

LAUNCHING into Adulthood: Self- Advocates & Families in Transition

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OBJECTIVES:

- Review key joys and fears for families and self-advocates during the transition
- Understand and apply stages of psychosocial development, systems theory concepts, and family systems theory concepts
- Approaches and resources in transition



Key *JOYS* & *FEARS* for Families during Transition

2019 Qualitative Longitudinal Study about Transition Experiences:

- Transition as gradual, long-term
- Concerns about getting needed services
- Mental health concerns as barriers
- Reflection on “having come a long way since their childhood” (Cribb et al. p. 1768)
- Accepting their child for who they are
- Challenge of getting the “balance” right: “It’s a very fine line. We can’t make him do stuff; he’s an adult. But it’s also not OK to just sit at home all day playing on the PlayStation. That’s not part of being in the adult world.” (p. 1775)

Key *JOYS* & *FEARS* for Families during Transition

2018 Literature Review of 17 Qualitative Studies about Transition:

- Feel a responsibility to educate support professionals about ASD
- “Difficulty navigating their role in their children’s transition” (Anderson et al. p. S324)

2015 Study of Parental Quality of Life:

- “Parents of transition-age youth and young adults with disabilities were generally satisfied with their family quality of life” (Boehm et al. p. 405)

Key *JOYS* & *FEARS* for Families during Transition

Parent Support Groups :

- Joy of seeing kid be successful at things they never anticipated, hitting milestones that they were not sure would be possible
- What is going to happen to my kid after I'm gone
- Fears that if I'm not there, my child will experience social rejection or other difficulties
- Fears of letting my kid fail, fear of regression because of setbacks, slippery slope
- Finding safe ways to stretch

Disability's *Impact*

- Possible delays in moving through developmental stages
- Identity influenced by disability - "I'm autistic."
- Too much IN-dependence (isolation)

- Display aspects from multiple stages
 - Immaturity in some areas
 - More mature in others

How do family structure and culture play a role?

Strong familial support foundational for long-term support and security (Sosnowy, et al 2018)

- Parents felt more confident when "siblings and relatives" have active roles in support
- Did not want put undue pressure on siblings to be lifelong, full-time caregivers
- Parental fears about daily activities and isolation

Parents on a spectrum

Number of children, birth order

Technology *Impact*

- Phones and Apps
- Electronic umbilical cord

Systems Theory & Ecological Perspective

- The client's family is a system
- Open/closed family system, dynamic/static environments
- Person-in-environment
- Input & output

Our services introduce a new “input” into the system. Expect some level of instability which allows for growth.



Bowen's Family Systems Theory

- Family members are intensely emotionally connected > enmeshment
- Differentiation of Self

Family Projection Process

- Anxiety is the root of dependence, avoidance, and emotional reactivity

**Incremental shift
towards
*interdependence***

Seeing the Forest



Progress is
not always
linear



Outsource / Resources

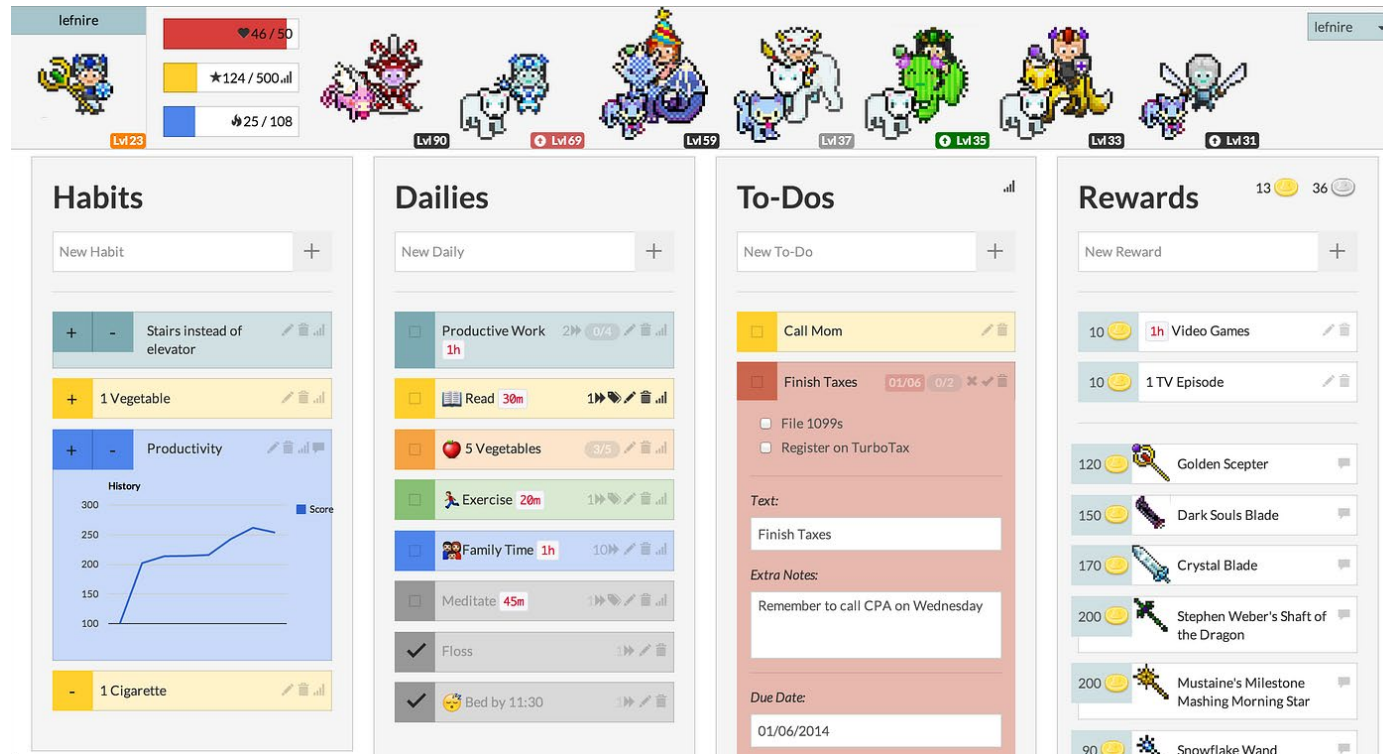


Image source: <https://medium.com/@dnlholliday/habitica-a-self-improvement-app-that-sticks-4334f699eb80>

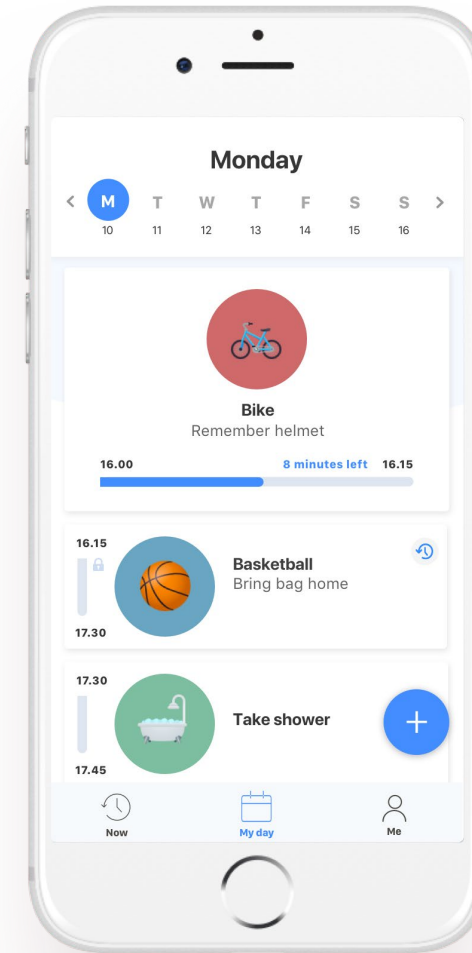


Image source: <https://www.tiimoapp.com/web-onboarding/>



Tripartite Responsibilities Chart

Mark box according to who takes responsibility, reference descriptions as needed on Pg. 2

Responsibility	Adult	Parents/Supportive Party	Both
Bedroom Cleanliness			
Laundry			
Bathroom Cleanliness			
Hygiene			
Cooking/Prep Breakfast			
Cooking/Prep Lunch			
Cooking/Prep Dinner			
Money Management			
Transportation			
Employment			
Problem Solving			
Social Skills			
Time Management			



Resource Sharing

2018 Qualitative Study:

“participants described wanting to collaborate with knowledgeable professionals, but also suggested a preference for learning from other families.” (Francis et al. p. 292)

An illustration showing a group of diverse people at a community event. In the foreground, a woman in a blue tank top and cap is looking at a document on a table. Other people are standing around, some looking at posters on a wall. The scene is brightly lit and colorful.

Resource Sharing

- Family to family communication
- Support groups
- Sources of up-to-date information about financial, legal, medical, social and behavioral services
- Advocacy organizations
- Social groups
- Community events

Transition Philosophy

We envision a future where all individuals have the opportunity to pursue their ideal living situation. We support independent living skills development through direct teaching, modeling, and shared problem-solving. We harness both intrinsic motivation and natural community supports to help individuals build sustainable solutions. We are committed to developing honest and trusting relationships, building community partnerships, and using evidence-based interventions to support young adults and their families.

COMMONWEALTH AUTISM

ADOLESCENT & ADULT PROGRAMS

Embrace Growth and Change.

Build Life Skills.

Navigate Adulthood.

Achieve Your Goals.



Program Offerings

Sexuality Education

Social Groups

Parent Support

Transition Coaching Supports

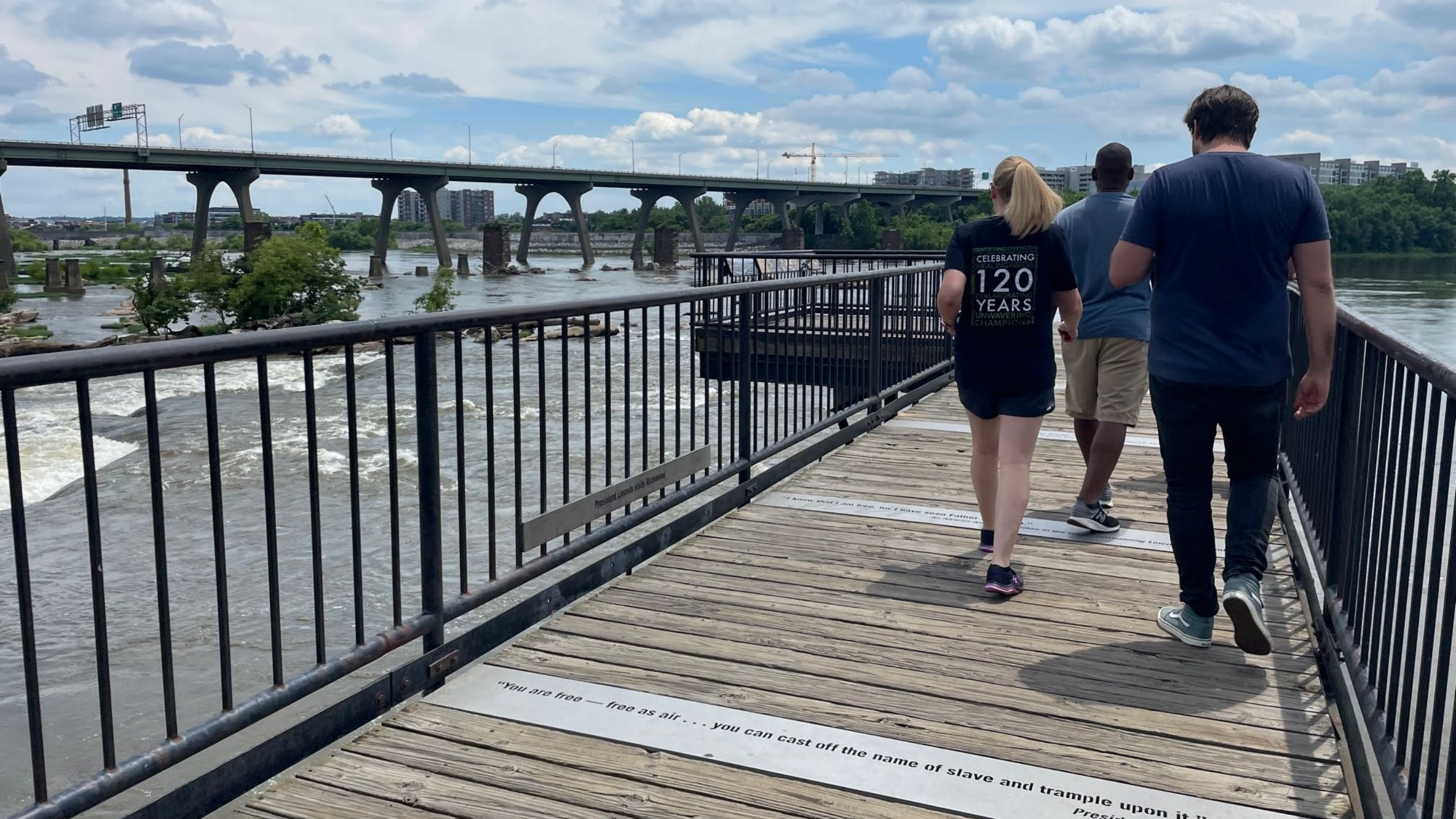
Community Engagement

Skill Maintenance

Education

Information & Resources

Career Readiness



CELEBRATING
120
YEARS
UNWAVERING
CHAMPIONS

"You are free — free as air . . . you can cast off the name of slave and trample upon it"
President Lincoln

President Lincoln visits Richmond







Person on the left: A woman with long reddish hair, wearing sunglasses, a grey t-shirt with a Captain America shield, and black pants.

Person in the middle: A man with short grey hair, wearing sunglasses, a dark blue t-shirt, and dark pants, with a jacket draped over his shoulders.

Person on the right: A man with brown hair, smiling, wearing a blue t-shirt with 'US NAVY SEABEES' and dark pants.



“‘Everyone is interdependent’... ‘Grownups, it’s not like we’re completely independent, like we never ask anyone for advice or help’.”
(Francis et al., 2018, p. 287)

“In the long run, it is the **judicious use of that dependence and its gradual transfer to other support systems** that results in the greatest success in independent functioning.” (Geller & Greenberg, 2009, p. 95)

Works Cited

Anderson, Kristy A., et al. "Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies." *Pediatrics*, vol. 141, no. Supplement 4, 2018, doi:10.1542/peds.2016-4300i.

Boehm, Thomas L., et al. "Family Quality of Life During the Transition to Adulthood for Individuals With Intellectual Disability and/or Autism Spectrum Disorders." *American Journal on Intellectual and Developmental Disabilities*, vol. 120, no. 5, 2015, pp. 395–411., doi:10.1352/1944-7558-120.5.395.

Cribb, Serena, et al. "'I Definitely Feel More in Control of My Life': The Perspectives of Young Autistic People and Their Parents on Emerging Adulthood." *Autism*, vol. 23, no. 7, 2019, pp. 1765–1781., doi:10.1177/1362361319830029.

Lynda L. Geller PhD & Michael Greenberg LCSW ACSW (2009) Managing the Transition Process From High School to College and Beyond: Challenges for Individuals, Families, and Society, *Social Work in Mental Health*, 8:1, 92-116, DOI: 10.1080/15332980902932466

Francis, Grace L., et al. "Transition Strategies and Recommendations: Perspectives of Parents of Young Adults with Disabilities." *British Journal of Special Education*, vol. 45, no. 3, 2018, pp. 277–301., doi:10.1111/1467-8578.12232.

Papadopoulos Chris. "Autism stigma and the role of ethnicity and culture." Principal Lecturer in Public Health, University of Bedfordshire. 2016

Sosnowy, Collette, et al. "Parents' and young adults' perspectives on transition outcomes for young adults with autism." *Autism*, vol. 22, no. 1, 2018, pp. 29-39, doi: 10.1177/1362361317699585

Thank You! Questions?

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