

# Navigating the System

What parents with children under 21 need to know

# The Arc of New Jersey

Programs and Services



# The Arc Hierarchy

Local County Chapters  
(Families & Service Providers)

State Chapters  
(State and  
Local Advocacy)

National  
Chapter  
(National  
Advocacy)

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# The Arc of New Jersey: Free Advocacy Services

- **Mainstreaming Medical Care**  
[www.mainstreamingmedicalcare.org](http://www.mainstreamingmedicalcare.org)
- **New Jersey Self-Advocacy Project**  
[www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)
- **Criminal Justice Advocacy Program**  
[www.cjapnj.org](http://www.cjapnj.org)
- **Planning For Adult Life**  
[www.planningforadulthood.org](http://www.planningforadulthood.org)
- **The Family Institute**  
[www.thearcfamilyinstitute.org](http://www.thearcfamilyinstitute.org)

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# The Arc of New Jersey: Services

- **ProjectHIRE** (Free to families, must be tied to funding through IEP or DVRS, Private pay)  
[www.projecthire.biz](http://www.projecthire.biz)
- **Camp Jaycee** (Private pay, PerformCare, DDD)  
[www.campjaycee.org](http://www.campjaycee.org)

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# State Services 5-21

Where do families go?

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# Ages 5-21 - Department Structure

**PerformCare**

**PerformCare  
(Point of  
Contact)**

**Children System of  
Care  
(Division in DCF)**

**The New Jersey Department  
of Children and Families  
(State Department)**

[www.performcarenj.org/families/disability/index.aspx](http://www.performcarenj.org/families/disability/index.aspx)

877-652-7624 - 24/7

**Services Children With:**

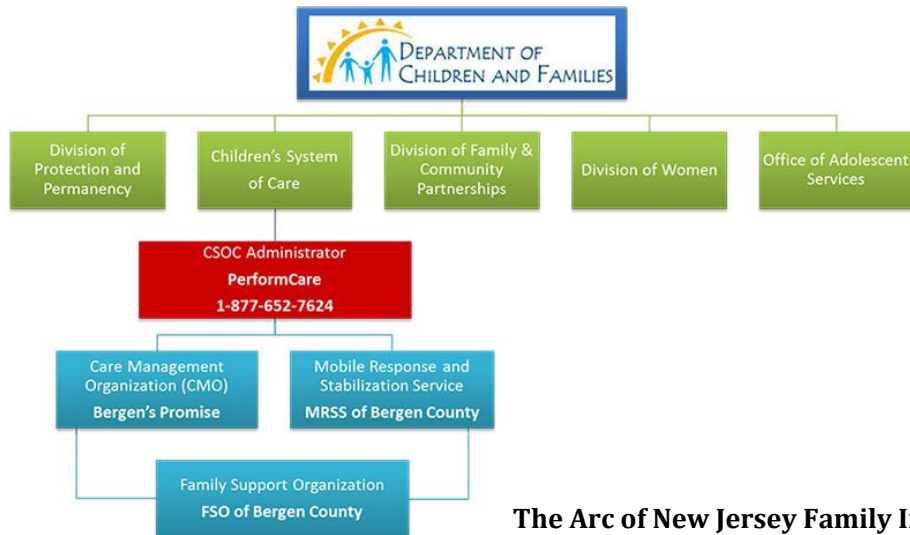
I/DD  
Mental Health  
Substance Abuse



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# Department Structure



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# Department Structure

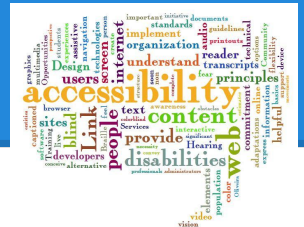
- The New Jersey Department of Children and Families (DCF) is the designated State department responsible for providing services for children and youth up to age 21 with intellectual and/or developmental disabilities (I/DD).
- In addition, the Children's System of Care (CSOC) is responsible for determining eligibility for childhood developmental disability services provided by the State of New Jersey for children under age 18.
- PerformCare New Jersey is the Contracted System Administrator for the New Jersey Children's System of Care.

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## Ages 5-17

- Eligibility is accessed through PerformCare [www.performcarenj.org](http://www.performcarenj.org)
- Applications are found on PerformCare's Website or you can call and complete one over the phone.  
1.877.652.7624
  - Electronic
  - Paper



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# Ages 5-17

- Eligibility is not based on family income, rather it is based on the needs of the child. Family need is also considered.
- The child must have substantial functional limitation in 3 or more of the following areas:
  - Self-care
  - Receptive and expressive language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living
  - Economic self-sufficiency

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## SECTION I - ACTIVITIES OF DAILY LIVING

at home within the last 6 months. You may indicate in the comment boxes any additional information such as

EATING	1 Mostly Independent	2 Needs Verbal Prompts Less Than Half of the Time	3 Needs Verbal Prompts More Than Half of the Time	4 Needs Physical Assistance Less Than Half of the Time	5 Needs Physical Assistance More Than Half of the Time	Not Applicable (N/A)
1. Eats with fingers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeds self with a spoon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Feeds self with fork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Cuts food with a knife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Drinks from a cup or glass	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments/Additional Information:  
(Briefly explain any N/A responses)

# Family Support Services



- Respite
  - Self/agency hire, After school, weekend, overnight
- Educational Advocacy
- Assistive Technology
  - Travel chairs, walkers, and positioning systems
- Home/Vehicle Modifications
  - Motorized ramps or lifts, widening of doorways, ramps and/or grab-bars, and their installation.

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# Family Support Services



- Family Support Services are designed to strengthen and promote families that provide care at home for a child or young adult.
- Call PerformCare and ask to fill out the “Family Support Application” Give a Realistic Picture
- Family needs to fill out this application every year

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## Other Possible Services

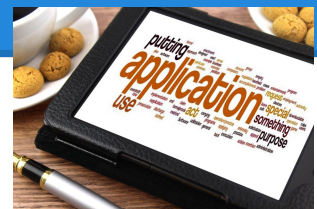
- Mobile Response
- Care Management (CMOs)
- Intensive In Home (IIH)
  - An array of rehabilitation and/or habilitation services delivered face-to-face by clinically licensed or certified practitioners in the home or community setting. (ABA, Social Skills Programs)
- Financial Assistance for Summer Camp (I/DD)

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## Age 18-21

- Eligibility goes through DDD
  - Family should and can apply starting at 18
- Application
  - <http://www.state.nj.us/humanservices/ddd/home>
  - 800-832-9173
- **If found eligible, the child will receive services through CSOC/PerformCare until 21 and then transition over to DDD.**



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# Mental Health and Substance Abuse Services

- Families can access behavioral and mental health services regardless of I/DD eligibility. Call PerformCare.

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## When Calling PerformCare



- What is your story? Paint a Picture
- Who is the member of your family with I/DD and what are the issues you are concerned about?
- How are you and your family coping?
- What kind of future do you want for your family member and what are the barriers?
- Give a realistic picture

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# Transition

14-21

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## Age 14-21



- IEP students are eligible for new evaluations every three years.
- Students with an IEP are entitled to remain in school until 21.
- The NJ Parental Rights in Special Education (PRISE) [www.nj.gov/education/specialed/form](http://www.nj.gov/education/specialed/form)

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# Medicaid Eligibility Track 1

- **Supplemental Security Income (SSI)/ Medicaid**
  - At age 18 the individual needs to apply for SSI by making an appointment with their county Social Security Office.
  - <http://www.ssa.gov/disabilityssi/ssi.html>
    - Monthly income of \$771 (2019)  
*And*
    - *No more than \$2000 in personal assets*
      - Ex. Savings/checking account or money left in a will



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# Special Medicaid Provisions

## “Disabled Adult Child” DAC

- An individual at 18 begins receiving Supplemental Security Income (SSI) and Medicaid.
- However when a parent retires, became disabled or passes way, SSI and Medicaid will stopped because the person begins receiving Social Security Disability (SSD) benefits based on a parent's work history.
- DAC Status allows person to keep Medicaid only.
- [bit.ly/njdacflyer](http://bit.ly/njdacflyer)

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## Medicaid Eligibility Track 2

- **NJ WorkAbility Program** (888.285.3036) offers full New Jersey Medicaid health coverage to people with disabilities who are working, and whose earnings would otherwise make them ineligible for Medicaid.
- A person with a permanent disability 16-64 can earn up to \$56,652 per year and have up to \$20,000 in personal assets.
- More for Married couples
- **Unearned Income** cannot exceed \$1,012 a month
  - Ex: SSDI based off a parents work history, disability or death benefit



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## Medicaid Eligibility Track 3

- **Community Medicaid**
  - Does not qualify for SSI/Medicaid
  - Monthly income of \$1,012
  - No more than \$4000 in personal assets
    - Contact your local Board of Social Services, also known as County Welfare Agency.



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# DDD Troubleshooting Form

- For individuals having trouble becoming eligible or believe that their loved one may not be eligible for Medicaid.
  - DDD.MediEligHelpdesk@dhs.state.nj.us
  - <http://www.state.nj.us/humanservices/ddd/services/medicaideligibility.htm>
  - Reach out to Beverly Roberts, Director of Mainstreaming Medical Care at: [broberts@arcnj.org](mailto:broberts@arcnj.org)

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# Guardianship & Supportive Decision Making

- 18 is the age of majority
- Caregivers should think about whether their loved one with I/DD can make medical, legal or financial decisions on their own.



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# Special Needs Trust

- A way to set aside funds for a person with a disability without jeopardizing vital government benefits (e.g., SSI, Medicaid, Section 8 housing).
- The beneficiary may continue to collect benefits: SSI, Medicaid, Food Stamps, HUD Housing, etc.
- The trust protects assets from being claimed by creditors or government agencies.
  - [www.plannj.org](http://www.plannj.org)



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# Achieving a Better Life Experience (ABLE) Act of 2014 ([www.ablenrc.org](http://www.ablenrc.org))

- Persons with disabilities can deposit up to \$15,000/yr in an ABLÉ tax-exempt savings account. Can open in other states.
- Eligibility: Age of onset of disability must occur before age 26 AND if a person receives SSI/SSDI the person is automatically eligible; If the person is not a recipient of SSI/SSDI, but still meets the age of onset disability requirement, they could still be eligible if they meet Social Security's definition and criteria regarding significant functional limitations.
- ABLE accounts won't affect continuing eligibility for SSI, Medicaid and other public benefits. (Current limit is \$2,000 in savings.)
- 529 College savings account can be rolled over into an ABLÉ account.
- For more information:  
[www.thearcfamilyinstitute.org/resources/able-account-go-bag.html](http://www.thearcfamilyinstitute.org/resources/able-account-go-bag.html)

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# Sibling Support

- Young sibs have many questions, but not always the language to verbalize their emotions
- During the teen and young adult years, sibs often become much more aware as they begin to realize the long-term supports their sibling may require.
- Many sibs feel overwhelmed. Empower sibs throughout all stages of life.
- Talk to adult sibs about end of life wishes, and creating an end of life plan (will, special need trust, burial arrangements, etc.), though it may be uncomfortable, can help ease the transition of caregiver role from parent to adult child.
- [www.thearcfamilyinstitute.org/resources/sibling-resources/sibling-support.html](http://www.thearcfamilyinstitute.org/resources/sibling-resources/sibling-support.html)

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# End of Life Planning

End-of-life planning can include:

- Advance Health Care Directive
- End-Of-Life Housing
- Estate Planning
- Funeral Planning
- Obituary and Death Notice

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# Thank You!



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