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21st June 2024

***„Keeping the student at the center:
A support planning
approach that works”***

Keeping the Student at the Centre: A Support Planning Approach that Works

Dr. Nancy Salem Hartshorne

Who am I?

- Psychology Professor at a Community College
- Parent of lots of boys
- International speaker on CHARGE syndrome
- Fierce advocate for quality of life for people with disabilities
- First and foremost: Jacob's mom

Delta College



Traditional Way to plan for supports

Individual Student Assessment



Traditional Assessment

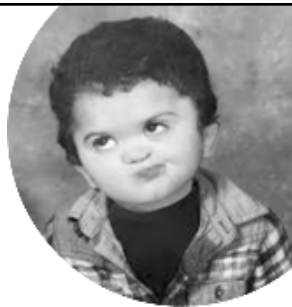


- Standardized tests
- Each team member does a separate assessment
- Parent may or may not have input
- Looks primarily at academic skills and behavior
- Goals and objectives are primarily for school-based intervention

What's wrong with traditional assessment?

For some children with multisensory impairment, traditional assessment can work.

For most, it will not
Sensory impairment
Communication difficulty
Medical Issues
Everything else!

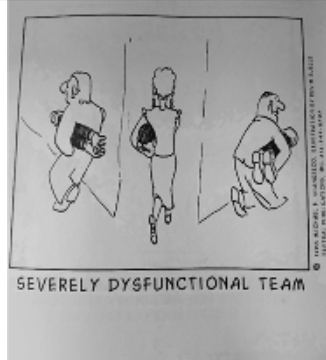


How do we see the whole child?



It takes a village

Assessment must be multi-disciplinary and ideally, integrated.



Assessment should Start with the individual and the Family

Take the time needed to get the whole picture



Person-Centred Planning: a holistic and positive approach involving everyone

What is Person-Centered Planning?

- "a family of approaches to organizing and guiding community change *in alliance* with people with disabilities and their families and friends."
 - Emphasis on changing the community, not the person
 - Emphasis on alliance with, not planning for
 - Emphasis on family and friends
- <https://www.youtube.com/watch?v=v77v7XW8GtE>

Common Beliefs in Person-Centered Planning

- 🔥 The *person* is the focus. The person and those who love the person are primary authorities on the person's life direction.
- 🔥 Learning through *shared action*. Although documentation happens, it's the action of people walking together that makes the path.
- 🔥 Tends to change things in a community like segregation, devaluing, and denial of opportunity. Stimulates hospitality. Gathers community members to help people work toward a desirable future.
- 🔥 Can only happen if it stems from respect for the dignity and completeness of the person.



A little bit of history

Historically, a person with a disability was seen many ways:

- Sub-human
- Menace
- Object of ridicule
- Sick
- Burden of charity
- Eternal child
- Holy innocent

These views encouraged all kinds of nasty practices.

In 1969, Wolf Wolfensberger noted that in order to see each person individually as a person of value, we'd need to change our thinking societally to emphasize **personhood, citizenship, and developmental potential**



**Rationale:
Why do
this?**

Experiences, needs, desires, and contributions of individuals with disabilities have been traditionally defined by segregated settings and limiting stereotypes.

All individuals have strengths, talents and skills that can be shared and utilized in their community.

We need to break the cycle of isolation in order for individuals to become participating members in their communities.

Having meaningful relationships is essential for one's well-being.

Adapted from Blue and Lewis

Principles and Values of Person-Centered Planning

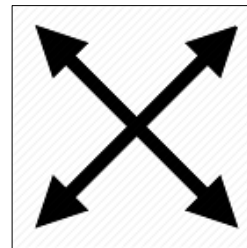


- Every person has strengths, gifts, and contributions to offer.
- Every person has hopes, dreams and desires
- Each person is the primary authority on his or her life, along with those who love them.
- Every person has the ability to express preferences and to make choices.
- A person's preferences and choices must always be considered.

**GOALS OF
PERSON
CENTERED
PLANNING**



Four Directions for Building a Community Life



Encourage Friendships



How did you meet your best friend or spouse?

Encourage or strengthen associational life



What sorts of groups do you belong to?



Build school, work, and homemaker roles

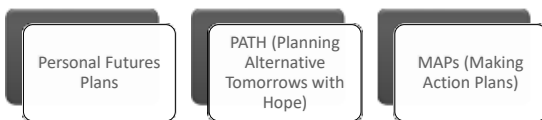
- Job opportunities related to specific interest; opportunities for home ownership/homemaking; involvement in school functions

Encourage Neighborhood Connections

- Opportunities for daily interaction/acts of neighborliness; becoming a valued customer or “regular” at local places



There are several types of planning processes. Here are a few:



Our focus today will be MAPs

Do more things and say 'No!' Don't do things that you want and say 'No!' ...George Bernard Shaw

**You are invited to
Jacob Hartshorne's 'Future'**

Please come and help us build the future making futures by participating in my Future-Concept Film!

1400s FEBRUARY 22, 2007
Time 8:00 P.M. to 9:00 P.M.
1400s 21, 22nd St. Georgetown, DC 20854
801.550.9000 (4th Fl. Single room of People and Washington)

1400s is a Future-Concept Film! I have prepared to help you see future
1400s is your personal future from me in a way that is my idea too. You are important to me!
1400s is being the best, with the most and the best way. Now join appointments & more!

1400s is a personal, individual, personal (or future) and a look into my world (1400s) (1400s) or you'll see the most future, here (1400s) (1400s)

Together we can make very future bright!

Who would you want at your meeting?

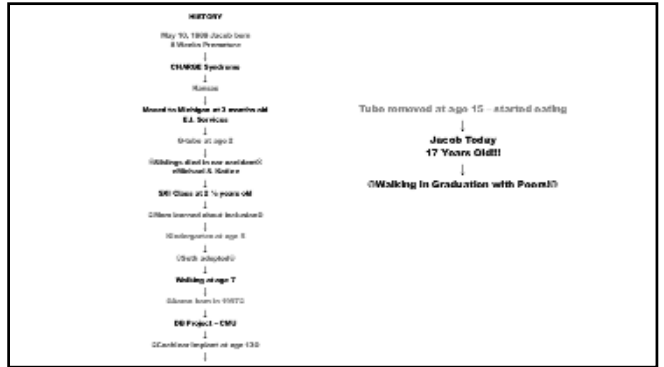
Who are your best friends? Who do you love most? Who loves you most? What community places do you go? Who do you see there?

Group Brainstorming Process

- Skilled Facilitator
- Everyone has an equal voice (but the person and their family have the most voice!)
- Fun and relaxed, but also respectful and serious
- Held at neutral or family choice of location, with fidgets and snacks!

What is this person's HISTORY?

- What people and events have shaped this person's life?
- What have been the highlights?
- How have others present been a part of this history?



DREAMS



- May be open ended
- Dreams do not have to be "realistic"
- No dream is too big or too small
- Dreams can be short-term and long-term
- Dreams give hope and a possible direction



Jon's Dreams

- He finds things that are satisfying to him
- Participate in sports team:
 - Manager/towels/water
 - Remain connected to faith community that loves him
 - Have a life long partner
 - Clearly be understood all of the time
 - Serve as an acolyte
 - Transfer of skills learned to life after school
 - Tap into/unlock his potential
 - Work with trees
 - Meaningful employment as an adult
 - Transfer his love of order to connections with other aspects of life
 - Be aware of and have joy in his surroundings
 - Regain trust of peers
 - Repair work
 - Help at a camp for kids with disabilities
- Use his interests to drive activities and schoolwork
- An appropriate physical facility for school
- Be surrounded by peers that aren't afraid of him
- Enjoy future roommates
- Supported living with no aggression (group home)
- Martial arts
- Independence
- Peers learn about him and understand him better
- Have a pet: fear of pets be gone so he can enjoy as companion and he can care for and gain a sense of responsibility
- Use aggression in a positive way
- Vocational skills
- Develop learning potential
- Increase comprehension.

Cara's Dreams




Jay's Dreams

| | | | | |
|-------------------------------|---|--|--|----------------------------------|
| Have his own job | Learn more about airport jobs | Have a relationship with brother | More people to support him in his home community | Eligibility for support services |
| Be as independent as possible | Have his own home | Connect with the deafblind community maybe through exercise? | Write his life story | Join a boxing group |
| Marriage and family | After-school Activities: Extended day program where they know his needs | Activities in the community/community connections | Social/leisure opportunities | |

FEARS / NIGHTMARES

- Barriers to realizing dreams
- May be uncomfortable or revealing
- May be emotionally charged
- How can fears and nightmares be avoided?



Jake's FEARS

No one to look over him when parents are gone

Communication misperceived as "behavior"

Message won't be understood (gain)

Institutional Living/Working (group home or crew work)

Social Isolation

Deterioration of health

Increase in challenging behavior

Getting lost/wandering away

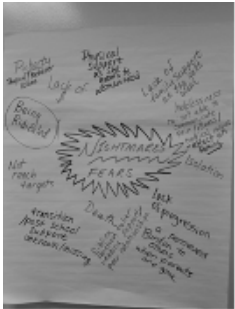
Lack of meaningful activities

Being punished for communication through behaviors

Possibility of abuse

Jon's Fears and Nightmares

| | | | | | | |
|--|--|---|---|---|--|---|
| Institutionalization | Those working with Jon give up on him | Lack of acceptance | His world stays isolated as it is now | No sense of belonging | Be alone | Unable to communicate his need or illness |
| Not being understood | Loss support system: family or otherwise | Aggression regression | Heart gets worse/health/wellness replacement upcoming | Low expectations of others | Potential not unlocked | Emotions trapped in body—unable to express them |
| Seriously injure himself or others | Not finding the purpose of his behavior | Adult services not/caring as current caregivers | Underestimates himself | People fearing him or thinking he's a terrible person | He will lose out and someone will not understand | He could be alone without a companion |
| Never be independent enough to live on his own in society as an adult. | | | | | | |



Cara's Nightmares

Jay's Nightmares

- Isolation from his community
- No access to needed resources
- Immigration status limits available resources (these are not available in home country)
- Being misunderstood

WHO IS ...?

- Strengths
- Skills
- Likes and dislikes
- Personal qualities
- Favorite activities
- Friends



WHO IS JON?

- Sneaky**
- Opinionated**
- Swimmer**
- + Water**
- A KM who needs help**
- Adaptable**
- Bother**
- Stubborn & Persistent**
- Squinty**
- Nephew-same age as cousin**
- Manipulative**
- Affectionate**
- Music Lover**
- Sense of Humor**
- A guy who gets & likes to bite & throw things**
- Tickle**
- Clever**
- Son**
- Teacher**
- Expressive**
- Hair Puller**
- Funny**
- Puzzle**
- Deaf & Blind**
- Perceptive**
- Not easily embarrassed**

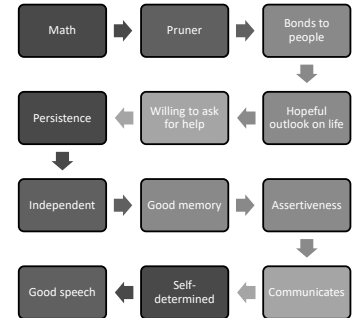
WHO IS



Jon Is:

- Driven, math skills, orderly, needs acknowledgement of good work, comedian, low self-esteem, likes being teased, expresses "no" in different tones, a pruner, a charmer, a good negotiator, capable, outgoing, socially interested, a perfectionist, good in sports, need for reassurance in school, good navigator, verbal, greeter, underestimates own abilities, goal oriented, needs praise, happy, needs to be sure, gives reminders, task completer.

Jon's Gifts, Strengths, and Talents



Jay's Gifts, Strengths, and Talents

- Memory
- Open to tactile sign
- Vocabulary
- Writing!
- Learning continues!
- Eager to learn
- Self-Care!
- Motivated by new things
- Great Tactile discrimination (is careful in exploring)
- Uses many educational tools to do his activities
- Curious!
- Socially interested
- Communicates with others back and forth through sign
- Focused
- Strong
- Some formal expression of emotions
- Fine and visual motor skills
- Hard-worker: determined
- Persistent!
- Goal directed
- Drawing
- Loves the structure of work routines
- Creative
- Flexible/Adaptable in jobs and variety in job exploration

CARA



What does Jon Like?

- School
- **Likes/Dislike**
 - Order
 - The principal
- School people
- People in general
 - Traveling
 - Staying in motels
 - Walmart
 - Food
 - Camp
 - The van
 - Nurses and doctors
 - Krystie
 - Assembly/repetitive work
- Spongebob
- Water
- Microwave
- Clean clothes
- Greets with facial expressions and likes you to do it back
- Routine
- Likes his own space

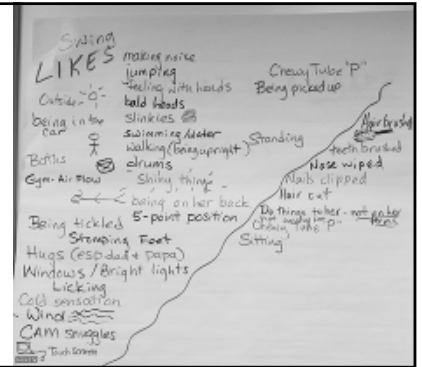
What does Jon Dislike?

- New academic material
- Dogs
- Disruption in routine
- Challenges, even physical ones
- Sharing
- Being in a situation where he's afraid or not in control
- Not feeling safe
- Lots of stairs
- Being wrong
- Losing (in a game)
- Being trapped physically or in his thinking

Jay's Likes and Dislikes

- Airplanes!
- Working with scent (flowers)
- Total Communication
- Learning new words/signs
- Seeing tasks to completion
- Clear expectations
- Warmth/Climate control of greenhouse
- Drawing and writing!
- Seasonal changes
- Reading
- Being successful
- Weather
- Written preview of activities
- Positive reinforcement, especially when frustrated
- Being physically active, swimming, exercising, body-building
- Being rushed
- Constructive feedback
- Not finishing a task
- Being misunderstood
- Bumping into things/people
- When things are unclear (expectations)
- Not being successful is frustrating

Cara's Likes and Dislikes



NEEDS

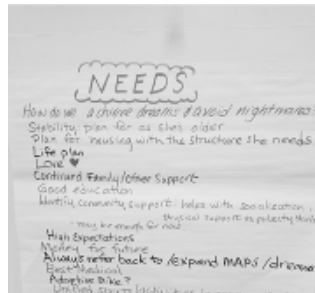


- Hopes, strengths, interests
- Activities, opportunities, supports
- The focus is positive
- Use brainstorming

Jake's Needs

- Social Relationships (male interaction)**
- Friendship
- Relax Support
- Invitation to go places
- Quality extended guardianship**
- Communication (PEE book, people who sign & understand his communication)
- Accommodating skin/haircare**
- Work/Recreation (volunteering with friends, beach house, work that fits)
- People he likes (roomed living alone)
- Home Life (photo, wearing chair, sensory toys, love lamp, swing, music system)
- Health & Safety (quality gym clothes for fitness, 24/7 care or monitoring, clear uniform leading if dangerous situations)
- Identity & appropriate adult services**
- Continues to educate others - CHARLES
- Balance between living alone & with others
- Not just accept, but embrace his uniqueness!

Cara's Needs



JON

- What does Jon Need?**
 - Get soiling and inappropriate touching under control
 - Interact with all sorts of people, male, female, etc.
 - Someone who knows how to read him always
 - Consistency between environments
 - A way to be assertive without being aggressive
 - Use the tools he has for communication more independently
 - Communicate when angry instead of lashing out
 - OT with sensory expertise
 - Service providers be knowledgeable about his syndrome
 - Loosen up about work
 - Transition to work he enjoys—work at a video store?
 - Help him to learn to enjoy his job/work
 - Generalize skills of daily living learned in school to other environments
 - Keep academic expectations high, as well as working on vocational stuff
 - Social integration in a safe way
- What Barriers are in the Way of Jon Getting what he Needs?**
 - Lack of appropriate physical facility
 - Lack of ongoing training for staff—high rate of burnout
 - Behavior
 - Real world won't always accommodate him
 - Challenge of balancing Jon's needs with others' and safety
 - Hearing equipment unusable
 - Inconsistency across people
 - Lack of communication (Jon)
 - Negative perceptions of Jon by peers and adults
 - Lack of shared focus among adults—pushing in different directions
 - Lack of support for caregivers
 - Lack of funding

Jay's Needs

- More formal expression of emotions
- More independence with money
- Tools: goals/charts/timers/visuals
- Relationship and communication with Brother
- Predictability
- Structure needed for task completion with no frustration
- Total communication
- Afterschool programming Movement/Change positions
- Visit airport
- Checklists
- A schedule
- The ability to communicate his need for a break
- Breaks!
- Force modulation strategies
- Support/training of self-regulation in chaotic situations
- Travel assistance
- Clear expectations/preview of what's coming
- Time for familiarity with new people before expectations are set
- Explore leisure activities
- Instruction to generalize work/communication/social skills
- Supported employment with a job coach and 1-1 support for safety and learning
- U.S. Citizenship
- Orientation and mobility instruction to build safety skills across all environments and in new situations
- Social skills training: especially how to express himself about appropriate topics
- An ability to explain why he feels the way he does

ACTION PLAN

- Move toward the dream while avoiding the nightmares
- What would a perfect day be like for this person?
- Who is willing and able to support?
- What, Who, and By When
- Make sure there is a clear plan for follow-up
- Use available agency supports AND natural supports.



Action Plan

What Who By When?

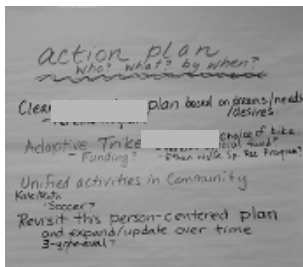
Revisit PCP

Jay's Action Plan

- Joint Physical Therapy with both brothers. They both love exercise. Program will be shared with dad. PT and Gym Teacher will work together to implement. Has begun and will schedule their PT sessions together next year.
- Self-regulation and leisure between brothers and with other students. OT will start now as part of her consultant role to work with others to make this happen across school environments.
- Visit airport and/or pursue community exploration around aviation. Job Coach will attempt connections for airport visit and other sites by October 2018. Brother will be included in this.
- After school activities: School for the Blind and Local District will discuss possibilities for this, to be implemented if possible by fall 2018.
- Community Activities: Social Worker will contact the Deafblind Center of Boston to see what is available. Administrator will meet with DB Advocate in June to discuss possibilities.
- Other activities: Dad will need more support of some kind to be able to implement other community-based activities alone. With three boys who are DB, it is difficult to monitor and assist all at once. The person-centered planning committee may want to follow up and assist him to investigate options.
- Complete autobiography. School will assist with completion of this by graduation.
- Follow-up meeting scheduled



Cara's Action Plan

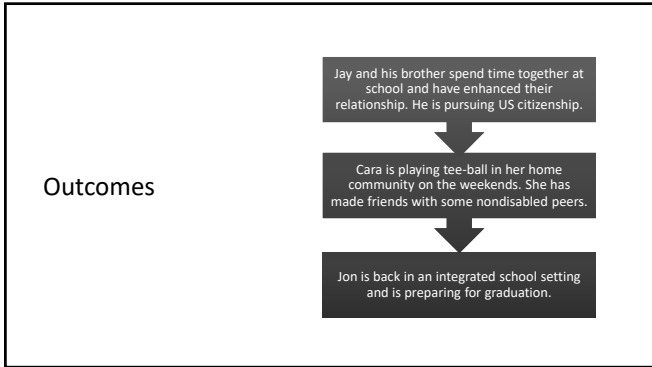


What would an Ideal School Setting look like for Jon?

- With peers at least some of the time
- Jon is respected as he is
- Kept in his own special needs classroom and regular ed. classrooms
- Prep for post-school life
- Working on priority areas
- Independence
- Physical setting: bathroom/shower nearby
- Self-contained educational setting with bathroom/shower
- Work in community vs. workshop
- Find work he enjoys—tend to plants alone? Nursery? Work in a video store?
- Parents are equal team members
- Trust between family and school

Action Steps to Take and Assignments

- At Jon's IER, the team will work on securing possible Extended School Year services for him.
- An Occupational Therapy evaluation and request for a plan of service, including sensory integration issues will be requested by the ESA.
- Behavior/educational report from Tim and Nancy
- Explore High School Classroom. Three staff members
- Bring Jon back to the M/S for adaptive PE this school year: PE Teacher
- Have Jon visit the High School and do familiar school work in the classroom during the summer: current educational staff
- Explore the possibility of Jon attending ARC in the afternoons during the summer and next school year: ESA
- Explore vocational options (e.g., nurseries, video stores): Who?
- Parents will visit alternative programs in planning for next year: Western High School Severe Disabilities classroom 35 miles away. Better facilities, fewer students. Would associate and/or interpreter travel with him on the bus?
- Other school? Very far—45 minutes. But could be a good option, educationally.
- A concern is that neither of these options would lead to further peer opportunities in his own community.



OUTCOMES

Jake has had person-centered plans throughout his life, beginning at age 5. He is now age 33. He lives in his own home. He has 24/7 assistance to take part in all aspects of his life. He has three individualized part-time jobs in the community, based upon his likes and skills, and garnered through community connections. He spends leisure time doing what he enjoys and visiting those he loves to be around. He has an enviable life!

- ## Things to Remember
- Find a skilled and seasoned facilitator. Or, get trained yourself!
 - Keep the person at the front and center.
 - Collaborate with families to find out what's best for the individual.
 - Complete domain-based assessments as needed, remembering all the while that the person's quality of life should always be at the center of your focus while doing so.
 - How can you integrate your results and recommendations into a plan for this person's bright and enviable future?

How can you use Person-Centered Planning to enhance quality of life for your students?

- Wallpaper and markers can open the doors to a new world.
- It's often hard to find vision in the human service world.
- The person whose life is being focused upon has the loudest voice.
- Required for admission--a personal relationship.
- Of all the meetings you might choose to--or need to--attend, this one will be worth it!

Person-Centered Planning is a Celebration of Life!