



Transitioning to Enviably Lives for Adults with Autism

Ann Turnbull
turnbull@ku.edu

Beach Center on Disability
1200 Sunnyside Avenue, 3111 Haworth Hall
The University of Kansas
Lawrence, KS 66045-7534

785-864-7608 (phone); 785-864-5825 (fax)

www.beachcenter.org

The Meadows Center for Preventing Educational Risks
The University of Texas at Austin
March 11, 2010



Outcomes for Adults with Autism

- Long-term outcomes of 45 adults with autism (born between 1974-1984)
 - ✓ Only 56% had ever been employed with employment averaging 5 hours per week, mostly in volunteer or sheltered settings
 - ✓ 56% still living with parents, one-third living in group homes or foster care
 - ✓ Only 2 individuals live in supported living situation in a home of their own.



Families' Conclusion

“Parents often noted that it was difficult to know what was available and how to access it. The bureaucratic maze was annoying and stressful...they lamented that adult services were not as good as those for children.” (pp. 744-745)

Ganz (2007)



Economic Analysis of Autism

- \$3.2 million annual societal per capita costs or \$35 billion for entire birth cohort
- Adult care is typically more than 5 times more expensive than the next three largest cost categories (behavioral therapies, respite care, special education)



Memory of Jay Turnbull





High School Education (1983-1987)

- Vision for segregation
- No research-based practice
- Emphasis on leisure education and sheltered employment



Epiphany of Double Standard





How many adults do you know who experience severe autism who have an enviable life – one that you would want for yourself and your family?



Quality of Life in Adult Services

- Escalation of problem behavior
 - ✓ Hitting and choking
 - ✓ Property destruction
 - ✓ Refusal to participate
- Use of extensive punishment
- Onset of significant depression

“No matter how far down the wrong road you go, if it’s the wrong road – turn around”





Early Seminal PBS Article

The positive/nonaversive approach focuses on the lifestyle of the individual....Behavioral support should result in durable, generalized changes in the way an individual behaves, and these changes should affect the individual's access to community settings, to social contact, and to a greater array of preferred events....An effective behavioral support plan should integrate procedures for building access to activities, places, people, and events in addition to modifying the patterns of specific desirable and undesirable behaviors....(Horner et al., 1990, p. 127)

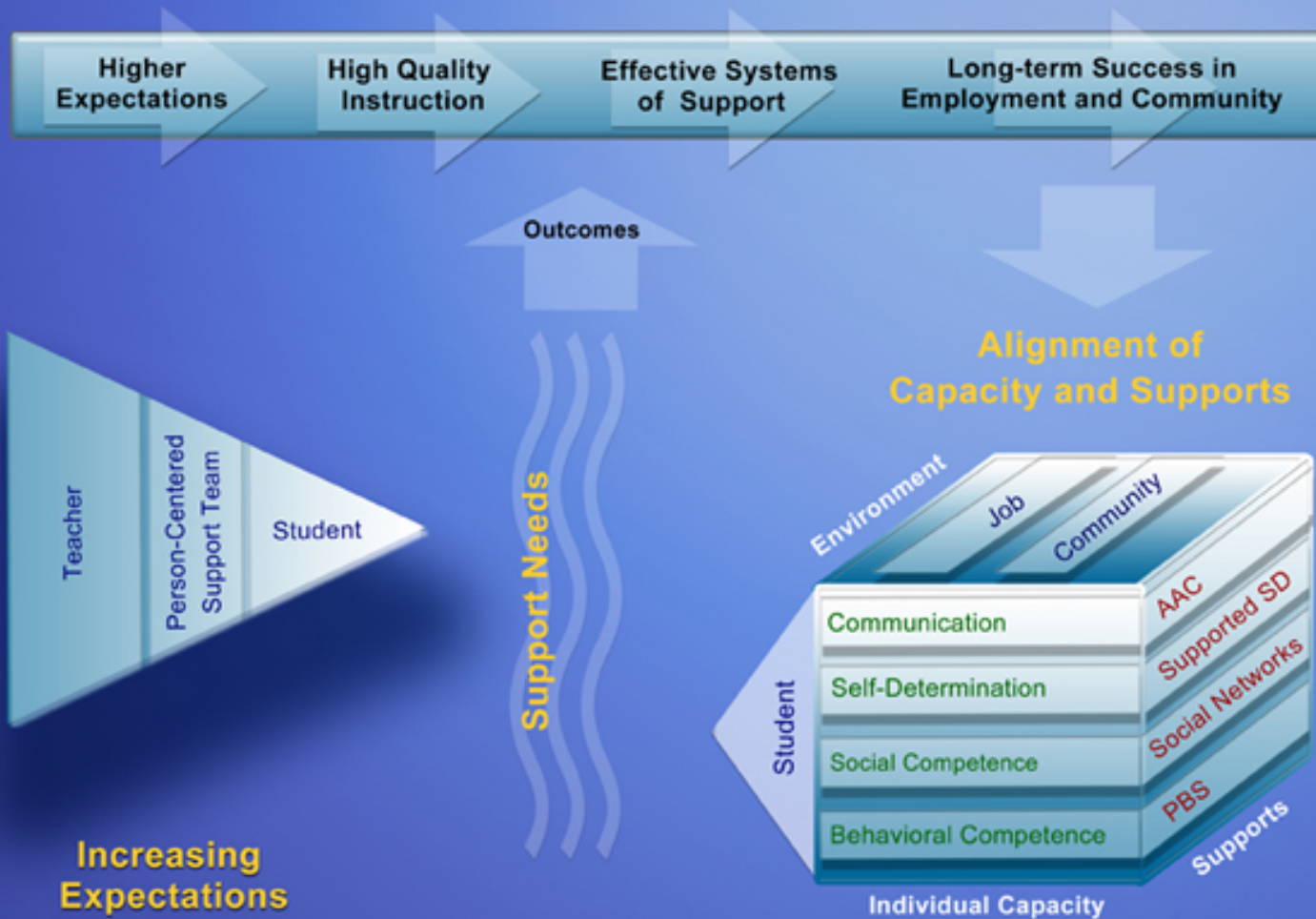


AAIDD Definition of Intellectual Disability

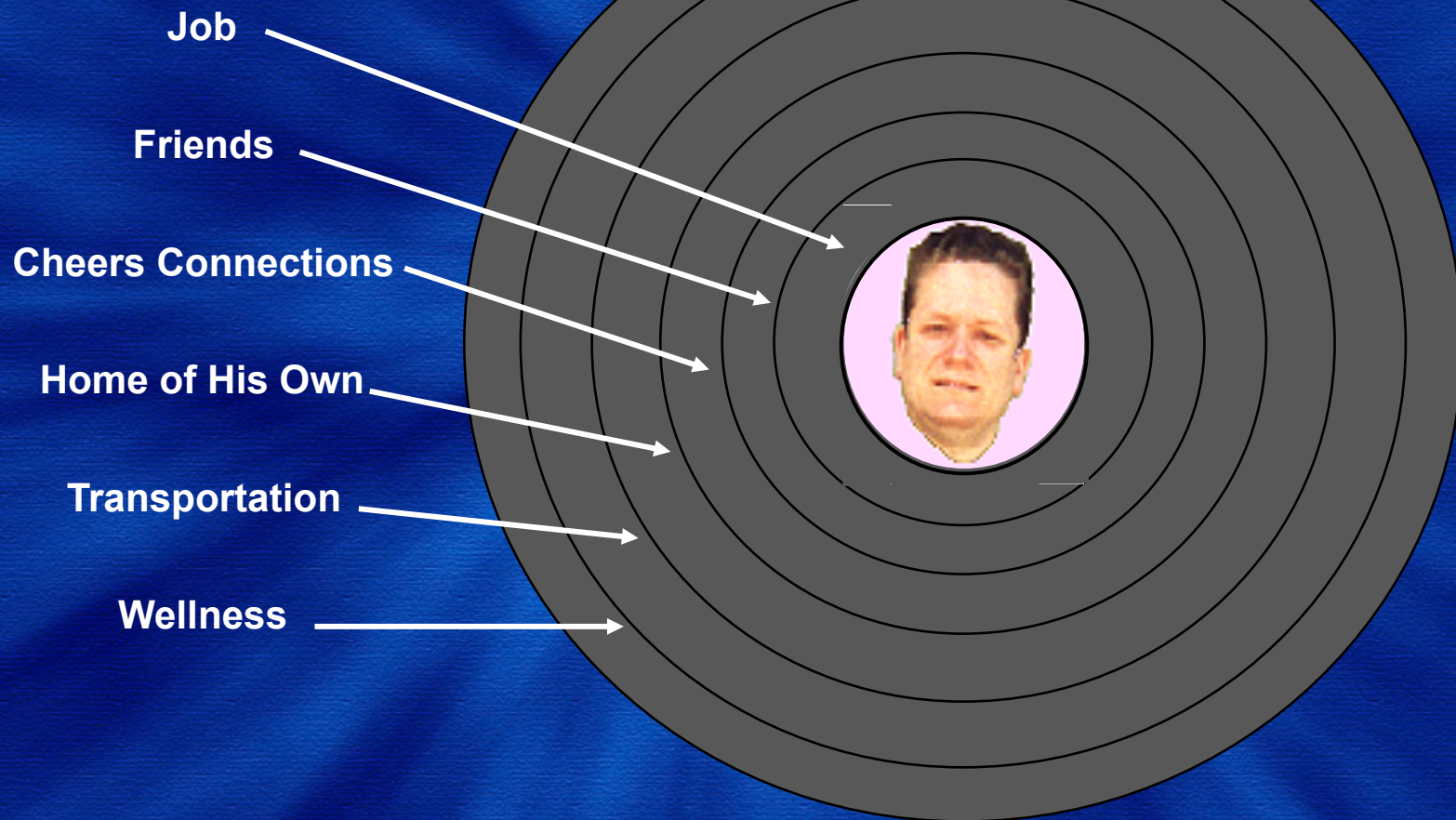
- Switch in 1992 from a severity paradigm to a socio-ecological paradigm.
- Concept of “systems of supports” – a coordinated set of resources and strategies across all life domains matched to the person’s needs and generated through a person-centered process.



Project Whole Lives Conceptual Framework



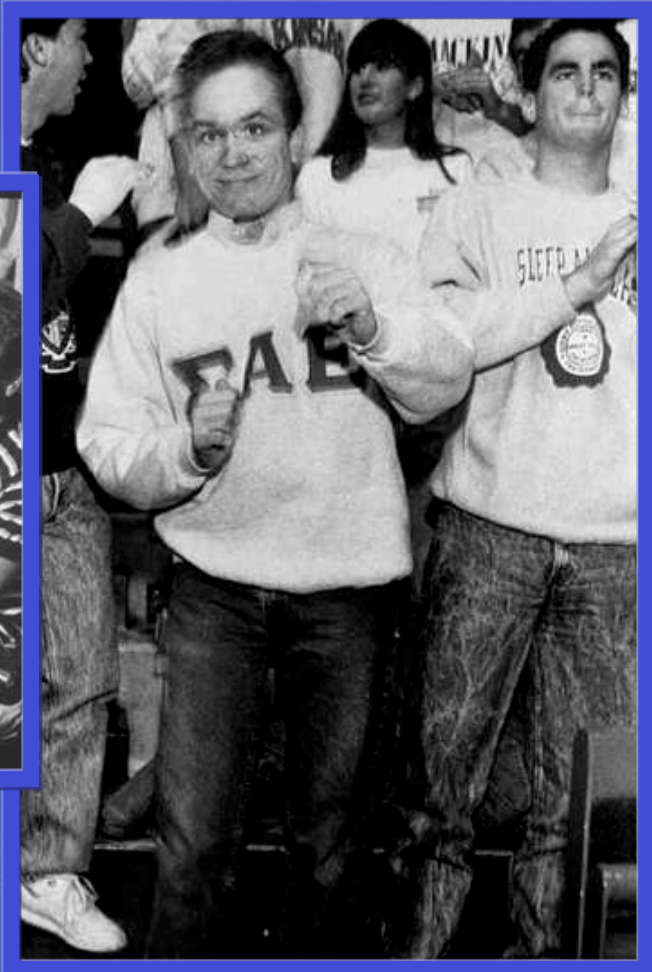
Jay's Adult Life – Age 21

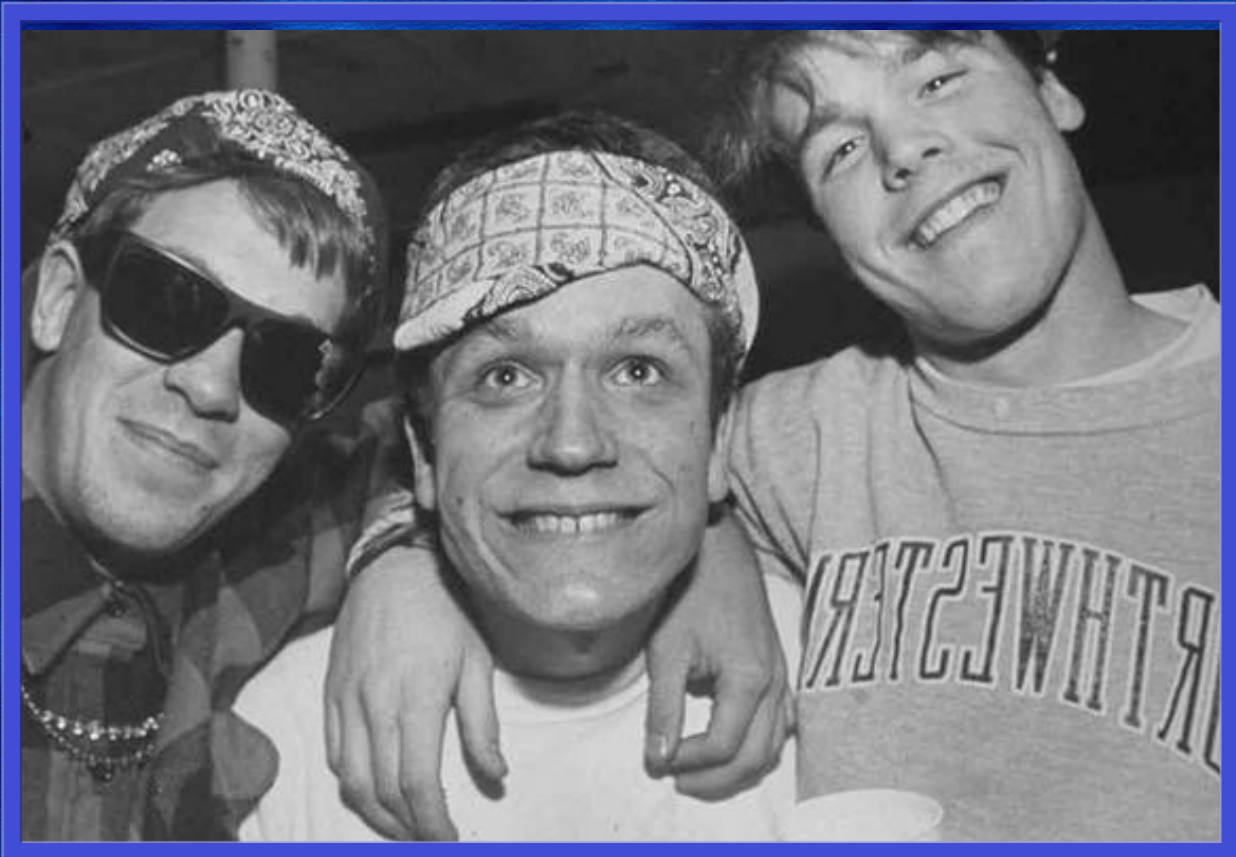




JT's Weekly Supports

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							

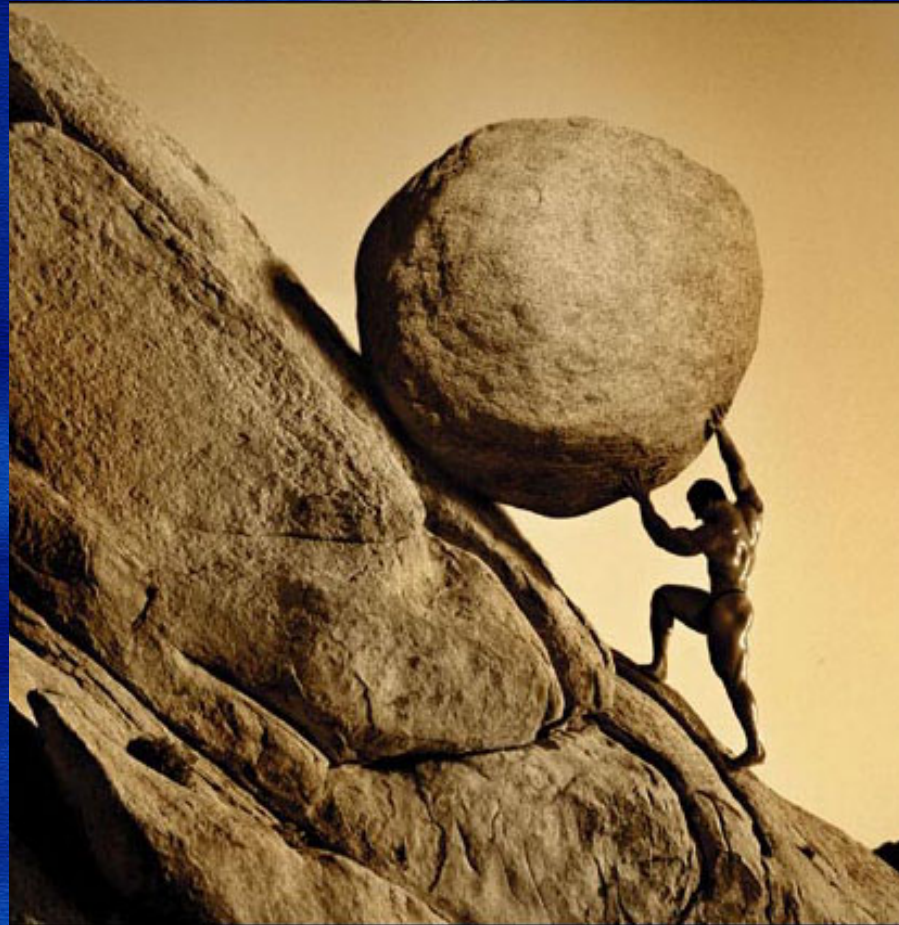






Group Action Planning





Sisphus from Greek mythology – uphill systems navigation



If only Sisyphus had had reliable allies for his systems navigation!



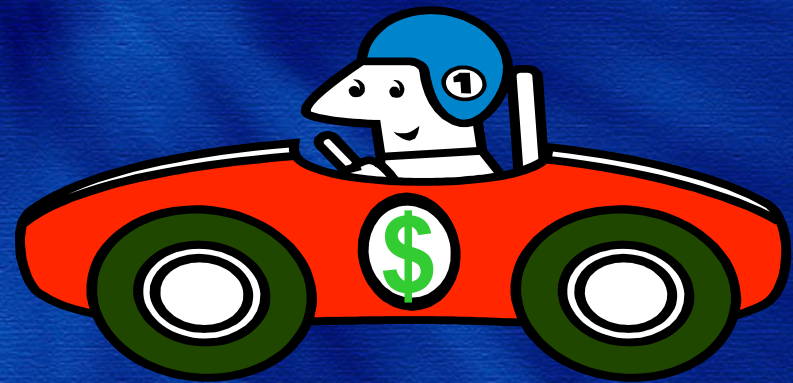
Robert Wood Johnson Systems Change Project 1999-2007 Participant Direction





Individual Budget Places the Individual and Family in the Driver's Seat!

The individual controls the Medicaid allocation with assistance from a fiscal intermediary.





Who is the Participant in Participant Direction?

- Participant acting independently on her/his own
- Parent(s) of a minor child
- A legal representative
- A non-legal representative

Centers for Medicare and Medicaid Services (CMS)



Participant Direction Opportunities

- Participant-Employer Direction
 - ✓ Participant rather than a service provider agency carries out employer responsibilities to recruit, hire, and supervise workers.
- Participant-Budget Direction
 - ✓ Participant has the authority and accepts the responsibility to manage his or her budget.



A Home of His Own





Home of His Own

- Obtain Section 8 housing voucher
- Consider floor plan that enables private space
- Furnish in light of preferences
- Consider access to public transportation
- Consider access to other daily environments



Most Amazing Housemates







Housemates

- Use Medicaid to pay housemates and provide free rent
- Have stable housemates who live at home
- Have housemates serve as support broker
- Select housemates to have responsive temperament
- Have housemates model “sense of connection” for all other support people
- Provide breaks and back-up for housemates



Personal Care and Breakfast

- Arrange work hours later in the day
- Infuse positive energy into wake-up routine
 - ✓ Converse about favorite activities in daily schedule
 - ✓ Choose breakfast menu
- Avoid issue of using an alarm clock
- Vary support person to add variety

Getting and Keeping a Job Through Friends





Work







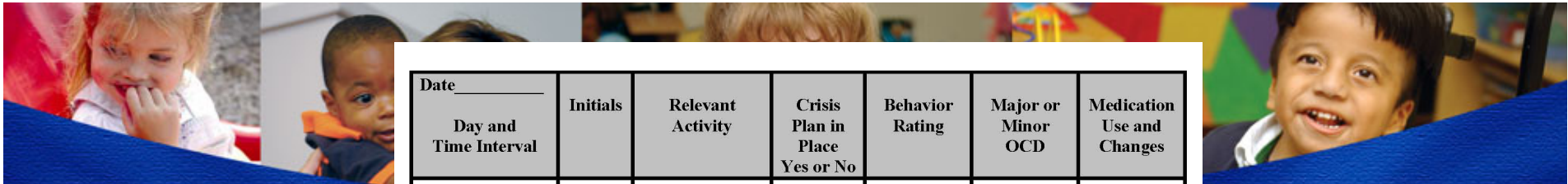
Work

- Obtain job coaching from Vocational Rehabilitation
- Develop a PASS Plan
- Calibrate job coaching to bipolar cycle
- Distinguish between depression and non-compliance



Work

- Provide support for depression and consequence for non-compliance
- Give cash every day
- Facilitate connections to co-workers
- Have a structured routine of tasks
- Use preferred tasks on difficult days



Date _____	Initials	Relevant Activity	Crisis Plan in Place Yes or No	Behavior Rating	Major or Minor OCD	Medication Use and Changes
S M T W T F S						
EARLY 7-9						
MID MORN 9-11						
MID DAY 11-4						
EVENING 4-9						

Behaviors

-2 Severe Depression: When JT has a severe depressive episode he will: refuse to leave his house, bedroom, chair in the bedroom, sleep for extended extreme periods of time, refuse to eat, drink or take his meds, stays in his room with the lights off, shades drawn, and will either not interact or minimally interact with others.

-1 Depressed or Below Happy: When in a depressive state JT will: not initiate interactions with others, have a lack of engagement in activities, nor talk or respond to others, will sit in his chair at home or work or both for extended periods, have less interest in eating, and drinking and taking his medications, will sleep more, be lethargic, may gag more frequently, may talk to himself, is more serious or sullen, have increased levels of obsessive compulsive disorder (lights off, door shutting, sticky note removal and fixating on broken things).

0 Happy/Engaged: When JT is happy/engaged he will: have short interactions with others, he will go to work as usual, talk about his schedule, walk and eat typically, engage in his normal schedule.

1 Manic/Wired: When in a manic state JT will be in a very good mood, talk a lot, initiate interactions with others, may have a glazed look or redness in his face, he will be animated and may skip or jump when he walks.

2 Psychomotor seizure or motor outburst: When JT has a psychomotor seizure or motor outburst, he will bang his knuckles on the table or wall loudly, scream, jump up and down, repeatedly hit his arms, legs, head or chest.

Additional comments or concerns:	<p align="center">Obsessive Compulsive Disorder Note Major or Minor Above</p> <p>0 None: no OCD behavior</p> <p>1 Minor: shuts doors, turns off lights, removes sticky papers, tears items, talks about certain things several times</p> <p>2 Major: repeatedly talking about or fixating on hair or eye glasses or other objects or items such that he cannot be effectively redirected after several prompts glasses, or destroying property</p>
Positive events that should be noted:	
Were there any strategies today that we used that worked particularly well?	



Speech/Communication Therapy





Speech/Communication Therapy

- Promote communication competence – conversation, email, phone
- Rotate therapist each semester while keeping supervisor permanent role
- Infuse energy and engagement
- Address client's and family's priorities







Massage and Yoga

- Pay for these services with SSDI or Medicaid (depending upon state-approved services)
- Get order from physician for massage and yoga for medical reasons



Music Therapy









Music Therapy

- Pay for these services with SSDI or Medicaid (depending upon state-approved services)
- Add sheer joy to each day
- Use music as a method of instruction
- Incorporate friends to maximize connection
- Use music to enhance self-concept and contribution

Companions





Companions

- Use Medicaid to pay companions
- Riffel family, relatives, and friends
- Tom set the tone of dignity and unconditional support
- Tom's and Jay's hospitality provided "a home away from home" for companions
- Reciprocating support to companions is essential



Cheers Connections

- Hang out as a “regular” in preferred settings
- Become acquainted with owners and other regulars and develop relationships
- Seek opportunities to reciprocate kindness
- Communicate directly about support needs



Eating at Restaurants





Volunteering at the Community Health Food Store





Dancing at Jazz Club





Participating in Worship





Bedtime and Sleep

- Decide on bedtime each evening
- Say prayers aloud with family
- Provide options when unable to sleep
- Prevent behavior problems during the night
- Accept responsibility for wet sheets

JT's Weekly Supports

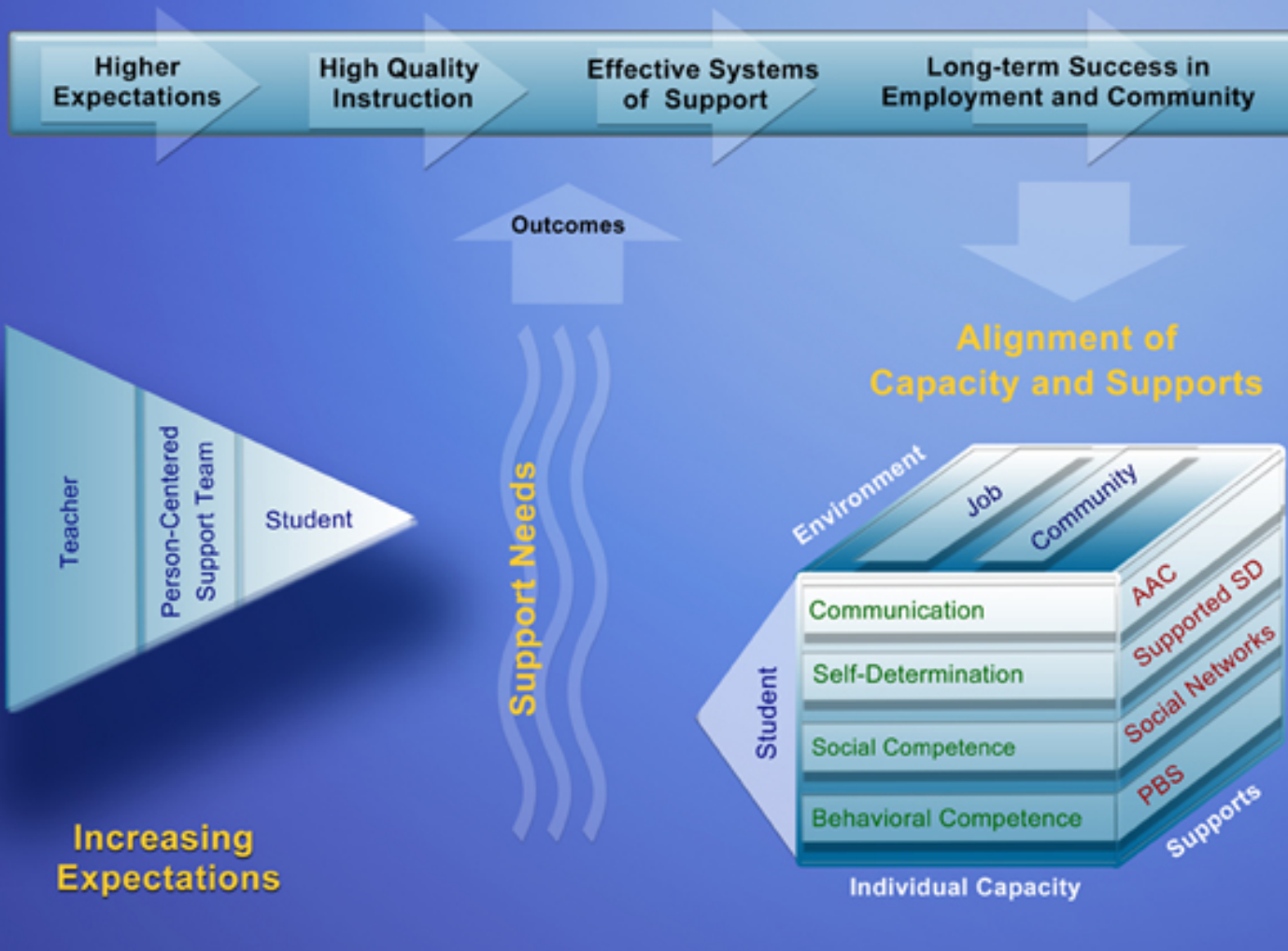
Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12-8:30 AM	F	H	H	H	H	H	H
8-8:30	F	H	C1	C4	C1	C1	H
8:30-9 AM	C1	H	C1	C4	C1	C1	F
9-9:30 AM	ST	H	C1	C4	C1	C1	F
9:30-10 AM	ST	H	C1	C4	C1	C1	F
10-10:30 AM	MS	H	C1	C4	C1	C1	F
10:30-11 AM	MS	YT	C1	C5	C1	C6	F
11-11:30 AM	H	H	C1	C5	C1	C6	F
11:30-12 PM	JC	JC	JC	JC	JC	C6	F
12-12:30 PM	JC	JC	JC	JC	JC	C6	F
12:30-1 PM	JC	CW	JC	JC	CW	C6	F
1:30-2 PM	JC	JC	JC	JC	JC	C6	F
2-2:30 PM	JC	JC	JC	JC	JC	C4	F
2:30-3 PM	JC	JC	JC	JC	JC	C4	F
3-3:30 PM	JC	JC	JC	JC	JC	C4	F
3:30-4 PM	H	C2	H	C5	H	C?	F
4-4:30 PM	H	C2	H	C5	H	C?	F
4:30-5 PM	H	C2	H	C5	H	C?	F
5-5:30 PM	H	C2	FR	C5	H	C?	F
5:30-6 PM	H	C2	FR	C3	C5	C?	F
6-6:30 PM	H/MT/GF	C2	FR	C3	C5	C?	F
6:30-7 PM	H/MT/GF	C2	FR	C3	C5	C?	F
7-7:30 PM	MT/GF	MT	C3	C3	H	C?	F
7:30-8 PM	MT/GF	MT	C3	C3	H	C?	F
8-8:30 PM	H	H	H	C3	H	C?	F
8:30-9 PM	H	H	H	H	H	C?	F
9-11 PM	H	H	H	H	H	H/C?	F

Sleep
Personal Care
Work
Leisure/Comm. Part.
Bkt/Lunch/Dinner
Speech Therapy
Music Therapy
Massage
Yoga
Church

H – Housemate	Y – Yoga Teacher
F – Family	JC – Job Coach
ST – Speech Therapist	C1-C6 – Companions
MT – Music Therapist	FR – Fraternity
M – Masseuse	GF – Girlfriend
Y – Yoga Teacher	CW – Co-Worker



Project Whole Lives Conceptual Framework



How can we lighten the load of creating enviable lives?





What are Frequently Used Terms?

- Case management
- Support coordination
- Service coordination
- Support brokering
- **Systems navigation**



Systems Navigation – Short Definition

Systems navigation is the process of making wise decisions in creating a coherent set of services and supports across life domains to foster both individual and family quality of life outcomes.



Marathon Navigation Skills

- Networking with progressive and reliable allies
- Envisioning great expectations
- Knowing and acting on rights
- Knowing evidence-based practices
- Mapping and accessing services
- Accessing public funds
- Leveraging private funds
- Keeping records



From Systems Failure...

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							

To Systems Navigation

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12-8:30 AM	F	H	H	H	H	H	H
8-8:30	F	H	C1	C4	C1	C1	H
8:30-9 AM	C1	H	C1	C4	C1	C1	F
9-9:30 AM	ST	H	C1	C4	C1	C1	F
9:30-10 AM	ST	H	C1	C4	C1	C1	F
10-10:30 AM	MS	H	C1	C4	C1	C1	F
10:30-11 AM	MS	YT	C1	C5	C1	C6	F
11-11:30 AM	H	H	C1	C5	C1	C6	F
11:30-12 PM	JC	JC	JC	JC	JC	C6	F
12-12:30 PM	JC	JC	JC	JC	JC	C6	F
12:30-1 PM	JC	CW	JC	JC	CW	C6	F
1:30-2 PM	JC	JC	JC	JC	JC	C6	F
2-2:30 PM	JC	JC	JC	JC	JC	C4	F
2:30-3 PM	JC	JC	JC	JC	JC	C4	F
3-3:30 PM	JC	JC	JC	JC	JC	C4	F
3:30-4 PM	H	C2	H	C5	H	C?	F
4-4:30 PM	H	C2	H	C5	H	C?	F
4:30-5 PM	H	C2	H	C5	H	C?	F
5-5:30 PM	H	C2	FR	C5	H	C?	F
5:30-6 PM	H	C2	FR	C3	C5	C?	F
6-6:30 PM	H/MT/GF	C2	FR	C3	C5	C?	F
6:30-7 PM	H/MT/GF	C2	FR	C3	C5	C?	F
7-7:30 PM	MT/GF	MT	C3	C3	H	C?	F
7:30-8 PM	MT/GF	MT	C3	C3	H	C?	F
8-8:30 PM	H	H	H	C3	H	C?	F
8:30-9 PM	H	H	H	H	H	C?	F
9-11 PM	H	H	H	H	H	H/C?	F

Sleep
Personal Care
Work
Leisure/Comm. Part.
Bkt/Lunch/Dinner
Speech Therapy
Music Therapy
Massage
Yoga
Church

H – Housemate	Y – Yoga Teacher
F – Family	JC – Job Coach
ST – Speech Therapist	C1-C6 – Companions
MT – Music Therapist	FR – Fraternity
M – Masseuse	GF – Girlfriend
Y – Yoga Teacher	CW – Co-Worker

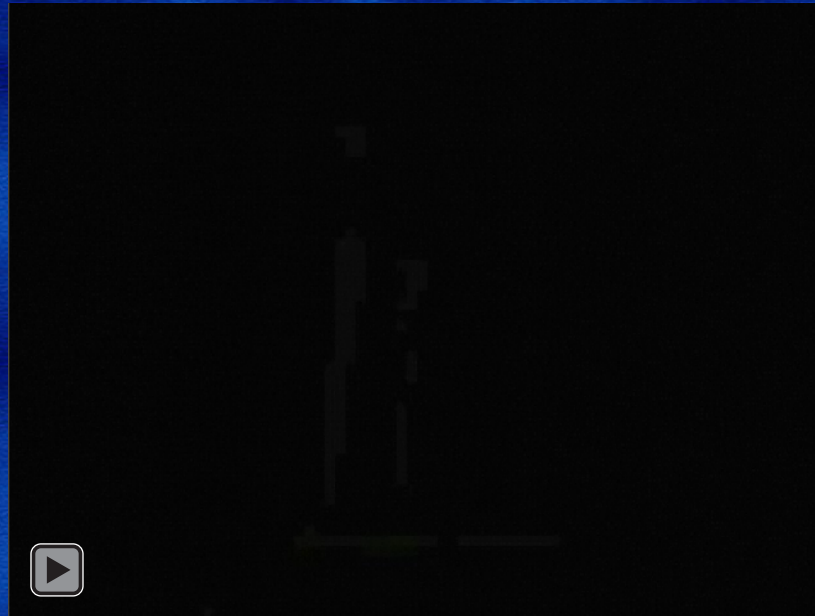


Role of Dignity

Behavioral interventions should maintain and support the personal dignity of the individual... Because the purpose of behavioral intervention is to assist people in becoming full participants in society, the procedures used to achieve this goal should be within the standards set by society...By its nature, behavioral technology involves continuous on-site technical and ethical judgment.
(Horner et al., 1990, p. 129)



Role of Dignity





It Takes a Village...

