



North Jersey Health Collaborative
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Overview of Cancer Screenings for Individuals with Intellectual and Developmental Disabilities (IDD)

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September 14, 2021
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About The Arc of New Jersey

- Largest advocacy and service organization for children and adults with intellectual and developmental disabilities and their families.
- Founded in 1949 by families of individuals with I/DD and remains today a consumer and family driven organization.
- Serves the entire state of New Jersey through our Local County Chapters and our State Office Programs.
- In addition to our Programs, The Arc of New Jersey is highly involved in public policy, advocacy and governmental affairs activities.



Departments of The Arc of New Jersey

- The Arc Family Institute
- Governmental Affairs/Public Policy
- Public Affairs/Communications

Programs & Projects

- Mainstreaming Medical Care
- New Jersey Self-Advocacy Project
- Project HIRE
- Criminal Justice Advocacy Program
- Planning for Adult Life



Acronyms and Definitions

Federal Definition of Developmental Disabilities. According to the Developmental Disabilities Act, section 102(8), "the term 'developmental disability' means a severe, chronic disability of an individual 5 years of age or older that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the individual attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the following areas of major life activity; Self-care; Receptive and expressive language; learning; Mobility; Self-direction; Capacity for independent living; and Economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."



Acronyms and Definitions (cont).

- **IDD** – Intellectual and Developmental Disability
- Examples of developmental disabilities include **intellectual disability, Down syndrome, autism, brain injury (before the age of 22), cerebral palsy, fetal alcohol syndrome, and spina bifida.**
- **DDD** – *Mission Statement: The NJ Division of Developmental Disabilities assures the opportunity for individuals with developmental disabilities age 21 and older to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices.*



Acronyms and Definitions (cont.)

- **DSPs – Direct Support Professionals.** DSPs are an integral part of life in the community for people with IDD. They work directly with people with IDD to support them to participate in their communities.
- **Medicaid Health Maintenance Organization (HMO) or Managed Care Organization (MCO).** In the Medicaid system, these terms have the same meaning. In NJ, everyone enrolled in Medicaid must also be enrolled in a Medicaid MCO.
- **Dual Eligible** – A person who receives both Medicaid and Medicare services.



Cancer Screening Prevalence among Adults with Disabilities

Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data. *Cancer Medicine*. 2020. Sep. 9 (18) 6888-6895.

- This study is from the Netherlands.
- Individuals with ID received less cancer-related care than individuals without ID. Differences increased with age and were larger for females than for males.
- Conclusion: Cancer may be underdiagnosed and/or undertreated in people with ID, or cancer is truly less prevalent. Urgent follow-up investigations were recommended.



Importance of knowing family history of cancer

- Obtaining family history of cancer and other diseases is standard practice for health care providers. But primary care providers don't always request a record of family health history for individuals with IDD.
- We developed Adult Personal Health Record and Medical History form for individuals with IDD. (English and Spanish).
 - Family history notations for cancer of breast, colon, ovary, prostate, melanoma, other cancer.
 - Our form has space to note history of cancer for mother, father, siblings, grandmother, grandfather



Health insurance coverage for second opinions or treatment

Access to care for individuals with IDD may be more complicated, depending on health insurance. Individuals with IDD may have one, two, or three types of health insurance.

- Medicaid
- Medicare
- Private health insurance (usually through the parent's employer).



Importance of Medicaid for having DDD services

- In New Jersey: Individuals with IDD MUST have Medicaid to start DDD services, and must have Medicaid in the future to continue receiving DDD services.
- If Medicaid-related problems occur, can contact Beverly Roberts at The Arc of New Jersey. Broberts@arcnj.org



Continuation of parents' private health insurance...

- Young adults with IDD can continue to be covered by the parent's private health insurance after age 26 – but the paperwork must be done before the son/daughter is 26.
- But if son/daughter is 26, and has already been removed from parent's health insurance, the company won't reinstate.
- Fact Sheet from The Arc of New Jersey, widely distributed.






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Health Screenings that Detect Breast Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it

Let's Talk About Health

Health Screenings that Detect Breast Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it:
A comprehensive guide for women with intellectual and developmental disabilities and their caregivers






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Health Screenings that Detect Colon Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it

Let's Talk About Health

Health Screenings that Detect Colon Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it:
A comprehensive guide for individuals with intellectual and developmental disabilities and their caregivers

Horizon. The Arc Mainstreaming Medical Care Program of New Jersey





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Health Screenings that Detect Prostate Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it

Let's Talk About Health

Health Screenings that Detect Prostate Cancer and Lifestyle Choices that May Help Reduce the Risk of Developing it:

A comprehensive guide for men with intellectual and developmental disabilities and their caregivers

Horizon
The Horizon Foundation for New Jersey

The Arc
of New Jersey
Mainstreaming Medical Care Program





Some individuals with IDD encounter barriers to care

Medicaid managed care.

- If enrolled in Medicaid in NJ, must be enrolled in Medicaid MCO.
- In urgent cases, may have difficulty getting a quick appointment with oncologist. Care manager at the Medicaid MCO may be able to help.
 - Care manager may be able to arrange a quick appointment for urgent situations or out-of-network approval on case-by-case basis.
- Some people don't know that a Medicaid MCO care manager is available, upon request, for enrollees with IDD.



Informed consent for medical procedures

- “Decisions which have greater risks and consequences than those generally encountered during daily life require informed consent. These types of decisions include:
 - whether to undergo medical treatments for complex illnesses;
 - whether to undergo invasive tests;
 - whether to have surgery.
- Informed consent requires the provision of information relating to the decision. This information should identify the proposed action and explain its purpose, the possible adverse consequences, the anticipated benefits, and any alternatives. **Informed consent requires not only that the individual receive adequate information about the proposed action, but, also, that the individual have "competence" or "capacity" to consent to the action.** Individuals who are not competent or lack capacity to provide informed consent will generally need some form of substitute decision-maker to make the decision.” (Source: Disability Rights Pennsylvania.)



Legal Guardianship issues and health care decisions

- At the age of 18, individuals with IDD are “adults” and the parent can no longer make health care decisions for a son/daughter who is not competent to agree to health care procedures -- unless the parent has obtained legal authority to make decisions, such as legal guardianship.
- What happens if adult with IDD is not competent to give informed consent for a health care procedure and does not have a legal guardian?
 - There will likely be extensive delay until someone who is legally authorized can give consent.
 - Doctors have concerns about legal liability.



Medical transportation - ModivCare

- Non-emergency medical transportation for Medicaid beneficiaries – available at no cost through **ModivCare**. Previously called LogistiCare.
- Several ways to book a ride. Reservations # 1-866-527-9933.
- If another type of transportation is available, please use it.
- https://www.nj.gov/humanservices/dmahs/home/logisticare_english.pdf
- If transportation problems occur, report to me, using our Medicaid Problem Form.



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