized Education Program) or the ITP (Individualized Transition Plan) meetings. Teachers are learning more about their students in the process and students are becoming more accountable for their roles in carrying out actions to get closer to their dreams. The change process can be challenging, but, as a result of this phased in effort, all the graduating students had plans this year, and next year’s graduates are preparing for their plans. It’s been about a 2-year process, getting closer and closer to making this a regular routine and an expectation for all students and teachers.

# **Slide 33: Bold Changes in Service Delivery**

As my second example, I’d like to talk a bit about a large organization that I’ve had the pleasure to work with in the Netherlands. It serves youth and adults with disabilities. Again, the changes were initiated because the leader had a vision. After receiving a tour of the facility, I provided a workshop to many of the staff and teachers, giving an overview of the PDP process and how it can be used with individuals who are transitioning through various stages in their lives. The administrator decided to bring a group of his staff to San Diego to learn more about strategies being used here and to share information about their practices. To be honest, one of the best outcomes was the opportunity for this group to spend time together, to think, reflect, share ideas, and take time to be creative and future thinking. We often don’t take the time to talk with our colleagues about where we would like to take our organizations, as too much of the time, we are reacting to the day-to-day pressures. At the end of their trip in San Diego, we were going to do a PATH plan to start the process for how they wanted to begin implementing change. By the end of the week, everyone was a tired and needed time to process and reflect, both individually and together. Since I was planning to be in the Netherlands a few months later, we decided to do the PATH while I was there. The exciting thing for me was that they had already taken some initial steps in conducting plans with students. They also had thought about the direction they wanted to go. In their North Star, they wanted to see “teachers responding differently, that is, taking on new roles and asking new questions.” They wanted to see management listening to teachers and have the curriculum be responsive to student needs and interests. It’s as if they wanted to shift the whole structure to truly be student-centered. Within the next year, they expected to complete many individual plans and have each team conduct a PATH. I’m excited to find out how much progress they’ve made since then as their goals were quite ambitious. Whether they accomplished all of them or not, the first and most important step was that they re-examined their values, vision, and mission and realized that they weren’t walking the talk, so to speak. They committed to aligning their mission with their practice, by moving the student from “sitting in the middle to driving the process.” They were determined to increase the intentional conversations that they had with students and that the conversations were a two-way dialogue. Finally, they were pursuing ways to research and evaluate the process to ensure that they were improving outcomes.

# **Slide 34: For More Information**

I’ll leave you with a quote by John McKnight, who said: “A true community is only able to grow and strengthen itself by including all of its members and finding room for them to develop their capacities within its own pattern of growth.”

Here’s a link to a short video and accompanying materials that offer more food for thought: <http://whatcanyoudocampaign.org>

Thank you for your interest. Please feel free to contact me for further information at the contact provided: [csax@mail.sdsu.edu](csax@mail.sdsu.edu%20)