SUPPORTING THE TRANSITION TO INDEPENDENCE

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Every Student with Special Needs is Supposed to Receive Transition Services (IDEA)

The term “transition services” means a coordinated set of activities for a student with a disability that:

- Is designed to be a results-oriented process that is focused on improving the academic and functional achievement of the [student] with a disability to facilitate the [student’s] movement from school to post-school activities, including
  - postsecondary education;
  - vocational education;
  - integrated employment (including supported employment);
  - continuing and adult education;
  - adult services;
  - independent living; or
  - community participation.

- Is based on the individual [student’s] needs, taking into account the [student’s] strengths, preferences, and interests; and

- Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation. [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]
Beyond the Classroom.....

• What can *families* do to encourage the transition to adulthood?
• What needs do older teens and young adults have in making this transition?
• What about those who are no longer in the school system? Those who were not identified with special needs while in school?
Transition to Adulthood:
A Critical Developmental Period

Developmental tasks include

- Acquiring adaptive self-care skills (everything from grooming and driving to banking)
- Developing mature social judgment
- Separating emotionally from family of origin
- Learning to behave appropriately in adult world
- Forming an adult identity
- Completing education and finding adult work
- Living independently
- Forming adult relationships
How Many Young Adults Live With Family?
(Pew Research Center analysis of American Community Survey data)

- All 18 to 24: 54% (2001) vs 65% (2011)
- College Graduates 18 to 24: 31% (2001) vs 45% (2011)
- All 18 to 34: 30% (2001) vs 41% (2011)
- College Graduates 18 to 34: 13% (2001) vs 21% (2011)
“Developmental Age”

• Teens and young adults with ASD commonly function 5 to 7 years below their chronological age in areas of social-emotional skills

• Consequences:
  – Interests of a younger person
  – Not on the same schedule with peers, e.g., uninterested in dating or grooming
  – Fearful of growing up and leaving home
What to Expect

• Expect transition to take longer in young people with ASD
• Expect to move in small steps
• Expect to have to address skills on different levels
• Expect that they will need reassurance that learning more independent behavior does not mean they will be abandoned
• **Expect that not only the young person but the FAMILY must make changes in their habits and viewpoint.
Shifting Perspective on Your Young Adult with ASD

Picture him or her BEING AN ADULT
Who’s Driving the Bus?

*Adults* “drive their own bus”.

*Children* are driven around by others, told what to do, how to do it, helped with many tasks, not held responsible for certain things, not expected to take care of themselves.
How Do They Leave the Nest?

• Parents do less for them
• They do more for themselves
• Making mistakes is a natural part of the process
Over-functioning

- Parents over-function when they do things for their children that their children should be doing for themselves.
- Included are not only everyday tasks but also things such as decision making, fixing mistakes, managing time, and regulating behavior and emotion.
Over-functioning by Parents Leads to...

• Young adult not learning age appropriate skills
• Young adult feeling incapable of acting independently and facing challenges
• Young adult behaving like a child
• Young adult feeling and acting “stuck”
• The whole family revolving around the young adult’s needs/wants
• Failure when young person leaves the immediate supports at home (e.g., going to college)

...Under-functioning by the Young Adult
Over-Supporting – Parents Often Disagree and Family Conflict Results
Areas of Over-Support?
What Am I Doing for My Child that He/She Could Do?

Examples
• I am making my son’s lunch every day
• I remind her every day to take her medications
• I clean his room and do his laundry when he forgets to do it

What to Do Instead?
• He can make lunch for himself
• She could make a schedule, set an alarm, etc.
• I can let him learn to do it himself and have the natural consequences if he does not
Barriers that Stop Progress
What’s Holding **You** Back?

Barriers to returning responsibility to your child
Some Potential Barriers

- I still think of my daughter as a child.
- If I let him try some of these things he might fail.
- It’s so much easier to do it myself.
- I’ve always done it this way... I would feel so guilty if I stopped.
- Deep down, I don’t believe he can do it.
- Others?
Making Your Boundaries Clear
Psychologically, boundaries are like an invisible fence that tells us where we end and the next person begins.

When boundaries are healthy, people respect each other’s individuality. They do not try to control each other directly or indirectly. They take responsibility for their own actions. They do not intrude on others’ right to make decisions and choices. They do not protect others from the natural consequences of their actions. They help as needed, but they do not take charge or engage in over-supporting. They do not allow themselves to be controlled by other people’s emotions and they know they are not responsible for keeping other people happy.

Babies cannot take care of themselves and are naturally very close to their caregivers. However, the process of growth and development leads to a healthy separation and gradually strengthening boundaries.
Whose side of the fence?

You’ve probably heard the expression “Good fences make good neighbors.” This saying is true because the fence shows whose property is whose and who has control of what.

Suppose Joe and Chuck are neighbors. If Chuck weeds his yard and throws the weeds into Joe’s yard, that’s a boundary violation and Joe should feel free to throw them back. Likewise, if Joe looks over into Chuck’s yard and says to himself, “Chuck’s yard looks messy; he should weed it”, then walks over and does all the weeding himself, that’s also a boundary violation. Chuck has responsibility for his own yard, and Joe should not be doing it for him. Either of these boundary violations would tend to destroy the relationship between Joe and Chuck.

Family relationships can be like Joe and Chuck. If we dump our responsibilities onto other people, that’s a boundary violation. In the same way, if we do things for other people that they can and should be doing for themselves, that too is a boundary violation. Over time, habitual patterns of boundary violations in a family lead to problems in relationships such as dependency, resentment, and conflict.
The Whose Side of the Fence Game!

For each situation, consider what you would do. Think about whose responsibility it is and what is on YOUR side of the fence and what is on someone else’s side.

1. Your child did laundry but left the laundry in the washer wet.

2. You and your child are in the store and your child would like to buy a book. S/he has run out of spending money.

3. Your child and your spouse/partner get into an argument.

4. Your child gets angry and starts yelling/cursing at you.

5. Your child is saving money to buy something s/he wants, and tells you they do not have enough money to buy food or clothing.

6. Your child uses their own money for an expense you don’t approve of.
Boundaries and Over-supporting

Doing too much for your adult child (or other family members) is a type of boundary violation, because what we should be doing for them changes over time. The parent’s relationship with a growing young person is a moving target.

If we do not clearly define boundaries in our family, one person can wind up doing everyone else’s stuff. Or, we can find ourselves not recognizing that others are people independent of ourselves. Issues of control and dependence often go hand in hand.
Parents have boundaries, too.

- Talk about the need to separate. Address fears of being abandoned.
- Introduce responsibility by withdrawing supports gradually.
- Allow your young adult to have some privacy and make his/her own decisions.
- Allow the young adult to take on financial responsibility. Not only do they need to earn their own money, they need to decide how to spend it.
- Encourage independence with transportation.
- Do not make home “too comfortable”.

Letting Go
S: See the future.
A: Assemble your support group.
N: Nip excuses in the bud.
I: Implement changes.
T: Trust your child’s ability to take on new responsibility.
Y: Yield control.
SEE THE FUTURE

- Set realistic goals and challenge unrealistic thinking
- Keep your eye on the long term goal
- Visualize your child in new roles
Assemble your support group

• Stay connected with families in similar situations.
• Recognize that you are not alone.
• Permit yourself to reach out to others for support.
• Acknowledge and work on removing feelings of shame about your family’s circumstances.
• Share what you learn with others and be a support to them.
• Seek supports outside the family to help with self-management skills at school and work.
○ But she might fail! He might get hurt!
○ Poor baby, it’s not his fault...
○ I feel so guilty because of....so I have to make it up to him.
○ I’m afraid of my child’s anger.
○ It’s so much easier to do it all myself.
○ Something bad might happen if I don’t....[do X, Y, Z for my child]
○ This has been my “mission” so long I don’t know how to stop.
○ If my child really grows up, s/he won’t need me any more.
Implement Changes

• Make changes in your expectations about responsibility and behavior
• Start with the “low-hanging fruit”
• Expect to add changes gradually over time, not all at once
• Expect push-back but do not tolerate abusive behavior
• Praise progress
• When there is a lack of progress, do not back off the expectations of change
• Set limits in the form, “If you do/do not do X, then I will do Y.” Then follow through!
• Permit consequences to happen
Trust your adult child’s ability to take on new responsibility

- No more nagging – nagging sends the message you don’t believe they can do it. It also sets up a dynamic of resistance.
- Remember this is your child’s journey, not yours.
- Avoid doing or saying things that send the message you are ashamed of your child.
Learn how to let go of *control*.

- The need to control grows out of anxiety – e.g., perfectionism, fear of loss, fear of not being good enough, etc.

- Controlling behavior can be destructive of relationships

- No one can control their way to a risk-free environment
Last but not Least....

• Seek help for mental illness where it occurs
• Recognize the role that family dynamics play in the development of young people and their transition to adulthood
• Address family problems that may be affecting your child’s functioning
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