



Help for Families of Children with Birth Defects

If you have a child that was born with a birth defect, there are resources that can help your family.

If you need help with paying for medical care and meet the income requirements, these programs can help:

- Medicaid: Healthsource RI- [855-840-4774](tel:855-840-4774) or <https://healthsourceri.com/>
- Supplemental Security Income (based on parent's income): [800-772-1213](tel:800-772-1213)
- Katie Beckett (based on child's income): [401-462-0633](tel:401-462-0633)



If you need to talk to other parents, these support groups can help:

- Peer to Peer Connections at the Rhode Island Parent Information Network (RIPIN): [401-270-1010](tel:401-270-1010), x139
- Down Syndrome Society: [401-463-5751](tel:401-463-5751)
- Spina Bifida Association of Greater New England: [888-479-1900](tel:888-479-1900)
- The Rhode Island School for the Deaf: [401-222-3525](tel:401-222-3525)



Online (internet) support groups for parents of children with specific conditions are also available:

- Heart defects: <https://mendedhearts.org/about-us/>
- Craniosynostosis: craniocarebears.org
- Cleft lip/palate: <https://acpa-cpf.org>
- Gastroschisis: averysangels.org
- Hearing loss supports: <http://www.cdhh.ri.gov/>



There are community organizations that can help you too:

- First Connections: A Rhode Island Department of Health home visiting program that can help connect families to services: <http://health.ri.gov/find/services/detail.php?id=34>
- Visiting Nurse Association: <http://www.health.ri.gov/healthcare/providers/homehealthagencies/>
- RIPIN: help with healthcare, education, support groups, referrals: RIPIN.org or [401-270-0101](tel:401-270-0101)
- RIREACH: help with healthcare questions: [855-747-3224](tel:855-747-3224)



If you need help with education and development services, you can contact:

- Early Intervention: helps families support the growth and development of the child, birth to age three, who is delayed or has a medical condition known to cause delays:
<http://www.eohhs.ri.gov/Consumer/FamilieswithChildren/EarlyIntervention.aspx>
- Children's Neurodevelopment Center: [401-444-3500](tel:401-444-3500)
- Cedar Family Centers (Medicaid requirement): RIPIN [401-270-0101](tel:401-270-0101) or Three Cedar [401-444-7703](tel:401-444-7703)
- Special Education or Individual Education Plan (IEP): your local school department



Learn about other places that can help you. Visit RIBDP web page at:

- www.health.ri.gov/programs/birthdefects/