Child with a Disability Kit

Your child on one page, the school plan, the benefits, and the plan for when you cannot be there.

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If you only read one page

Parents of a child with a disability become experts fast. These seven points are what experienced parents wish they had known first.

1. **Write a one-page profile of your child.** How they communicate, what calms them, what to avoid, and their medical needs. Hand it to every new teacher, sitter and emergency room.
2. **Ask for services in writing.** Request an evaluation, an IEP or a 504 plan in a dated letter. Written requests start the school's legal timelines.
3. **Keep a paper trail.** Every evaluation, email and meeting note, in one place. Bring a second person to important meetings.
4. **Do not leave money directly to your child.** An inheritance in their name can end SSI and Medicaid. Use a special needs trust or an ABLE account instead.
5. **Plan for age 18 at 16.** Adulthood changes decision-making and benefits. Look at supported decision-making, powers of attorney and guardianship early.
6. **Write a letter of intent.** Routines, preferences and wishes for the future, for whoever cares for your child after you.
7. **Name a guardian in your will.** And talk to that person now, so they are ready if it happens.

Then start here: **About your child**, page 5.

What is in here

5 worksheets in three sections. Start with the first section, then whichever page someone is about to ask you for. A page filled in roughly is worth more than a blank one.

01

Your child

Who they are, and who looks after them.

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About your child

One page a new babysitter, teacher or ER nurse can read in two minutes. Keep a copy in the diaper bag or backpack.

The full guide: hubstone.com/guides/child-with-a-disability

Name ______________________ Date of birth ______________________

Diagnoses ______________________ Blood type ______________________

How they communicate

How they tell you what they need

____

____

Words, signs or devices they use ______________________

What helps and what does not

Helps	Upsets them

Medical

Allergies ______________________

Medications, see the full list at ______________________

Equipment and how it works ______________________

Seizure or emergency plan kept at ______________________

Parent to call first ______________________ Phone ______________________

Second contact ______________________ Phone ______________________

Care team

Everyone involved in your child's care, and what each one handles.

The full guide: hubstone.com/guides/child-with-a-disability

Role	Name	Phone or email	Next appointment
Pediatrician			
Specialist			
Specialist			
Occupational therapist			
Physical therapist			
Speech therapist			
Behavior therapist			
Case manager or service coordinator			
Respite provider			
Pharmacy			

Medical records and evaluations are kept at ______________________

Therapy notes and progress reports are kept at ______________________

02

School and benefits

The IEP or 504 plan, and every program and renewal date.

School plan

The IEP or 504 plan, its dates, and who to call about it.

The full guide: hubstone.com/guides/child-with-a-disability

Plan ☐ IEP ☐ 504 plan ☐ Neither yet

School ______________________ Grade ______________________

Case manager ______________________ Phone or email ______________________

Last annual review ______________________ Next annual review ______________________

Last evaluation ______________________ Next evaluation due ______________________

The current plan is kept at ______________________

Services and accommodations

Service or accommodation	How often	Being delivered

Dates to know. An IEP is reviewed at least once a year, and your child is reevaluated at least every three years. Transition planning for life after school must be in the IEP by age 16.

What to raise at the next meeting

____

____

____

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Benefits and money

What your child receives or is waiting for, where the paperwork is, and when each one renews.

The full guide: hubstone.com/guides/child-with-a-disability

Program	Status	Renews or reviews	Paperwork kept at
SSI			
Medicaid			
Medicaid waiver or waiting list			
State disability services			
Private insurance			
ABLE account			
Special needs trust			

Parents' income counts until 18. For a child, Social Security counts the parents' income and resources when deciding SSI. At 18 the child is reviewed again under adult rules, and many who were turned down can qualify.

ABLE accounts. An ABLE account lets a person with a disability save without losing SSI or Medicaid, up to limits. Up to $100,000 in the account does not count against SSI. The disability must have started before age 46.

> Waiver waiting lists can run for years in some states. Apply early, even before you need the services.

03

Planning ahead

Guardians, trusts, and the decisions that change at 18.

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Planning ahead

Who steps in if you cannot, how money is left to your child, and what changes at 18.

The full guide: hubstone.com/guides/child-with-a-disability

If you cannot care for them

Guardian named in your will ____________ Phone ____________

Backup guardian ____________ Phone ____________

Letter of intent is kept at ____________

A letter of intent tells the next caregiver what your child's days look like, what they love, and what you hope for them. It is not a legal document, and it is often the page caregivers say they needed most.

Leaving money

Do not leave it to them directly. An inheritance or life insurance paid straight to your child can end SSI and Medicaid. Leave it to a special needs trust instead, and name the trust on every beneficiary form.

- [ ] Special needs trust set up
- [ ] Trust named on life insurance beneficiary forms
- [ ] Trust named on retirement account beneficiary forms
- [ ] Relatives told to leave gifts to the trust, not the child

At 18

Plan for decisions ☐ Supported decision-making ☐ Powers of attorney ☐ Guardianship ☐ Not decided

Attorney ____________ Phone ____________

Start the process by ____________ Documents kept at ____________

Guardianship removes rights, so courts increasingly expect families to consider less restrictive options first. Ask an attorney in your state about the choices.

This does not have to stay paper

You have just written down the things your family would otherwise have to work out under pressure. Keep this binder somewhere two people know about, and tell them it exists.

Paper goes stale. A phone number changes, a policy renews, a parent moves, and the page you filled in last spring is quietly wrong.

Hubstone holds the same record and keeps it current. Enter something once, and share each page only with the people who should see it. When a detail changes, the record changes with it, and the reminder comes before the deadline. The Child with a Disability Kit is free, on paper and in the app.

Fill it in once

Scan to start at hubstone.com/start. No card needed.