
Taking Action: Planning for Lifelong Success

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PARENT, ADVOCATE, ACTIVIST



My hope for you today is to feel empowered and instilled with optimism for the future.

- Stay engaged in the disability community, you can't do this alone
- Life after the entitled school years is often scattered with challenges and set backs, be persistent and hopeful.
- We cannot rely on the social service system to meet the needs of our sons and daughters, there isn't enough money and there never will be!
- Dream, innovate, activate!
- Sometimes my trainings are cathartic for me too

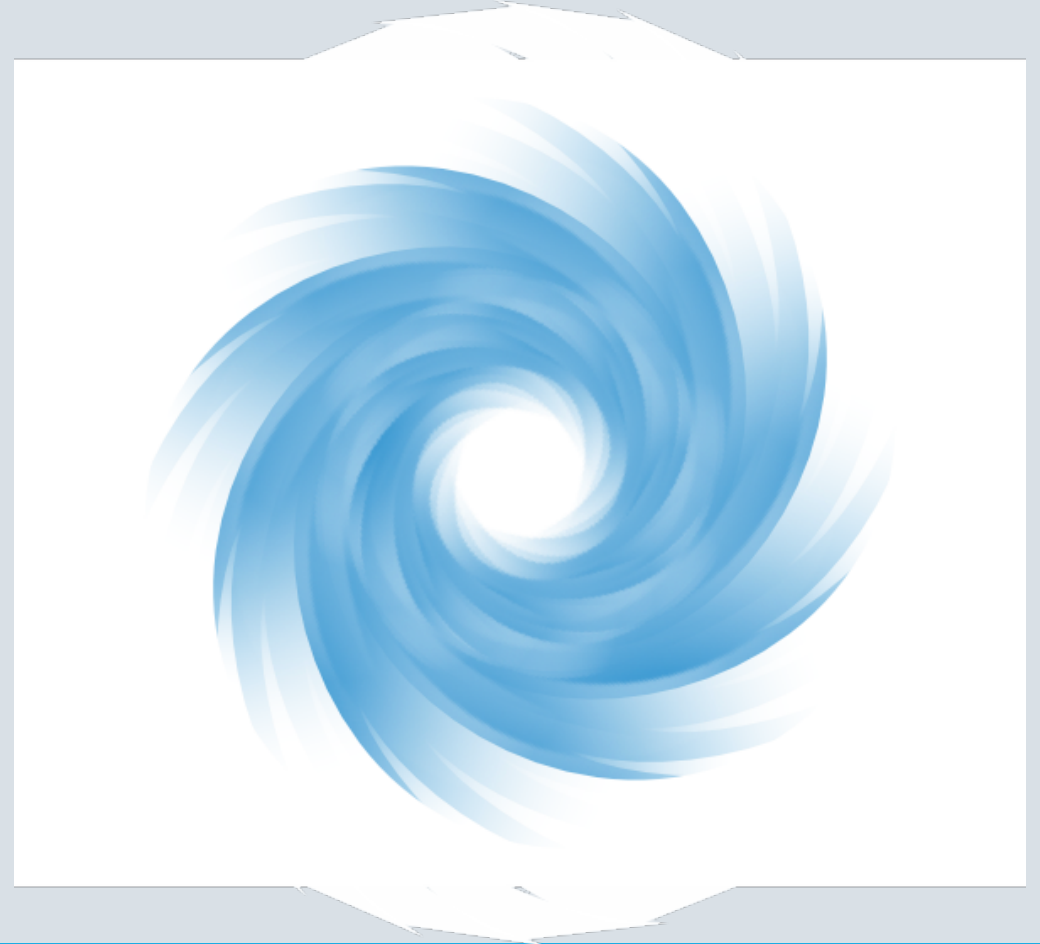
What are your hopes and dreams for your son or daughter, what are theirs?

- Safely living, working and recreating in our community
 - Having money for life, fun and expenses and not be exploited
 - Being with family
 - Having friends and spending time with them
 - Contribute to the community – it's not all about you darlin'!
 - Access to Healthcare
 - Access to services based on the disability of autism
 - Lifelong Learning Opportunities
- 



Life Does Not Happen in a Vacuum!

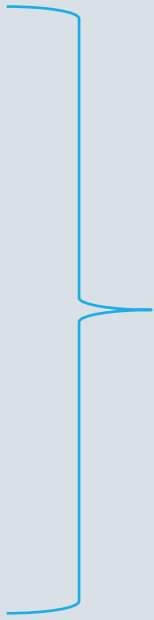
1. Capture history, if you don't it always has a way of repeating itself!
2. Reminder of who a person is.
3. Keep the end in mind and work backwards.
4. Celebrate each movement on your path, however small or big.
5. A picture is worth a thousand words.
6. Use your plan as your calling card!



Person Centered

What is:

- Self-determination
- Self-directed
- Supported decision making



Why are these important points to know and what are the implications for a person with autism?

Clue: They all need Social-Communication, Critical Thinking, and Executive Function skills!

Person Centered Planning

Person-centered planning is a way of helping someone to plan their life and support, focusing on what's important to the person. Person-centered planning has five key features:

1. The person with autism is at the center of the planning process
2. Family and friends are *partners* in planning
3. The plan shows what is important to a person now and in the future and what support they need
4. The plan helps the person to be part of a community of their choosing and identifies a way for the community to welcome and **involve** them
5. The plan puts into action what a person wants for their life and keeps on listening - the plan remains '*alive*'

PCP: Why is this Tried and True Tool Coming Back to the Forefront?

CMS (Center for Medicare and Medicaid Services)

- New policies;
 - Services must be Person Centered
 - Provided individualized supports
 - Promote communication, choice and autonomy

Person Centered Planning is Ideal for Autism

- Person-Centered planning is based on the individual though planning tools often need to be adapted
- Sometimes terminology needs to be modified so that it can be understood by the person with Autism and support people as well
- It is essential that the person's preferred ways of communicating are taken into account so that they can play a full part in the planning process

Person Centered Planning: Process of Life Planning

- The principles of inclusion are incorporated to ensure the person is not isolated from society
- Reaffirm that support needs are proactive, instead of a medical model where a person may passively be involved in the support services they receive and their impairments viewed as a problem leading to exclusion from the community
- PCP is more of a social model where the individual is encouraged to be proactive in ensuring equality and inclusion into the community of their choosing
- In practical terms, PCP involves careful planning for an individual taking into consideration their strengths, preferences, areas of difficulty and related support strategies/ systems at each stage of their education and transitions of life.

Inclusion versus Involvement

INCLUSION



INVOLVEMENT



When Should a PCP be Facilitated?



NOW!

Anytime is the right time, but here are some points from a practical vantage point:

- Parents Divorce
- Parent Remarriage
- Blended Family
- Transition from Elementary to Secondary Education
- Approaching age of transition into adulthood (14-21 years)
- Moving from the educational system into the adult world
- Moving from parent's home
- Change in health



Person Centered Planning, Perfect for the Transition Years of Entitled Education

1. Provides a process that makes a Transitions IEP “Legally Defensible”

- a. Input from the entire team
- b. Identifies strengths and interests for life beyond school
- c. Identifies steps to achieve community participation
- d. Addresses all aspects of the person’s life;
 - i. Living
 - ii. Employment
 - iii. Recreation, Leisure
 - iv. Sexuality
 - v. Spiritual needs
 - vi. Financial and everything in between

Don’t be misled that the focus needs to be only on employment...that is highly important but does not capture a whole-life.



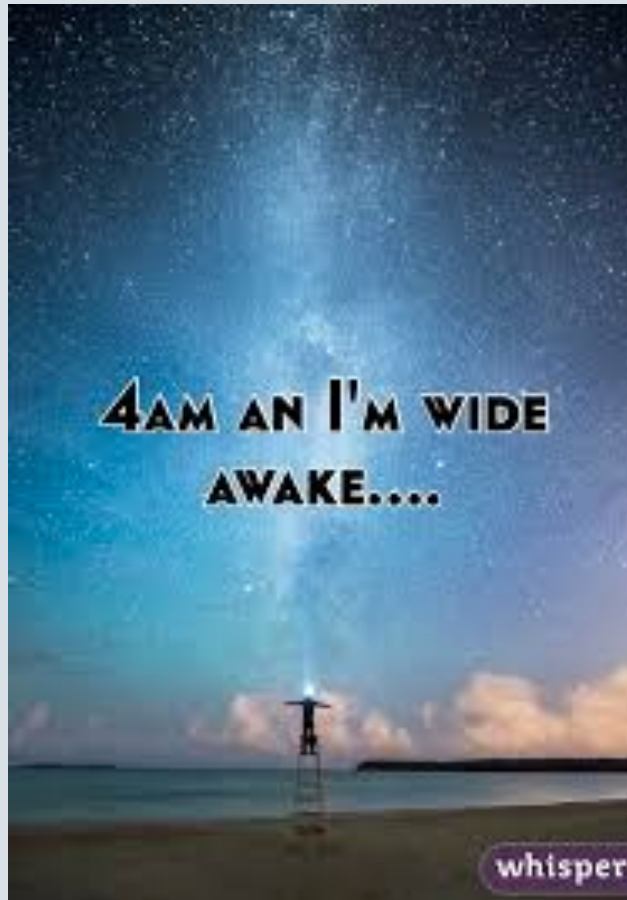
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Quality of Life Indicators: the same for Adults with Autism as they are for anyone else.

Building a Bright Future for a “Whole-Life” Starts Today!

- Health
- Diet
- Hygiene
- Emotional Well-Being
- Spirituality, beliefs and values
- Living Environment
- Family and Social Relationships
- Companionship
- Education
- Fulfilling work
- Enjoyable leisure activities
- Independent living skills
- Financial Security

So, what keeps you awake at night?



Thoughts that go through the Minds of Moms and Dads in the Wee Morning Hours!

- What happens if I die?
- Will people know that he needs 5-10 seconds to process language when he is stressed?
- Where will she go if I get sick?
- Will she have a choice or end up in some other part of the state where we'll have to choose between moving to be closer to her or seeing her infrequently due to our need to work until we're 82?
- Will he understand why he isn't living with us anymore?
- Will she think we've abandoned her?
- Who will care for her?
- Will they be good to him?
- Will they "get her"?
- How long will it take for them to know that when she takes the milk and butter out of the fridge, she's asking for Annie's mac and cheese?
- Will they try and get her to sleep with her head at the head of the bed rather than the foot of the bed where she has comfortably slept for years now?
- Will people understand that he needs visual supports to communicate his wants and needs?
- Will her support staff understand that when she puts on her heavy coat that it doesn't mean she is hot.
- Will his brother help with his support needs when I am gone?
- She will live with us! (until when?)
- What happens if his favorite DVD breaks?!?
- What if he is bullied?
- What if he is arrested?

Our Role as Lifelong Case Manager

Definition of a Case manager:

- Helps people who are in difficult situations with advice,
- Figure out what kind of help they need,
- Help them find the services they need, create plans for treatment or recovery, work with other health and human service providers, and keep tabs on client's progress with treatment plans.

Sound familiar? Don't go it alone, have a plan and strengthen your sea legs!



PCP Tools

Essential Lifestyle Planning (Smull 1988)

Essential Lifestyle Planning

Find out...

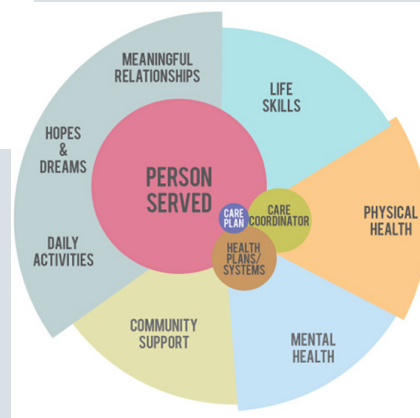
Non-negotiables	Strong Preferences	Highly Desirables
People who really know & care about [the person] say...		
To be successful in supporting [the person]...		
[The person's] reputation says...		
If this is going to happen, we must...		

✓ Listen to words & behavior

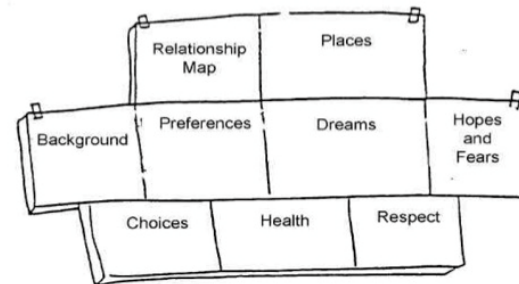
...in order to...

- Discover the person's core values & preferences
- Account for the person's disability & safety
- Develop a vision for the future
- Mobilize & change community services

transition!



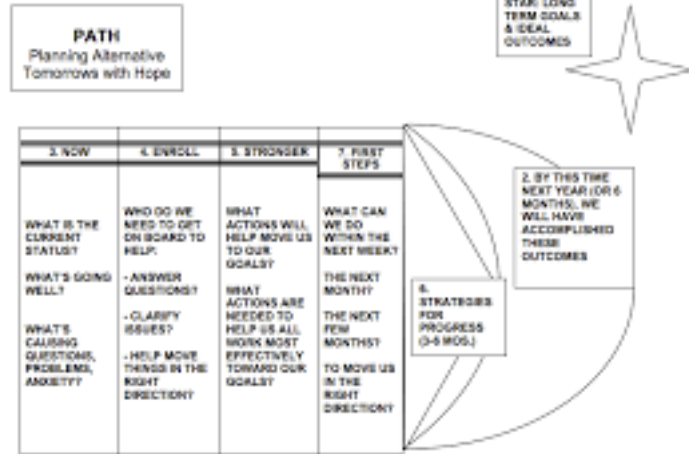
Personal Futures Planning: Mapping



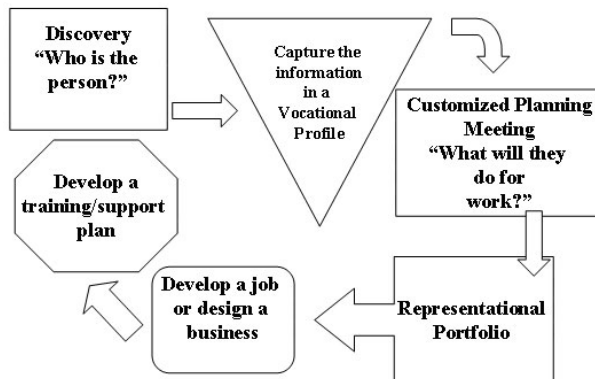
transition!



8 March 2010 - Anne A.



Individualized Career Planning Model Components Diagram



Agencies to Consider

Remember they will not meet all your son or daughter's needs...create, activate, innovate!

DDA – Wavier Services

DVR – Order of Selection

MHD

DSHS

Medicaid

Post Secondary Education - College: Office of Disabilities

Able Saving Plan

Special Needs Trust

- ARC of WA, Trust I or Trust II
- Through an attorney

Key Words to Remember!

- Person Centered
- Self-Directed
- Supported Decision Making
- Whole-life
- Quality of Life Indicators
- Involvement
- Participation
- Inclusion
- Autism Spectrum Disorder Research and Evidence Based Supports

Make a Plan...Soon!

Thank you!

