

# Timelines: Planning for Your Life on the Autism Spectrum

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**Autism Spectrum Disorder** (ASD) is generally a lifelong **diagnosis**. It can be overwhelming to think of all the things you can do to help your loved one (or yourself) from the time of diagnosis through adulthood. Below is a checklist to help you focus on some of the most important considerations. Checklist items correspond with more in-depth articles in the CAR Autism Roadmap™. A list of recommended articles related to the Timelines are included at the end of each section. To expand a section and reveal its contents, click on one of the bold headings below.

## Across the lifespan

- Learn about ASD and **treatment** options
- Stay organized
- Develop a support network
- Write a will
- Consider the possibility of special needs trusts
- Encourage independence by teaching life skills
- Learn to be a good **advocate** and teach **self-advocacy** skills to your loved one on the autism spectrum
- Find recreational and extracurricular activities to promote socialization
- Discuss your child's diagnosis with him or her in a way that is age and developmentally appropriate
- Find time to relax
- Make sure your family is safe
- Prepare for life cycle events, family transitions, holidays, etc.
- Collect **data** to track your child's progress and to help evaluate the effectiveness of treatments
- Investigate different funding options for services, including private insurance (does your state mandate autism coverage and if so, is your child covered?) and public benefits (such as waivers, **Medical Assistance**, and **Social Security**)

## Birth to 3

### *Educational To Do List:*

- Contact your local **Early Intervention** program and schedule an evaluation
  - Evaluations must happen **once a year** as long as your child is receiving **Early Intervention** services for infants and toddlers
- Attend **annual** Individualized Family Service Plan (**IFSP**) meetings to review your child's educational progress and to reevaluate the service plan
- Stay in **touch** with your **Service Coordinator** so that you are informed about your child's program
- Work with your **Service Coordinator** and therapists to learn how to work with your child on your own at home
- **Age 2.5** Prepare to **transition** from the Infants and Toddlers **Early Intervention** Program to the Preschool **Special Education** system
  - Attend a **Transition Meeting** to develop a **transition plan**, which will become part of your child's **IFSP**
  - Investigate/visit preschool programs in your area
  - Your child will need to be evaluated in order to receive Special Education services in preschool
  - If your child does not qualify for Preschool Special Education services, consider **dispute resolution** or find other educational opportunities for your child
  - The formal transition process must start no sooner than 9 months before your child turns three and no less than 90 days before your child's 3rd birthday

### *Family To Do List:*

- Consider making an appointment with a **Developmental Pediatrician** to identify challenges and any co-occurring medical or **genetic** conditions and to measure progress going forward

- Explore child care options, if needed

## Preschool

*Age 3 to 5 or 6, depending on when your child enters kindergarten*

*Educational To Do List:*

- Contact your local **school district** for an evaluation for Preschool Special Education
  - In Pennsylvania, evaluations for Preschool Special Education must happen at least **every 2 years**
  - In New Jersey and many other states, a reevaluation must occur at least **every 3 years**, unless conditions warrant a reevaluation sooner
- Attend **annual Individualized Education Program (IEP)** meetings to review your child's educational progress and to reevaluate your child's Special Education program
- **By the end of February** of each year, hold an IEP meeting to determine your child's need for **Extended School Year** services in the summer
- **One year before transition to kindergarten**, prepare to transition from the Preschool Special Education System to the School Age Special Education System
  - The **IEP team** should develop a transition plan one year before the transition occurs
  - Attend a **transition meeting** with kindergarten personnel and preschool staff (**by February** of the year of transition)
  - The transition plan will include activities to help your child adjust to elementary school, such as visiting the new school and/or developing a **Social Story** and/or developing a **Social Story**
  - Reevaluation is not required before transition, but one may be requested
  - The **IEP team** will decide if a new IEP needs to be developed or if the program developed for preschool should be continued

*Family To Do List:*

- Consider making an appointment with a **Developmental Pediatrician** to identify challenges and any co-occurring medical or genetic conditions and to measure progress going forward
- Explore child care options, if needed
- **Age 3** Make first dentist appointment
- Begin teaching your child about his or her body
- Toilet training, if/when your child is ready
- **Waiver** eligibility in Pennsylvania begins at age **3**

## Elementary School

*Age 5 or 6 until 10-12, depending on when your child begins kindergarten and where you live*

*Educational To Do List:*

- Contact your local **school district** for an evaluation for School-Age Special Education
  - Special Education Evaluations must occur **every 3 years**, unless your child has an **intellectual disability** (then they happen **every 2 years**) or unless conditions warrant a reevaluation sooner
- Attend **annual Individualized Education Program (IEP)** meetings to review your child's educational progress and to reevaluate your child's Special Education program
- **By the end of February** of each year, hold an IEP meeting to determine your child's need for **Extended School Year (ESY)** services in the summer (Pennsylvania and New Jersey have this set date, but, regardless of where you live, it is a good idea for the **IEP team** to begin thinking about ESY at this time)
- If your child does not qualify for Special Education services, learn about 504 Plans and how they can provide accommodations within the school setting to help your child
- Review rules of state **standardized testing** and discuss testing options in IEP meetings
- Make sure your child's IEP contains a plan of action for field trips
- Talk to your school about ways to prevent **bullying** and how to react if **bullying** occurs; include in your IEP if necessary
- **3-6 months before transitioning to middle school**, work with your **IEP team** to create Social Stories™ and/or maps with pictures, and to schedule visits to the middle school to help familiarize your child with the new setting

### *Family To Do List:*

- Explore child care/after school care options, if needed
- Teach hygiene and grooming skills, including toilet training, if appropriate
- Continue teaching your child about his or her body, and begin discussions about [puberty](#) and sexuality
- Schedule and attend regular medical and dentist appointments
- Talk to your child about ways to prevent [bullying](#) and how to react if [bullying](#) occurs
- Be aware of signs of co-occurring conditions, such as [anxiety](#) , [depression](#) , [executive functioning](#) difficulties, ADHD, [sleep](#) disturbance, etc., and seek help when needed
- Review your current [treatment](#) plan and decide whether your child may be ready for different or more frequent therapy through private services outside of the education system, for example, a social skills group or supplemental [speech](#) therapy

## Middle School

*Age 10-12 to age 13 or 14, depending on where you live*

### *Educational To Do List:*

- If your child has a new diagnosis contact your local [school district](#) for an evaluation for School-age Special Education
  - Special Education Evaluations must occur **every 3 years**, unless your child has an [intellectual disability](#) (then they happen **every 2 years**) or unless conditions warrant a reevaluation sooner
- Attend **annual** Individualized Education Program (IEP) meetings to review your child's educational progress and to reevaluate your child's Special Education program
- **By the end of February** of each year, hold an IEP meeting to determine your child's need for [Extended School Year](#) (ESY) services in the summer (Pennsylvania and New Jersey have this set date, but, regardless of where you live, it is a good idea for the [IEP team](#) to begin thinking about ESY at this time)
- If your child does not qualify for Special Education services, learn about 504 Plans and how they can provide accommodations within the school setting to help your child
- Review rules of state [standardized testing](#) and discuss testing options in IEP meetings
- Talk to your school about ways to prevent [bullying](#) and how to react if [bullying](#) occurs; include in your IEP if necessary
- **3-6 months before transitioning to high school**, work with your [IEP team](#) to create Social Stories™ and/or maps with pictures, and to schedule visits to the high school to help familiarize your child with the new setting
- **When your child turns 14**, make sure transition to adulthood goals are included in your child's IEP and invite your child to IEP meetings (required at 14 for students living in Pennsylvania, New Jersey, Delaware, and some other states; not required until **age 16** elsewhere)

### *Family To Do List:*

- Explore child care/after school care options, if needed
- Teach hygiene and grooming skills
- Continue discussions about [puberty](#) and sexuality
- Continue to schedule and attend regular medical and dentist appointments
- Talk to your child about ways to prevent [bullying](#) and how to react if [bullying](#) occurs
- Be aware of signs of co-occurring conditions, particularly seizures, which are more likely to occur during adolescence, and seek help when needed
- Review your current [treatment](#) plan and decide whether your child may be ready for different or more frequent therapy through private services outside of the education system, for example, one-on-one counseling, such as [Cognitive Behavior Therapy](#) , or social coaching

## High School

*Age 13 or 14 to age 18-21, depending on if you choose to stay in high school that long*

### *Educational To Do List:*

- If your child has a new diagnosis, contact your local [school district](#) for an evaluation for School-age Special Education
  - Special Education Evaluations must occur **every 3 years**, unless your child has an [intellectual disability](#) (then they happen **every 2 years**) or unless conditions warrant a reevaluation sooner

- Attend **annual** Individualized Education Program (IEP) meetings to review your child's educational progress and to reevaluate your child's Special Education program
- **By the end of February** of each year, hold a meeting to determine your child's need for **Extended School Year** (ESY) services in the summer (Pennsylvania and New Jersey have this set date, but, regardless of where you live, it is a good idea for the **IEP team** to begin thinking about ESY at this time)
- If your child does not qualify for Special Education services, learn about 504 Plans and how they can provide accommodations within the school setting to help your child
- Include any necessary testing accommodations in your child's IEP
- If your child plans on taking the PSAT, SAT, or ACT in high school, you will need to apply to College Board or the ACT to receive accommodations **at least two months in advance** of the test date
- Talk to your school about ways to prevent **bullying** and how to react if **bullying** occurs; include in your IEP if necessary
- Make sure transition to adulthood goals are included in your child's IEP and invite your child to IEP meetings
  - transition is a process that must begin at **age 14** for students living in Pennsylvania, New Jersey, Delaware, and some other states; elsewhere, transition is not required to begin until **age 16**
  - Consider when your child might graduate (students receiving Special Education may delay graduation until the end of the school year when they turn **21 years old**)
  - Review graduation requirements in your child's **school district**
  - Consider what your child will do after graduation (for example, employment, higher education, or an organized day program) and where your child will live (at home, assisted living, independent living, etc); the transition plan in your child's IEP should strategize how to achieve these goals
  - **Two years before graduation** individuals can be referred to their local **Office of Vocational Rehabilitation** (OVR) to determine eligibility for **vocational** support and services; a representative from OVR can be invited to your IEP meeting
  - **During the year of graduation**, the **IEP team** will develop a **Summary of Performance** to summarize your child's achievements and document areas of continuing need

#### *Family To Do List:*







- Notice and develop skills that could lead to future employment
- Discuss with your child his or her goals for the future in terms of employment and higher education
- **At least two years before graduation**, if your child is interested in higher education, explore options and available supports within them
- Explore housing options
- If appropriate, help your child establish credit
- **Age 15** Discuss with your child whether he or she wants to learn how to drive; investigate the legal requirements of your state and what preparation your child will need; individuals can obtain a driver's license at **age 16** in most states
- **Age 16** Assist your child in obtaining a state identification card and/or driver's license, as appropriate
- **At least one year before your child turns age 18**, consider issues of **Guardianship** and **Power of Attorney**
- **Age 18** Register to vote
- **Age 18** Boys must register with the selective service
- **Age 18** Individuals may qualify for **Social Security** benefits
- Continue to teach and enforce hygiene and grooming skills
- Continue discussions about **puberty** and sexuality, with a focus on relationships
- Continue to talk to your child about ways to prevent **bullying** and how to react if **bullying** occurs
- Continue to schedule and attend regular medical and dentist appointments; pay **attention** to any co-occurring medical conditions
- Review your current **treatment** plan and decide whether your child may be ready for different or more frequent therapy through private services outside of the education system, for example, one-on-one counseling, such as **Cognitive Behavior Therapy**, or social coaching

## Adulthood

### *Age 18 and above*

- **Age 18** Register to vote
- **Age 18** Boys must register with the selective service



- **Age 18** Individuals may qualify for **Social Security**  benefits
- Transfer medical care from pediatrics to an adult medical care **provider** , and schedule **annual** dental and medical check-ups
- Consider working with a **psychologist** , social coach, or **job coach** , as needed, to help build skills, self-understanding, and understanding of expectations within the adult world
- **Age 25** Begin to research health insurance options; Children are no longer permitted to remain on their parents' health insurance policy once they turn **26** and must obtain their own health insurance at that time
- Develop employment experiences, either paid or volunteer; keep an updated resume and list of references
- Seek out work and educational accommodations and support, as needed; note that supports from the **Office of Vocational Rehabilitation**  may not continue throughout adulthood; different offices have *time limits*, and you should contact your local office to find out requirements in your region
- Think about to whom you want to disclose your diagnosis (employer, coworkers, new friends, etc.) and make a plan for doing so; consider discussing these issues with a **therapist** 
- Develop and maintain good credit by paying bills on time and sticking to a budget; monitor your credit reports **once a year**
- Explore transportation options, particularly if you begin a new job or day program
- Reevaluate housing and vocational options and support, as needed, to make sure they remain appropriate

The Center for Autism Research and The Children's Hospital of Philadelphia do not endorse or recommend any specific person or organization or form of treatment. The information included within the CAR Autism Roadmap™ and CAR Resource Directory™ should not be considered medical advice and should serve only as a guide to resources publicly and privately available. Choosing a treatment, course of action, and/or a resource is a personal decision, which should take into account each individual's and family's particular circumstances.