

# Resources and Information for Down Syndrome Diagnosis

## Overview:

AB116 is a law that requires healthcare providers, including midwives, to give written, evidence-based information to individuals when a Down syndrome diagnosis is confirmed. This includes pregnant individuals, parents, or guardians of the child. Healthcare providers must also offer resources and support services to those who want them. This document provides a list of links and resources to meet the requirements of AB116.

## Links and Resources

### 1. Understanding Down Syndrome:

- National Down Syndrome Society (NDSS) [National Down Syndrome Society \(NDSS\)](#)
- Down Syndrome Diagnosis Network (DSDN) [Down Syndrome Support | DSDN Down Syndrome Diagnosis Network | United States \(dsdiagnosisnetwork.org\)](#)
- Down Syndrome Research Foundation (DSRF) [Home - Down Syndrome Resource Foundation \(dsrf.org\)](#)

### 2. Prenatal Care:

- American Pregnancy Association [American Pregnancy Association | Expecting with Confidence](#)
- Science Direct [Recommendations to improve the patient experience and avoid bias when prenatal screening/testing - ScienceDirect](#)
- National Down Syndrome Pregnancy [An Updated Prenatal Testing Pamphlet About Down Syndrome For Pregnant Women And New Parents | National Down Syndrome Society \(NDSS\)](#)

### 3. Pediatric Care:

- American Academy of Pediatrics (AAP) [Home | AAP](#)
- National Association for Down Syndrome (NADS) [National Association for Down Syndrome | Serving the Down Syndrome community since 1960 \(nads.org\)](#)

### 4. Early Intervention and Support Services:

- Nevada Early intervention Services (NEIS) [Early Intervention Programs \(nv.gov\)](#)
- National Early Childhood Technical Assistance Center (NECTAC) [National Early Childhood Technical Assistance Center \(NECTAC\) | Frank Porter Graham Child Development Institute \(unc.edu\)](#)

### 5. Legal and Advocacy Resources:

- The Arc [Support & Events – The Arc Nevada \(arcnv.org\)](#)
- National Down Syndrome Congress (NDSC) [National Down Syndrome Congress \(ndsccenter.org\)](#)
- Lettercase
  - <https://www.lettercase.org/issues/state-laws/>

- <https://www.lettercase.org/education/advocacy-organizations/>
- <https://www.lettercase.org/news/>
- The National Association of Perinatal Social Worker <https://www.napsw.org>
- Down Syndrome Adoption Network

## 6. Educational Resources:

- National Down Syndrome Society - Education Resources- [Education Program | National Down Syndrome Society \(NDSS\)](#)
- LuMind IDSC [LuMind IDSC Foundation | Accelerating Down syndrome research](#)
- Down syndrome material in Spanish <http://downsyndromepregnancy.org/materials-in-spanish/>
- Intellectual Disability and Health <http://www.intellectualdisability.info/historic-articles/articles/passport-to-health>
- Massachusetts Down syndrome Congress  
<https://mdsc.org/centers-of-excellence/national-parents-first-call-center/>
- LifeCourse Nexus <https://www.lifecoursetools.com>
- Nevada Medical Home Portal <https://nv.medicalhomeportal.org/>

## 7. Financial and Insurance Assistance:

- Healthcare.gov - Medicaid and CHIP coverage [Medicaid & CHIP coverage | HealthCare.gov](#)
- To get reimbursed for travel to go farther for care <https://tricare.mil/primetravel>
- TRICARE ECHO: <https://www.tricare.mil/Plans/SpecialPrograms/ECHO>

## 8. Community Support Groups:

- Down Syndrome Association of Greater Cincinnati (DSAGC) [Home - DSAGC](#)
- Global Down Syndrome Foundation [Home | Global Down Syndrome Foundation](#)
- Exceptional Military Families [teresa.andrews@spaceforce.mil](mailto:teresa.andrews@spaceforce.mil)  
<https://exceptionalmilitaryfam.com/>
- Exceptional Family Member Program [EFMP - Exceptional Family Member Program Resources | Military OneSource](#)
- Lettercase  
[https://www.lettercase.org/support-for-black-and-hispanic-new-and-expectant-parents/?fbclid=IwAR3Tk9kiqP\\_F2YOvX8oVT8bd418TNcNsRNgnVHydORQfLFTGK\\_ab45GUM\\_ME](https://www.lettercase.org/support-for-black-and-hispanic-new-and-expectant-parents/?fbclid=IwAR3Tk9kiqP_F2YOvX8oVT8bd418TNcNsRNgnVHydORQfLFTGK_ab45GUM_ME)

## 9. Parent and Provider Training and Mentor Resources:

- Recommendations to Improve the Patient Experience and Avoid Bias When Prenatal Screening/Testing: <https://authors.elsevier.com/a/1gAcC6uM4niAMM>
- Lettercase training for doctor/med professional delivering diagnosis

<https://www.lettercase.org/pht-206-understanding-disability-and-best-practices-for-communicating-a-diagnosis/>

#### 10. Fact Sheets and Other Materials

- <https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-usa-factsheet.pdf>
- Downloadable Booklet about child loss  
<http://downsyndromepregnancy.org/book/coping-with-loss/>
- What I wish I knew  
<http://downsyndromepregnancy.org/25-things-i-wish-theyd-told-me-in-the-hospital-when-my-son-was-diagnosed-with-down-syndrome/>

#### 11. Mass Recommended Book list

- <https://docs.google.com/document/d/1sIM3lQcl0NviF5cR5-FGpaywyS1kKY-iM54yH-QYE14/edit?usp=sharing>
- DSDN New parents resource book list <https://docs.google.com/document/d/1c8-6vVXo05KJ0prT1WPkHE2ENbpzgXrSgrRMN6PJxfs/edit#heading=h.596wprwpz42g>
- Global Down syndrome Foundation  
[https://www.flipsnack.com/globaldownsyndromefoundation/2022\\_pnp\\_english/full-view.html](https://www.flipsnack.com/globaldownsyndromefoundation/2022_pnp_english/full-view.html)
- Down Syndrome Indiana's Lucky Mama  
Project: <https://www.facebook.com/watch/?v=200184111263029>
- Prenatal diagnosis <https://themindsjournal.com/what-is-anticipatory-grief/>