Person Centered Planning for Individuals who are Deaf-Blind

Clara Berg & Susanne Morrow

New York Deaf-Blind Collaborative
Person Centered Planning

Objectives:

- To understand the **underlying values** of a person centered planning (PCP) process
- To learn about **the process and tools** to use in a PCP process
- How **to include extended family members** and friends as active participants in a PCP process
- **To facilitate** a PCP process including ongoing review and revision of the PCP maps or plans
WERE WE DREAMING?
IT ONLY TOOK 14 YRS TO GET TO 2011
What is Person Centered Planning?
Person Centered Planning is a process, directed by the family or the individual with long term care needs, intended to identify the strengths, capacities, preferences, needs and desired outcomes of the individual.”

John O’Brien & Connie Lyle

http://www.vcu.edu/partnership/cdservices/resources/PCP-CMSdefinition04-04.pdf
Person Centered Planning

“...involves the development of a ‘toolbox’ of methods and resources that enable people with disability labels to choose their own pathways to success; the planners simply help them to figure out where they want to go and how best to get there.”

http://www.ilr.cornell.edu/edi/pcp/
This "person centered" team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve these goals.

Person Centered Planning depends on the commitment of a team of individuals who care about the focus person. These individuals take action to make sure that the strategies discussed in planning meetings are implemented.

http://www.pacer.org/tatra/resources/personal.asp
“Person centered work begins within each and every one of us and radiates out toward others.”

Michael Kendrick, Keynote Presentation for the Conference "The Promise of Opportunity" – March 2000
What is the Purpose of PCP?

...to have a way to **clarify a vision** of a person’s future that assures that they will have a life rich in experiences, relationships, and productive activities that are meaningful to that person;

...to develop a vision of a person’s future, based on what is **important and positive** for that person;
What is the Purpose of PCP?

...to engage in a process to identify a person’s skills, capabilities, preferences and gifts;

...to seek to identify a person’s needs, and the supports that can be provided to meet those needs
The PCP process allows the team to shift from a system-driven process to an individual-focused process.
“A person centered plan can help those involved with the focus person see the total person, recognize his or her desires and interests, and **discover completely new ways of thinking about the future of the person.**"

Beth Mount & Kay Zwernik, 1988
Let’s try creating a plan taking into consideration Kenny’s preferences
Some basic values

• That everyone has a right to plan their own lives and be at the center of any planning that is done for them.

• That everyone has a right to be part of their community.

• That everyone has a right to live their lives as they want, and if they need support to do this for this support to be provided in a way in which they want it.

When should a Person Centered Planning session take place?

Any time!

A PCP can be conducted at *anytime* in a person's life. It is best done before transition services are determined. Person centered planning can be a very useful tool to develop the transition plan but can be utilized for anyone at any age.

http://www.pacer.org/tatra/resources/personal.asp
school

community
Engaging in the PCP practice early on allows the parents/family members to become the leaders in the planning for their child’s future.

PCP is not a one-time event!

PCP is an on-going, repetitive process that is revisited on an as-needed basis.
Person Centered Planning

- Engage in the PCP process – the sooner the better!
- The more you practice the better you become!
- The team members may change but the child and family remain constant.
Engaging in the PCP process assists the team in writing clear, attainable, outcome-orientated IEP and transition goals for the individual.

The PCP team has a better understanding of the individual, the family, and their hopes & dreams.
So HOW do we do it?
Organizing a PCP session

1. **Schedule time with the necessary players:**
   - Student
   - Family members & friends
   - IEP team
   - Representative(s) from relevant agencies

Even if the student cannot identify his/her preferences or choices, his/her presence has a significant impact on the team & the overall planning process.
2. Arrange for comfortable meeting space that can accommodate a large team, keep in mind the following:

- Consider **lighting and background noise** for support equal access
- Arrange **sign language interpreters**, spoken language translators or other communication supports, when necessary
3. Prepare materials that will be necessary for creating the maps and for note taking
   ▪ Large paper & markers or a computer with projector
   ▪ Snacks & beverages
   ▪ Assign who is going to be recording and a time keeper
   ▪ Whoops & whistles!
CONDITIONS TO PARTICIPATE

1. HIGH EXPECTATIONS
2. GREAT IMAGINATION
3. POSITIVE ATTITUDE
4. Goals, Roles, Process

**GOALS**
for the session must be clear, measurable and attainable

**ROLES**
Everyone must know what is expected of them

**PROCESS**
Everyone on the team agrees and engages in the process for the session
Organizing a PCP session

5. Determine the type and number of maps that will be created during this individual session

Sample maps:
- Background Map
- Personal Preferences Map
- Relationship Map
- Places Map
- Hopes, Dream & Fears Map
- Choices Map
The **Background Map** is extremely critical as it provides a visual way to document the life experiences of an person.

- Different **colors** can be used to indicate different phases throughout one’s life.
- This map is a way to summarize and collapse various data from a person’s file.
BACKGROUND MAP

Background Map

Birth
- Sheldon 9/20/79
- Kenny 7/28/80
- Jan. 01
- Karen 7/13/01
- NICU
- NICU
- ongoing therapies

Perkins School
- SIB
- CSE meetings
- Perkins School
- SIB
- CBI's FS
- SIB

May 2nd, 06
- Hand injury/head banging
- Good
- & bad times at Perkins
- good team work
- 10/1992
- 1991 1st PCP
- Sheldon's Bar Mitzva
- Karen's Bat Mitzva
- 7/1993
- 1993
- Grandma Frieda

Res hab services
- JGB
- 1995
- 1995
- Searching x services!
- 3/1998
- 2/1995
- Coming back home
- Mononucleosis
- 1/1995
- 1993

Work at the farm
- Sheldon college
- Karen college
- 7/1996
- 1997
- 1999
- Grandma Juana
- Kenny at the farm
- 2000
- 6/2001
- 2001 to present

Green – Happy
Red – Challenges
Blue – On going

10/15/2014
WHO IS KENNY?
- Beautiful
- Sensitive
- Good nature
- Funny
- Innocent
- Handsome
- Lovable
- Persistent
- Determined

- Great companion
- Brave
- Hard worker
- Family guy
- Routine oriented
- Perseverant
- True friend
- Lover boy
- Productive
- Cute
The **Relationship Map** is extremely important as it allows the team to identify critical people in the life of the individual and identify gaps in other areas.

- Oftentimes the **Service Providers** section is heavily scattered with names while the **Friends & Community** sections are rather bare.

- When assessing a person’s relationships those within the community and family should be separated out.

- This map can assist the team in focusing their efforts in facilitating meaningful relationships that are of interest to the individual and family.
The **Communication Map** is one of the most crucial maps for individuals who are deaf-blind. It helps the team identify preferred modes of communication.

- Separate maps should be constructed for expressive & receptive communication skills.
- The team should consider communication strategies that work that are applicable across various environments.
- This is an excellent tool that is easily used for individuals who have difficulty expressing their needs, observations of key players are essential.
What Doesn’t Work!

- Loud background noise
- Too many people talking at the same time
- People not identifying themselves before they speak
- Dead hearing aid batteries
- People not knowing sign language
- People assuming I understand them when I need time to process what they said

What Works!

- Good lighting
- One-on-one conversations
- People use sign language while talking to me
- Standing within 3 feet when signing/talking
- People identifying themselves before they start talking and let me know where they are standing/sitting

Receptive Communication
The **Personal Preferences Map** is one of the most crucial maps that helps the team in identifying interests, strengths, likes and dislikes of the person.

- Separate maps should be created for ‘likes’ and ‘dislikes’ or ‘things that work’ and ‘things that don’t work’.
- Items across environments should be noted, such as: likes water in the bathroom and outside
- This is an excellent tool to use for individuals who have **difficulty expressing** their desires for themselves because input is given from observations from people who know the individual best.
- Identifying likes and dislikes can lead to successful vocational environments (i.e. connected to above; likes water – water plants in greenhouse).
Things that **WORK**

**Kenny**

Water activities
Family
Outdoors
Animals
Motion vehicles
Space to walk
Different smells
Josh

Things that DON’T WORK

To be alone
To be rushed
Changes in schedule
Not having access to technology
To exercise
Not having choices
How do we use the preferences and/or choices?

Utilizing his strengths to improve on his weaknesses

- **Expressive sign or sound** (communication)
- **Water the plants** (Vocational)
- **Wash his face, Hands w/soap** (ADL)

**Element:** Water

**Functional Activity:**

Utilizing his strengths to improve on his weaknesses through preferred activities such as communication (expressive sign or sound), vocational tasks (watering plants), and daily living skills (washing face and hands with soap).
The Dreams/Hopes & Fears/Concerns Maps are extremely important as they help the individual, family and service providers identify issues and concerns for the future.

- Very often we are focused on educational and vocational outcomes that we forget about the day-to-day wishes and fears of the individual and family members.
- This map puts an emotional perspective on the overall planning process.
- The team should consider creating separate maps from the student, family and professional perspectives and then compared.
How is he going to get a job?
Who is going to help him?
How is he going to pay his bills?
When is he going to be ready to live independently?
Where will he live?
The **Choices Map** is extremely important as it helps the team see very clearly the locus of control possessed by the individual.

- Being **self-determined** is directly linked to levels of control in areas that a person desires control over.

- This map helps identify what levels of control are currently in practice and areas that could be increased.
Choices Map

Choices made by ME!

Choices made by others
Fears and Nightmares

Choices Map

Choices made by KENNY!

- What to wear (especially gloves, type of coat)
- Willingness for task
- Asking for food if hungry
- Willingness to eat what is offered
- To go to sleep - if between certain hours
- Whom he wants to be with if it can be honored
- Games to play (ball, keyboard, balloons, etc.)

Choices made by others

- What to wear
  - to dress him appropriately
- What to eat/drink
  - healthy diet
- When to sleep
- When to get up
  - work days
- Where to go
- Who is keeping him company (sometimes)
Making it real...
PCP embraces the following concepts on a daily basis:

- Integrate **communication** into every action or decision-making process
- Allow him/her **control** over his/her actions
- Allow him/her **time** to take the initiative and **process** information
- Honor his/her **choices**
- Enjoy the activity and have **fun**
“The success of the Person Centered Planning process is not measured by the content of the plan, but by the quality of the life that a person experiences as a result of the plan.”

Evelyn Popper
Creating Circles of Support
What is a Circle of Support?

It is about how we take care of each other in families and communities. It is the 'structure' of our relationships.”

Circles of Friends is not a program. It is a way of living. It has an underlying philosophy of interdependence.

http://www.inclusion.com/circlesoffriends.html
What are the benefits of a Circle of Support?

- It allows the individual to identify representatives in various aspects of his/her life and note gaps in relationships.
- It broadens the life experience of the individual by developing relationships with various persons that may have been typically outside of his/her circle.
Circles of Support

- Why is it important for a person with disabilities?

“With friends, we have opportunities to become involved in community and school activities, to be exposed to new experiences, and to enjoy life more fully. Friendships between people with and without disabilities enrich the lives of both, in many ways.”

http://thechp.syr.edu/relshp.htm
Building Social Capital
Think of building social capital as similar to creating a bank account, readily available for withdrawals when they are needed.
Building Social Capital

- Instead of depositing money into the bank you are adding resources of people and networks from which to draw upon in times of need.

- Having social capital allows you to draw upon previously established relationships and networks. The relationships are reciprocal in nature.
Need a pick-up from the after school program? 
-Call Sally down the block

Need a transition counselor in the adult service agency? 
-Call the HKNC Regional Representative

Need a job experience? 
-Call your contact at the local rotary club & town hall

Need a weekend leisure activity? 
-Call your contact at the YMCA & Girls Scouts
Building Social Capital

Why is it important for individuals who are deaf-blind?

Three areas of measure that are valued in Western civilization:

- Jobs and meaningful things to do
- Housing and living choices
- Transportation to engage in community

“The Critical Nature of Social Capital” by Al Condeluci, PhD
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# LIST OF PARTICIPANTS

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Review...

Person Centered Planning
- To look at an individual in a different way.
- To assist the focus person in gaining control over their own life.
- To increase opportunities for participation in the community.
- To recognize individual desires, interests, and dreams.
- Through team effort, develop a plan to turn dreams into reality.
Important points...

- There is NO right or wrong way of doing the PCP process
- Personalize the process to suit the needs and PERSONALITY of the student/family
Important points...

- Have fun!
References & Resources

**Person centered Planning – Finding Directions for Change Using Personal Futures Planning Facilitator Sourcebook** by Dr. Beth Mount.

**Building New Worlds – A Sourcebook for Students with Disabilities in Transition from High School to Adult Life** by Dr. Beth Mount and Connie Lyle O’Brien.

**Exploring New Worlds For Students With Disabilities In Transition From High School to Adult Life** by Dr. Beth Mount and Connie Lyle O’Brien with the support of Fredda Rosen, Job Path, and the Pinkerton Foundation.

**Families, Professionals, and Exceptionality – Positive Outcomes Through Partnerships and Trust** by Ann Turbull, Rud Turbull, Elizabeth Erwin and Leslie Soodak.

**The Critical Nature of Social Capital** – Al Condeluci, PhD
Thank you for participating. For more information please contact us at the number or email below.

Queens College
65-30 Kissena Boulevard
PH 200 - NYDBC
Flushing, NY 11367
NYDBC@qc.cuny.edu
www.qc.cuny.edu/nydbc
718-997-4856

NYDBC Staff
Dr. Samuel Morgan, Director
Susanne Morrow, Coordinator
Clara Berg, Family Specialist
Eneida Lamberty, Assistant
Dr. Patricia Rachal, Principal Investigator