



Soaring Into Adulthood

A suggested timeline for caregivers

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Early Childhood

- Early intervention evaluation and services
- Document diagnosis
- Home and Community Based Waiver Services (OPWDD)
- FAPE (Free and Appropriate Public Education)



Document Diagnosis



Talk to your pediatrician!

1. **If he or she will not speak to your child's disability (will not sign a form indicating your child has a disability, will not put a diagnosis on a health form, will not sign an affidavit for legal guardianship of your child) you will need to find a new pediatrician.**
2. **Ensure that your child's disability is on your school health form moving forward. Unless "learning disability" is accurate, and the *only* diagnosis, insist your doctor be more specific. i.e., Autism, Intellectual Disability, Down Syndrome. Having "learning disability" or "ADHD" alone will not be helpful for securing services.**

Home & Community Based Waiver Services

- School aged children can apply for OPWDD Eligibility to receive Medicaid Waiver Services through the Home & Community Based Waiver Services program.

Examples of Medicaid Waiver Services for School Age Children

- Respite
- Community Habilitation
- Social Activities
- Summer Camp
- Self-Direction



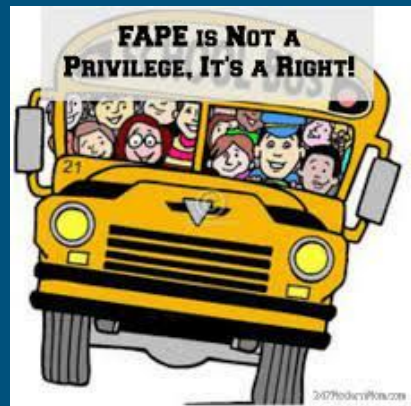
https://omh.ny.gov/omhweb/bho/docs/hcbs_brochure_english.pdf

FAPE

FAPE covers four key components:

- Free (at no cost to the parent)
- Appropriate (IEPs outline a program for students to meet their unique needs)
- Public (students have the same rights attend public schools as all children)
- Education (guarantees students with disabilities receive related services too)

If your assigned school isn't providing the services your child is entitled to you can seek support from an educational advocate and look for an alternate placement.



Middle Childhood

- Increase independence in the home
- Enroll in social activities (sports, clubs, volunteer)
- Start talking about what it means to have a disability
- Teach advocacy
- Financial review



Middle Childhood/Adolescence - Finances



Do a full financial review.

- Make sure there are no resources in their name. family bank accounts, retirement plans, life insurance policies, or legal settlements.
- Make sure they are not the beneficiary of any family members accounts/investments, etc.
- Set up Supplemental Needs Trust in order to save for your child safely.
- Look into opening an ABLÉ account

*Existing financial benefits such as SSDI, child support, survivor benefits, etc. These may affect your child's plan.

Adolescence - Transition IEP

As of age 14, parents are asked to identify goals for their child's adult life at CSE meetings. Encourage your child to take part in these meetings, if appropriate.

- Vocational education
- Continuing and adult education
- Integrated employment and/or supported employment
- Adult services
- Independent living
- Community participation



ABLE Accounts

ABLE ACCOUNT BASICS

- Can open on your own
- Max of \$100K before it impacts SSI funds, \$520K total
- \$17K in deposits per year
- Choice of FDIC insured checking or investment accounts



List of Qualified Disability Expenses:

Education

Housing

Transportation

Employment training and support

Assistive technology and related services

Personal support services

Health

Prevention and wellness

Financial management and administrative services

Legal fees

Expenses for ABLA account oversight and monitoring

Funeral and burial

Special Needs Trusts



What is it?

A trust that holds funds for your loved one but does not impact your loved one's financial eligibility for government programs. If you have loved ones with special needs, you can use a special needs trust to leave behind money that will improve their quality of life.

Example:

Instead of leaving property directly to your loved one, you would leave it to the special needs trust.

Adolescence - Vocational Exploration & Training

Engage in Career Exploration

- Encourage discussions about work and your child's interests
- Talk to friends and family about their jobs & what it took to get them
- Read books about different types of work

Volunteer/Internship Experiences

- If your child's school doesn't provide in-school internships, you can look for volunteer opportunities in your community.
- Look into helping out neighbors with petcare, yard work, shopping, etc.



Supplemental Security Income (SSI)

Eligible as of 18th birthday

Not more than \$2000 in personal assets (parents income is irrelevant)

\$841/month is maximum payment as of January 2023

Documentation of disability from medical doctor.

5 year look back at assets in child's name

More information: <https://www.ssa.gov/pubs/EN-05-11000.pdf>



Social Security

Supplemental Security
Income (SSI)

Adolescence - Guardianship

Article 17-A Guardianship – governed by Article 17-A of the Surrogate's Court Procedure Act. Article 17-A appoints a guardian for adults (age 18 or over) who are intellectually or developmentally disabled.

Parents can apply when their child reaches 17.5 years of age.

Gives parents oversight of all legal, medical and financial decisions.

Hard to reverse.



Adolescence - Supported Decision Making

Widely recognized as less restrictive alternative to guardianship

Involves months long process to create a detailed plan for support identifying people in that can provide support in each area of life.

Signed into law in NYS in July 2022



More info: <https://sdmny.org/>

18 years old - Apply for Medicaid



Once your child hits 18, they will qualify for Medicaid, regardless of your income.

Medicaid is needed to fund adult service programs.

Apply shortly after your child turns 18.

The easiest way to apply for Medicaid is to apply for SSI. If you get Medicaid due to a SSI determination that is in your favor, you will automatically be put on the “right” kind of Medicaid.

If you choose not to apply for SSI, you can apply for Medicaid directly. Do NOT apply for Medicaid through the Marketplace website. Unfortunately, that system is not set up for families who need Medicaid for waiver/transition services. You must go to a local Medicaid office, apply in person, and stress to them that you need Medicaid to access HCBS waiver services. If you have documentation of OPWDD eligibility, please submit a copy with your Medicaid application.

18 years old - Apply for OPWDD Eligibility

OPWDD, or the Office for People With Developmental Disabilities, coordinates supportive services to adults and children with developmental disabilities and their families.

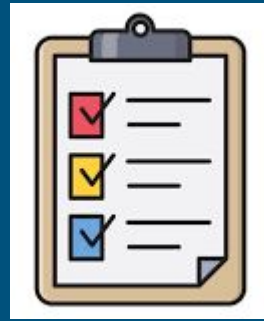
If you haven't gotten OPWDD eligibility previously, apply as soon as your child turns 18.

Camp	Health Care
Counseling	Housing/Individual Support Services
Crisis Intervention	In-home Services
Day Services/Day Habilitation	Parent Advocacy and Training
Employment Services	Recreation
Environmental Modifications/ Adaptive equipment	Residential Services
Family Care	Respite Services
Family Support Services	Service Coordination
Financial Assistance	Transportation
Forensic Services	Waiver Services

**Office for
People With
Developmental
Disabilities**



Applying for OPWDD Eligibility



Eligibility Criteria

In order to be eligible for OPWDD, your child must have a documented disability that was onset before the age of 22 and is expected to continue indefinitely.

You will need:

- 1) Recent comprehensive psychological evaluation
- 2) An assessment of adaptive behavior
- 3) A social or psycho-social history
- 4) Medical exam with diagnosis documented
- 5) Educational/school records
- 6) OPWDD Transmittal form

Once you have eligibility:

- 1) Attend a FRONT DOOR workshop
- 2) Take the EAA and DDP2 or CAS screening tools.
- 3) Secure care management

Transition Programs

Many schools offer specialized programming for students ages 18-21.

These programs include vocational training and experiences, community exploration, travel training, goal setting and future planning.

All students with IEPs are eligible for funded education through their 21st birthday, take advantage of that!



Late Adolescence (18-20)



Take stock of your child's evaluations.

1. You will need new evaluations ready to go when your child is 18. You need a psychological + vineland, a psychosocial, and a medical evaluation that states your child's disability.
2. *Do not assume the DOE has done these for you.* Their evals often aren't sufficient, and the **DOE does not do psychosocial evaluations.**
3. Generally, evaluations should be from within the past 3 years.
4. Take stock of your evals again their last year of school. Make sure the batteries that were used are for adults, not children. **Adult services do not accept evaluations designed for children.**

Post-21 Programming

- Day Habilitation
- Day Hab Without Walls
- Private Residential Programs
- Supported Employment
- Self-direction
- Trade schools
- Transition and Postsecondary Programs for Students with Intellectual Disability (TPSID)
- ACCES-VR



Post-21 Programming

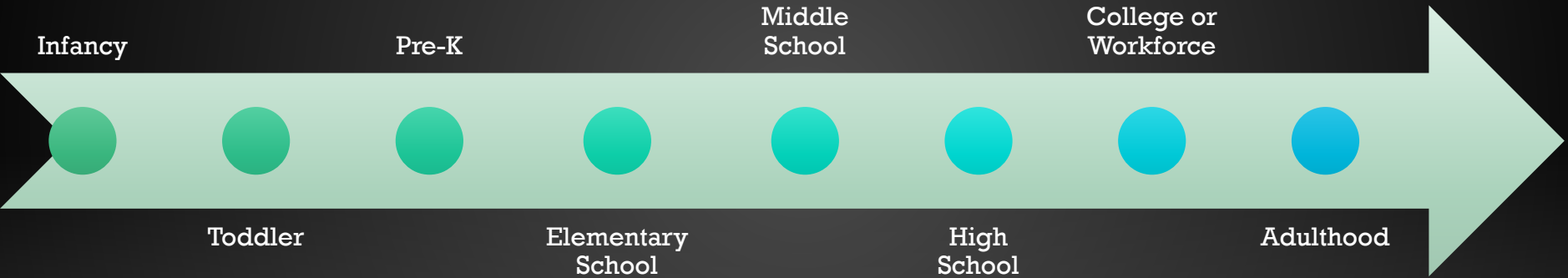
- ★ Talk about options, goals, strengths, etc with your child
- ★ Start exploring & visiting programs
- ★ Apply for desired programs by respective deadlines
- ★ Be confident that you have taken all the steps necessary to help your child soar into adulthood!



Passing the Torch

PARENTAL INFLUENCES ON THE DEVELOPMENT OF INDEPENDENCE

LIFE SPAN



When are our children
independent?

WHAT IS THE PARENT-CHILD RELATIONSHIP?

- At the core, parents are there to:
 - Help their children develop values and morality
 - Be an emotional support – providing loving, nurturing relationships
 - Guide their children towards independence
- Parents end up wearing multiple hats:
 - Parenting Hat
 - Friend Hat
 - Educator Hat
 - Coaching Hat
 - Mentoring Hat



WHAT DOES IT MEAN TO “LET GO”

- “Letting Go” is an emotionally charged phrase
 - Brings up ideas of abandonment
- “Letting Go” is not letting go of your parent-child relationship, it is a *shifting* of responsibility and accountability from you to your children
- This shifting of responsibility *is* the development of independence
- The responsibility to shift accountability falls on the parents' shoulders

DOMAINS OF LETTING GO

Academics

- Remembering to do homework
- Studying For Tests
- Breaking Down Assignments

Social

- Making Plans
- Dropping off at events

Independent Living

- Waking Up in the Morning
- Going to Bed
- Laundry
- Cleaning Room

Self Advocacy

- Emailing Teachers
- Asking for extensions on assignments
- Requesting Missing Work

Executive Functions

- Scheduling
- Appointments
- To Do Lists
- Breaking Down Tasks

CONCERNS

Are you ready to let go?

I like helping...

I don't want them to grow up

If I do it, I know it will work

I don't have the time to teach them...

I don't like seeing them struggle

Are they ready?

They aren't mature enough

They don't show a desire to do it

They don't like to struggle

They *like* when I help

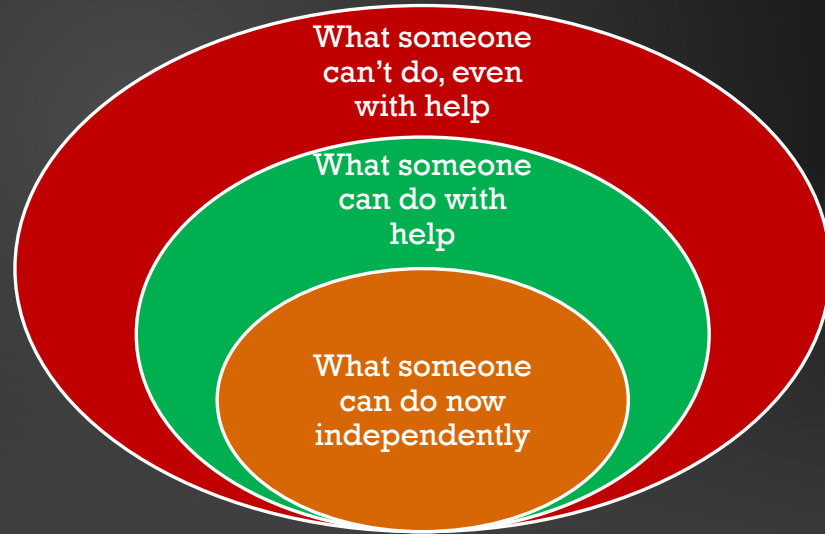
REAL TALK: WHAT ARE YOUR FAMILIES GOALS?

- It is important to step back and think about what goals we are trying to achieve
- When we are “going through the motions” we can lose sight of what we are doing, and how it relates to goals
- Acknowledge when you are doing **compensatory** supports and **long-term skill development**
 - **Compensatory** – getting over the hurdle by any means necessary
 - **Long Term Skill Development** – forward looking, often filled with struggle (and learning!), may look differently than how you do it

Goals	Compensatory	Long-Term Skill Development
Completing Homework	- Doing their homework for them	- Asking questions to guide them through assignment
Maintaining a Clean Room	- Clean their room for them	- Support in breaking down the task into manageable units (laundry one day, vacuuming another, etc)
Scheduling/Calendar/Planning	- Have a shared family calendar that you update and maintain for everyone	- Dedicating 30 minutes a week to helping them <i>learn</i> to maintain their own calendar
Social Opportunities/Being Social	-identify and find social opportunities	-involving them in the process of <i>how</i>

QUICK NOTE ON LONG TERM SKILL DEVELOPMENT

- Vygotsky's Zone of Proximal Development
- Learning occurs in the **green**

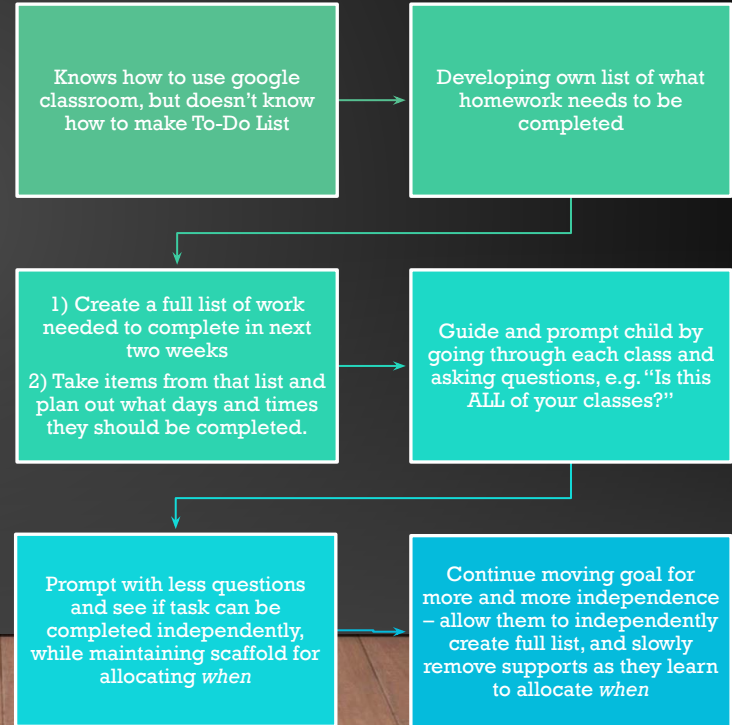


LONG-TERM SKILL DEVELOPMENT

- Instructional Scaffolding – breaking down learning into manageable chunks, that initially have supports built in that eventually fade out over time (as learning occurs)



Homework Completion



WHEN ARE COMPENSATORY SUPPORTS APPROPRIATE?

- To help maintain mental health and confidence
 - This mentality can become a bit of a quicksand paradox – continuing to provide compensatory supports prevents long term skill development
- When learning is not going to occur, and the consequences are not productive
 - E.g. If someone has a traumatic event, or is having an anxiety attack, that is not the opportunity for long term skill development (high anxiety prevents learning), so the role of compensatory supports is to remove the anxiety so that learning can occur again

FINAL THOUGHTS

- Everyone is different, and everyone's growth towards independence looks differently
- Focus on what *you* can control and influence – this is actionable – so focus on your role as the parent
- The parent-child relationship is inherently emotional, which can make it irrational at times – outside supports can help remove emotion from the transition in an objective way
- Some of the concepts discussed in this presentation are not easy to implement – understanding compensatory vs. long term skill development is something that people train to work on – so understand expectations that you place on yourself