



**Department
of Health**

DOWN SYNDROME AWARENESS

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**EARLY INTERVENTION COORDINATING COUNCIL MEETING
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WHAT IS DOWN SYNDROME?

- Down syndrome is a condition in which a person has an extra copy of chromosome 21
- Chromosomes are small "packages" of genes in the body's cells, which determine how the body forms and functions
- When babies are growing, the extra chromosome changes how their body and brain develop
- The chromosomal difference can cause both physical and mental challenges for the individual

DOWN SYNDROME AWARENESS PROGRAM

On December 13, 2024, Governor Hochul signed Assembly Bill A44138A

- an act to amend the public health law (Subdivision 1 of section 207) in relation to Down syndrome diagnosis awareness, that includes but is *not limited* to the following:

Create a Down Syndrome Awareness Program

- up-to-date and evidence-based information about Down syndrome
- life expectancy, expected intellectual and functional development
- intervention and treatment options
- resources
- national/local Down syndrome organizations

HOW DID THE DEPARTMENT RESPOND TO THIS LEGISLATION?

To be in compliance with this legislation, the Department updated the Bureau of Early Intervention's webpage with the following:

- Making Down syndrome information and resources available electronically
- Creating a website page dedicated to Down syndrome information and resources to be added on the Early Intervention Program website
- Sending out a listserv to Early Intervention providers and interested stakeholders about the addition of the Down syndrome information and resources page
- Ensuring the page is maintained and updated with information and resources periodically

WHAT IS INCLUDED ON THE DOWN SYNDROME WEBPAGE?

- Information about Down syndrome
- National and New York State Resources and Supports
- NYS Early Intervention Program Clinical Practice Guidelines for Down Syndrome
- Information about making a referral to the Early Intervention Program
- NYS Children and Youth with Special Health Care Needs (CYSHCN) Program Information

DOWN SYNDROME INFORMATION WEBPAGE



An official website of New York State. [Here's how you know.](#) ▾

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Individuals/Families

Providers/Professionals

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Health Data

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Search

Early Intervention

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Autism

Down Syndrome

Electronic Mailing Lists

Families

Child and Family Outcomes

Social-Emotional
Development

State Systemic Improvement
Plan (SSIP)

Memoranda, Guidance and
Clinical Practice Guidelines

Competency Areas for
Delivery of Early Intervention
Services

<https://www.health.ny.gov>

You are Here: [Home Page](#) > [Early Intervention Program](#) > Down Syndrome

Down Syndrome

What Is Down Syndrome?

Down syndrome is a chromosomal abnormality. A person with Down syndrome has three copies of chromosome 21, instead of the usual two.

What Causes Down Syndrome?

The extra copy of chromosome 21 is the direct cause of Down syndrome. Down syndrome is not caused by something the mother does (or does not do) during pregnancy. Down syndrome can occur in one of three forms:

- **Melotic nondisjunction** – An error occurs in the separation of chromosome 21 during cell division in the process of forming the embryo.
- **Translocation**– The extra copy of chromosome 21 is attached (translocated) to another chromosome.
- **Mosaicism** – An error occurs during cell division (mitosis) at some point after formation of the embryo.

How Common Is Down Syndrome?

Down syndrome is a relatively common genetic disorder, occurring in about one of every 800 to 1,000 live births. The chance of having a baby with Down syndrome increases significantly with the mother's increasing age. The risk of having a second child with Down syndrome is higher,



Department
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HOW IS THIS BILL RELEVANT TO THE EARLY INTERVENTION PROGRAM?

- This bill aligns with the mission of the New York State Early Intervention Program
- Primary purpose of early intervention is to mitigate the impact of the condition on a child's developmental progress
- Down syndrome is an “auto qualifying diagnosis” in the Early Intervention Program
- The Program aims to support parents in nurturing their infant/toddler's development

RESOURCES

- National Association for Down Syndrome (NADS)
- National Down Syndrome Society (NDSS)
- Down Syndrome Aim High Resource Center
- US Department of Health and Human Services- National Institutes of Health
- Centers for Disease Control and Prevention (CDC)
- Down Syndrome Family Network
- NICHD Information Resource Center

The following resources can be found on the Down syndrome page found here: health.ny.gov/community/infants_children/early_intervention/down_syndrome



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