Transitioning from School to Adulthood

A Guide for Families and Caregivers

national down syndrome society
ndss

Written by:

Matthew J. Schuelka
Founder and CEO, Fora Education

Alisha M.B. Braun
Associate, Fora Education

Acknowledgements

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Introduction

Human beings are always changing and transitioning from one age to the next and from one life circumstance to another.

Particularly when we are young and school-age, we transition from one school grade to another, and at times to different schools or to different modes of learning and ways of relating to our peers – from preschool to elementary school, then to middle school, high school, and on to adulthood.

Students that have disabilities undergo the same kinds of transitions as everyone else, but sometimes they need additional support to facilitate those transitions. The transition from school to adulthood is fraught for anyone but can be especially challenging for a youth with a disability as they move from the routine and consistency of school to the unpredictable nature of adult society. Often, adult services can be challenging to navigate, and pathways and options can be unclear. The individual education plan (IEP) that you have used for many years will no longer be applicable once you exit out of a school district's special education services.

The intention of this guide is to provide direction, advice, and information, and to present a collection of resources that you can use to help navigate your transition to adulthood as smoothly as possible. Our goal is to point you in some useful directions, but it is ultimately up to you to decide what will be helpful for you in your transition journey. In the sections that follow, you will find guidance on transition planning, person-centered planning, building a transition IEP, and exploring pre-employment services. Next, you will find guidance on postsecondary education and training, including exit options from high school, pathways in postsecondary education, and ways to navigate the postsecondary landscape. Following this section, there

is a section on employment – how to prepare for it, how to think about work readiness skills, and what employers can and should do to accommodate and include. There are also sections on independent living, legal and financial planning, advocacy, systems of support, and social, emotional, and mental health support.

This is a national guide intended for youth living in the United States who have Down syndrome or other intellectual and development disabilities. It is important to note that every state in the United States has its own laws, policies, and programs that deal with school, transition, and adult living and working support. This guide provides general guidance, but you should always defer to your home state's resources and specific guidance. You will also find referrals to widely available transition advice and resources. We have tried to compile and summarize as much as possible, but there is not "one" way to transition. You should follow the advice and guidance that seems best for you. In the reference list, you will find links pointing you to many other guides and resources.

A Note About Language and Intended Audience

Much of this guide is written in second-person style, with the intended audience being the youth with a disability. All instances in this guide of the use of the word "you" refer to the youth with a disability. However, this guide is also intended for parents, families, and caregivers. In these cases, the word "you" can be interpreted as meaning the family and their child together. Teachers and other professionals involved in the transition process are also encouraged to use this guide, and in some cases the word "you" can refer to both those professionals and the youth with a disability. Keep in mind that the youth with a disability is always central in this guide.

1. Transition Planning in School

Inclusive Education and Transition Policies in the United States

There are three main laws in the United States that address the rights of students with disabilities in K-12 public schools and that are relevant to transitioning beyond K-12 and into adulthood:

- The Individuals with Disabilities Education Act (IDEA)
- Section 504 of the Rehabilitation Act
- Title II of the Americans with Disabilities Act (ADA)

Title II of the ADA and Section 504 are nondiscrimination laws, while the IDEA is a statute that mandates free appropriate public education (FAPE) in the least restrictive environment (LRE). Transition is mandated by the IDEA and requires that school districts and special education services work with families and youth with disabilities to plan for transition. The IDEA (2004) policy definition of transition services is shown in the box below (§ 300.43).

Transition services and postsecondary goals are a required component of a student's IEP once a student turns age 16, or earlier if deemed appropriate by the IEP team or if required by your state. For example, in Ohio, schools must begin transition planning at age 14.[1]

The student's school district is responsible for transition planning and the provision of transition services. The student and all members of the student's IEP team are involved in transition planning, to ensure that

IDEA Section 300.43 Transition services

(a) Transition services means a coordinated set of activities for a child with a disability that—
(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child'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;
(2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes—
(i) Instruction;
(ii) Related services;
(iii) Community experiences;
(iv) The development of employment and other post-school adult living objectives; and
(v) If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

(b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education.

their preferences and interests are an integral component of the planning process. All members of the IEP team should maintain a person-centered planning approach.[2]

The IDEA requires that the student's IEP include specific transition-planning components:

1. Appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills.

2. The transition services (including courses of study) needed to assist the student in reaching those goals.

3. Age-appropriate transition assessments based on the individual needs of the student, to be used to determine appropriate measurable postsecondary goals.

One thing that you may see as you embark on transition planning and your transition journey is something referred to as **Indicator 13**. This is an indicator required by IDEA for states to report the percentage of youth with IEPs, aged 16 and above, that have an IEP that includes appropriate measurable postsecondary goals that are annually updated and based upon an age-appropriate transition assessment; transition services, including courses of study that will reasonably enable the student to meet those postsecondary goals; and annual IEP goals related to the student's transition- services needs. There also must be evidence that the student was invited to the IEP team meeting where transition services are to be discussed and evidence that, if appropriate, a representative of any participating agency was invited to the IEP team meeting with the prior consent of the parent or student who has reached the age of majority.[3] This is not something you need to be worried about as the youth with a disability or the family of a youth with a disability, but it is something you may hear referenced by your IEP team as a state requirement for them.

The differences between the IDEA, ADA, and Section 504 can be confusing at the transition stage. The table on the following page should help clarify the purpose of each separate law:[4]

Comparison of IDEA, Section 504, and ADA

What these laws provide	IDEA	Section 504	ADA
Legal rights for people with disabilities	●	●	●
An Individualized Education Program (IEP) for eligible K–12 students	●		
Special education and related services to meet a student's unique needs	●		
A 504 plan for eligible K–12 students		●	
Accommodations (such as audiobooks or extra time) for K–12 students	●	●	
Accommodations for college students		●	
Reasonable accommodations in workplaces (with 15 or more employees)			●
A requirement that public schools find and evaluate – at no cost to families – students who may have a disability	●		
Education funding for schools	●		
A free appropriate public education (FAPE) in the least restrictive environment (LRE) for students	●	●	
Procedural safeguards that protect families' rights (such as access to school records)	●	●	
Due process (or an impartial hearing) for resolving disputes between families and schools	●	●	
Freedom from discrimination at private schools (including colleges and universities) that get federal funding		●	●
Freedom from discrimination in workplaces (with 15 or more employees)			●
Access to places that offer goods and services to the public, such as restaurants and websites			●

Table 1. Comparison of IDEA, Section 504, and ADA

There are also laws regarding participation in higher education. The Higher Education Opportunity Act (HEOA) was signed into law in 2008 (Public Law 110-315). For the first time, the HEOA provided financial aid to students that have intellectual and developmental disabilities and that attend college programs meeting the requirements of a Comprehensive Transition Program (CTP). The legislation also provided grants to create or expand model transition and postsecondary programs for students with disabilities, leading to considerable growth in the number of college programs nationwide that cater specifically to students with disabilities.

Pre-employment transition services (Pre-ETS) that occur at transition age while the student is still in school or still a student in the local education agency transition program are also required by law. The Workforce Innovation and Opportunity Act (WIOA) (Public Law 113-128) was signed in 2014 as an amendment to the Rehabilitation Act and requires state vocational rehabilitation agencies to fund and coordinate Pre-ETS.

Postsecondary Transition Planning
Preparing for the Transition IEP Meeting

Ideally, to ensure the student's preferences and interests are at the forefront of transition planning, IEP teams are student-led and begin with a discussion of the student's post-school visions.[5] Self-directed IEPs are especially important for students from culturally and linguistically diverse backgrounds to bridge values of diverse cultures and secondary education to facilitate culturally appropriate transitions.[6] Research findings stress the importance of placing more emphasis on, specifically, teaching students how to participate in transition discussions.[7] To help students actively participate in the IEP transition-planning process in preparation for the meeting, a self-inventory[8] is located in Appendix A: Student Self-Inventory Worksheet.

After a student completes the self-inventory worksheet, the Utah Parent Center recommends teaching them how to share information from the inventory with their IEP team using the SHARE formula:

When applying the SHARE method, the student is advised to practice sharing the material and engaging in role play.

S = Sit Up Straight
H = Have a Positive Attitude
A = Active Listening
R = Relax
E = Eye Contact

Another student-centered framework is PINS, which helps develop a transition plan by focusing on the student's preferences, interests, needs, and strengths (Utah State Board of Education, 2021).[9]

P = Preferences
I = Interests
N = Needs
S = Strengths

To apply the PINS framework to help prepare for the transition IEP meeting, students and family members can use the free Transition Elevated app, available online or via the App Store. After answering a series of questions online, the app will produce a transition plan report for you that you can bring

to your IEP meeting. A sample student report can be found here. The app was originally designed by the Disability Rights Center of Kansas. Individuals living in other states may use this free app for brainstorming and planning purposes, but you should definitely familiarize yourself with your state laws to ensure the information is applicable.

The figure below depicts the "who" of transition planning (i.e., the IEP team).[10]

Community Professionals
- Related service providers (if appropriate)
- Vocational rehabilitation counselor (if appropriate)
- Other appropriate agency personnel

Family
- Parents or guardian
- Invited participant

Student

School Personnel
- Special education teacher
- School counselor
- General education teacher
- Local Education Agency (LEA) representative
- Transition specialist

Figure 1. Team Members Involved in Transition Planning

The following table summarizes each team member's role as it relates to transition planning:[11]

Team Member	Transition Planning Roles
Student	Communicates preferences, interests, strengths, and limitations. Identifies goals for adult life.
Parents or guardian	Support the student. Provide information about the student's interests, strengths, and limitations.
Special education teacher	May coordinate the transition activities at some schools. Suggests appropriate accommodations and modifications. Provides input about the student's academic and social performance.
General education teacher	Provides input about the student's academic and social performance.
School counselor	May coordinate the transition activities at some schools. Provides information about needed career, personal, and social competencies. Stays current on opportunities and services available to students. Advocates for students with disabilities as they transition to adult life. Helps identify community or adult services that may assist the student in achieving their post-school goals.
Transition specialist (when available)	Coordinates transition activities. Can administer and interpret formal and informal career and vocational assessments. Assists the team in matching student skills and interests with appropriate post-school outcomes. Helps identify community or adult services that may assist the student in achieving their post-school goals.
Related service providers (if appropriate)	Provide information about the related services the student is currently receiving. Provide information about the related services the student will continue to need once they leave high school.
LEA representative (e.g., the principal)	Supports school personnel. Ensures availability of resources to implement the IEP.

Vocational rehabilitation counselor (if available)	Coordinates a range of services related to employment and job placement.
	Assists in locating funding sources to pay for postsecondary training or education.
	Helps identify community or adult services that may assist the student in achieving their post-school goals.
Other agency personnel (as indicated)	Helps identify community or adult services that may assist the student in achieving their post-school goals.
	Provides information about eligibility criteria for adult services.

Table 2. Description of Transition Planning Team Member Roles

To help plan whom you'd like to invite to the transition IEP meeting, the following planning chart may be helpful:

People to Invite to My Transition IEP Meeting Fill in the blanks with the names of the appropriate individuals.
Family Members
Teachers
Other School Personnel
School Counselor and/or Vocational Rehabilitation Counselor (if available)
Community Agency Representatives (e.g., Mental Health, Independent Living)
Current or Prospective Employer

In order to ensure a successful transition IEP meeting, you would be wise to keep the following in mind:[12]

- Your plan is a tool for you to think about as you look to the future.

- Ask for a copy of your Transition IEP.

- Review your goals from last year.

- Make notes about the things you want to keep and the things you want to change.

- Write down any questions you have about the plan. Ask questions throughout.

- Be prepared to discuss:

  - Goals

  - Disability

  - Strengths

  - Interests

  - Accommodations and modifications

- Be prepared to express your opinions and listen to the opinions of others.

Principles of Self-Determination

Self-determination is the principle that a person must have control of their relationships with other people, groups, systems, and cultures that are important to them. All people – regardless of ability – have the right to self-determination. However, self-determination is also based on context and on the environment that surrounds us.

Self-determination skills include informed choice and decision-making, setting personal goals, problem solving, and communicating effectively. Persons with disabilities should understand their life choices and have the empowerment and skills to make informed decisions, sometimes supported by professionals and advocates. In other words, self-determination means:

Control over day-to-day decisions

- what to wear

- what to eat

- what time to go to bed

Control over long term decisions

- where and with whom to live

- where and if to work

- where, when, and with whom to create

Questions for Self-Determination

1. Identify your personal preferences

What do you want to do after high school?

_____

_____

_____

What do I want my life to be like?

_____

_____

_____

_____

2. Set goals so that you can live the life you want

What are one or two big goals I can work on this year?

_____

_____

_____

_____

Can I break these big goals down into several smaller goals?

_____

_____

_____

_____

_____

3. Work to reach your goals

Can I reach my goals alone or do I need support?

_____

What type of support do I need?

_____

_____

_____

Where can I get that kind of support?

_____

_____

_____

4. Check your progress and problem-solve if necessary

Am I making the progress I want?

_____

Are there other supports I could use?

_____

_____

_____

How can I use my self-advocacy skills to move forward? [13]

_____

_____

_____

_____

_____

A great collection of online resources for self-determination is provided by the Virginia Department of Education's project *I'm Determined!*[14] Many video resources are found on the site, including the *Parent Path to Success* and *Critical Decision Points* resource pages. The *I'm Determined!* framework for self-determination is based on the three pillars of **Competence**, **Autonomy**, **and Relatedness**. There are a series of videos on each pillar here.

The *I'm Determined!* project contains so many useful resources and tools that they would double the size of this guide if we reproduced them all. We encourage you to go to the *I'm Determined!* website to check them out for yourself. However, we will highlight a few things from the *I'm Determined!* tools here. The following is a useful age guide for self-determined transition planning:[15]

Aged 10-12	• Complete chores at home • Explore and discuss what you want to do in the future (dreams) • Demonstrate the ability to make choices / develop decision-making strategies • Follow directions, and finish what you start
Aged 12-14	• Describe employability skills • Explore Career and Technical Education Program options • Begin developing a career portfolio – including copies of required identification • Engage in community services/volunteering
Aged 14-15	• Continue career exploration – participate in job shadowing • Continue development of your career portfolio – including copies of assessment, work samples, etc. – then, link this information to your Summary of Performance • Begin to set goals for yourself for after high school • Evaluate future financial needs and how these relate to career choices
Aged 15-16	• Continue career exploration – situational assessments • Continue development of career portfolio; include résumé development • Identify and explore all sources of potential employment • Understand/state what it is that you can "bring" to an employer • Understand private/government resources for employment
Aged 16-17	• Continue development of your career portfolio – include updates to all documents • Begin narrowing job selection from just "a job to make money" to "a job that interests you" • Understand how to acquire the accommodations and supports needed for employment • Discuss what additional training/skills are needed to continue to enhance employment • Engage in competitive employment
Aged 18-21	• Develop skills for employment/volunteer position sustainability • Master employability skills • Acquire the accommodations and supports needed for employment • Make use of private/government resources for employment

A helpful transition planning tool – which we will more fully cover in the next section – is the *I'm Determined!* Good Day Plan, pictured here:

Name: _____   Date: _____

Good Day Plan

Answer each of the four parts in this Good Day Plan. Think about what happens on the best days and write or type out what happens, if it's happening now, what you can do to have a good day, and what help you can use along the way.

Good Day What happens on a good day?	**Now** Does it happen now?	**Action** What needs to happen to make it a good day?	**Support** Who can help me?

I'M DETERMINED

Resource provided by I'm Determined, a state-directed project funded by the Virginia Department of Education.
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Scan code for more guidance, videos, and examples.
For additional resources visit www.imdetermined.org/resources.

Figure 2. I'm Determined! Good Day Plan

In <u>Appendix B: I'm Determined! Student Rubric for IEP Participation</u>, we have reproduced a useful rubric for IEP Participation. This tool can be used to help facilitate self-determination as you advocate for your needs and create a vision for your future adult self with assistance from your education and care providers.

Tools for Person-Centered Planning

Many tools and resources are already available – and often free online – for person-centered planning for transition:[16]

Making Action Plans (MAPS)

MAPS is an older, but still widely used, person-centered planning tool meant to be employed at the beginning of the transition process. MAPS is a visual tool that works to address the self-identity, the life goals and dreams, and the fears of the youth with a disability, helping them identify resources and action steps needed to realize their goals. Generally, MAPS is facilitated by professionals – which can include teachers and family, as well as the youth with a disability themselves when appropriate. The MAPS visual is composed of:

- **A Story** that gives an opportunity for the youth with a disability to share their self-identity and key events from their life.

- **Dreams** that identify positive life outcomes for the future.

- **Nightmares**, which are anxieties and fears that the youth with a disability has for both the present and future.

- **Contributions** that describe strengths, skills, interests, activities, people, and other resources that are a part of the life of a youth with a disability.

- **What It Takes** to identify additional needed resources, people, organizations, skills, and attributes.

- **An Action Agreement** that identifies the who/what/when of an action step to support the realization of life goals and dreams.
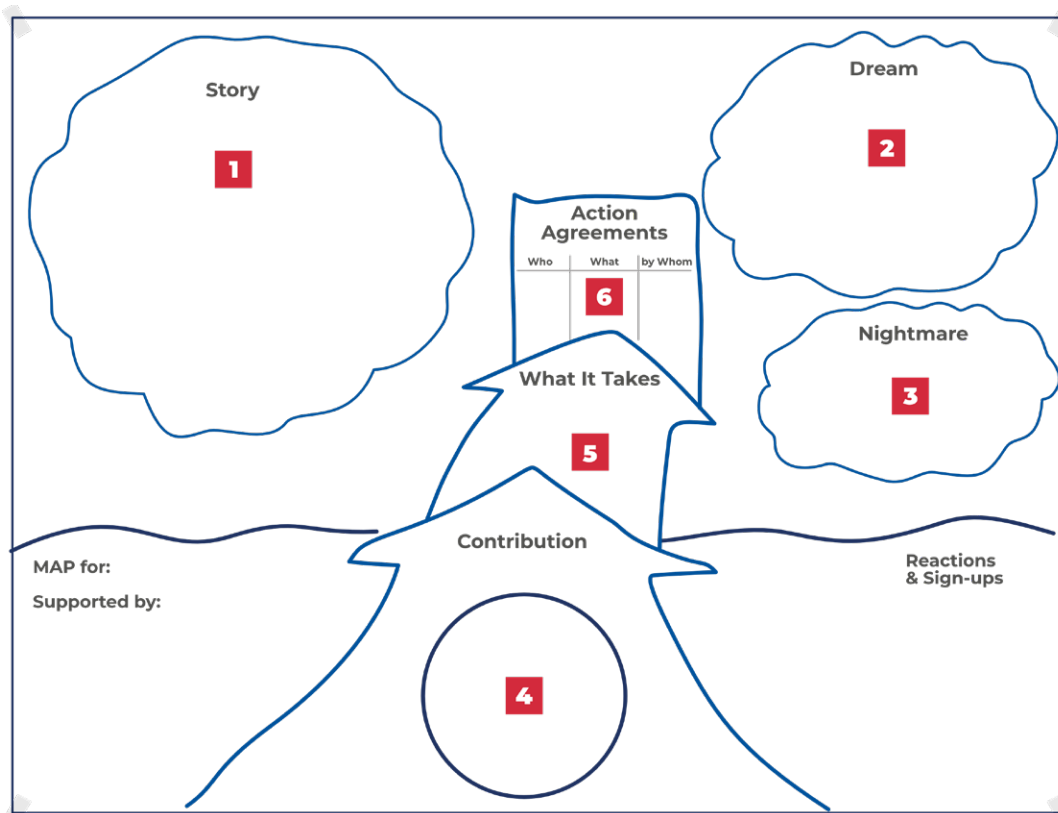
Here is the MAPS Template:

Figure 3. MAPS Template

Planning Alternative Tomorrows with Hope (PATH)

PATH is also a visual planning tool that can use visuals and creativity to create action steps and locate community resources.

There are seven steps in the PATH planning process:

1. **North Star.** This is the *big picture* for the youth with a disability. These are long-term goals and ideal outcomes. No limitations should be placed upon these goals and aspirations.

2. **By this time next year.** These are medium-term goals, identified by the youth as achievable in 6-12 months, that will contribute toward reaching the North Star.

3. **Now.** The youth identifies their current successes and challenges, as well as their current level of performance. This can also include short-term goals.

4. **Enroll.** The youth, perhaps in collaboration with the PATH facilitator, identifies the people and organizations that can help support them to reach their short-term, medium-term, and long-term goals. This can be helpful in identifying who should be a part of the transition team.

5. **Stronger.** This is the action-step planning area, where you and the youth will brainstorm the specific steps necessary to reach various goals.

6. **Strategies for Progress.** Somewhat similar to step 5, but measurable targets in 3-6 months.

7. **First Steps.** This is the time element of the planning process, where you and the youth identify a timeline for the action steps.

Here is the PATH Template and Example:[17]
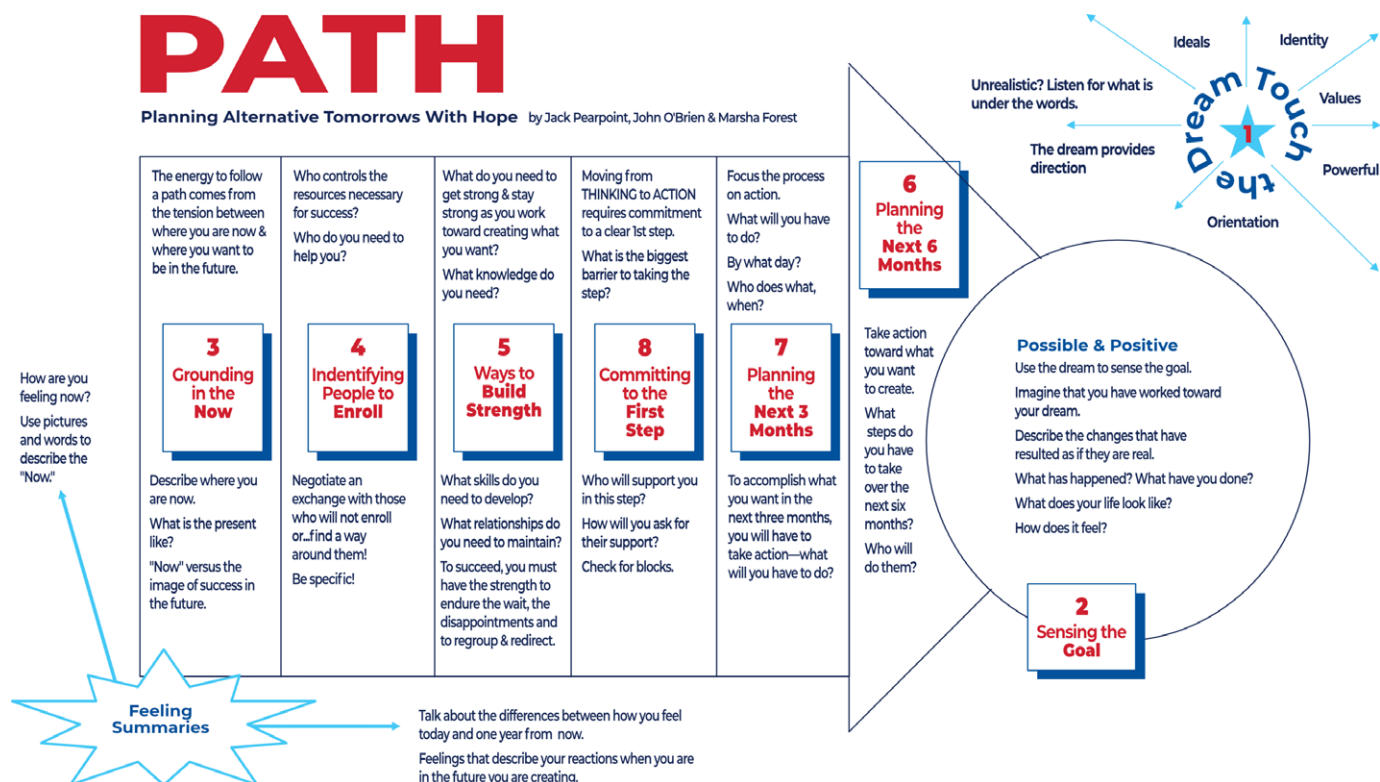

Figure 4. PATH Template

Personal Futures Planning (PFP)

PFP is an idea and process similar to MAPS and PATH. Like the last two examples, PFP focuses on:[18]

- What are the person's strengths and interests?

- What is the individual's dream for the future?

- Who are the important people in the person's life?

- What resources are available?

- What challenges or obstacles are present?

These are represented in a series of visuals with the following prompts:

MAPs

1. Relationship
Who is in the life of the focus person?

2. Places
Describes community presence, where someone lives, works, visits, and so on.

3. Background
What has happened to the focus person up to now?

What is the Life Pattern?

4. Preferences
Lists the individual's potentials and interests. Also lists things not enjoyed or appreciated.

5. Dreams
Personal dreams and desires for the future.

6. Hopes & Fears
Things which look hopeful in reaching the dream. Fears which stand in the way.

Charting the LifeCourse (CtLC)

One of the newer and more widely used person-centered planning tools is Charting the LifeCourse (CtLC), originally developed at the University of Missouri and then adapted and contextualized worldwide. CtLC focuses on the following life domains for person-centered planning:[19]

- Daily life and employment
- Community living
- Socialization and spirituality
- Healthy living
- Safety and security
- Advocacy and engagement
- Supports for family
- Other supports and services

For example, two tools from the Charting the Life Course – establishing a "Vision for What I Want" and assessing "What I Don't Want – help map a Trajectory to a Good Life:

Trajectory to a Good Life

VISION FOR WHAT I WANT:
Supporting Positive Life Experiences

WHAT I DON'T WANT:
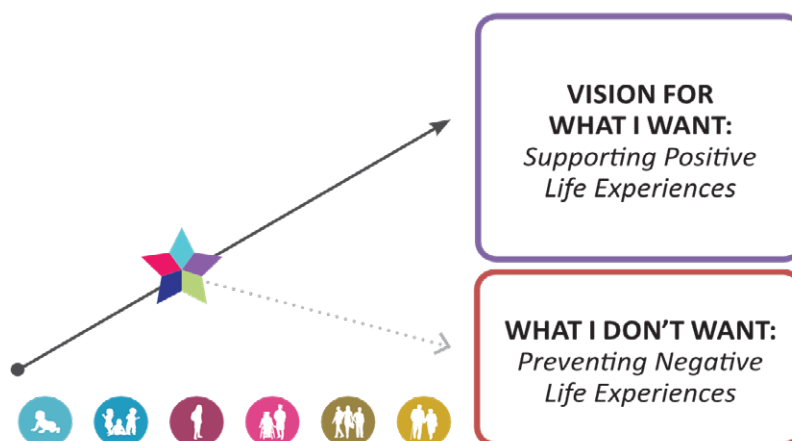*Preventing Negative Life Experiences*

Figure 5. CtLC Trajectory to a Good Life

Another tool helps develop planning by using an Integrated Support Star model:
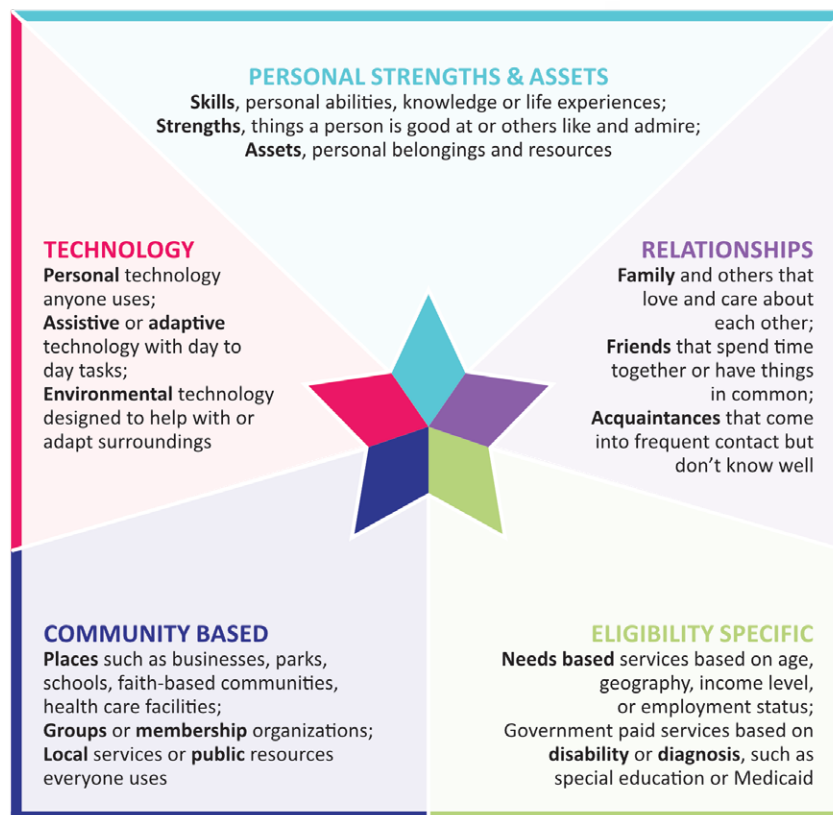
Integrated Supports for a Good Life

PERSONAL STRENGTHS & ASSETS
Skills, personal abilities, knowledge or life experiences;
Strengths, things a person is good at or others like and admire;
Assets, personal belongings and resources

TECHNOLOGY
Personal technology anyone uses;
Assistive or **adaptive** technology with day to day tasks;
Environmental technology designed to help with or adapt surroundings

RELATIONSHIPS
Family and others that love and care about each other;
Friends that spend time together or have things in common;
Acquaintances that come into frequent contact but don't know well

COMMUNITY BASED
Places such as businesses, parks, schools, faith-based communities, health care facilities;
Groups or **membership** organizations;
Local services or **public** resources everyone uses

ELIGIBILITY SPECIFIC
Needs based services based on age, geography, income level, or employment status;
Government paid services based on **disability** or **diagnosis**, such as special education or Medicaid

Figure 6. CtLC Integrated-Support Star

The tools for CtLC can be found free [online](). This is the most comprehensive and "modern" of the person-centered planning tools and the one that is most recommended. However, any of the tools presented in this section are effective and useful, and the choice of planning tool should be based on the context of the situation. Your IEP transition team may be familiar with a certain planning tool that they are comfortable using. Multiple planning tools can certainly be used as well.

The Role of Families and Advocacy in Transition

The following is advice for families, parents, and caregivers on how to support your child with a disability as they transition from school-age youth to adults:[20]

Understand your child's disability. Even if you are quite aware of your child's *medical diagnosis* related to their disability, you should try to understand how that diagnosis specifically expresses itself in your child. How does the disability impact your child in terms of learning, communication, and/or mobility? Remember that disability expresses itself differently in each individual, and no two people are exactly alike. You are intimately familiar with your child now that they have reached transition age, but you should rethink these things in a new way, now that your child is preparing to become an adult in society. How might your child's disability impact their postsecondary education, training, employment, and independent living?

You are part of a team. You should not be a passive observer of the child's education and transition planning that you hope will occur at your child's school. You should be an integral member of the individualized education plan (IEP) and Transition IEP process. Be sure that the school collaborates with you instead of ignoring you. If you feel that the school is ignoring you or your child, be sure to seek further support for your own advocacy.

Encourage the journey. All youth experience stress and difficulties as they embark on the journey to adulthood – whether they have a disability or not. Encourage your child to create a vision for their future and understand the steps that are necessary to get there. Use person-centered planning tools such as Charting the LifeCourse, MAPS, and others that were featured in the previous section. Remind your child that it is good to have a plan, but that it is also important to follow your life's journey wherever it may lead you. Flexibility and the ability to adapt are also important life skills.

Set high expectations. As was evidenced in the introduction to this guide, setting high expectations for your child is vitally important for them to realize future employment and life outcomes. Advocate for your child and ensure that their IEP and transition plan reflect high expectations and ambitious goals. Expectations should be realistic and achievable, but also creative. Set the goals with high expectations, and then backwards map them to figure out how they can be achieved and whether they need to be modified or adapted.

Keep good records and share what you know. It is important to save all documentation related to your child – school records, medical records, tax and government assistance information, and so forth. Keep these records organized, and ensure that you have the ability to share them with relevant authorities and professionals. It will be important to produce these records when applying for jobs, training opportunities, and experience at postsecondary educational centers, government offices, and other locations. Make sure that you also *show* and *teach* your child about good record keeping and organizational systems. They will have to be responsible for these records as well.

Build self-confidence and self-determination. Encourage your child to feel comfortable asserting themselves, to participate in IEP meetings, making plans with their teachers, and voicing their goals to other professionals. Help them find effective ways that they can communicate and encourage alternative forms of communication when needed. Self-determination is an important principle in allowing a person to take control of their relationships with other people, groups, systems, and cultures that are important to them. Encourage your child to make their own decisions and teach them skills for self-advocacy.

Support independence. Preparing your child to be an independent adult, like building self-confidence and supporting self-determination, is part of your job as a parent or caregiver. This does not necessarily mean that your child will live apart from you – that depends on the life plan that has been discussed and implemented. It is important to feel supported and connected to others. However, supporting independence can also mean helping your child develop skills in learning new things, managing their time, taking responsibility for their actions, making connections with people in the community, and understanding their own preferences and tastes.

Teach "soft skills." Most specific employment skills are learned "on-the-job" through training and mentorship. However, what is not taught are the "soft skills" that are crucial for successful employment. These can include appropriate communication, emotional intelligence, interpersonal skills, taking direction from others, conflict resolution, positive regard and respect for others, self-efficacy, growth mindset, understanding personal boundaries, empathy, and many other skills that are important in adult society and the workplace. Important for you, as a parent or caregiver, is having an understanding that these "soft skills" are not innate but can be learned and developed in your child over time.

Help identify potential community supports and employment opportunities. While independence and self-advocacy are important things to foster in your child, you will also need to help support their engagement with the community and their search for employment opportunities. Many youth will utilize some form of community support that can enable them to live, learn, and work as adults. This may include government assistance such as Social Security, Medicaid, and state programs. It may also include civil society and social enterprise organizations that support persons with disabilities in training and employment.

Often, families believe that the teachers and other professionals that work with their children know what is best and defer to their judgement and opinions. While teachers and other professionals do have at least some expertise and experience, **families are the true experts when it comes to their children, second only to the youth with a disability themselves.** Working hand-in-hand with professionals is important, but it should be viewed as a collaboration, and all stakeholders should pay close attention to the balance of power in working toward what is best for the youth with a disability. The youth with a disability should always be at the center. On the following page is a diagram of the best evidence-based practice when it comes to thinking about collaboration among the youth with a disability, families, and professionals (teachers, doctors, social workers, and others):[21]
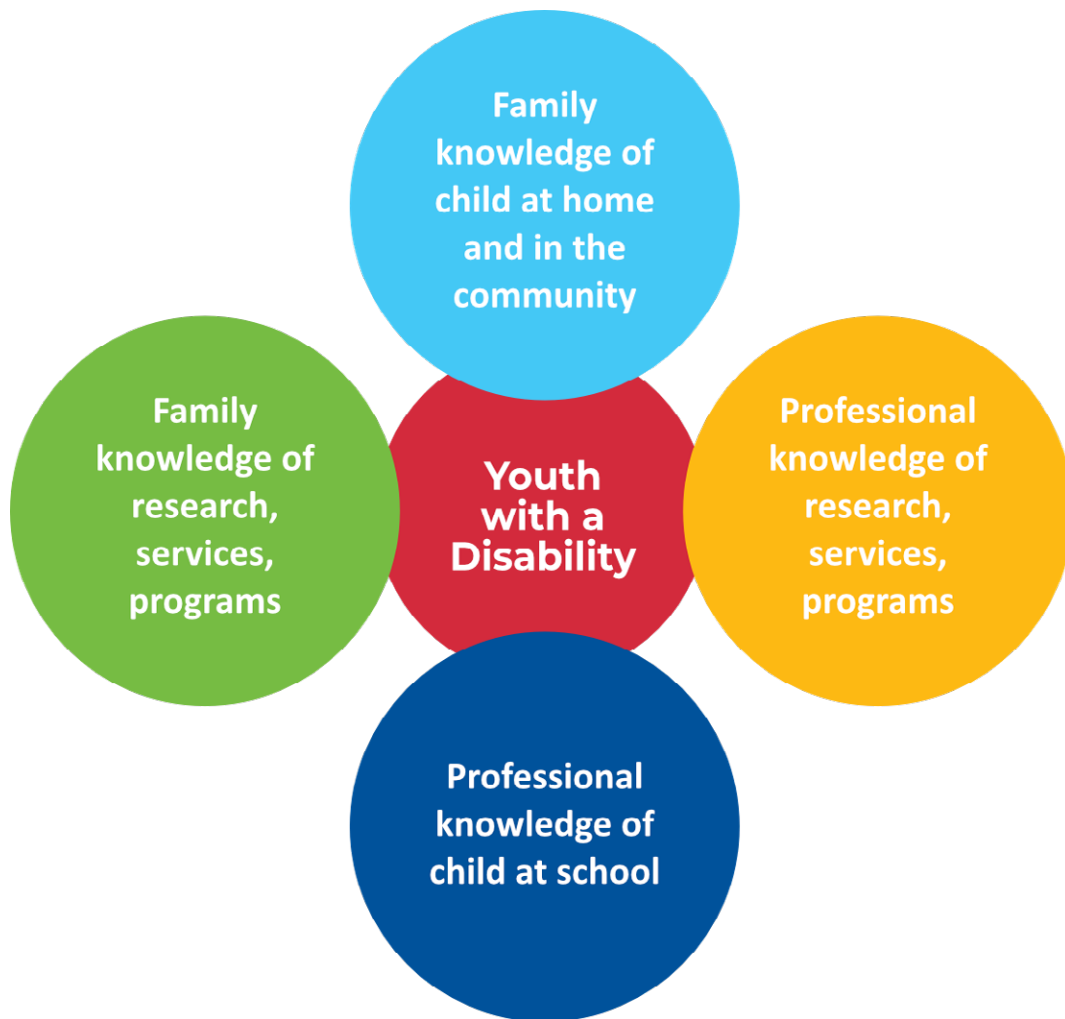
Figure 7. Balance of IEP Team Knowledge

Both the family and professionals should be in service to the youth with a disability and help support them in better understanding themselves and their preferences, abilities, available opportunities, and life goals.

Building a Transition IEP

You should use person-centered planning tools to help plan a successful transition for a youth with a disability. However, the transition goals should also be formally written as achievable steps in the student's IEP The Transition IEP is a process,[22] and it is a summary document of all the ongoing activities taking place during transition planning. In this section we will discuss life and work skills curriculum development. These will populate much of the IEP transition area in terms of learning objectives and educational outcomes.

Goals that are written in IEPs should employ the SMART goal principles, which are: [23]

S	**Specific**	Make your goals specific and narrow for more effective planning
M	**Measurable**	Define what evidence will prove you're making progress and reevaluate when necessary
A	**Attainable**	Make sure you can reasonably accomplish your goal within a certain timeframe
R	**Relevant**	Your goals should align with your values and long-term objectives
T	**Time-based**	Set a realistic, ambitious end-date for task prioritization and motivation.

Figure 8. SMART Goals

Every state and school district will have different requirements for what an IEP should look like and what areas should be included. You should check with your IEP team and any state resources for an exact picture of what a transition IEP will look like for you. Generally, a transition IEP should contain the following elements:[24]

Student's Current Strengths, Interests, and Preferences:

_____

_____

_____

Student's Post-secondary Goals and Vision for Their Future as an Adult:

_____

_____

_____

Education/Training
(Goals based on academics, functional academics, life competencies, technical training, job training)

Goals	Current Academic and Functional Levels	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion

Employment
(Goals based on career pathway awareness, work skills, employment knowledge)

Goals	Current Work Skills and Experience	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion

Independent Living / Adult Living Skills
(Goals based on self-determination, communication, health, well-being, finance skills, technology skills)

Goals	Current Independent Living and Adult Living Skills	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion

Community Participation
(Goals based on civic skills, interpersonal skills)

Goals	Current Community Participation	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion

Other Relevant Services
(Goals based on related services such as counseling, physical/speech/occupational therapy, or mentoring, where available)

Goals	Current Services	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion

(Expand all tables above as needed. Students should have multiple goals for each section.)

Developing Education and Training Skills

The Transition IEP is often supplemental to your regular educational IEP. However, there is some overlap between the two, particularly in developing goals for education and training skills. Not every student will have the goal of completing their secondary education, but they still need to meet basic educational standards to support their transition. Even if your personal goals do not include postsecondary education, basic educational goals in literacy and numeracy, critical thinking, and non-cognitive skills are essential to prepare you to enter life as an adult.

Examples of learning outcomes and goals for education and training skills include:

- Reading and writing (e.g., sight-word vocabulary, spelling, handwriting, typing)

- Math (e.g., basic computation, money, measurement)

- Problem solving

- Listening comprehension

- Speaking

- Digital and computer skills

- Developing outside interests (e.g., art, music, sports)

- Foreign language

- Following and giving directions accurately

- Communicating information

- Understanding and processing information

- Requesting or offering assistance[25]

An example of an education/training goal written using SMART targets is provided below:

Education/Training (Goals based on academics, functional academics, life competencies, technical training, job training)					
Goals	**Current Academic and Functional Levels**	**Person/ Agency Involved**	**Strategies**	**Achievable Outcome**	**Date for Completion**
Numeracy: Student will learn to identify money, count correctly (addition), and give correct change (subtraction).	Student can recognize some coins and banknotes, but has challenges in giving correct change.	Special Education Teacher Community (real-world practice)	Use Dollars & Cents App (free) Simulate community shopping setting in classroom Go into community for guided practice	Student will identify all coins and banknotes, count correctly, and independently give correct change in a real-world community setting 3 times.	End of semester one

Notice in the example above that education skills (in this case, numeracy) can be both academic and applicable to functional life skills. When preparing youth with disabilities for transition, be sure to emphasize these real-life links and connections.

There is not necessarily detailed guidance in determining *how* learning outcomes and goals will be achieved, other than, perhaps, an identified strategy or activity. This will depend on the specific skills in question and what curriculum, tools, and resources are available. This is a competency-based approach to transition IEP planning, rather than a prescriptive curriculum. The collaborative transition team is responsible and empowered to make teaching and learning choices in order to realize the learning outcomes.

Developing Employment Skills

There is a major overlap between education and training skills and employment skills. Education skills should be focused on generalizing to real-life situations. An important general life skills base – literacy, numeracy, critical thinking, task organization and completion, etc. – helps support employment skills.

An example of an employment goal in the Transition IEP, written using SMART targets, is provided on the next page:

Employment (Goals based on career-pathway awareness, work skills, and employment knowledge)					
Goals	**Current Work Skills and Experience**	**Person/Agency Involved**	**Strategies**	**Achievable Outcome**	**Date for Completion**
Student will answer an email in a professional manner.	Student knows how to email, but usually only with their family and when using casual language and tone.	Special Education Teacher	Scenarios practiced in classroom	Student will answer 3 emails using appropriate greetings and salutations and maintain a professional tone throughout.	End of Semester two

Developing Independent Living and Adult Living Skills

The principles of person-centered planning and self-determination are important in developing skill goals and targets for independent living and adult living skills. We recommend the following learning outcomes for the youth with a disability to demonstrate self-determined characteristics:

- Being able to say what their disability/ies is/are

- Being able to make choices from at least a few options

- Awareness of personal preferences, interests, strengths, and limitations

- Ability to differentiate between wants and needs

- Ability to make choices based on preferences, interests, wants, and needs

- Ability to consider multiple options and to anticipate consequences for decisions

- Ability to initiate and take action when needed

- Ability to evaluate decisions based on the outcomes of previous decisions and to revise future decisions accordingly

- Ability to set and work toward goals

- Ability to use problem-solving skills

- Ability to pursue independence while recognizing interdependence with others

- Display of self-advocacy skills

- Ability to self-regulate behavior

- Use of self-evaluation skills

- Display of independent performance skills and ability to adapt to changes

- Demonstration of persistence

- Effective use of communication skills

- Ability to accept personal responsibility

- Demonstration of self-confidence

Learning outcomes can be written in the "Goals" box in the transition IEP. Of course, outcomes and goals need to be relevant to each individual youth with a disability.

Independent living and functional adult skills that can be identified in the transition IEP include:

- Good hygiene

- Time management

- Healthy lifestyle

- Using a mobile phone

- Using transportation

- Money management

- Nutrition/meal preparation

- Using technology and assistive technology

- Accessing community services and supports

- Community participation

- Civic responsibility

- Community safety

- Developing friendships

- Appropriate dress

- Appropriate behavior
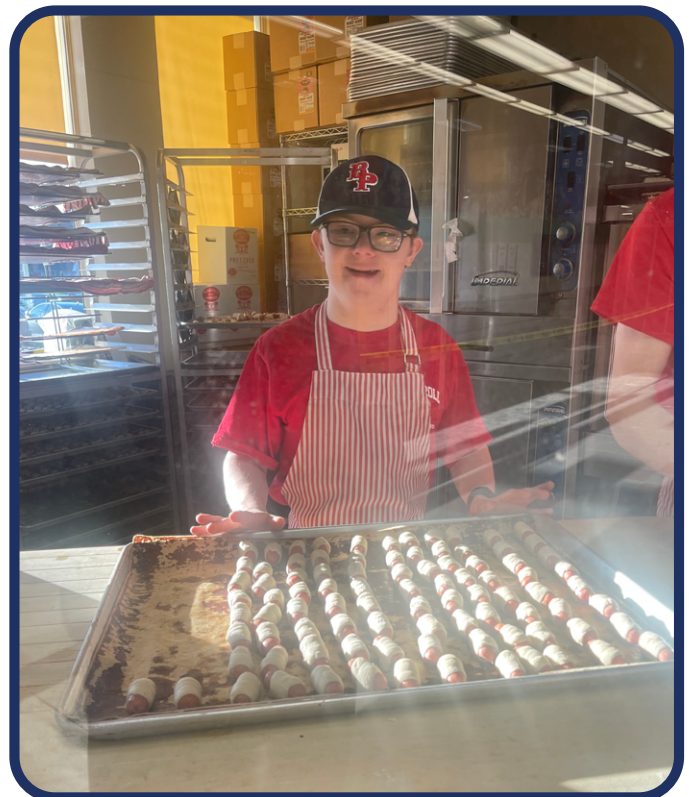
Please note that there are many opportunities in the transition IEP to cross-reference goals that cut across categories of education, training, employment, and adult living skills. These do not need to be reproduced every time in every category, but it is worth noting how one goal fulfills multiple categories. Below is an example of an independent-living and adult-living skills goal written using SMART targets that also cross categories:

Independent-Living / Adult-Living Skills
(Goals based on self-determination, communication, health, well-being, finance skills, technology skills)

Goals	Current Independent Living and Adult Living Skills	Person/ Agency Involved	Strategies	Achievable Outcome	Date for Completion
Student will engage in healthy life choices in eating and exercise. Also Fulfills: • **Education** (Writing) • **Life Skills** (Cooking) • **Community** (Locating and Accessing Services)	Currently, student prefers unhealthy food and only engages in occasional light exercise.	Special Education Teacher Parents Physical Education Teacher TVET Home Economics Teacher Community Members	Keep a food and exercise journal Locate exercise and fitness opportunities in the community Locate online exercise resources Readings on healthy food	Student will keep a consistent food and exercise journal for three months. Student will make a list of preferred exercises and physical activities. Student will locate safe community exercise activities or online exercise resources. Student will demonstrate making healthy food choices by preparing a healthy meal.	End of Semester one

Another important and emerging area to develop independent-living and adult-living skills is digital literacy. In the 21ˢᵗ century, much of the work that we all do uses technology to some degree, and this will only increase over time. Not only will youth with disabilities need technology to help support their entrance into the workforce or into post-secondary education, but they will also need to know about appropriate conduct and safety when using such technology as social media and other communication or interactive digital media.

Using digital tools empowers and provides much more accessibility for youth with disabilities to be included in employment and community settings. Increasing opportunities have arisen for persons with disabilities to be included in employment through the use of technology and practices such as remote working, screen readers, and other assistive technology. However, as with any tool, there is a social responsibility to use digital tools correctly and positively.

Suggested topics for digital literacy and digital skill building include the following:[26]

Basic Digital Skills
(for all students):

- Internet basics
- Browser basics
- Searching online
- Creating online accounts
- Sharing online
- Connecting online
- Online safety
- Expressive and receptive language online
- Email use
- Understanding of spam
- File organization
- Social media privacy and safety
- Video communication

Advanced Digital Skills
(for students with certain career goals):

- Workplace communication
- Task management
- Specific work applications, such as word processing, spreadsheets, etc.
- Cloud file storage
- Data entry
- Digital presentations
- Creation of digital résumés and bios
- Networking
- Creating a personal digital brand
- Online job applications

Developing Community Participation Skills

Community participation skills will also have significant crossover with other skill categories, such as employment and adult-living skills. That being said, there should be some stand-alone community-participation skills that you can put in this category. These include goals such as:

LEARNING:

- How to **vote** and democratically participate in society

- How to **access** government services and obtain permits such as a driver's license

- How to **locate** community resources, such as banking, shopping, food sellers, and the post office

- How to **find** community groups and participate in hobbies and activities with other community members

- Where youth can **volunteer** in their communities

An example of a community participation goal in the Transition IEP using SMART targets appears below:

Community Participation (Goals based on civic skills, interpersonal skills)					
Goals	**Current Community Participation**	**Person/ Agency Involved**	**Strategies**	**Achievable Outcome**	**Date for Completion**
Student will locate community volunteering or organizations that they can participate in. Also fulfills: **Education** (Writing) **Education** (Speaking) **Life Skills** (Positive Community Interactions) **Life Skills** (Interpersonal Communication)	Student currently volunteers at a local park, picking up litter. However, this is only 1x month.	Special Education Teacher Parents Community Members Community Organizations	Engage in the community through CBI activities. Use community interaction guide.	Student will interview 3 community organization members. Student will write a report on 2 community organizations that they can participate in, listing contact information, information about the organization, and why they are interested in them.	End of Semester two

Connecting to Adult Services

The last goal category on the transition IEP is making connections to other relevant services. One of the biggest challenges in transitioning a youth from school services to adult services is the falling off of services in adult life. The youth with a disability will find that they are less supported as an adult than they were while they were in school.

This goal category is an important connection point for the collaborative transition team and is important in connecting youth and their families to societal support and adult services. A smooth 'hand-off' between the school and postsecondary institutions, training opportunities, agencies, and employers are crucial. To that end, specific adult services and organizations will need to be relevant to the needs of each youth with a disability, based on their particular person-centred planning goals.

Concluding Suggestions for a Transition IEP

To reiterate, the above examples for a transition IEP demonstrate just some of the suggested areas on which to focus. The structure, format, and look of the IEP will be determined by your home state requirements. You should work with the IEP team and use their process in forming the transition elements of the IEP.

General questions that you may ask about your transition IEP – which will follow the guidelines of your home state and the practices of your school district – can include the following:

- Does the Transition IEP contain one or more postsecondary goals for your child that reflect their interests, strengths, preferences, and abilities?

- Are the goals based on age-appropriate and disability-appropriate transition assessments?

- Are the goals in line with your child's PLAAFP?

- Are the goals standards-based and ambitious as well as realistic, clear, and understandable?

- Can the goal(s)/objectives be measured?

- Does the post-secondary goal(s) occur after your child graduates from high school?

- Are there supporting annual IEP goals that reasonably support the child to meet the postsecondary goal(s) or make progress toward meeting the goal(s)?

- Does the course of study match up with the student's post-secondary goals?

- Do the transition services in the IEP focus on improving your child's ability to move from high school to post–high school?

- Do these listed transition services relate to a type of instruction, related service, community experience, employment, or other post-school adult-living objective (and, if appropriate, independent living skills)?

- Does the plan show a multi-year advancement/progression?

- Are people from other agencies invited to the Transition IEP meetings when transition services are being discussed that are likely to be coordinated, provided, or paid for by these other agencies?

- Is the ultimate outcome of the Transition Plan clear?

Pre-Employment Transition Services

Pre-Employment Transition Services (Pre-ETS) offers students with disabilities an early start at career exploration and preparation for adult life. This occurs when the student is still in high school or in a transition program. The focus of Pre-ETS is on developing work skills, social skills, and community connections while a student is in high school. The figure below defines 5 components of Pre-ETS: job exploration, workplace readiness training, work-based learning experiences, training on self-advocacy, and postsecondary educational counseling.

Job Exploration
Explores career path options that are best suited to your skills, abilities, aptitudes, and interests.

Work Readiness Training
Focuses on employability and related skills that prepare you to work. Resume writing, mock interviews and searching and applying for jobs are part of this training.

Pre-Employment Transition Services

Work-based Learning Experiences
Provides practical exposure to different careers and hands-on training for employability skills. These experiences focus on practicing social skills and building relationships.

Self-Advocacy Training and Peer Mentoring
Teaches you how to talk about your needs and make decisions about your own life to become more independent.

Postsecondary Educational Counseling
Provides information about continuing education options, school choice, accessing financial aid, etc.

Figure 9. Pre-Employment Transition Services

To access free Pre-ETS services, contact your school staff or your state's department of vocational rehabilitation. Here are a few examples of informational Pre-ETS links for families to access services in a few states:

- Massachusetts Rehabilitation Commission Pre-ETS Parent Informational Pamphlet: https://www.mass.gov/doc/pre-ets-informational-pamphlet/download

- Montana Vocational Rehabilitation and Blind Services Pre-ETS Parents/Guardians link: https://dphhs.mt.gov/detd/preets/Parents

- Florida Division of Vocational Rehabilitation Steps to Get Started link: https://www.rehabworks.org/student-youth/student-steps.html

In their analysis of Pre-ETS policies across 38 states, Carlson, Thompson, and Monahan recommend the following website search process shown here.

One of the most well-known Pre-ETS programs is Project SEARCH. The Project SEARCH Transition-to-Work Program is a business-led, workplace-immersive, one-year employment preparation program for youth with intellectual and developmental disabilities. Participants are usually high school students on an IEP who complete the program during their last year of high school or during their transition age programming (18+). The Project SEARCH program combines classroom instruction, career exploration, and hands-on training with worksite rotations. Program participants develop an individualized career plan and complete three targeted internships aligned with their skills and interests. Participants follow an employment skills curriculum focused on team building, workplace safety, technology, maintaining employment, self-advocacy, financial literacy, health and wellness, and preparing for employment. The goal for the Project SEARCH program is competitive employment for its graduates.

Find out more about the Project SEARCH Transition-to-Work Program here:

https://www.projectsearch.us/find-a-program/

Step 1

Go to state department of vocational rehabilitation, linked from: https://rsa.ed.gov/people.cfm

Step 2

Identify website's page on policies and procedures. Search for Pre-ETS policy and procedures. If not identified, continue on to Step 3.

Step 3

Identify website's page on polices and procedures. Search for policy and procedures manual. Review policy and procedures manual for the following topics: pre-employment transition services, transition services, school-to-work services, or youth services. If not identified, continue on to Step 4.

Step 4

Request a copy of the Pre-ETS policy by email from the state director of VR and/or the state Pre-ETS coordinator.

Figure 10. Pre-ETS Web Search Guide

2. Postsecondary Education and Training

While you are putting together a transition team, thinking about goals for the future, and building that into a transition IEP, you need to think about what options you have in terms of the future you are planning. In this section, you will get some ideas around what is possible in terms of how to exit high school and what could follow in terms of postsecondary education and training options.

Secondary Exit Options

When planning your secondary and postsecondary trajectory, you will need to understand your state's diploma options and the ramifications of receiving different types of diplomas. Students who receive non-standard diplomas can have limited access to postsecondary education and limited employment options. Additionally, if a student graduates from high school with a standard high school diploma, they are no longer entitled to receive special education services unless the state or district has a policy for continued services under such circumstances. However, most states do not have such a policy, so it is important to familiarize yourself with your specific state policies on state graduation requirements and continuation or cessation of special education services upon graduation. Examples of standard and non-standard diplomas include:

- **Standard Diploma**

  Students must complete a certain number of credits and a minimum GPA in most cases. A majority of states allow accommodations and modifications to credit and GPA requirements for a student receiving special education services. These allowances include reduction of credits, alternative courses, lessening of performance criteria, portfolio assessments, and extensions. Many states allow an IEP to provide evidence of credit-earning activities and defer to the IEP to determine eligibility for receiving a standard diploma.

- **Honors Diploma**

  For students achieving at a high academic level. This option is not offered in a majority of states.

- **IEP or Special Education Diploma**

  In some states, students that are on an IEP may earn an alternative diploma as they meet their individualized goals. This diploma can be confusing to employers and postsecondary education institutions.

- **Occupational Diploma**

  This option is for students enrolled in occupational and vocational programs, as determined by the policies and offerings in certain states and school districts.

- **Certificate of Attendance or Achievement**

  This option is for students that have not received the grades or credits necessary to receive a standard diploma. Often, states with this option use it to recognize consistent attendance but not achievement. Typically, a student with a disability receiving special education services will qualify for standard diploma accommodations or for another of the options listed above.

As will be stressed throughout this guide, you need to check with your state's specific policies regarding all aspects of the transition process, including diploma options.

Postsecondary Pathways

You can explore many pathways as you plan postsecondary options. These pathways may include, but are not limited to:

Certificate or trade school programs

- Typically, completed in 1 or 2 years or less.
- Examples: *carpentry, culinary, cosmetology, dental assistant, nursing assistant.*

Two-year technical school or community college

- These schools have various admission requirements.
- Those with open admission usually accept anyone with a high school diploma or GED.

Four-year college or university

- These schools tend to look at GPAs, academic preparation, and standardized college admission test scores.
- These schools tend to consider volunteer and community work.
- Typically, these schools require personal statement essays.
- All colleges and universities have disability services offices that offer the student help in making a disability service plan. This plan, which is given to professors, includes required accommodations, modifications, and accessibility supports.

College experiences for students with intellectual and developmental disabilities

- A growing number of 2-year and 4-year colleges offer transition programs on campus.

- At the time of this publication, there are 334 postsecondary education programs for students with intellectual and developmental disabilities.

- Think College has information and a nationwide directory for these programs; further information is also included in Appendix B: Think College Search.

- Think College also offers a spreadsheet of summer programs available for students to experience college life before attending full time.

- Each program has its own alternative admission criteria that do NOT include a regular high school diploma, SAT, ACT, or specific high school GPA. Instead, a desire to go to college, a desire to live more independently, and a desire to get a job after college are important for admission.

- To help you get started, explore the Think College Family Resources webpage. It includes a variety of parent resources in multiple formats, including written guides and tip sheets, podcasts, TED Talks, and videos, as well as ways to connect with other parents navigating inclusive postsecondary education, such as the Facebook parent group.

Other postsecondary and training options, including:

- Adult Basic Education classes

- Workforce training

- Apprenticeships

- Job Corps experience

- Military training

- Day Training and Habilitation (DT&H), which offers life skills and work-related training.

Think College, from the Institute for Community for Inclusion at the University of Massachusetts Boston, provides an excellent summary of how to plan for college and incorporate that planning into the transition plan. See Appendix C: College Planning Timeline.

What to Look for and Questions to Ask When Considering Postsecondary Education Options

If you believe that receiving a postsecondary education and training is the right fit for you and your goals, here are some things to consider:

- **School size**: Some schools have large classes with little interaction with professors, while others have small classes with many opportunities to interact with them. Which do you prefer, and how do you learn best?

- **Rural or urban location**: Do you want to live in a big city with an array of cultural and extracurricular activities, or do you plan to spend most of your time on campus studying and meeting new people? Consider the cost implications of different environments, transportation needs, campus and community accessibility, security and safety issues, and what support systems are in place.

- **Academic programs**: Ensure that the chosen program is aligned with your IEP transition plan and will help you reach your career goals. Talk with current students, professors, and staff about academics, retention and graduation rates, and job placement rates.

- **Housing**: Some schools have dorms, while others (including most vocational programs) do not. What are your living preferences, and what accessibility accommodations do you need?

- **Student support services**: Ask each school what types of academic accommodations and modifications they consider to be reasonable for students with disabilities. You will have to self-advocate and self-disclose your disability if you choose to obtain academic accommodations. Schools differ widely in their norms, culture of inclusivity, and the disability support systems they have in place.

When considering which college, university, or technical school is right for you, it is also recommended that you connect with the disability office at the school. All schools will have an office like this, although it may be called something different or be organized in a different way. Here are some questions that you can ask at the disability office:

- How current must my testing be to apply for accommodations?

- How many students use your services?

- What Assistive Technology (AT) services do you offer? Do you have an AT expert on staff?

- What accommodations do you offer? What are the procedures and timelines to receive them?

- How many disability support counselors do you have on your staff? Do they act as liaisons?

- If a professor is not in compliance regarding the student's needed accommodations, how is the situation resolved?

- What is the procedure to get extended time on exams? How much notice is required? Do students arrange extended time with processors or through the Disabilities Services Office?

- Where do students take exams? Who proctors?

- What do you consider the most difficult majors/classes for students with disabilities on this campus?

- Will I have both an advisor in the Disabilities Services Office and a regular academic advisor? If both, how will the two advisors work with each other?

- What is the graduation rate for students with disabilities similar to mine?

- Do you track students who have used your services after graduation? If so, what do your findings show about their success after graduation?

Another major consideration for higher education – for all students with and without disabilities in the United States – is cost. Plan ahead for how you and your family will pay for postsecondary education. There are a variety of potential funding sources available, including federal financial aid, scholarships, Medicaid waiver funds, vocational rehabilitation, Veteran's Affairs, private loans (be very careful about these), Social Security programs, and even local school districts that have arrangements with local colleges for students of transition age. This handout [27] summarizes various funding sources to consider with greater depth. This handout [28] also summarizes federal financial aid eligibility, types, and recommendations for students with intellectual disabilities. Organizations such as Ruby's Rainbow [29] provide college scholarships for students with Down syndrome. The PACER Center in Minnesota provides a wide range of excellent online resources for families.[30] NDSS also offers a number of scholarships for individuals with Down syndrome who are pursuing post high school programs.[31]

> **NDSS has a number of scholarships offered to individuals with Down syndrome who are pursuing post high school programs.**

The Differences Between High School and Higher Education

The range of options available can provide you with a relatively seamless transition between high school and a postsecondary education option such as college. For example, programs that are specific for students with intellectual and developmental disabilities within colleges will provide more support and services similar to what was experienced in special education in high school. The difference between high school and higher education, of course, is that you will be an adult, most likely living independently or semi-independently. Ineligibility for the services you had under the IDEA when you were in K-12 can result in many differences.[32]

Laws. There is no IEP in college. Educational rights covered by the IDEA do not apply to postsecondary education. Colleges must comply with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. The accommodations you receive in college will depend on your individual needs and will be based on your disability documentation. You will receive a disability plan from the disability services office at your college or university, but this is not a legal document.

Accommodations. Some of the accommodations you used in high school may not be provided at college. Books in alternative formats, extended time on tests, access to early registration and taking tests in a limited-distraction room are some of the common college accommodations.

Advocating. One important difference between high school and college is that you will have to seek help when you need assistance and advocate for yourself. Instructors will expect to talk with you, not with your parents, when learning about the accommodations you need in their class and when an issue arises.

Classes and grades. While in high school, your classes are relatively small, school personnel generally determine your schedule, and your grades are based on a large number of assignments. In college, you may have larger classes, meet less frequently, and have less interaction with instructors. Additionally, your grades for a course may be determined based on fewer, larger, assignments. Finally, note that families do not have automatic access to your grades and transcripts because of a law called the Family Educational Rights and Privacy Act (FERPA) that restricts access to educational records only to those whom you choose.

Structure of classes. The structure of your classes will also be different. Depending on the number of days per week that you meet, classes might last from 50 minutes to 3 hours.

Responsibilities. In general, you will have a lot more freedom in college, but you will also have many more responsibilities in this new environment. This can be big adjustment and can often prove stressful. You will need to figure out new ways of coping, managing, and regulating. All youth entering college – whether or not they have a diagnosed disability – go through this transition and adjustment period, in which they work to learn what it means to be an adult in adult society.

Relevant Laws in Postsecondary Education

Both Section 504 of the Rehabilitation Act of 1973 and Title II of ADA apply to higher education institutions, but the responsibilities of higher education institutions differ from those of K-12 school districts. Section 504 and ADA Title II protect postsecondary students from discrimination, but postsecondary schools aren't required to provide FAPE (free and appropriate public education). Instead, higher education institutions are required to provide appropriate academic adjustments to ensure there is no discrimination on the basis of disability.

The anti-discrimination focus of Section 504 and ADA Title II also applies to school housing, ensuring that higher education institutions provide comparable, convenient, and accessible housing.

These two U.S. Department of Education, Office for Civil Rights pamphlets have helpful FAQ sections for students and families:[33]

- **Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities**

  - https://www2.ed.gov/about/offices/list/ocr/transition.html

    - Details when and how to obtain an academic adjustment from your postsecondary school.

- **Transition of students with disabilities to postsecondary education: A guide for high school educators**

  - https://www2.ed.gov/about/offices/list/ocr/transitionguide.html

    - FAQs are divided into pre-admission and post-admission sections; they conclude with tips for self-advocacy and for obtaining services.

Updating Disability Testing and Academic Adjustments

Plan ahead while you are still in public school if you wish to obtain an academic adjustment from your postsecondary school or training institution. Each higher education institution has its own disability documentation requirements, so ask the Disability Service Office at your future school about what they require. Here are common types of documentation required:[34]

- A diagnosis of your current disability, along with supporting information, such as:

  - Date of diagnosis

  - How that diagnosis was reached

  - Credentials of the professional making the diagnosis

- How your disability affects a major life activity

- How your disability affects your academic performance

An IEP or 504 plan is generally not sufficient documentation.

If you need a new evaluation, contact your state vocational rehabilitation agency to see if you qualify for an evaluation at no cost to you. Complete the following steps:

1. Find your state vocational rehabilitation agency at https://rsa.ed.gov/

2. Click "About RSA" (https://rsa.ed.gov/about)
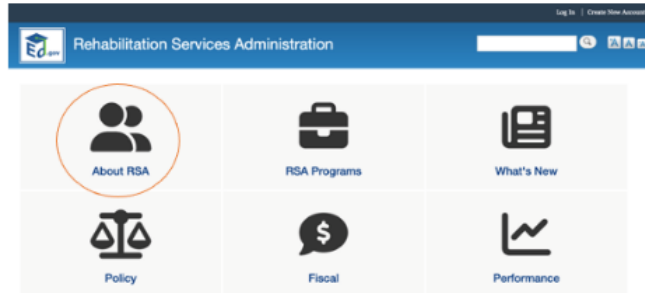
3. Then click "State Liaisons" (https://rsa.ed.gov/about/people/state-liaisons)
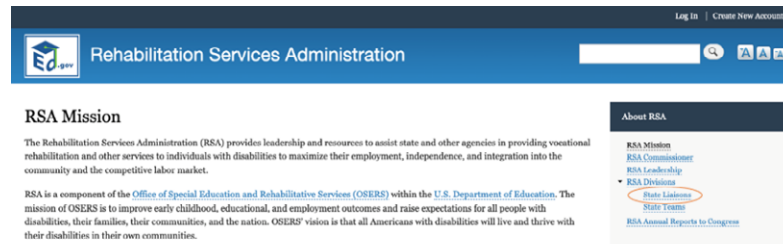
4. Scroll down to locate your state. Email your listed state liaison using the contact information provided.
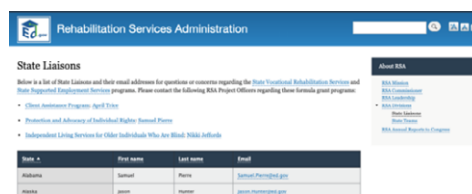
3. Employment

People with Down syndrome and other intellectual and development disabilities have the same reasons as anyone else for working. These reasons include earning money, learning new skills, meeting new people, feeling valued, contributing to society, and being independent.[35] Research on well-being and what makes a "good life" shows that young adults with Down syndrome desire autonomy, particularly in the domains of living independently and employment.[36]

Planning for Employment in the Transition Process

Employment is a very important consideration in the transition process. As you get closer and closer to the completion of high school, having a vision for employment and knowing how to get there become crucial for a smooth transition.

Employment can be part of the career goals you're working toward before graduation from high school and should be integrated during your transition-planning process to inform your career goals and prepare you for your long-term future. As you think about employment while in school, you should be given experiences that help you explore careers, learn employment skills, and engage in work-based learning. Some examples of work-based learning experiences during your high school years can include:[37]

- Job shadowing

- Service learning

- Externship

- School-based enterprise

- Mentorship

- Internship

- Entrepreneurship

- Cooperative education

- Immersion

- Clinical experience

- Youth registered apprenticeship

- Registered apprenticeship

Each state has its own career preparation curriculum, options, and requirements, but the list above can be helpful in sparking ideas for ways to integrate work-based experiences and learning into your transition-planning process.

Employment Options

You have many different employment options to consider. Some primary types of employment for your consideration include:

Competitive Inclusive Employment (CIE)

Competitive employment is just that – competitive – and it is a goal that many young adults with Down syndrome can reach if they have good work skills and previous work experience.[38] This is what you can consider to be mainstream employment, working alongside other adults that may or may not have a disability. **Employment First** means that employment in the general workforce should be the first and preferred option for people with disabilities and is part of a national plan to increase real jobs for real wages for persons with disabilities.[39] The Association of People Supporting Employment First (APSE) is a national advocacy organization focused on facilitating the full inclusion of people with disabilities in the workplace and community.

Supported Employment

Like CIE, supported employment occurs in the community in real work locations. Unlike CIE, the worker in supported employment requires long-term or ongoing support to be successful (NDSS, 2024).[40] The worker is supposed to receive whatever support they need indefinitely; however, because of expense concerns, agencies and governments often impose time limits on how much support is provided. In supported employment, the person with a disability works for someone else, in an environment usually chosen by a caregiver, teacher, or job coach.[41]

Self-Employment/Entrepreneurship

Research shows that self-employment and entrepreneurship can empower people with disabilities to impact their community through social and economic participation.[42] In addition, research demonstrates that it's possible to teach self-employment skills to young adults with Down syndrome and other disabilities. For example, Dotson and colleagues[43] used a group teaching approach to teach self-employment skills to young adults with Down syndrome, autism, and other disabilities so that they could start their own recycling company. Self-employment and entrepreneurship skills need to be developed and built into transition planning if this is the goal. These skills may also be further developed in postsecondary education and training institutions and through local agencies, programs, and community organizations.

Volunteering

Volunteering is a good way to gain job training or get around waiting lists for supported employment programs.[44] Volunteer opportunities can be set up as part of a school transition program while you are still in high school or in a transition-age program. Other community organizations and local government programs support volunteer opportunities for persons with disabilities. Check out what is available in your community!

Internships/Apprenticeships

Like volunteering, these may be paid or unpaid opportunities to learn valuable skills that can be part of a school transition program while you are still in high school or in a transition-age program. Internship and apprenticeship opportunities may also be found through a process similar to a competitive job search. The Apprenticeship Inclusion Models (AIM)[45] initiative was sponsored by the Office of Disability Employment Policy (ODEP) at the U.S. Department of Labor to ensure that apprenticeships are accessible to people with disabilities. Specifically, AIM's objectives are to address the accessibility of apprenticeship recruitment, assessment, mentoring, training, instruction efforts, and their general approach to supportive services.[46]

Customized Employment

Customized employment can be used to assist and benefit job seekers with complex disabilities who have been traditionally underserved in the competitive workforce. The individual employee's unique interests, skills, and preferred conditions of employment are identified through an assessment called "Discovery." The information gained through Discovery is organized, analyzed, and presented in an individual job seeker profile. The profile is then used to: (1) plan individual employment opportunities, and (2) map and negotiate employment possibilities (positions), job supports, and workplace conditions with interested employers.

Customized employment, therefore, is a voluntary, flexible, non-comparative, and interest-driven employment negotiation between an individual job seeker and an employer. It is a person-centered, strengths-based strategy designed to negotiate competitive jobs in ways that fit the known abilities and potential contributions of a job seeker. In summary, customized employment is a formal process designed to plan and negotiate real jobs with competitive wages and benefits – one job seeker, one employer at a time.

Customized employment fosters new ways of thinking about the employability of individuals who are highly underserved in the competitive workforce and unlikely to benefit from traditional or legacy models of job development (i.e.), where job seekers compete for established employment positions with formal job requirements and qualifications). A few commonly used strategies for planning, negotiating, and customizing jobs include but are not limited to the following:

- **Job carving** – this strategy involves the carving of tasks or restructuring of job duties from existing employment positions in order to fit the skills and abilities of a job seeker.

- **Job creation** – this strategy means suggesting new tasks, duties, or jobs that directly contribute in meaningful ways to existing work processes (or perhaps a new work process) of a company's business operations and bottom line.
- **Self-employment** – this means supporting a job seeker with unique interests, strengths, and skills to launch an entrepreneurial business plan that will result in economic opportunities through self-employment.
- **Business within a business** – this strategy includes entrepreneurial innovations such as introducing a self-contained microenterprise within an already established business. A business within a business contributes meaningfully to an existing company's business operations or enhances its customer services (e.g., introducing a coffee kiosk enterprise inside an existing store).[47]

Preparing for Employment

In order to be eligible for work in the United States, anyone over the age of 14 or 15 (depending on the state and type of work) needs to have certain documents and other materials. The Parent Educational Advocacy Training Center has prepared a good *Employment Checklist* for youth with disabilities preparing for work.[48] That guide describes the following in much more detail, along with interactive checklists, but the basics are summarized here:

Documents you need to be able to work:

- State-issued photo ID
- Employment certificate / work permit
- Employment forms from your employer, such as tax forms, emergency contact forms, and employment eligibility forms
- Social Security number or green card

Things you may need when applying for a job:

- A résumé that includes previous jobs, industry credentials, work-based learning experiences, volunteer work, and skills
- At least three references (*names and contact information of individuals that you have talked with about providing a recommendation for you*)
- A completed job application
- Your high school or college transcript *(usually needed only on your first job)*

Things you may need for a job interview:

- Your résumé, to give to the person interviewing you

- Work samples, if appropriate *(for example, if you are going to work as a*

- graphic artist or a writer)

- A transition portfolio *(in case you want to share other information with an employer, such as your Academic and Career Plan, transition assessments, etc.)*

- A list of accommodations that you may need to be successful on the job *(an employer can ask about specific accommodations only after they offer you the job)*

- The name and contact information for your vocational rehabilitation counselor if you have one

- A list of questions you want to ask the employer about the job or the company *(make sure you have researched the company)*

- Clean, appropriate clothing for an interview (*for example, no jeans, tee shirts, torn clothing, low necklines, etc.)*

- Appropriate personal appearance (*trimmed beard, combed hair, brushed teeth, deodorant, light make-up, etc.)*

Things you may need when you start working:

- A bank account: make sure you know your banking information to share with your employer so you can be paid

- A personal email account

- A cell phone

- A calendar or an electronic organizer

- A watch, if cell phones are not allowed at your job

- An alarm clock (to make sure you get to work on time)

- A driver's license if you can drive

- A transportation plan if you do not drive (bus, metro, Uber, carpool, family), including a backup plan

- Lunch (and/or a snack) and water

- Money (lunch, snacks, etc.)

- Emergency contact information

Things you can do to prepare for employment:

- Meet with your school counselor and IEP Team and talk about what you would like to pursue as a job/career

- Go through a Person-Centered Planning process to identify goals, abilities, strengths, and challenges

- Identify a career pathway you are interested in and identify the education and skills needed to pursue it

- Be sure you have a good Transition Plan in your IEP that includes your course of study, goals, objectives, services, and activities that match your career goal

- Work toward earning an industry certification or credential

- Participate in high-quality work-based learning opportunities, including job shadowing, mentorships, externships, service learning, internships, and apprenticeships

- Participate in Pre-Employment Transition Services (Pre-ETS) through the Department of Aging and Rehabilitative Services (DARS)

- Participate in volunteer work, part-time jobs, and on-the-job training

- Participate in mock interviews and job fairs

- Explore specialized opportunities at Wilson Workforce Rehabilitation Center (WWRC) or in community-based programs

- Know your rights under the Americans with Disabilities Act (ADA)

This resource – [Resource Toolkit for Job Seekers with Disabilities](#)[49] – provides a library of support resources that may be useful. Topics include:

- Résumé writing

- Requesting and negotiating reasonable accommodations

- Where to search and apply for jobs online

- Interviewing techniques for people with disabilities

- Tips for selling your soft skills during an interview

- Time management tips to make your new job a success

- Tips to reduce distractions and increase focus at work

Who Can Help Prepare You for Employment

Job Coach or Employment Specialist

A Job Coach or Employment Specialist accompanies the person to work for several hours, weeks, or months, or until they're independently successful in the workplace. These types of support persons should practice:

Fading, by which they slowly fade from the jobsite, staying involved just long enough to ensure the worker is successful. They provide support that decreases and is finally eliminated. A **Follow-Up Specialist** may check in with the supervisor and employee to ensure workplace expectations continue to be met. The Follow-Up Specialist identifies any problems early on and addresses them. Any workplace will have **National Supports**, such as other coworkers that can provide guidance, a supervisor, work manuals and instructions, and representatives in human resources.

State Vocational Rehabilitation Agencies

In addition to providing support with updated testing and Pre-ETS, your state Vocational and Rehabilitation Agency (VR) administers Supported Employment services. To learn how to get in touch with your state VR, see the previous section on Pre-Employment Transition Services.

Private-Pay Providers

In addition to government service providers, private providers work to promote inclusion into mainstream employment, offering such services as recruiting, training, and education. For example, national companies such as Hire Disability Solutions can provide supported employment, and many local agencies and private companies in your state can do the same. For example, a Minnesota company called Kaposia specifically provides customized employment support.

Work Readiness Skills

Preparing for employment involves skill building that should start, first and foremost, in the IEP and transition IEP planning process. Once your goals and vision for employment are documented, you should map out the skills needed to realize this vision. In the [Building a Transition IEP](#) section above, this was given some consideration. In general, you can start to think of work readiness skills as an extension of the kinds of skills you are already building in your IEP. These can include:[50]

Communication Skills

- Read with Understanding
- Convey Ideas in Writing
- Speak So Others Can Understand
- Listen Actively
- Observe Critically

Interpersonal Skills

- Guide Others
- Resolve Conflicts and Negotiate
- Advocate and Influence
- Cooperate with Others

Decision-Making Skills

- Use Math to Solve Problems and Communicate
- Solve Problems and Make Decisions
- Plan

Lifelong Learning Skills

- Take Responsibility for Learning
- Reflect and Evaluate
- Learn Through Research
- Use Information and Communications Technology

You can also use the checklist below to begin to understand what is needed to prepare for employment in terms of specific skills. This checklist can be useful in highlighting emergent employment skills that should be written more explicitly in a transition IEP.[51]

Planning My Future

Y	N	
		I direct my IEP meetings or am actively involved in all IEP decisions.
		I know what my short-term employment goal is.
		I know what my long-term career goal is.
		I have a plan for achieving my long-term career goal.

My Job Search Skills

Y	N	
		I have researched employers I would like to work for.
		I have a completed a job application or an information sheet.
		I have a résumé.
		I can answer the most common interview questions.
		I know what questions to ask during an interview.
		I make good eye contact when interviewing.
		I know what I will wear to an interview.
		I have arranged transportation to and from interviews.
		I know how to follow up after an interview.
		I have scheduled job interviews with the companies I have identified.

My Disability

Y	N	
		I know what my disability is and can describe how it affects my work.
		If my disability is hidden, I have decided whether to disclose it or not.
		If I have decided not to disclose my disability, I know how to manage it on the job.
		If I have decided to disclose my disability or if my disability is evident, I know what accommodations and/or supports I need and can describe them to an employer.
		I have a routine for taking my medications if they are needed for my disability.

My Job-Keeping Skills

Y	N	
		I have appropriate skills and knowledge for the jobs I am applying for.
		I know how to fill out employment forms.
		I have arranged transportation to and from my job.
		I perform at or above expectations for work maturity skills.

My References

Y	N	
		I have letters of reference from teachers, former employers, or others.
		I have a copy of my school records.
		I know how to request a copy of my school records.

The Employability Skills Tracker – which is actually from the Canadian Down Syndrome Society, but has universal application – is a good resource to for collecting baseline data. Use it to plan, as a reference tool to teach a new skill, and to record individual progress.

In the tracker, skills are broken down into the following categories:

- Communication and interpersonal skills

- Problem-solving skills

- Teamwork skills

- Personal management skills

- Organization skills

You can then rate each skill as:

- Independent (3 boxes filled)

- Needs some improvement (2 boxes filled)

- Needs full support (1 box filled)

An example from the tracker looks like this:[52]

Figure 11. Example from the Employability Skills Tracker

Career Exploration Ideas

Exploring career options and possible jobs can and should be built into the transition IEP. You can explore career interests and work values through:[53]

- Informational interviews

- Job shadowing

- Internships

- Apprenticeships

- Asking a school guidance counselor for tools to help your child explore their interests

  - Online career exploration websites, such as: O*Net OnLine database of occupational information, which provides comprehensive details on key job attributes and worker characteristics.

  - O*Net OnLine database of occupational information, which provides comprehensive details on key job attributes and worker characteristics.

Ideas on career exploration were presented in previous sections on person-centered planning and building a transition IEP.

Job Ideas for Individuals with Down Syndrome

People with Down syndrome should not be limited in the kinds of employment and jobs that they want to pursue, nor should they be expected to be in the same job for their entire lives (just as with everyone else). That being said, some possible job pathways that have proved successful for people with Down syndrome in the past are:[54]

- Public speaker
- Charity organizer
- Food service assistant
- Barista
- Retail worker
- Hotel worker

- Housekeeper/cleaner
- Teaching assistant
- Jobs in the arts/media/TV
- Sports role, including participant and/or coach
- Model

- Advocate
- Customer service assistant
- Intern
- Apprentice
- Hairdresser
- Entrepreneur

How Families Can Support Work Readiness Skills and Career Exploration

Preparing youth with disabilities for employment, and developing work readiness skills, begins, first and foremost, at home with everyday tasks and expectations. Examples of these natural skill-building home activities include:[55]

- Chores (e.g., mow the lawn, shovel snow, wash dishes, vacuum, dust)

- Independently take public transportation or taxis

- Manage a weekly allowance to develop money skills

- Open a savings account and discuss responsible spending

- Babysit younger siblings or relatives

- Help grandparents around the house

- Take care of a flower bed or garden

- Help prepare meals

- Reply to an email on their own

- Write their own note or message

- Answer the phone

Families can also help with career planning by identifying strengths, having high expectations, catching early signs of job problems, practicing job skills such as interviewing, and using personal networks to help find volunteer, internship, and employment opportunities.

Employer Supports for Inclusive Employment

This section was developed by Fora Education in a guide called *Supporting Inclusive Employment for Persons with Disabilities.*[56] The intended audience for this report was employers who wanted to become more inclusive. We are including this here because, as you move into employment and think about how to prepare for work and being in the workplace, you should understand how employers should be including you and providing you with accommodations and accessibility.

We recommend the following steps for ensuring accessibility and successful accommodation in the workplace:

1. Plan for inclusion

- Make sure that there is awareness of disability rights
- Engage and activate "disability champions" (CICs, job coaches, and other colleagues)
- Develop an inclusion and diversity vision and culture
- Assess existing resources and identify areas of need
- Make sure that persons with disabilities are key stakeholders in any initiative or plan
- Develop person-centered plans

2. Provide reasonable accommodation

- Employ communication strategies that are accessible. Don't assume that "one size fits all"
- Provide a variety of ways to engage with learning materials / work materials and tasks
- Critically examine policies and procedures – is there a specific reason why something is the way it is? Or has it just "always been that way"?
- Provide flexibility in assignments, due dates, tests, projects, and other tasks. Ask yourselves whether it is more important for this task to be completed on time or to be done inclusively and with quality?
- Work with persons with disabilities to discover what they need and what works best for them. Chances are, doing this will also benefit others

3. Evaluate how things went and return to step one

There are various categories of workplace accommodations. The most common include:

- purchasing or modifying equipment or products
- making the worksite accessible
- job restructuring
- modifying schedule and allowing leave time

- modifying methods (e.g., tests, communication, training)

- modifying policies

- providing readers and interpreters

- reassignment

Some general ideas for accessibility strategies and accommodation activities include:[57]

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Providing Accessibility and Accommodation for Application and Interview Stage

- Ensure that a statement is presented, front and center, about equal employment opportunity along with information about how to request an accommodation on hiring materials and career portal.

- Modify the applicant tracking system/career portal to ensure accessibility (ability to magnify print, screen-reader friendliness, closed-captioning of videos, etc.). You can use a free accessibility checker, such as https://www.accessibilitychecker.org.

- Modify (caption and audio-describe) recruiting videos or multimedia to ensure accessibility (similar to above).

- Inform candidates about the entire hiring process so they can decide if an accommodation is needed.

- Ensure physical accessibility to the interview site.

- Plan for how to provide readers or interpreters for interviewing/onboarding before a request is made for these services.

- Ensure accessibility of pre-hire tests and informing candidates of the process for pre-hire tests in advance.

- Provide pre-hire and onboarding materials in alternative formats (Braille, audio, large print) as needed.

- Ensure accessibility (captioning and audio-describing) of training videos or multimedia.

- Ensure accessibility of online HR systems.

- Plan for allowing a service animal to accompany a candidate at an interview.

</div>

Providing Accessibility and Accommodation for Current Employees

- **Modify schedules or allow flex time and/or remote work**; for example, allow an employee with MS to telework during flare-ups.

- **Make the workplace or workstation accessible**; for example, provide a reserved parking space for an employee with chronic fatigue, or provide a variety of different kinds of desks and chairs.

- **Provide assistive technology**; for example, provide a screen reader for an employee who has progressive vision loss. Assistive technology does not need to be expensive. There are free screen readers available; for example, see the ones listed here: https://www.nvaccess.org/download/. Most modern technological tools, such as computers, laptops, and smart phones, come with a lot of built-in accessibility tools and settings.

- **Purchase a service**; for example, an interpreter, closed captioning, and/or computer-aided transcriptions for an employee with hearing loss. These kinds of services are getting much cheaper and are sometimes even free because of increasing use of AI-assisted software. See this article for some ideas and resources: https://www.notta.ai/en/blog/best-speech-to-text-app-for-hearing-impaired.

- **Restructure a job**; for example, removing marginal functions for an employee on the autism spectrum to minimize face-to-face communications.

- **Adjust the work location**; for example, moving an employee with attention deficit to a location with fewer distractions.

- **Adjust supervisory methods**; for example, putting instructions in writing for an employee with memory loss.

- **Provide accommodations for emergency evacuation**; for example, ensuring effective communication for employees with hearing loss, or safe means of egress for employees with mobility impairments.

- **Reassign to a different set of tasks or role**; for example, an autistic person may need to be on a project that does not require as much social interaction. That does not mean that this person cannot contribute meaningfully to other aspects of the project or other projects within the company.

Accessibility and accommodation should be made keeping the individual person with a disability in mind. It should not be assumed that the same accommodation will work for two different individuals.

4. Independent Living

Independent living is one of the biggest changes that a youth with a disability undertakes as they transition from being a teenager to being an adult. "Independent living" can mean a lot of different things and will look different depending on the abilities and capacities of the youth, cultural expectations and norms, economic contexts, and availability of housing and other resources.

Essential Life Skills

Planning for independent living begins with thinking through essential life skills in the IEP and transition IEP process. In one research study,[58] the life skills of greatest importance to adolescents and adults with Down syndrome included: learning about healthy foods (35%), preparing meals (34%), providing personal information when needed (35%), and describing symptoms to a doctor (35%). In the Building a Transition IEP section, there were guidance and examples for thinking through independent life skills and community engagement. Relevant skill and need areas for independent living can include:[59]

- Daily living skills (e.g., cooking, cleaning, shopping, hygiene)
- Transportation
- Self-advocacy
- Financial support
- Financial activities (e.g., banking, paying bills)
- Medical and support services

Social skills and inter-relational skills are important things that parents can help build at home in addition to what the student learns at school and what is in their IEP. For example, parents can:

- Use social skills stories to build skills for understanding situations.
- Define boundaries with a 5-point scale (from "mild" to "extreme" or "acceptable" to "unacceptable").
- Teach social boundaries with a circle chart.
- Practice role playing.
- Create opportunities to practice skills.

- Explore a social skills training program.

- Help your young adult try social skills groups.

These concepts are explained in much more depth and with examples in the PACER Center Guide *Skills for Independent Living: Parents Help Build Social Skills*.[60]

Another good resource is Beyond Down Syndrome's Independence Checkup Assessment.[61] This is a Google form survey designed for families of youth with Down syndrome to assess their loved one's progress toward independent living. After the form is submitted, you will receive your score and more information to advance your journey toward independence.

Appropriate Levels of Independence

Up to age 18, your family makes virtually all important decisions. Once you turn 18, you are legally considered an adult, and legal procedures may need to be taken to protect you if you are unable to make reasonable decisions on your own. Adults need to sign a consent to release information if a court-appointed guardian is not in place. The question in this case is: Will the individual be able to make sound medical, financial, or legal decisions independently? If not, families need to be aware so they can obtain guardianship before the youth turns 18. Other legal considerations include conservatorship, power of attorney, and advance directives.[62]

Guardianship laws allow other people to make life choices for a person with a disability**. Supported decision-making laws** allow people with disabilities to make their own choices with support. It is important to note that each state has different laws about guardianship. Some states have enacted supported decision-making laws.

You can find more information on this at the National Resource Center for Supported Decision-Making website:[63]

- Click on your state on the map to find information about your state's laws and programs related to guardianship and supported decision-making.

- Information for each state includes:

- Links to guardianship laws

- Links to supported decision-making statutes

- History of supported decision-making state legislation that has been enacted, is pending, or was previously introduced

- Links to case law and court orders

- State grant programs (if awarded)

- Links to additional resources, such as tips on making guardianship decisions and fact sheets on alternatives to guardianship

Health/Medical Care

Receiving health care as an adult is another challenging area to navigate, but resources and supports are available. The PACER Center provides a comprehensive checklist on health skills called Transition Health Plan for Youth with Disabilities and their Families.[64] The skills checklist is meant to help families plan for youth to assume greater responsibility for their adult health care.

On the checklist are 6 topic areas:

1. Basic health skills

2. Self-advocacy

3. Managing medical appointments

4. Adult health care after age 18

5. Independent living

6. Health care financing

For all items from each of the above areas, the user chooses from two action-step options: "practice at home" and "discuss with IEP team or medical provider." For example, under the Health Care Financing area, there are the following prompts:

Health Care Financing	Health Skills Assessment			Action Steps	
	Independent	Some support needed	Support needed	Practice at home	Discuss with IEP team or medical provider
Locate and provide key information on insurance card for co-pay and identification number					
Understand your insurance guidelines (services allowed, referrals, etc.)					
Apply for appropriate government health care benefits					
Develop plan for insurance coverage after age 18, or after age 26 if you have health coverage under your parents until age 26					

As an adult with a disability, you are entitled to the following medical/health benefits from the federal government:[65]

Medicare

Medicare offers free or low-cost medical benefits to people with disabilities, through three provisions cover different services:

Medicare Part A: Hospital Insurance

Medicare Part A helps cover inpatient care in hospitals, including critical access hospitals in rural areas, and skilled nursing facilities for temporary treatments. It does not cover custodial care, which helps you with activities of daily living or long-term care. It also helps cover hospice care and some home health care. You need to meet certain conditions to get these benefits. Most people don't pay a premium for Part A because they or a spouse already paid for it through their payroll taxes while working.

Medicare Part B: Medical Insurance

Medicare Part B helps cover doctors' services and outpatient care. It also covers other medical services that Part A doesn't cover, like some of the services from physical and occupational therapists, and some home health care. Part B helps pay for these covered services and supplies when they are medically necessary elements, such as ambulance services and medical equipment. Most people pay a monthly premium for Part B.

Medicare Part D: Prescription Drug Coverage

Medicare Part D is available to everyone with Medicare, not just those who are disabled. To get Medicare prescription drug coverage, you'll need to join a plan approved by Medicare that offers Medicare drug coverage. Most people pay a monthly premium for Part D coverage.

Medicaid

Medicaid is different from Medicare because it offers health insurance only to people under 65 with certain disabilities and at any age in the case of end-stage renal disease. Medicaid eligibility criteria differs from state to state. Many states have expanded their Medicaid programs to cover more low-income adults. If you are not sure if you qualify for Medicaid, you should apply. You might be eligible, depending on your household income, family size, age, disability, and other factors. You can learn more about Medicaid in your state through Medicaid.gov.

Get more information about applying for Medicare and Medicaid at CMS.gov.

Disability Insurance

SSA offers Social Security Disability Insurance (SSDI) to provide financial help to people who become disabled after earning enough Social Security work credits within a certain time. To be eligible, you must have a qualifying disability and have earned enough Social Security work credits throughout your employment history. You can apply online as soon as you become disabled.

SSA offers another program called the Ticket to Work Program, which is a free, voluntary program. It helps people who receive Social Security disability benefits reenter the workforce and become financially independent, all while keeping their benefits. Ticket to Work connects you with free employment services to help you decide if working is right for you, prepare for work, find a job, or maintain success while you are working. You can learn more on the Ticket to Work site, where you will find resources that you might find helpful.

You should also check your options with private insurers and insurance coverage options at Healthcare.gov. Your state will most likely have some state-level health and medical insurance programs as well.

Housing

Options for living as an adult with a disability can include:

- Living at home with family

- Living in an apartment

- Living in their own home

- Living alone with support services

- Group homes

- Subsidized housing (via Section Eight subsidized housing program of the U.S. Department of Housing and Urban Development [HUD])

These are some questions to consider when thinking about living and housing options:[66]

- Where will the young adult live?

  - What are the youth's goals and attitudes toward future housing?

  - Is the family proactively developing a plan for future housing needs?

  - Does the family have a case manager, or do they need to call state or county disability services to arrange for a case worker to assist them?

  - Will the family choose to keep their adult home for a period of time or until they are no longer able to care for the young adult?

  - Are group homes or more individualized settings (e.g., adapted apartments) available in the community?

  - How does housing need to be customized to fit the individual's needs for the least-restrictive environment, including physical accommodations, accessibility features, or other modifications?

- Are in-home care staff needed? The types of staff available to families include:

  - Personal care attendants (PCS), nursing staff, and service support professionals (SSP).

The PACER Center runs a Housing Learning Center Portal containing many resources to support parents on their journey throughout the individualized housing and services process, including:[67]

- Registration for virtual housing workshop series (2024)

- Housing videos and trainings

  - Housing workshop series video library of recordings of past workshops from 2023, 2022, and 2021.

- Five-part video series called "Home Is…" features young adults with disabilities describing what home means to them and what they've learned along the way.

- Video series of parents' journey, creating an individualized housing option for their 29-year-old twin daughters, Jennifer and Amy.

- Parent handouts on navigating housing and service options, including:

    - [Navigating the Maze of Housing and Services: Advocacy Tips handout](#)

    - [Navigating the Maze of Housing and Services: Terminology You Need to Know handout](#)

    - [Tips When Considering Housing and Services handout](#)

Transportation

Transportation is one of the biggest barriers to life outcomes such as competitive employment. The challenges of transportation very much depend on the location and context of your address. If you live in a big city, then there will be more transportation options. If you live in a rural or semi-rural area, then public transportation will certainly be a challenge to overcome.

Here are some questions for families to consider regarding transportation:[68]

- What form(s) of transportation will the youth be able to access?

    - Will they be able to drive?

    - Can they learn to use public transportation?

    - Are they eligible for adapted mobility services?

Lyft has partnered with NDSS to connect people with disabilities to affordable, convenient transportation through ABLE accounts. ABLE accounts are tax-advantaged savings accounts for people with disabilities and their families. To learn how to link your ABLE account to Lyft, [follow the directions in this article](#).[69] You should also check with your local transportation provider for disability-accessible options and services.

Transportation skills should definitely be built into the transition IEP while you are still in school. These skills include learning how to take the bus or train (buying a ticket, getting a pass, learning how to read the route map, etc.), crossing the street safely, taking a taxi or using a ridesharing app, perhaps riding a bicycle, and other skills that will be relevant to your situation, preferences, and goals.

Recreation

In a systemic review of the effect of exercise interventions on daily life activities and social participation by individuals with Down syndrome, research shows that exercise, such as bike riding, dancing, judo training, and strength training, has a positive impact both on daily life activities and on the social participation of individuals with Down syndrome across the lifespan.[70]

The Special Olympics Family Resource Webpage is a good source for information on encouraging healthy living, fitness, and recreation.[71] Within this resource guide are links to:

- Family community building and engagement resources, such as:
  - Community Builders Toolkit for Family Leaders, Section 5: Promoting Healthy Lifestyles
  - Handbook for Training at Home. Includes guidelines and tools for family home training, such as:
    - My Athletics Practice and Competition Schedule worksheet
    - Goals for the Season worksheet
    - Fitness/Nutrition Wheel worksheet
    - Training log
    - [Note: Even if a family decides not to participate in the Special Olympics, this handbook has some great worksheets that could be used to promote health and fitness at home]
  - Find your local Special Olympics program; click on state to find local website and contact information.
  - Healthy Start online toolkit, with videos and written information on promoting the health and wellness of children, youth, and parents/caregivers.

Many local gyms have discounts and specific programs for adults with disabilities. You might also want to check with your local Parks and Recreation department for recreation and leisure activities.

Other Services and Supports

Here are some other questions for families to consider during transition:[72]

- Until age 18, family members and others have located information and services for their young child with special needs. How will that change?

  - Who will be responsible for arranging the youth's care?
  - What responsibilities will the youth have? What will need to be done by someone else?
  - Who will identify community resources such as:

- Family-to-Family Health Information Centers

- Parent Training and Information Centers

- Independent Living Centers

One option for support could be utilizing a **Center for Independent Living (CIL).** These are defined in Section 702 of the Rehabilitation Act of 1973 as consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provide an array of independent living services. You can find your local CIL by going to the ILRU CIL Directory.[73] Find a Center for Independent Living (CIL) in your local community by clicking on the map. At a minimum, 51% of staff are persons with disabilities and 51% of the Board of Directors are persons with significant disabilities. A CIL provides, at a minimum, the following core services:

- Information and referral

- Independent living skills training

- Individual and systems advocacy

- Peer counseling

- Transition assistance from nursing homes and other institutions to community-based residences.

- Assisting individuals to avoid institutional placement.

- Transition of youth with significant disabilities after completion of secondary education to postsecondary life.

5. Legal and Financial Planning

Parents often worry about setting up a stable future for their adult child with a disability as they age. This is a completely legitimate concern. With the right legal and financial documents and protections in place, these concerns can be assuaged somewhat.

Guardianship

When a child reaches age 18, their parent (or caretakers) may, if appropriate, apply for legal guardianship to make decisions on behalf of their adult child. The following Q&A comes from the Special Needs Financial Planning [website](link) (which also contains much other useful information):[74]

What Is Guardianship?

Guardianship is a legal process that gives the guardian permission to take care of and make decisions for an incapacitated adult. An incapacitated person is someone with a clinically diagnosed condition that keeps them from being able to make or communicate decisions about their physical health, safety, or care. An incapacitated adult may also be called a protected person or, in legal terms, a ward.

A guardian is approved and appointed by the court and has the legal authority and responsibility to care for the person and their property. The guardian will also be supervised by the court and required to provide an annual report on the status of the protected person.

What Are the Types of Guardianship?

Types of guardianship may vary from state to state. It is important that you consult with your special-needs planning attorney and/or financial advisor and that you search your state's guardianship association or advocacy organization for information specific to your locale. Some of the most commonly used forms of guardianship are listed below:

- A **guardian of the person** is responsible for monitoring the care of the person with disabilities, also called the protected person. The guardian need not use their own money for the protected person's expenses, provide daily supervision of the protected person, or even live with them. The guardian must attempt to ensure, however, that the protected person is receiving proper care, housing, and supervision. The guardian is also responsible for decisions regarding most medical care, education, vocational planning, and end-of-life decisions.

- A **guardian of the estate or conservatorship** should be considered for persons with disabilities who are unable to manage their finances and have income from sources other than benefits checks, or who have other assets and/or property. The conservator is responsible for handling the protected person's financial resources but is not financially responsible for the protected person by drawing on their own resources. In most jurisdictions, the conservator must file with the court an annual accounting of the protected person's funds.

- A **limited guardianship** may apply only to certain areas of decision making, such as decisions about medical treatment, in order to allow the protected person to continue making their own decisions in all other areas. The benefit of a limited guardianship is that the guardian's responsibilities can be tailored to fit the protected person's special needs in the least restrictive manner. Further, under a limited guardianship, the protected person has not been declared incompetent.

- A **temporary guardian** or conservator may be appointed by the court in an emergency situation when certain decisions must be made immediately. In many states, a permanent guardianship or conservatorship must be requested along with the temporary appointment. The duration of a temporary appointment is dictated by state law; generally, it is up to 90 days. There may also be an option to name one person as a temporary guardian and then have another person(s) serve as the permanent guardian.

- A **successor guardian should** be named in your (the original guardian's) legal documents, such as your will, to make it easier for the next person to step into their role as your successor guardian. You may want to consider a co-guardianship during your lifetime with the person you would like to be your successor guardian.

How long do the responsibilities of a guardian last?

Guardianship ends when the protected person dies. Guardianship also ends when a guardian dies, is unable to perform their duties, or petitions the court that they no longer want guardianship of the individual. The court will appoint a new guardian – many times, the successor guardian is identified by the parents.

What are the financial responsibilities of a guardian?

In general, the guardian or conservator is responsible for handling the individual's financial resources but is not personally financially responsible for the protected person by drawing on their own resources.

A protected person may have a special needs trust established for them, and there will be a trustee appointed to oversee the management of the assets in the trust. The guardian will request funds from the trustee to maintain the protected person's household, and pay for trips, vacations, clothing, etc., for the protected person's benefit. It is important that the guardian and trustee have a respectful and trusting relationship, as the trustee may resist making some requested distributions if the guardian and trustee have a conflict.

Benefits

Perhaps the biggest area of confusion and challenge for parents of adult children with disabilities is considering the difference between **Supplemental Security Income (SSI)** and **Social Security Disability Insurance (SSDI)**.

SSI

SSI is a needs-based program, meaning it is designed for individuals with limited income and resources. Eligibility is not based on work history, but rather on overall financial need. With SSI, "resources" refers to possessions of considerable value, so it's important to be aware of [SSI eligibility asset limits](#) as well. To qualify, applicants must have less than $2,000 in resources (or $3,000 for couples) and a very limited income. Additionally, they must be either age 65 or older, blind, or have another type of disability.

The federal benefit rate for SSI varies yearly and is determined by the government. [Some states also provide a supplementary payment](#). The amount an individual receives can be affected by other income and living arrangements.

SSI recipients may also be eligible for Medicaid and Supplemental Nutrition Assistance Program (SNAP) benefits.

SSDI

SSDI, on the other hand, is an insurance program. Eligibility is based on an individual's work history and the amount of Social Security taxes they've paid. Typically, to qualify, you need to have earned a certain number of work credits, which are based on your yearly wages or self-employment income.[75]

SSDI benefits are based on your earnings record, meaning the amount you receive is related to your past income. The average SSDI benefit amount was around $1,277 per month as of January 2021.

SSDI recipients are eligible for Medicare after a 24-month qualifying period. They may also be eligible for dependent benefits, meaning certain family members could receive benefits based on the recipient's work record.

Both programs require a medically diagnosed disability, lasting for at least 12 months. In some cases, an adult with a disability may be eligible for both SSI and SSDI, resulting in what is called "concurrent benefits." To be eligible for concurrent benefits, a person must meet the medical disability criteria for both programs. Additionally, their income after receiving SSDI benefits must be low enough to meet the income requirements for SSI. This typically happens when the individual has a limited work history, which results in lower SSDI payments.

Individuals qualifying for both programs can receive SSI to supplement their SSDI benefits, potentially gaining them access to both Medicaid and Medicare. This can help you maximize both your healthcare coverage and the financial support you receive.[76]

The official guide to work incentives and employment supports for adults with disabilities is the Social Security Association (2023) Red Book.[77] It can be used as a reference guide for educators, advocates, rehabilitation professionals, and counselors who assist people with disabilities, as well as a self-help guide for applicants and beneficiaries. The Red Book is available in pdf (see link or reference above) and HTML format, as well as in Spanish and other alternative formats. As noted above, the most recent Red Book was published in 2023. Yearly versions are not printed, but it is important to be aware that yearly updates to the dollar thresholds for several work incentives are made effective January 1 of every year. Yearly updates can be found online in the What's New tab: https://www.ssa.gov/redbook/eng/whatsnew.htm[78]

Financial Planning

The NDSS Financial Wellness Guide,[79] updated in 2023 provides a comprehensive overview of the issues and elements of financial planning as an adult with a disability. Besides an explanation of social security benefits, the guide also contains information on the following:

- Medical benefits

  - Medicare

  - Medicaid

- Residential and housing benefits

  - Medicaid

  - Section 8 housing

  - Group homes / assisted living

  - Skilled nursing facilities

- A workplace benefits overview on pages 20-25, which defines:

  - 401(k)s, 403(b)s, 457s and the employer match

  - Life insurance

  - Long-term disability insurance

  - Employee assistance programs

  - Health care spending accounts: HSAs and FSAs

Some families look to hire a financial planner that may have some experience in working through the benefits and financial planning needed to care for an adult with a disability. This can be a big asset and relief for parents that have the means to hire a financial planner. However, some financial planners may make false assumptions about the income status and earning potential of people with disabilities, particularly non-White women with disabilities.[80]

Tips on how to prepare financially for your child with Down syndrome include:[81]

- Build a team.

- Apply for financial benefits.

- Establish legal guardianship.

- Create a letter of intent.

- Get a special-needs trust.

As outlined in the NDSS [Financial Wellness Guide](), there are six pillars to financial wellness:[82]

- Protect yourself and your family.

- Spend and save with savvy.

- Honor your emergency fund.

- Save for retirement.

- Manage your debt.

- Think big.
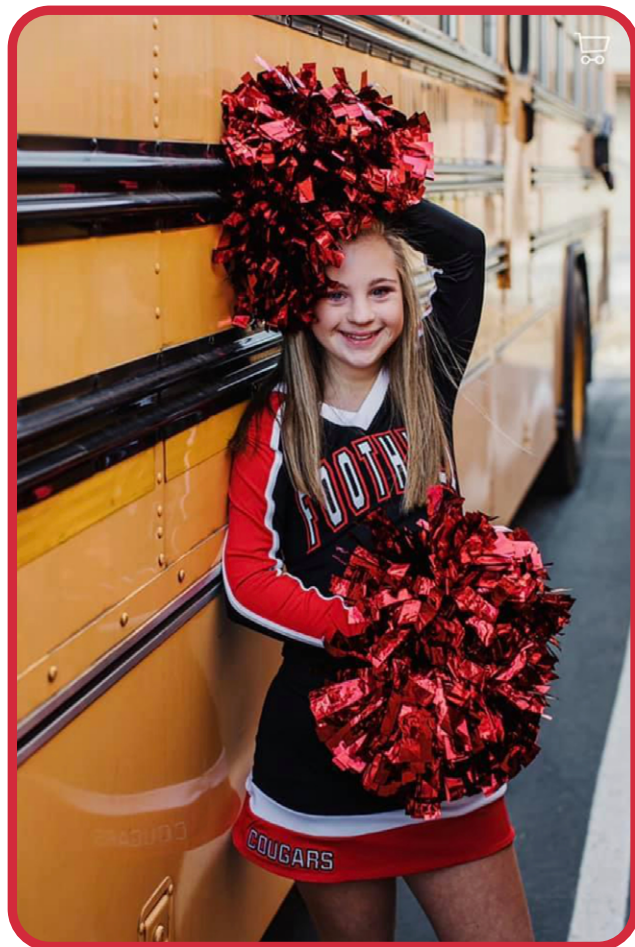
Financial Planning Checklist

The following is a Financial Planning Checklist that you and your family will find useful in preparing your transition to adulthood.[83]

Have you:

☐ Created a broad, far-reaching Life Care Plan that covers long-term care for your family member?

☐ Written a "Letter of Intent" or "Letter of Instruction" concerning your family member's needs both now and in the future?

☐ Had a family meeting to make sure everyone knows about – and where to find – the Life Care Plan and Letter of Intent?

☐ Identified all the ways you can create the future you and your family member envision, such as government benefits, employer benefits, insurance, and personal assets?

☐ Reviewed all medical-health-plan options and coverages, including what it takes to qualify for Medicaid and Medicare and the Children's Health Insurance Program as well as the details of your plan at work?

☐ Looked at available resources for managing care, including online resources?

☐ Researched all the benefits available to you at work, especially insurance policies (both basic and supplemental coverages) and how they can help you manage your tasks and supplement your special-needs plan?

☐ Chosen a guardian, trustee, and successors to oversee the care and resources of your family member should you be unable to?

☐ Used a wide variety of legal tools (i.e. wills, trusts, durable powers of attorney and living wills/advanced directives), to devise your estate plan?

☐ Studied all beneficiary designations, titling, or ownership to make sure any inheritances will not impede your family member's government benefits?

☐ Talked with an attorney who specializes in first-party, third-party and pooled special-needs trusts to determine which is the proper fit for you and the family member?

☐ Considered starting an ABLE account to save for and manage disability-related spending?

☐ Carefully thought through the following considerations before your family member turns 18?

  – Will the family member with a disability need help taking care of themselves and/or their finances?

  – Do they have any particular social and/or recreational interests?

  – Do they plan to work?

  – Will they need any specific transportation and/or housing accommodations or anything else that improves quality of life?

The NDSS [Financial Wellness Guide](#) contains planning tools based on the checklist above that are specific to different age levels, from Up to Age 3, Aged 3–22, and Aged 22+.

Personal Budgeting

The NDSS Financial Wellness Guide, updated in 2023, also provides sections on following a realistic monthly budget as one of the 6 pillars of financial wellness:

- **Steps to create a budget:[84]**

  1. First, add together your take-home income, any earnings from savings and brokerage accounts and any supplemental income you might receive. Then, subtract estimated taxes you might owe the next year (if taxes haven't already been withheld).

  2. Next, add up what you spend in a given month on essential fixed expenses, such as your mortgage or rent; utilities and loan repayments; your additions to savings that haven't already been deducted from your pay; and discretionary expenses, such as eating at restaurants.

  3. Subtract your expenses from your income. If you have more income than expenses from that surplus, you can establish an emergency fund (or further build an existing one) and set aside savings specifically to meet your important lifelong goals. Those savings can be deposited in an interest-bearing bank account or bank savings product such as a Certificate of Deposit (CD). You can also consider investing in stocks, bonds, mutual funds, and exchange traded funds (ETFs). However, keep in mind that these investments are subject to various investment risks, and it is possible to lose money.

Taxes

Depending on your legal guardianship status and/or residential status, you might need to file your taxes. A National Disability Institute webpage resource, [What to Know About Filing Your Taxes,](#) walks people with disabilities through steps to prepare for tax season and offers advice and free resources. Sections in the resource include:[85]

- Why file?

- How to prepare?

- Where to file?

- When to file?

- Tips & tax credits

If you are an adult with disabilities filing taxes for yourself, here are two important considerations:[86]

- **Impairment-Related Work Expenses deduction** – These are business expenses that are necessary for you to be able to work. These expenses are deductible only if you have a physical or intellectual disability that is a functional limitation to employment or that substantially limits one or more major life activities, such as walking, speaking, and performing manual tasks.

- **Elderly and disabled tax credit** – This is available to every U.S. citizen who has reached age 65 during the tax year, or those under 65 who are retired and on permanent and total disability and who received taxable disability income in 2023. You may be eligible for this credit in the amount of $5,000 to $7,500, depending on your circumstances.

You should also consider:[87]

- **ABLE Accounts.** The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create tax-advantaged savings programs for eligible people with disabilities (also known as designated beneficiaries). Contributions to ABLE accounts can help designated beneficiaries save for qualified disability expenses. Distributions are tax-free if used for qualified disability expenses.

- **Special needs trusts (SNTs) and Health Savings Accounts (HSAs).** These are important financial and tax-planning tools that can significantly contribute to a person's quality of life. Be sure to understand the opportunities that each of these tools provides.

Publication 907: Tax Highlights for Persons with Disabilities, from the IRS, also provides information for people with disabilities and their families, with tips on the following topics:

- Income
- Itemized deductions
- Tax credits
- Household employers
- Business tax incentives
- ABLE accounts

IRS Publication 907 includes a section, at the end of the document, with resources for people with disabilities and their families to help prepare their taxes. These include the Taxpayer Advocate Service (TAS), Volunteer Income Tax Assistance (VITA), and Low-Income Taxpayer Clinics (LITCs). Additional IRS information on special tax assistance for individuals with disabilities can be found here.[88]

Another IRS publication that may be useful is [Publication 3966: Tax Benefits and Credits: Living and Working with Disabilities](#).[89] This is a 3-page fact sheet on tax credits and benefits, available to taxpayers with disabilities and parents of children with disabilities. It summarizes the detailed information in IRS Publication 907 and links to additional IRS publications on specific disability-related credits and benefits, such as the Earned Income Tax Credit (EITC).

Considerations for Families Filing Taxes for Their Adult Child with a Disability as a Dependent

As a parent or legal guardian, you may file your own taxes that include your adult child with a disability as your dependent. You can claim a person with disabilities as a dependent when:[90]

- They have lived with you for more than half of the tax year.

- You have provided at least half of their support for the tax year.

- They are your child, stepchild, or foster child, or a descendant of any of these.

- They are your brother, sister, or stepsibling, or they are your father, mother, grandparent or other direct ancestor.

- They are not filing a tax return of their own.

Depending on your adult child's income, and your personal income, you may be able to claim the following tax credits:[91]

- **Other dependent tax credit**: For dependents or other qualifying relatives (including parents/grandparents), and even qualified dependents who are not related to the taxpayer, and who are aged 17 years or older, a $500 credit may be available.

- **Child and dependent care tax credit**: This is for expenses incurred so that parents can work or look for work. Both married people must work, or one must work while the other is a full-time student, has a disability, or is looking for work (provided that the spouse looking for work has earnings during the year). This credit equals up to 50% of childcare expenses, limited to $8,000 for the care of one child and $16,000 for two or more qualifying persons.

- **Qualified retirement savings contributions credit**: This is for contributions to [ABLE accounts](#) by designated beneficiaries.

6. Advocacy

We have touched on advocacy in this guide – advocacy during IEP transition meetings, in postsecondary options, and in employment. In this section, we will provide a specific focus on advocacy in all aspects of transition and will provide enhancements of points made in some of our previous sections.

The outcomes for employment and meaningful social engagement for adults with disabilities have not been entirely positive. Individuals with developmental disabilities face significant barriers that limit their opportunities for competitive, integrated employment, including employer concerns over compliance with accommodation requests, perceived lack of job readiness, and negative attitudes and biases toward candidates with disabilities.[92] While considerable progress has been made regarding gender, sexual orientation, race, and ethnicity, people with disabilities are the nation's largest "minority" group that lags behind in the workplace. Reasons for this include problems in the disability benefits system, subminimum wage practices (e.g., "sheltered workshops"), flaws in the education system, and employers' misconceptions.[93] But the idea that hiring people with disabilities is indeed a misconception. Accessibility and accommodation in the workplace do not result in high costs, and much of the work in making employment accessible is conceptual and not economically burdensome. For example, in a study on workplace accommodations in the United States, 56% of employers reported that accommodations for persons with disabilities did not cost *anything*, and another 39% experienced only a relatively small, one-time cost of less than $500.[94]

Advocates and self-advocates have identified assumptions and attitudes – mostly from employers, but also from co-workers and society at large – as the biggest barrier to inclusive employment.[95] Therefore, advocacy and self-advocacy for the right to quality transition programs, postsecondary education and training options, and employment are very important.

Advocating During Recruitment

When employers consider advocacy strategies to use for recruitment, they should advocate for:[96]

- **Inclusive Job Postings**
  - Simply state that your company welcomes applications from people with employment accessibility barriers – and that such applicants may contact the designated hiring lead directly via email or phone. This can help mitigate electronic application barriers.
  - Candidate Representation

- Some candidates with disabilities may use some type of professional or family-based support to help them apply for work and get through the interview process. Although this may seem irregular to some employers, this type of support will help you better assess the ability of the candidate and identify a "fit" for available positions. Allow third-party representation.

- **Interview Alternatives**
    - Some candidates may have self-confidence or communication difficulties that interfere with successful interviewing. Third-party representatives may ask for some consideration or accommodation around attending the interview as communication support – or allowing for alternatives such as a video interview or even a job trial to demonstrate skills and abilities directly. Consider including alternatives to your usual recruitment processes to explore candidate talents in new ways.

While the past has been challenging for adults with disabilities in the United States in terms of positive life outcomes, things are steadily improving. Trends in corporate America show an increase in diversity-focused hiring. Major companies have launched neurodiversity hiring initiatives, including Microsoft, SAP, EY, Ford, and JP Morgan Chase.[97] As you read in the Chapter 3 section [Employer Supports for Inclusive Employment](#), there is a range of accommodations and accessibility practices that should be in place during recruitment.

Advocating While Applying and Interviewing

When looking for jobs, you can call and ask who oversees hiring for a position. *Is it the boss, a hiring manager, or a human resources person?* When you find out the name of the person in charge of hiring, try to connect with them directly to let them know that you've gone through a career exploration process and that this job is your well-informed and well-researched top choice. You can request a job interview or a job shadow opportunity to prove that you can do the job.[98]

Most job advertisements and applications now occur online. Job-posting sites include Indeed, Monster, ZipRecruiter, Handshake, SimplyHired, and many more. When looking for jobs online, make sure to do the following:[99]

- Get your résumé ready.
    - How to [name your résumé and cover letter.](#)
- Know your employment history.
    - How to [find and keep track of your employment history](#).
- Review sample job application forms.
    - [Sample job application](#) to download and fill out.
    - [List of common questions asked on a job application](#).
- Create accounts on job sites.

- Apply for jobs directly on company websites.

  - Gain further information on [how to apply for jobs directly on company websites](#), including the benefits of doing so, and how to search for and navigate through company websites.

- Know your schedule and availability.

  - [How to answer interview questions about availability](#).

- Follow job application instructions.

- Apply for jobs via email.

  - Further steps and tips on [how to apply for jobs using email](#).

- Take employment tests (e.g., talent assessments, emotional intelligence tests)

  - More detail on different [types of pre-employment tests](#).

- Follow up with your application.

Remember that looking for work is a job, and it can take some time. Stay positive, believe in yourself, and don't get discouraged. Even if you're not getting a job right away, you're building your network and learning new skills.

The interview process in hiring can be another major hurdle when seeking inclusive employment, and you will have to be a strong self-advocate for your rights.

During observations of how disability is addressed in interviews, one research study found that even inclusive employers use a person-deficit approach when talking to applicants with disabilities. The implication of this is important for people with disabilities. They need to inform potential employers about the assets of disability (i.e., move away from a deficit understanding of disability to an asset-based perspective). Achieving self-awareness and building self-advocacy skills are critical for people with disabilities in advocating for disability as an asset. Educators, employment service providers, social workers, and families can support people with disabilities in building self-advocacy skills.[100]

Here are some tips on what to do before, during, and after the interview:[101]

1. Confirm the address and the time of the interview and whom you are meeting with – know where you are going and how to get there on time. Consider taking a practice run on the route to the meeting place, especially if it involves transit to an area you are not familiar with.

2. Do you need more time to answer questions? Do you need a support person with you? Do you need to have the information in plain language? Consider letting the employer know if you need anything before the interview.

10 Interview Tips:

1. Prepare
2. Plan Ahead
3. Practice
4. Dress Appropriately
5. No Distractions
6. Don't Be Late
7. Be Friendly and Smile
8. Listen Carefully
9. Follow-up After the Interview
10. Don't Give Up!

3. Find out more about the workplace and the job – knowing some things about the company's history, such as who started the business, is a great way to impress the interviewer and be a stand-out candidate for the job.

4. Write down questions to ask the interviewer at the end of the interview.

Some specific tips for adults with Down syndrome include:[102]

- Watch YouTube videos to see what to expect in an interview.

- Practice answering interview questions with a friend or family member.

- Have a family member or friend help you prepare to talk about yourself, your skills, your experiences, and why you want the job.

- Role-play the interview with a friend or family member.

- Practice good eye contact, displaying confidence, careful listening, and staying on topic.

- Ask the employer for an alternative to a sit-down interview, such as a working interview to learn and demonstrate the required tasks.

These are all skills that can be developed and even worked on as goals in the Transition IEP.

Advocating During Onboarding

Research has found that, during initial onboarding and transition into employment, job seekers with disabilities struggled to advocate for themselves because of other mental health considerations, describing feelings of heightened anxiety that diminished their well-being.[103] The majority of job seekers spoke of a

general lack of onboarding supports from their employers, making the transition into employment difficult. From that research, recommendations for inclusive onboarding included:

- More routine and regular check-ins.

- Peer supports such as a "buddy system."

- Establishing an employee resource group to support new employees.

- Ensuring that onboarding includes accessibility for different learning styles and neurodiversity.

As you start a new job, consider these two ways to show that you are willing to learn and try your best:[104]

- **Show up:**

  – Be prepared for your first day of work.

  – Be well rested.

  – Prepare your work clothes and everything else you need for your workday.

  – Plan your route to work, and leave early so you do not arrive late.

  – Arrive at work 15 minutes before your shift starts so that you can get ready to start.

  – Greet your new co-workers with a friendly smile and eye contact.

- **Be present:**

  – Give your supervisor or coworkers your full attention while they explain how to do your job.

  – Establishing eye contact, displaying positive body language, and not interrupting are ways to show people that you are paying attention.

  – Watch closely to see how things are done.

  – Be open to trying new things and doing things differently. Each workplace/company will have its own specific way of doing things along with rules that must be followed.

  – Ask questions if you do not understand something.

Here are some recommendations to help you learn and remember during onboarding:

- Take notes (or record instructions on your phone).

- Make a list (or take pictures on your phone).

- Ask a coworker to show you how to do something, instead of telling you.

- Practice the new skill.

- Tell your supervisor how you learn best.

- If they have an employee handbook, take it home and read it through.

- Make sure to stay until the end of your shift and say goodbye before you leave.

- As you travel home after your first day of work, think of the people you met at your new job. Make a point of remembering the names of two key people that are helping you learn your job.

  1. What is your supervisor's name?

  2. What is the name of a friendly coworker whom you can ask for help?

Specific tips for adults with Down syndrome when starting a job:[105]

- Be clear upfront about what accommodations you need to be successful, such as:
  – Visual schedules
  – Written lists
  – Special equipment
  – Timers

- Start slowly with short shifts and limited days to get comfortable.

- Follow the example of other staff members, including through job shadowing.

- Ask questions and ask for help when you need it.

- Find a trusted adult to talk with about your experiences at work.

Advocating While in Your Job

There are a range of accommodation and accessibility ideas that you can advocate for while you are in your job. As you move from application to interview to onboarding to regular working, consider what self-advocates, employment specialists, and employers of adults with intellectual disabilities note regarding accessible processes throughout the employment cycle, including:[106]

- Opportunities for in-person applications

- Customized or modified interview processes

- A lengthened onboarding period

- "Buddy" or mentorship programs

- Regular and timely feedback

- Flexibility throughout the employment cycle

- Plain language during all stages of the employment cycle

7. Systems of Support

No one agency or person can meet the needs of all transitioning students; transition planning requires shared expertise and a wide range of services from multiple service providers.[107] Collaboration among agencies, families, and students is a strong predictor of positive post-school outcomes. Specifically, research has established that interagency collaboration increases the likelihood that students with disabilities will graduate from high school, attend postsecondary education or training, and secure paid employment.[108]

To support your family during the transition process and maximize positive outcomes for your youth, it is important to build a comprehensive network of supports. The figure below from the IRIS Center in Vanderbilt's Peabody College[109] depicts a sample network of agency and community resources to help meet the individual's needs.

Figure 12. Creating a Network of Supports

Some of the agencies and community resources included in the sample network have already been discussed in this guide, such as independent living centers. This chapter outlines additional agencies that can enhance your awareness of what supports are available to you , all of which you should consider when building your own network of supports.

Home and Community-Based Supports (HCBS)

Individuals with Down syndrome and other developmental disabilities rely on HCBS to live, work, and be involved in the community.[110] HCBS are types of person-centered care delivered in the home and community. HCBS are funded by state waivers and within individual states, HCBS care is provided by lead agencies and other service providers. This means it is important to research the types of HCBS services that are offered in your state.

HCBS programs fall into two categories: (1) health services and (2) human services. Common types of HCBS care in each category are listed in the table below (CMS, 2023):[111]

Health Services Meet Medical Needs	Human Services Support Daily Living
- Skilled nursing care - Therapies: Occupational, speech, and physical - Dietary management by a registered physician - Pharmacy - Durable medical equipment - Case management - Personal care - Caregiver and client training - Health promotion and disease prevention - Hospice care (comfort care for patients likely to die from their medical conditions)	- Senior centers - Adult daycare - Congregate meal sites - Home-delivered meal programs - Personal care (dressing, bathing, toileting, eating, transferring to or from a bed or chair, etc.) - Transportation and access - Home repairs and modifications - Home safety assessments - Homemaker and chore services - Information and referral services - Financial services - Legal services, such as help in preparing a will - Telephone reassurance

Table 3. Common Types of HCBS Care by Category

Intellectual/Developmental Disabilities Agencies

Each state has a publicly funded intellectual/developmental disability (I/DD) agency that offers a variety of programs and services to people with disabilities who qualify, based on available resources. The types of services funded vary considerably across states and include things like assisting people to gain employment, assisting people in facility-based work or non-work activities, and assisting people in community non-work activities.[112] I/DD agencies focus on serving people with intellectual or developmental disabilities, including Down syndrome, who meet the state's eligibility criteria.

Check with your local I/DD agency's service coordinator to learn about what employment services are available, how they are organized, and how to access them. The Arc recommends the following tips to families when inquiring with your I/DD agency:[113]

- Invest some time to learn how the system of services works in your area in order to make informed choices. Browse the Internet and visit your local I/DD agency.

- Typically, state I/DD agencies do not provide direct services. Instead, they fund local community rehabilitation providers (CRPs) to deliver services.

- I/DD agencies often collaborate with Vocational Rehabilitation (VR) agencies. VR agencies typically fund the initial placement of services until a job is found. Then, I/DD agencies intervene to fund on-the-job supports when needed. However, you may contact a service coordinator at your I/DD agency to verify how services are delivered in your area.

- When you contact an I/DD agency service coordinator, make sure that you ask for services that lead to employment in the general labor market.

- Note that the names of I/DD agencies vary by state. Often, I/DD agencies are called Division or Office of Developmental Disabilities, or Department of Office of Intellectual Disabilities, or Department of Developmental Services. State I/DD agencies are funded under the U.S. Department of Health and Human Services (DHHS), Administration for Children and Families and State (ACFS).

- Remember: Most services are available at no cost to you, although, depending on your financial resources, you may be asked to contribute in paying for some services.

You can find your state's I/DD agency contact information on the National Association of State Directors of Developmental Disabilities Services website. Click on your state on the map to find contact information for your state's I/DD agency.

National Down Syndrome Society (NDSS)

Aligned with the mission to empower individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions,[114] NDSS has an Employment Program with the goal of increasing access to the workforce for all people with Down syndrome. To meet this goal, NDSS collaborates with affiliate organizations, employers, government agencies, and other stakeholders to positively impact the professional lives of people with Down syndrome by:[115]

- Advocating for policies to increase access to competitive integrated employment (CIE)
- Providing resources, support, and training to the community
- Offering technical assistance to businesses
- Highlighting the successes of employees and business owners with Down syndrome

For more information, visit the NDSS Employment Program website, or email employment@ndss.org.

Local Down Syndrome Affiliates

To find local Down syndrome affiliates in your community, use the interactive NDSS Affiliate Map pictured below, or download the complete alphabetical list of affiliates from the NDSS Local Support website.

The Arc

The Arc's mission is to promote and protect the human rights of people with intellectual and developmental disabilities (I/DD) and actively support their full inclusion and participation in the community throughout their lifetimes.[116] The Arc has more than 600 local chapters (find your local chapter here) and over 1,000 national and community programs.

The Arc is also a strong advocate for competitive integrated employment (CIE), supporting "Employment First" policies and the Workplace Innovation and Opportunity Act (WIOA) reviewed earlier in this guide. To learn more, read their full position statement on employment.[117]

Vocational Rehabilitation (VR) Agencies

State Vocational Rehabilitation (VR) Agencies were discussed previously in Chapter 1. Transition Planning in School and Chapter 3. Employment regarding pre-employment transition services (Pre-ETS). However, they are mentioned again here as a reminder as an agency to incorporate them into your personalized network of supports.

8. Social, Emotional, and Physical Well-Being

While the transition process can be an exciting time full of exhilarating possibilities, it is also a time of concern and stress for youth with disabilities and their families. Research has established these causes for concern as youth and families struggle to navigate the system, deal with financial strain and increased caregiving demands, confront limited employment possibilities, and maybe even experience transition collapse and defeat.[118] Taking care to address your emotional well-being during transitions is critical to effectively coping with your inevitable feelings of stress and uncertainty during this period of time, so that you can focus more closely on your personal growth and fulfillment.

This chapter offers helpful advice and tools for you and your family to promote self-care and resilience during transitions by taking proactive steps to cope with stress and anxiety and support your mental and physical health.

Coping with Stress and Anxiety

Anxiety can happen during all stages of the transition process. Feelings of anxiety can be especially heightened in people with disabilities during various stages of transition. For example, in a research study conducted during job interviews, feelings of anxiety were found to be particularly dominant among applicants with disabilities, compared with the experiences of job applicants without disabilities.[119]

You can use numerous coping strategies to combat feelings of stress and anxiety. The following four steps and corresponding resources have been developed specifically for people with Down syndrome and are recommended by Advocate Health Care's Adult Down Syndrome Center (Rowley, 2023):[120]

1. **Identify your triggers or causes of stress.**

    The first way to help manage stress is to know what situations cause stress. Once you know what causes your stress, you can create a plan to cope with it. There are some stressors that we can avoid, and others that we cannot. The My Stress Triggers visual shows examples of things that might make us feel stressed.[121]

2. **Notice feelings of stress in your body.**

    Recognize how early signs of stress manifest in your body. This will help you know when to use your plan to deescalate before the stress becomes overwhelming. Use the Body Changes visual to help you notice signs of stress in your body.[122]

3. **Select activities that help you feel calm.**

   Try out some strategies to calm your body and mind. Learn what works best for you. It is a good idea to have at least a few strategies that you can use when feeling stressed. Breathing techniques can be especially useful because they do not require equipment or supplies and can be done anywhere.

4. **Make a plan.**

   Make a specific plan for each of the triggers you identified in Step 1.

Health and Wellness

In taking a holistic approach to your health and wellness, in addition to taking care of your emotional well-being by managing stress and anxiety, you also need to be sure to take care of your physical well-being.

After you transition out of high school and are no longer taking physical education classes in school, you need to keep your body moving. For adults with Down syndrome, research endorsed by the American Medication Association[123] stresses the importance of taking a comprehensive approach to weight management, appetite control, and an enhanced quality of life through regular exercise and healthy eating habits. To help ensure a healthy lifestyle, specific resources have been developed for adults with Down syndrome and their families, such as the 321go! program highlighted below.

321go!

The NDSS 321go! program is designed to promote healthy lifestyle choices in physical activity, nutrition, and emotional wellness for people with Down syndrome and their families.[124] NDSS recommends devoting at least eight weeks for your 321go! journey to maintain a daily focus on overall well-being.

9. Conclusion

As you can see if you have made it all the way through this guide in depth, there is a lot to think about when it comes to transition. However, we hope it is also clear that many resources are available out there for you.

In this guide, we have tried to cover all of the major topics of consideration when it comes to transition to adulthood for youth with Down syndrome and other intellectual and developmental disabilities. But this guide is not exhaustive. Many more resources are available in the world that may not have been covered here. We hope this guide will at least point you in the right directions and with the right topics in mind as you search for the programs and resources that will work best for you.

We want to acknowledge all the resources that we used and pulled into this guide. Thank you to all of the organizations, advocates, and researchers that have done great work in thinking about the issues surrounding transition and that have provided materials and strategies that we have reproduced in this guide.

As you embark on your transition-to-adulthood journey, remember that you do not have to do it alone. In the United States, and all around the world, millions of others are on the same path. Many local organizations and people – as well as national ones – are there to help. Your transition journey will only be yours, because you are unique and have specific preferences, strengths, weaknesses, and experiences. We wish you the very best in living the life that *you* choose.

Glossary

The following is a glossary of acronyms and terms that you will encounter in the world of transition services.[1]

504 Plan   *Students in any K-12 schools with a 504 plan are often those who do not require special education services yet have a documented disability and need accommodations and/or related services in order to be successful in school.*

ABLE Accounts   **Achieving a Better Life Experience**
The ABLE Act of 2014 allows states to create tax-advantaged savings programs for eligible people with disabilities (also known as designated beneficiaries). Contributions to ABLE accounts can help designated beneficiaries save for qualified disability expenses. Distributions are tax-free if used for qualified disability expenses.

Accommodations   *These are adjustments that may need to be made within a work or school setting to allow an otherwise qualified employee or student with a disability to perform the tasks required. Under the Americans with Disabilities Act, Reasonable Accommodation means: A) modification to the job application process; B) modification to the work environment or the manner under which the position held is performed; and C) modification that enables an employee with a disability to enjoy equal benefits and privileges of employment. The term "reasonable" implies that the accommodation is one that does not cause an undue hardship for the employer. Examples of workplace accommodations include making existing facilities used by employees readily accessible and usable by individuals with disabilities; restructuring jobs / establishing part-time or modified work schedules; reassigning to vacant positions; adjusting or modifying examinations, training materials, or policies; and providing qualified readers or interpreters. Under the Individuals with Disabilities Education Act (IDEA), the term "accommodation" is used primarily with regard to the development and provision of alternative assessments that are valid and reliable for assessing the performance of students with disabilities.*

ADA **Americans with Disabilities Act**

Federal disability antidiscrimination legislation passed in 1990 to guarantee basic civil rights to persons with disabilities. Protections include the equal right to employment, transportation, government services, and telecommunications.

ADL **Activities of Daily Living**

A shorthand acronym often seen in an IEP or transition plan that focuses on daily living skills such as getting dressed, cooking, completing household chores, and so on.

Age of Majority *The legally defined age at which a person is considered an adult, with all the rights and responsibilities of adulthood. In your state, this is most likely 18 years old.*

AT **Assistive Technology**

A broad term that includes a wide range of high- and low-technology devices or services for people with disabilities. Assistive technology promotes greater independence by helping people complete tasks at home, school, or work that they could not do on their own, or would have great difficulty doing.

CBI **Community-Based Instruction**

CBI is an instructional method for teaching functional living skills in real-world settings.

CIE **Competitive Integrated Employment**

Work that is performed on a full-time or part-time basis for which an individual is: (a) compensated at or above minimum wage and comparable to the customary rate paid by the employer to employees without disabilities performing similar duties and with similar training and experience; (b) receiving the same level of benefits provided to other employees without disabilities in similar positions; (c) at a location where the employee interacts with other individuals without disabilities; and (d) presented opportunities for advancement similar to other employees without disabilities in similar positions.

CIL **Center for Independent Living**

Community-based, not-for-profit, non-residential organizations that provide advocacy, peer counseling, independent living skills training, and information and referral to persons of any age with any disability.

Conservator *A person appointed by a judge to protect and manage the financial affairs and/or a person's daily life due to disability needs.*

CtLC

Charting the LifeCourse

A person-centered set of visual and mapping tools used to plan for transition and positive life outcomes in adulthood.

CTP

Comprehensive Transition Program

Degree, certificate, or non-degree programs for students with intellectual disabilities that meet specific criteria. If students with intellectual disabilities are attending a CTP, they are able to use federal financial aid to help pay for attendance.

Customized Employment

Customized employment is a flexible, non-comparative, and interest-driven employment negotiation between an individual job seeker and an employer. It is a person-centered, strengths-based strategy designed to negotiate competitive jobs in ways that fit the known abilities and potential contributions of a job seeker. Customized employment is a formal process designed to plan and negotiate real jobs at competitive wages and benefits one job seeker, one employer at a time.

CWIC

Community Work Incentives Coordinator

Staff that work in WIPA projects (see below) to support persons with disabilities in securing and keeping employment.

DSS

Disabled Student Services

Offices on college or university campuses that work with disabled students to arrange for the disability-related services they need in order to equalize the playing field. These offices are often referenced by other names.

Employment First

Employment First is a framework and nationwide movement that seeks to deliver meaningful employment, fair wages, and career advancement for people with disabilities. Many states have adopted Employment First policies through legislation and/or executive orders to facilitate competitive integrated employment for individuals with disabilities, including individuals with the most significant disabilities.

FAFSA

Free Application for Federal Student Aid

An application that allows a college to determine a student's eligibility for grants and loans. It must be completed every year in order to receive financial aid.

FAPE

Free Appropriate Public Education

A federal regulation in the IDEA, specifying that all children with disabilities aged 3 through 21, including children with disabilities who have been suspended or

expelled from school, are entitled to a free and appropriate public education. Districts must provide FAPE to all students with disabilities who have not reached age 22 and have not earned a regular high school diploma.

FERPA **Family Educational Rights and Privacy Act**
A federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

Functional Vocational Assessment *Assessment to determine a student's strengths, abilities, and needs in an actual or simulated work setting or in real work sample experiences.*

Guardianship *A legal process that gives the guardian permission to take care of and make decisions for a protected person (or, in legal terms, a ward).*

HCBS **Home and Community-Based Services**
The major goal of home-based services is to maintain the youth at home and prevent an out-of-home placement (i.e., in foster care or in residential or inpatient treatment). Home-based services are usually provided through child welfare, juvenile justice, or mental health systems. Home-based services are also referred to as in-home services, family preservation services, family-centered services, family-based services, or intensive family services. The services are tailored to the individual needs of families.

HEOA **Higher Education Opportunity Act**
Federal law contains a number of important provisions that improve access to postsecondary education for students with intellectual disabilities.

HSAs **Health Savings Accounts**
A type of savings account that lets you set aside money on a pre-tax basis to pay for qualified medical expenses.

IDEA **Individuals with Disabilities Education Act**
A law that mandates rules and regulations around how children with disabilities are to be educated in public schools. IDEA requires that transition planning and services be provided by the local education agency.

IEP **Individual Education Plan**
Written statement for a child with a disability; it is developed, reviewed, and revised in accordance with the IDEA.

Independent Living Skills

Skills or tasks that contribute to the successful independent function of an individual in adulthood.

Indicator 13

An indicator required by the IDEA for states to report the percentage of youth with IEPs, aged 16 and above, who have an IEP that includes appropriate measurable postsecondary goals that are annually updated and based upon an age-appropriate transition assessment; transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals; and annual IEP goals related to the student's transition services needs.

IPE

Individualized Plan for Employment

A vocational rehabilitation plan that targets a specific job goal and services that are necessary to reach the goal. The plan can be amended at any time and should be reviewed annually.

IRC Section 529 Plans

Although considered college savings plans, these have been expanded to be used for certain K-12 tuition and expenses as well as qualified apprenticeships in the trades. Plus, the cost of certain services used by some children with disabilities is considered a qualified higher education expense for 529 college savings plans.

Job Coaching

Providing consultation and training to the job seeker or the business to facilitate successful employment.

Job Shadowing

Exploring different occupations and types of work environments by following and watching people actually performing the jobs.

LEA

Local Education Agency

Public boards of education or other public authorities who exercise administrative control over public elementary schools or secondary schools in a city, county, township, school district, or other political subdivision of a state.

MAPS

Making Action Plans

A person-centered planning set of visual and mapping tools to plan for transition and positive life outcomes in adulthood.

Medicaid

Medicaid is a jointly funded, Federal-State health insurance program for certain low-income people. It covers approximately 36 million individuals, including children, the aged, people with disabilities, and people who are eligible to receive federally assisted income maintenance payments.

Medicare   *Medicare is the federal program that provides health care coverage to Americans aged 65 or older, or who have a disability, no matter what their income. You are eligible for Medicare if you are 65 years or older, and you are a U.S. citizen or have been a permanent legal resident for 5 continuous years, or if you are disabled and have had Social Security for at least 2 years, or if you get continuing dialysis for permanent kidney failure or need a kidney transplant, or if you have Amyotrophic Lateral Sclerosis (ALS-Lou Gehrig's disease).*

PABSS   **Protection and Advocacy for Beneficiaries of Social Security**
A program under the Ticket to Work act that ensures employment and employee rights and reasonable accommodations under the ADA, and assists in obtaining vocational rehabilitation, among other things.

PASS Plan   **Plan for Achieving Self Support**
A Social Security program that allows you to set aside income and assets for expenses related to a specific work goal.

PATH   **Planning Alternative Tomorrows with Hope**
A person-centered planning set of visual and mapping tools to plan for transition and positive life outcomes in adulthood.

Person-Centered Planning   *A process that assists persons with disabilities and their families to plan for the future to enable the individual with a disability to be an active and contributing member of the community through structured exercises focusing on the individual's strengths and preferences.*

PFP   **Personal Futures Planning**
A person-centered planning set of visual and mapping tools to plan for transition and positive life outcomes in adulthood.

Pre-ETS   **Pre-Employment Transition Services**
The Workforce Innovation and Opportunity Act requires that Vocational Rehabilitation Services, in collaboration with local education agencies, have Pre-Employment Transition Services (Pre-ETS) available statewide to all students. Families and team members should consider student needs within the five Pre-Employment Transition Services activities: job exploration counseling, work-based learning experiences, counseling on opportunities for enrollment in postsecondary education programs, workplace readiness training , and instruction in self-advocacy.

PSEO — **Postsecondary Enrollment Options**
A program that allows eligible 10th-, 11th- and 12th-grade students to earn college credit while still in high school.

Rehabilitation Counselors
Staff that work with various state departments and community programs to provide services, information, and collaboration on employment.

Self-Advocacy
Understanding one's disability, being aware of the strengths and weaknesses resulting from the limitations imposed by the disability and being able to articulate a reasonable need for accommodation.

Self-Determination
The principle that a person must have control of their relationships with other people, groups, systems, and cultures that are important to them. All people – regardless of ability – have the right to self-determination. However, self-determination is also based on context and on the environment around us.

Self-Employment
Self-employment is earning income without being employed and paid by someone else. Self-employment isn't like being a traditional worker because self-employed individuals aren't tied to an employer. Being self-employed gives people flexibility but comes with certain tax implications.

Sheltered Employment
Designed to assist individuals who, for whatever reason, are viewed as not capable of working in a competitive employment setting in their local community. The term "sheltered employment" is often used to refer to a wide range of segregated vocational and non-vocational programs for individuals with disabilities, such as sheltered workshops, adult activity centers, work activity centers, and day treatment centers. These are often not the preferred settings for adults with disabilities.

SMART Goals
A method of planning and writing goals in documents such as an IEP. SMART stands for specific, measurable, attainable, relevant, and timebound.

SNAP — **Supplemental Nutrition Assistance Program**
SNAP provides food benefits to low-income families to supplement their grocery budget so they can afford the nutritious food essential to health and well-being.

SNTs — **Special Needs Trusts**
Trusts that will preserve the beneficiary's eligibility for needs-based government benefits, such as Medicaid and Supplemental Security Income (SSI).

SSA

Social Security Administration

Federal agency that provides welfare programs such as SSI, SSDI, and many others.

SSDI

Social Security Disability Insurance

SSDI is a government-based insurance program. Eligibility is based on an individual's work history and the amount of Social Security taxes they've paid. Typically, you need to have earned a certain number of work credits, which are based on your yearly wages or self-employment income, to qualify.

SSI

Supplemental Security Income

A government needs-based program designed for individuals with limited income and resources. Eligibility is not based on work history, but rather on overall financial need. To qualify, applicants must have less than $2,000 in resources (or $3,000 for couples) and a very limited income. Additionally, they must be either age 65 or older, blind, or have another type of disability.

Supported Employment

Working in a competitive job and receiving supports necessary to maintain that employment.

TWWIIA

Ticket to Work Incentives Improvement Act of 1999

A law that allows the Social Security Administration to fund community-based programs to assist individuals with disabilities receiving Social Security funds in their return-to-work efforts.

TPSIDs

Transition and Postsecondary Programs for Students with Intellectual Disabilities

High-quality, inclusive comprehensive transition and postsecondary programs for students with intellectual disabilities at institutions of higher education. They provide individual supports and services to students focusing on academic enrichment, socialization, independent living skills (including self-advocacy skills), and integrated work experiences and career skills that lead to gainful employment. The U.S. Department of Education provides grants to institutions of higher education or consortia of institutions to enable them to create or expand these programs.

Transition IEP

An IEP written during a student's eighth-grade year or at the IEP meeting conducted during the year the student turns age 14. This IEP deals with issues related to making the transition to adult life after high school, including diploma decisions.

Transition Planning	*The term "transition planning" means a coordinated set of activities for a student with a disability that: A) is designed within an outcome-oriented process, that promotes movement from school-to-post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; B) is based upon the individual student's needs, taking into account the student's preferences and interests; and C) includes instruction, related services, special education, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, the acquisition of daily living skills and functional vocational evaluation.*
Transition Services	*A coordinated set of activities for a student with a disability, provided by the school district.*
Vocational Rehabilitation	*The process of assisting individuals with disabilities to obtain, regain, maintain, and advance in employment through diverse services tailored to meet the needs of eligible individuals. Each state has a public VR agency.*
Waivers	*Programs that allow people to receive Medicaid long-term care services in the community.*
WIOA	**Workforce Innovation and Opportunity Act** *Federal legislation providing for activities related to career exploration and paid and unpaid work experiences.*
WIPA	**Work Incentives Planning and Assistance** *Community-based organizations that receive Social Security funding to assist beneficiaries in making informed decisions about work and supporting their transition to economic self-support.*
Work-Based Learning	*Meaningful and engaging educational opportunities connecting classroom learning to learning on job sites in the community.*
Workforce Development	*Activities focused on preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, capabilities, interests, and informed choice of the individual – or assisting individuals and employers in obtaining education, training, job placement, or job recruitment.*

Wrap-Around Services   *Individualized, community-based mental health services for children and youth with severe emotional and behavioral disorders in their homes, schools, and communities. This wrap-around approach – sometimes described as serving participants "holistically" – requires that a program effectively collaborate and network with multiple agencies and institutions. In the wrap-around model, case managers coordinate the provision of services from multiple service providers and involve families in the participatory process of developing an individualized plan focusing on youth and family strengths in multiple life domains.*

About the Authors

Matthew J. Schuelka, Ph.D., is the Founder and CEO of Fora Education, a non-profit LLC that specializes in education research, consultancy, technical partnership, products, and services. Dr. Matt Schuelka is a global expert on education policy, evaluation, practice, and research, with two decades of experience and a focus on inclusive education, inclusive employment, and supporting persons with disabilities across the lifespan. He has worked in higher education since 2010, having taught at Johns Hopkins University, Stanford University, the University of Minnesota, Royal Thimphu College, the University of Nottingham (Malaysia campus), and the University of Birmingham (U.K. and Dubai campuses). He is the author or editor of numerous books, including *The Handbook on Diversity and Inclusion in Education* (SAGE, 2019) and *Global Directions in Inclusive Education* (Routledge, 2022). Dr. Schuelka has been a primary investigator for large-scale international research projects, as well as a consultant with numerous domestic and international development agencies related to transition. This includes working for the Institute on Community Integration at the University of Minnesota, creating a school-to-work transition guide and training for the Jamaican Ministry of Education, developing community inclusion coordination and entrepreneurship programs for adults with disabilities in Bhutan, supporting community engagement for youth with disabilities in Singapore, and creating transition resource guides and toolkits for persons with disabilities in Malaysia.

Alisha M.B. Braun, Ph.D., is a teacher, researcher, and consultant. She has experience at all levels of education from preschoolers to adults and has worked in higher education since 2010, having taught at Michigan State University and the University of South Florida. She is the author of numerous research articles and book chapters on diversity and inclusion, education policy, comparative and international education, and qualitative research methods. Dr. Braun has consulted for agencies such as UNESCO and has 13 years of international research experience leading independent and collaborative community-based research projects and service-learning study-abroad programs in Tanzania, Ghana, Botswana, South Africa, England, Singapore, and the United States. She is an active consultant for U.S.-based and international education development agencies and is an Associate at Fora Education.

Appendices
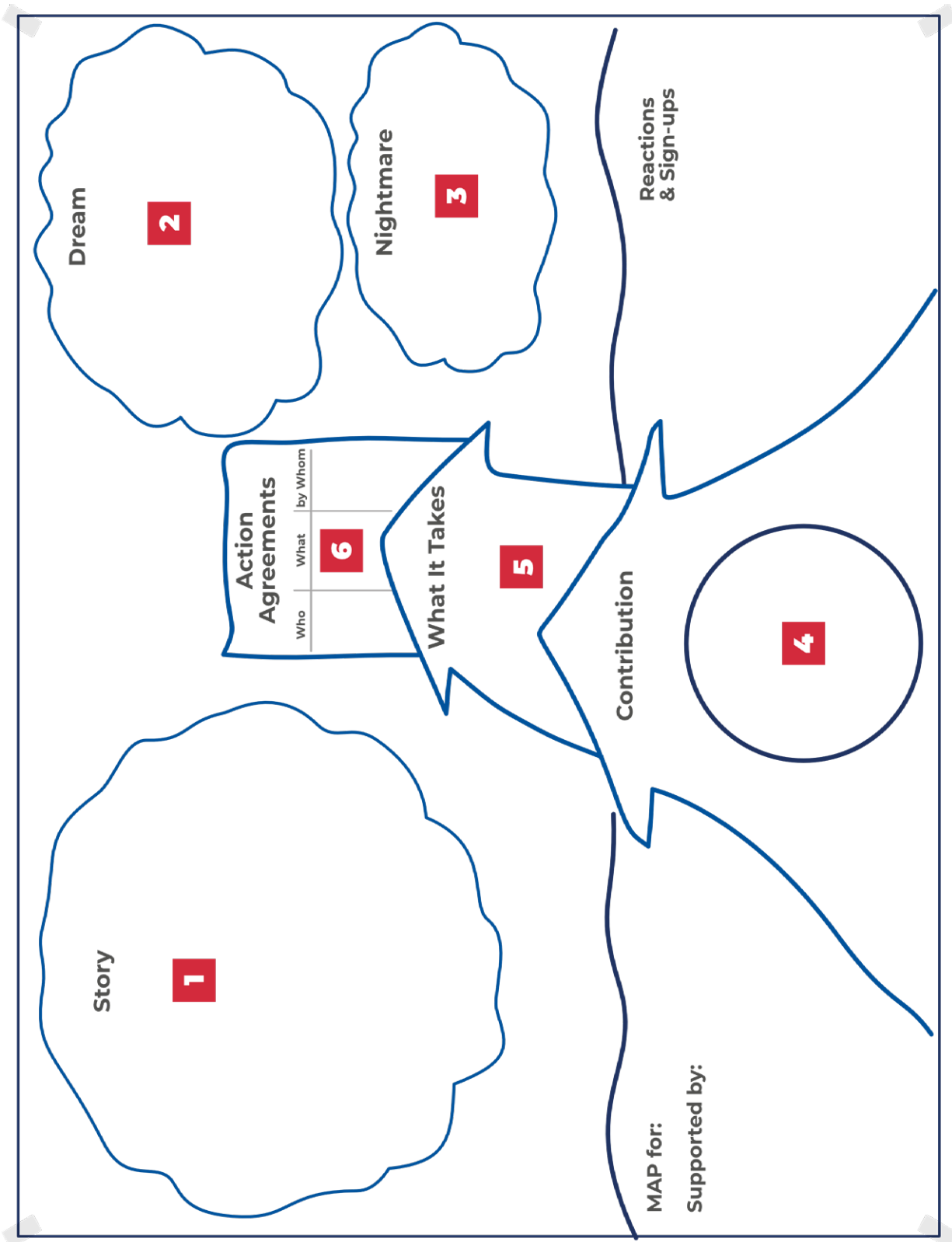
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PATH Template

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Goal (2)

Next Three Months (6)

Next One Month (7)

1st Steps (8)

Stay Strong (5)

People to Help Me (4)

Now (3)

Self-Inventory Worksheet

Name:

Learning Strengths *List as many as possible.*

Learning Weaknesses *If there are a lot, prioritize and list the most important ones.*

Learning Instructional Preferences

How do I learn best?

What kind of group is best for me (e.g., large, small)

What kinds of tests are best for me? (e.g., written, untimed)

What kinds of study materials are best for me? (e.g., written, audio)

What kinds of aids help me? (e.g., audio recorder, computer, tablet, calculator, friend taking notes for me, buddy)

Skill Goal Chart

List goals you're willing to work on in each class or area of growth. Here is an example to get you started.

Class Area	Skills Needed for This Class	Skills I Need to Improve
English	Writing sentences	Using commas correctly
Math	Being prepared	Being prepared
Study Skills	Skimming	Outlining
Social Skills	Accepting criticism appropriately	Accepting criticism appropriately

Class Area	Skills Needed for This Class	Skills I Need to Improve

Appendix B: Think College Search

Note: This graphic is from page 2 of the Weir parent/family workbook.[125] The number of college programs is currently 334, so the 315 reported here is already out of date.

College Planning Timeline

**Getting ready for college takes a lot of planning.
Use this timeline during grades 9 to 12 to get started on the process.**

9 10 11 12

EVERY YEAR IN HIGH SCHOOL

BUILD YOUR COLLEGE READINESS SKILLS.
Take general education classes to make your academic skills stronger. These classes can also help you to explore your career interests. Understand your disability and your learning style so you can share this information with your college advisor and disability services specialist. Practice using accommodations in high school, so you'll be ready in college.

DEVELOP A PERSON-CENTERED PLAN.
Ask family, friends, and other people to help you figure out your goals for after high school.

EXPLORE AND COMMIT TO EXTRACURRICULAR ACTIVITIES.
High school is a great time to try different extracurricular activities, like clubs, to see which ones are most interesting to you. This is also a great chance to make new friends.

FIND SUMMER VOLUNTEER OPPORTUNITIES/JOBS/INTERNSHIPS.
Summer is a wonderful time to earn extra money and explore different career fields. Check with your transition specialist for information about Pre-Employment Transition Services (Pre-ETS) and work opportunities in your area.

MEET REGULARLY WITH YOUR IEP TEAM AND GUIDANCE COUNSELOR.
Make sure your goals and disability needs are included in your Individualized Education Program, or IEP, and your Transition Planning Form. It's important to speak up about your desire to go to college so your team has time to help you prepare.

JUNIOR YEAR

LEARN MORE ABOUT COLLEGE.
Start by talking with your family, IEP team, guidance counselor, and classmates. Research colleges online, and make a list of schools that match your career and personal goals. Use Think College's College Search to find options.

MAKE VISITS TO COLLEGE CAMPUSES NEAR YOU.
Go to open houses, take campus tours, and meet with disability services staff. These staff people can tell you about accommodations, and how they're different in college from what you've had in high school.

SENIOR YEAR (FALL)

PUT TOGETHER ALL APPLICATION MATERIALS.
Make sure you and your guidance counselor have all the materials you need for college admission. If you don't know what these materials are, ask your guidance counselor. If they've never heard of this, share this timeline with them.

HAVE UPDATED EVALUATIONS BEFORE STARTING COLLEGE.
Be strategic about when your last 3-year evaluation will occur, prior to college. One way to be strategic is to plan for this evaluation with your IEP team. You may need to complete some evaluations, or tests, to make sure you have the most current information for disability services staff. These evaluations will help them make sure you get the accommodations you need.

SENIOR YEAR (SPRING)

SUBMIT YOUR APPLICATION.
Most colleges have due dates between January 1 and March 1 of each year. Check the websites of the colleges you're interested in to see what their exact deadline is.

SET UP AN APPOINTMENT WITH YOUR COLLEGE ADVISOR.
Share a current copy of your person-centered plan. It will help your college advisor get to know your interests, preferences, strengths, and needs.

SET UP AN INTAKE MEETING WITH YOUR COLLEGE'S DISABILITY SERVICES.
Work with your IEP team to get a current copy of your documentation of disability to share at your meeting. This will help you get the accommodations you need.

REGISTER FOR CLASSES.
Most colleges offer registration to new students beginning in April. Set up a meeting with your college advisor to get the classes you want at the times you need.

LEARN HOW TO USE PUBLIC TRANSPORTATION.
Contact your local transit authority to enroll in a travel training program. Your transition specialist can help you set this up.

ATTEND NEW STUDENT ORIENTATION.
Most colleges offer orientation for their new students between June and August. Don't miss this chance to get to know your new school and classmates!

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