



# **16th CHARGE conference**

**24. – 26. June 2022**

*Oberwesel,  
Germany*



**Tim Hartshorne**

**June 24, 2022**

***„Who´s in CHARGE?“***



## Who's in CHARGE?

Tim Hartshorne  
Central Michigan University

## Words of a teacher

"After having taken Andy home for a night, I'll never yell at a parent for leaving something out of a diaper bag, being fifteen minutes late for an appointment, or any other minor thing."

## The World of Disabilities

- Difference – leading to a felt minus
- Work
  - Limitations due to time and resources
  - An escape
- Friendship
  - Lack of social support
  - Change in participation
- Love
  - Expectations
  - Commitment



## Parent experiences

- *Parental Guilt: The Courage to be Imperfect*

"How do you know if you have the right doctors and therapists doing the right things and enough of them? How do you know if you're doing all the right things and enough of them? I have been avoiding phone calls and insurance stuff, etc, because I just want us to be normal."

## Parent experiences

- *Need to defend the child*

"Our first battle was over getting deafblind consultative services. We fought and fought. Now we are going through it again. Maybe it's just the looming battle, but I feel like weeping. Yes, it can be necessary to fight like the devil, but that doesn't make it right."

## Parent experiences

- *Capability of the child*

"When she was an infant the hospital sent out evaluators. They sat me down and told me she would never walk, talk, or be independent. After he left I cried and had such terror my world spun. Then I thought "Baloney." She ended up learning lots. Her performance always goes above and beyond potential. Always."



## Parent Experiences

- *Can I cope?*

"Tonight I am so very tired of being the person figuring out what's going on. It's been a while since I've felt so isolated, scared, on and on. Right now, it's as though nothing is enough to really help. I'm damned tired of this. I would like some help, too. I need it now. My daughter needs it now."

## Birth and the NICU

- Shock
- Will my baby live
- What is wrong with my baby
- Can I keep my baby alive



## The first four years: Staying alive

- Heart surgery
- Choanal Atresia repair/cleft repair
- Aspiration pneumonia
- Ear infections



## How?

My son is five, is about to have his 44<sup>th</sup> surgery, I would like him to go to school some day, but right now he is sick too often and they really don't have a program for him. So, it is pretty much me 24 hours a day, seven days a week. All I do is take care of him.

## The start of school

- Your child does not belong
- We do not provide those services
- Listen to the experts
- Lower expectations



An adolescent with CHARGE is confronted by many issues.



*I would just like to be able to live by myself, to have friends and a social life, and to have a job.*

### Quality of Life

- Love
- Friendship
- Work
- Health, sleep, anxiety
- Housing, transportation, service availability



### Making decisions

- Even simple ones



### Parental Decision Making in the Removal of Gastrostomy Tubes or Buttons

Rachel Malta



#### What sources do parents consult when deciding to remove the G-tube/button?



Sources Consulted	Number of Participants (n = 37)
Professional	
Pediatrician	29
Gastrointestinal (GI) Specialist	17
Speech-Language Pathologist	15
Nutritionist	14
Surgeon	13
Ear/Nose/Throat (ENT) Specialist	10
Occupational Therapist	10
Nurse	6
Professionals with Knowledge of CHARGE syndrome	6
Physical Therapist	5
General Practitioner	3
Psychologist	1
Social Worker	1
Teacher	1

**What sources do parents consult when deciding to remove the G-tube/button?**

	Non-Professional
Child with CHARGE syndrome	20
Other Family Members	19
Other Parents of Children with CHARGE syndrome	10
Internet (G-Tube website)	10
Books on G-Tubes	8
Blogs about topic	4

**Does social media play a large role in the decision? What percentage of parents used social media to gather advice or opinions?**

- Facebook used most frequently (n=13)
- Myspace, Google+, and Twitter not used as much (n=1 for each)
- Others included: CHARGE Listserv (n=4), no traditional social media at time of removal (n=3).

**Open Ended Question Responses:**

What additional support would have helped in making this decision for your child?

- 25 responses
  - 6 reported connection with others in comparable situations was important to them
  - 2 reported it would be helpful to consult different sources to ensure they had all information
  - 2 reported it was important to trust that they knew their child best and look at what their child was ready for or needed
  - 6 reported step-by-step, explicit instructions on post-tube removal and stoma closure would have been helpful
  - 7 participants noted medical professionals could have given better guidance and follow-up with parental concerns.

**Open Ended Question Responses:**

At any time, did you feel your ability to make decisions for your child was compromised (by situation, by people, by opinions, etc.)?

- 32 responses
  - 11 indicated they had experienced diminished autonomy during the process
    - 5 noted pushback from medical professionals and nurses regarding concerns that the stoma was not closing
    - Anecdotes regarding alternative timelines imposed or suggested, or service decisions without parent input

If you are a parent looking to make this decision, what would be helpful to you to feel supported and encouraged in this decision?

- Medical professional support
- Information from different sources for informed decision
- Connection with others in similar situations
- Self-confidence in their parental knowledge of their child

**Conclusions**

- The process to remove was not usually a sudden one and reflected a number of steps to ensure the child had a safe swallow and would be able to handle complete oral feeding.
- Open communication and understanding of the parents' perspective is needed for a smooth transition and process, though participants reported this was not always their experience.

**Other major decisions**

- Whether to get a cochlear implant
- What kind of a school to attend
- Choosing a communication system
- Using growth hormone
- Using psychotropic medication for behavior
- Using other meds
- Whether or not to go ahead with a particular surgery



## Cochlear Implantation

- Anatomical issues
- Surgical issues
- Cultural issues
- Predicting outcomes



## Choosing a school

- Availability
- Neighborhood school
- Special school like school for the deaf or school for the blind
- Special education classroom
- Inclusion or mainstream
- Homeschool



## Communication system

- American Sign Language
- Signing Exact English
- Oral/Aural
- Picture Exchange
- Whole Language



## Growth hormone

- Small stature a feature of the syndrome
- Are they actually growth hormone deficient
- Growth hormone treatment is expensive
- Are the results due to the treatment or natural growth



## Psychotropic medication

- Need to understand the purpose of the behavior
  - Pain
  - Sensory issues
  - Anxiety
- Evidence for effectiveness
- Knowledge of the prescriber
- Alternatives



## Other meds

- Sleep
- Secretions
- Anesthesia
- Allergy
- General concern with interactions and complications



## Whether to have surgery

- a. restoration surgery for palate and lip
- b. otoplasty
- c. heart surgery
- d. trach
- e. g-tube
- f. elective surgeries
- g. back surgery (scoliosis)



## There is another decision to be made

- I can decide that I am inadequate to the task and should just give up.
- I can decide to rise to the challenge and create something good from all of this.
- "I just want my child to be normal."

## NORMAL IS A SETTING ON A WASHING MACHINE



## MARATHON SKILLS

Ann P. Turnbull

- Meet basic needs
- Know your self and your family
- Love your child unconditionally
- Establish relationships
- Experience and benefit from emotions
- Take charge
- Anticipate future/transitional planning
- Establish balance



## Contact information

- Dr. Tim Hartshorne  
Department of Psychology  
Central Michigan University  
Mount Pleasant, MI 48859  
989-774-6479  
hartsits@cmich.edu  
[www.chsbs.cmich.edu/timothy\\_hartshorne](http://www.chsbs.cmich.edu/timothy_hartshorne)





# **Nancy Salem-Hartshorne**

**June 24, 2022**

***„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



 THE CHARGE SYNDROME FOUNDATION



## 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!

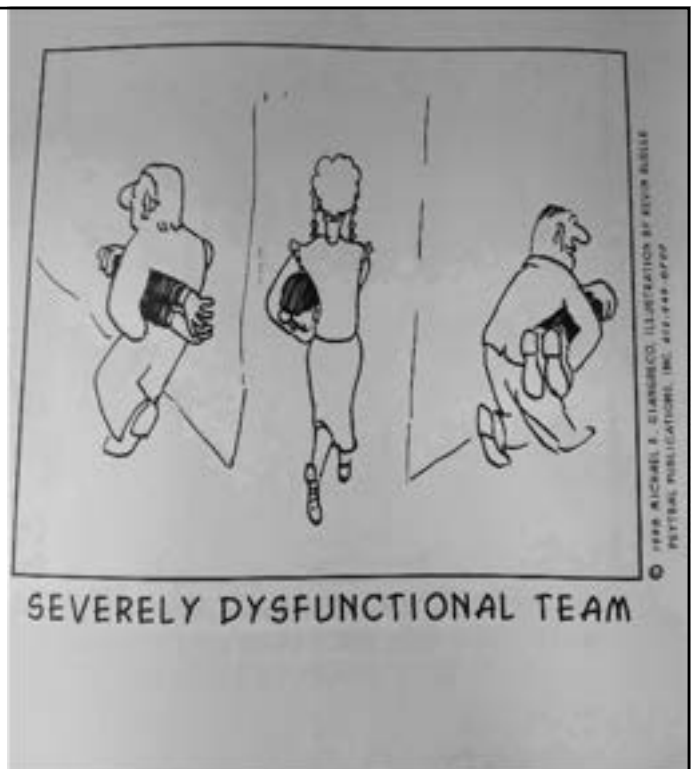


How do we  
see the  
whole child?



## 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=y77y7XW8GtE>

# 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**

Being Present And Participating In  
Community Life

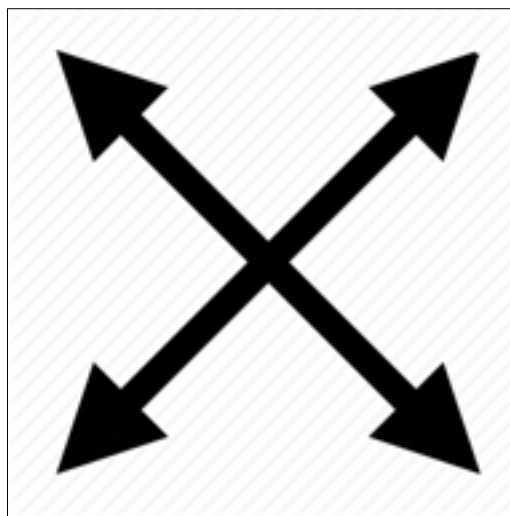
Gaining And Maintaining Satisfying  
Relationships

Expressing Preferences And  
Making Choices

Continuing To Develop Personal  
Competencies

Fulfilling Respected Roles And  
Living With Dignity

**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:

Personal Futures Plans

PATH (Planning Alternative Tomorrows with Hope)

MAPs (Making Action Plans)

Our focus today will be MAPs



*Some see things and say 'Why?' But I dream things that never were; and I say, 'Why not?'"—George Bernard Shaw*

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

*Please come and help unlock the doors into my exciting future, by participating in my Person-Centered Plan!*

**When:** February 15, 2007

**Time:** 1:00-5:30 p.m.

**Where:** St. John's Episcopal Church,  
Mt. Pleasant (406 W. Maple, corner of  
Maple and Washington)

**What is a Person-Centered Plan?** A team approach to help plan my future.

**Why am you invited?** You know me in a way that no one else does. You are important to me!

**What to bring?** An open, creative mind and a loving heart. Also, your appetite—we'll eat!

**RSVP to:** DB Central, Michigan Services for Children and Youth who are Deafblind (888) 774-2725  
Or reply via email: [nancy.hartshorne@cnich.edu](mailto:nancy.hartshorne@cnich.edu)



*Together we can make my 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

## JAKE'S

### DREAMS

**People in his life he likes and know about CHARGE**

Visit a beach regularly - time share

Live independent of parents & being comfortable

**Vibrating Chair**

**Not be Alone**

Find a way to unlock potential

Home in parent's neighborhood (cool, safe, fun)

**Eat, Chew & enjoy food!**

**Ability to communicate pain & other needs**

Social life outside of family

Independent in bathroom

**Meaningful daily activities**

Visits with his brothers

## 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



## 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 "behaviors"

Message won't be understood (pain)

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

Lose support system: family or otherwise

Aggression regression

Heart gets worse/health (valve 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 as caring as current caregivers

Underestimates himself

People fearing him or thinking he's a terrible person

He will lash 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 JACOB

**Sneaky**

**Opinionated**

**Swimmer**

**↳ Water**

**A Kid who needs help**

**Adaptable**

**Brother**

**Stubborn & Persistent**

**Equestrian**

**Nephew-same age as cousin**

**Manipulative**

**Affectionate**

**Music Lover**

**Sense of humor**

**A guy who spits & likes to bite & throw things**

**Ticklish**

**Clever**

**Son**

**Teacher**

**Expressive**

**Hair Puller**

**Funny**

**Puzzle**

**Deaf & Blind**

**Perceptive**

**Not easily embarrassed**

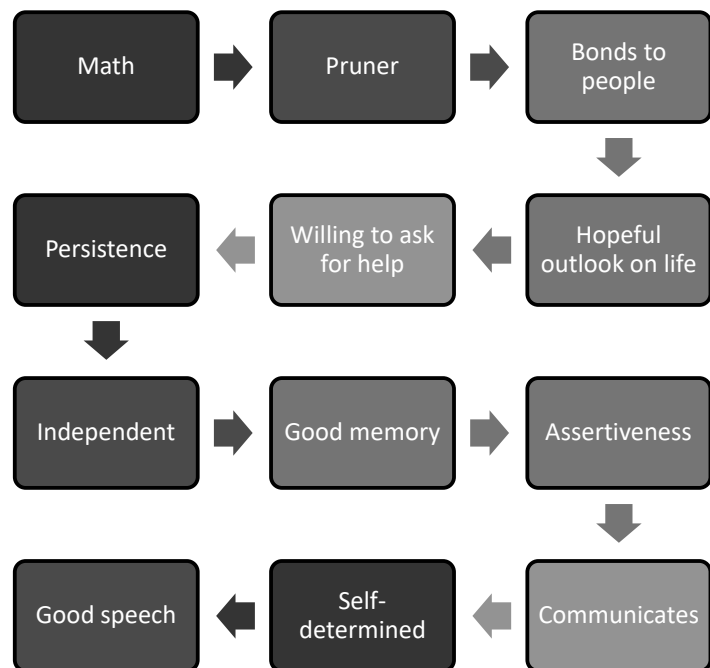
# WHO IS



## 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.

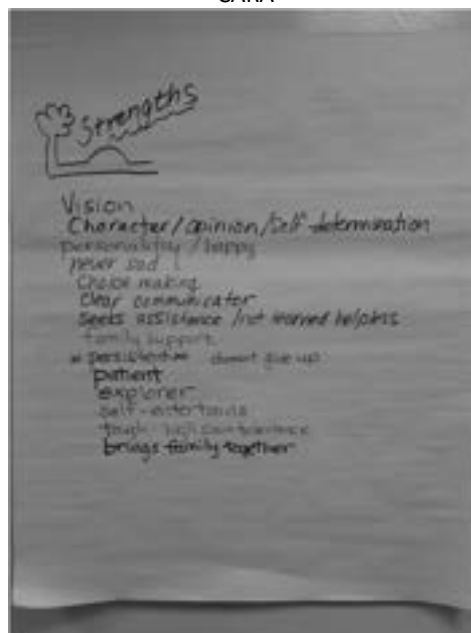
## Jon's Gifts, Strengths, and Talents



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

### Likes/Dislike

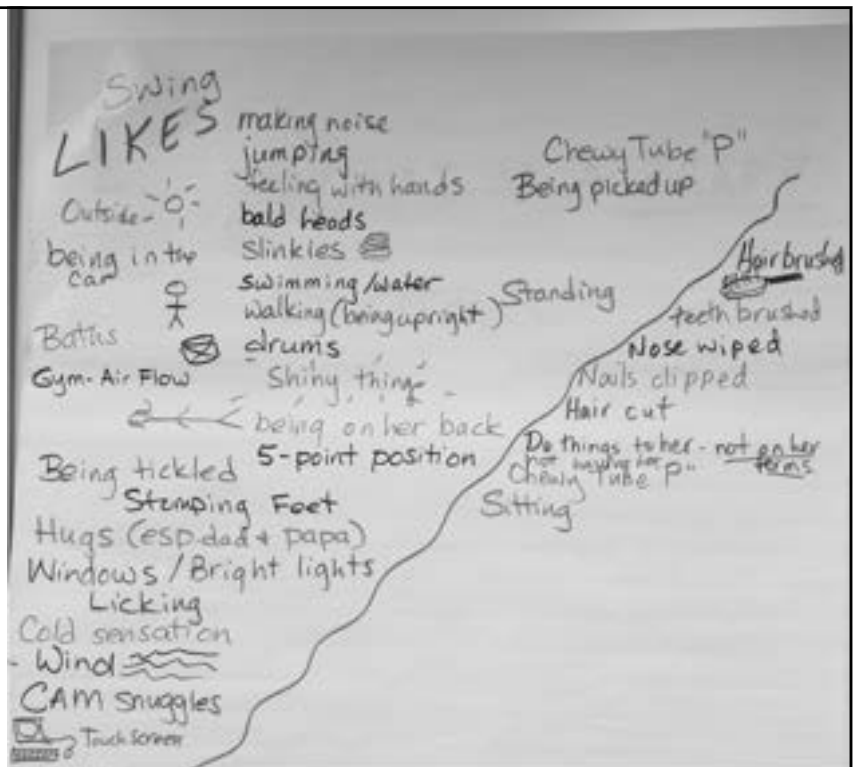
### What does Jon Dislike?

- 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



## **Social Relationships (male interaction)**

Friendships

Natural Supports

Invitations to go places

## **Quality continued guardianship**

**Communication (PECS book, people who sign & understand his communication)**

Accommodating vision/hearing

**Work/Recreation (swimming with friends, beach house, work that fits)**

People he likes (mom/dad living close)

**Home Life (hot tub, vibrating chair, sensory toys, lava lamps, swing, music system)**

**Health & Safety (quality physician he likes, 24/7 care or monitoring, clear understanding of dangerous situations)**

## **Meaningful & appropriate Adult services**

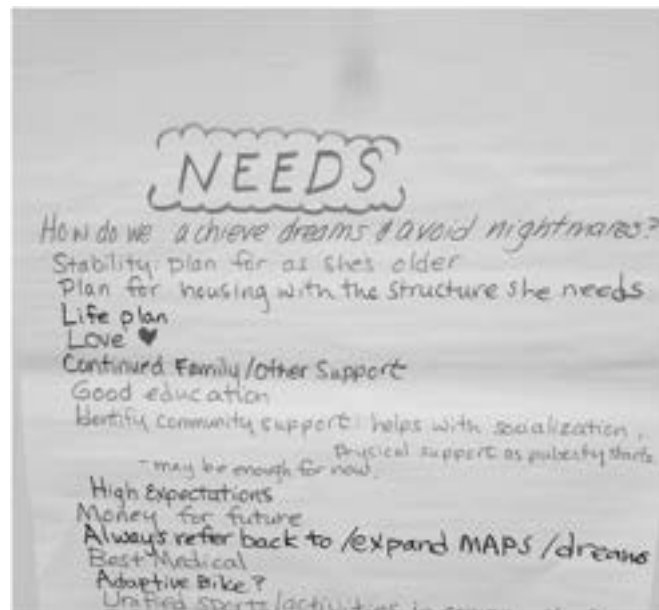
Continues to educate others - CHARGE

**Balance between being 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?

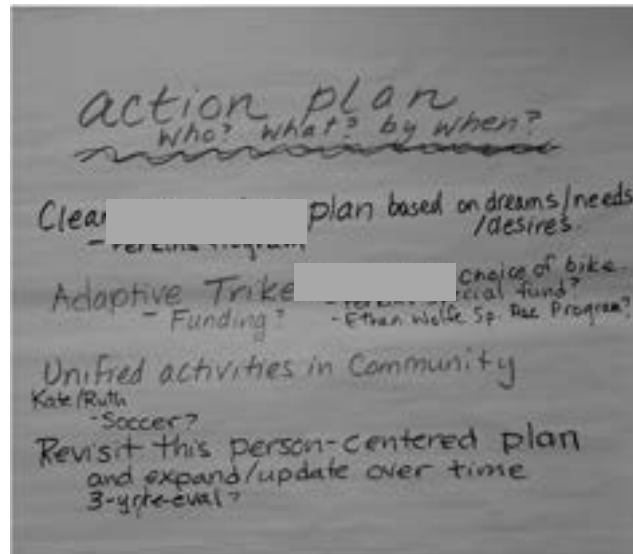
Revisit PCP

## 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



## Jon'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
- Keep up with academics both in special needs classroom and regular ed. classrooms
- Preparation of 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 IEP, 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

Jay and his brother spend time together at school and have enhanced their relationship. He is pursuing US citizenship.

Cara is playing tee-ball in her home community on the weekends. She has made friends with some nondisabled peers.

Jon is back in an integrated school setting and is preparing for graduation.

## OUTCOMES

Jake has had person-centered plans throughout his life, beginning at age 5. He is now age 33.

Jake 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!



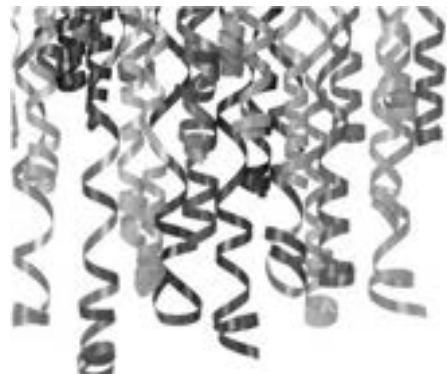
## Things to Remember

- 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!

## References

Some of the materials for this presentation come from:

Amado, A. N., & McBride, M. (2001). *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning. A Manual for Person-Centered Planning Facilitators*. Minneapolis, MN: University of Minnesota, Institute on Community Integration.