

First 30 Days After a Diagnosis — Checklist for California Families

A week-by-week roadmap for parents of newly diagnosed children in California.

A new diagnosis can feel like standing in a hallway with too many doors. You do not have to walk through all of them this week. This checklist breaks the first 30 days into manageable steps so nothing critical slips through while you also give yourself room to breathe.

Week 1 — Pause, Gather, and Build a Support Circle

The goal this week is simple: get the paperwork you are entitled to and let a few trusted people in.

- Give yourself permission to process the diagnosis. Cry, sleep, journal, take a walk. Do not make big decisions yet.
- Ask your pediatrician for the written diagnosis in plain language, including ICD-10 codes if possible.
- Request referrals in writing to any relevant specialists (developmental pediatrician, neurologist, geneticist, psychologist).
- Request copies of all medical records from the past 12 months (you have a legal right to them).
- Ask your pediatrician about Early Start or Regional Center referral — they can fax one directly.
- Tell one trusted friend or family member. Keep your circle small this week.
- Join one California-specific parent support group (Family Resource Center, 211, or a local Facebook group).
- Save every business card, appointment card, and after-visit summary in one pile. You will sort it in Week 2.

Week 2 — Open the Two Main Doors: Regional Center and/or School District

In California, two systems do most of the heavy lifting for children with disabilities. Which one you call depends on your child's age.

- If your child is under 3: call Early Start (1-800-515-BABY) or your local Regional Center intake line.
- If your child is 3 or older: call your school district's special education office and request a written assessment in writing (email is fine).
- Write the date of your request — the district's assessment clock starts from this date.
- Call your Regional Center directly if you suspect intellectual disability, autism, cerebral palsy, epilepsy, or 5th category eligibility (ages 3+).
- Start a physical binder with these tabs: Medical, Evaluations, School/Regional Center, Insurance, Financial, Correspondence, Notes.
- Add a digital backup: a free cloud folder with scanned PDFs organized the same way.
- Start a dated log of every phone call: date, person's name, phone number, summary, next step.
- Put a copy of the diagnosis letter and any referrals at the front of your binder.

Week 3 — Apply for Benefits You May Already Qualify For

Applications take time to process. Starting them now means help arrives sooner.

- Apply for SSI (Supplemental Security Income) if your household income is modest. Call 1-800-772-1213 or apply in person.
- Apply for Medi-Cal for your child (a child with a disability may qualify even if the family does not).
- Ask your county about California Children's Services (CCS) for medically eligible conditions.
- Call your county IHSS office to screen for Protective Supervision (paid caregiver hours for a parent, in many cases).
- Contact your regional Family Resource Center (FRC) — free parent-to-parent support and navigation.
- Ask your Regional Center service coordinator whether your child may qualify for respite hours.
- If your child is in the hospital or recently was, ask the social worker about hospital-based financial aid and Medi-Cal enrollment help.

Week 4 — Plan for the Long Road

By now you have opened several doors. This week you step back and start thinking 6-12 months out.

- Read a plain-language overview of the HCBS Waivers: DDS Waiver, HCBS-DD, ABI Waiver, HIV/AIDS Waiver.
- Understand your insurance stack: private insurance primary, Medi-Cal secondary, Regional Center payer of last resort.
- Prepare for your first IPP (Individual Program Plan), IEP (Individualized Education Program), or IFSP (Individualized Family Service Plan) meeting.
- Write down your top 3 goals for your child before any planning meeting. Bring them in writing.
- Schedule a free 30-minute consultation with a special needs trust and estate planning attorney (many offer this).
- Look into CalABLE (tax-advantaged savings) for your child's future.
- Screen to see whether you qualify for Self-Determination Program (SDP) once your Regional Center case is open.
- Review the IHSS hours your child may qualify for and request a reassessment if needs increase.

Don't Forget Yourself

You are your child's most important long-term resource. You are allowed to need things too.

- Eat three meals. Drink water. Sleep when you can.
- Schedule one short respite break this month — a friend, a family member, or paid respite hours.
- Check in with your partner or co-parent. Agree on how you will divide calls, paperwork, and appointments.
- Tell your own doctor what is going on. Ask about a mental health referral if you need one.
- Pick one thing you love that has nothing to do with the diagnosis, and do it for 20 minutes this week.
- Lower the bar. Laundry can wait. Frozen pizza is a dinner.

Key Phone Numbers & Links

Resource	Phone / Link	What it's for
Early Start (0-3)	1-800-515-BABY (1-800-515-2229)	Early intervention referrals and intake
Regional Center lookup	dds.ca.gov/rc	Find your local Regional Center by ZIP
Disability Rights California	1-800-776-5746 disabilityrightsca.org	Free legal advocacy and publications
SSA (SSI)	1-800-772-1213 ssa.gov	Apply for SSI; check status
IHSS county offices	cdss.ca.gov/in-home-supportive-services	Find your county IHSS office
Family Resource Centers (FRC)	frcnca.org	Parent-to-parent support statewide
Medi-Cal	dhcs.ca.gov BenefitsCal.com	Apply for Medi-Cal
California Children's Services (CCS)	dhcs.ca.gov/services/ccs	Medically eligible conditions program