

# Education and Employment

Going to school and getting a job are often major milestones of growing up. Living with a rare disease can make it difficult—but not impossible—for some to do these things. Whether you need information about educational support programs or want to know what to tell your employer, RAREis Transitions can help you navigate.

#### Education

- **What is an educational support plan?**
- **Why should I get ready?**
- **Who can help me?**
- **When should I start?**

#### Employment

- **What should I know about employment?**
- **Should I disclose my condition or disability?**
- **What do I need to disclose?**
- **Who should I tell and when?**

# Education

## What is an educational support plan?

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- It is a plan listing different types of academic accommodations that are individualized to the specific needs of the student. The Individuals with Disabilities Education Act (IDEA) gives eligible children with disabilities the right to receive special services and accommodations.

## Why should I get ready?

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- The proper support and accommodations can create a better learning environment to help your child develop and reach their full potential in school.

## Who can help me?

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- Special education departments in your school or the school district
- School social workers
- [Disabilities Service Office of your college or university](#)
- Your advocacy organization

## When should I start?

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Under Part C of IDEA, states provide for **early intervention services** for children younger than three (3) years of age if a disability is suspected or known. Contact your state's Part C coordinator for more information. You can start your search [here](#). Children three years and older can receive support in their local school system. Contact your school and begin the conversation a few months before your child turns three.

Because people living with rare diseases may need some extra support at school, it's important for families to know about the support tools available to them. An individualized education program (IEP) or a 504 plan may help students facing learning challenges get the extra support they need and deserve. The table on the next page shows the differences between these two programs.

	IEP	504 Plan
<b>What is it?</b>	A legal written document that's individualized for any student in a public school who qualifies for special education	A legal plan for any student in a public school who has a disability
<b>Who is eligible?</b>	Student must fit 1 of 13 disability categories, which include autism, intellectual disability, and emotional disturbance	Student can have any disability, including physical or mental impairment
<b>What is in it?</b>	Document outlines specific and measurable goals and includes: <ul style="list-style-type: none"> <li>•How the student is doing currently</li> <li>•How educational services will be delivered</li> <li>•When services start</li> <li>•How the student will be able to participate in class</li> </ul>	Doesn't have to be written or list specific goals, but includes: <ul style="list-style-type: none"> <li>•Specific accommodations for the student to participate in the classroom</li> <li>•Who will provide services and support</li> <li>•Who is responsible for making sure the plan is carried out</li> </ul>
<b>Who creates the program?</b>	By law, a multi-person team, including: <ul style="list-style-type: none"> <li>•The student's parent</li> <li>•The student's teacher</li> <li>•A special education teacher</li> <li>•A school psychologist</li> <li>•A special education services representative</li> </ul> You can also have representatives weigh in from other classes such as gym, art, or music that aren't part of the core classes, but are important for development.	No legal standard regarding who is involved, but typically includes: <ul style="list-style-type: none"> <li>•The student's parent</li> <li>•The general classroom teacher</li> <li>•A special education teacher</li> <li>•The school principal</li> </ul>
<b>How often is progress reviewed?</b>	Required at least once a year	Not required, but usually once a year
<b>How much does it cost?</b>	No cost to families	No cost to families
<b>Who funds the program?</b>	The state receives money for eligible students from the U.S. Department of Education	The state doesn't get extra money for eligible students, but the federal government can penalize schools for not helping students
<b>How much does it cost?</b>	No cost to families	No cost to families
<b>Key takeaway</b>	A special education program is customized for a student who meets very strict criteria	Support and services are offered, but not customized, for a student who has a physical or mental impairment

# Employment

## What should I know about employment with a rare disease?

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- You are protected by the Americans with Disabilities Act (ADA) if you have a physical or mental impairment that substantially limits a major life activity. The law requires employers to make a reasonable accommodation to the known physical or mental limitations of otherwise qualified individuals with disabilities unless it results in undue hardship and applies to any business with 15 or more employees.

## Who should I tell and when?

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- It is best to disclose your condition on a “need-to-know” basis. An appropriate person would be someone in the human resources department, your immediate manager or the supervisor responsible for managing employees.
- Under ADA law you are entitled to:
  - Have information about your disability treated confidentially and with respect
  - Seek information about hiring practices
  - Disclose your disability at any time
  - Receive reasonable accommodations for an interview
  - Be considered for a position based on your skill and merit
  - Have respectful questioning about your disability for the purpose of determining whether you need accommodations

# Employment

## Should I disclose my condition or disability to my employer?

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- Disclosing a disability to your employer is not required; however, in order to benefit from ADA protections, you must disclose your disability.

## What do I need to disclose?

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- There is no required information to share and disclosure will be different for everyone. If you have a visible disability, it is often helpful to explain how you plan to accomplish work tasks. If your condition is not as visible, you will have to decide what information you feel comfortable revealing:
  - General information about your condition
  - Why you are disclosing this information
  - How the condition does or does not affect your ability to perform key job tasks
  - Types of accommodations that have worked for you in the past or you anticipate needing in the workplace