

Roadmap for Supporting New and Expecting Parents

Advocacy - Birth to Pre-K

Presented by the Down Syndrome Collaborative Founders

Christy Cooper, Sarah Cullen, Stephanie Meredith, and Stephanie Thompson

Resources



Scenario 1



Scenario 2



Scenario 3





PRE-DECISION
EXPECTANT PARENTS



POST-DECISION
EXPECTANT PARENTS

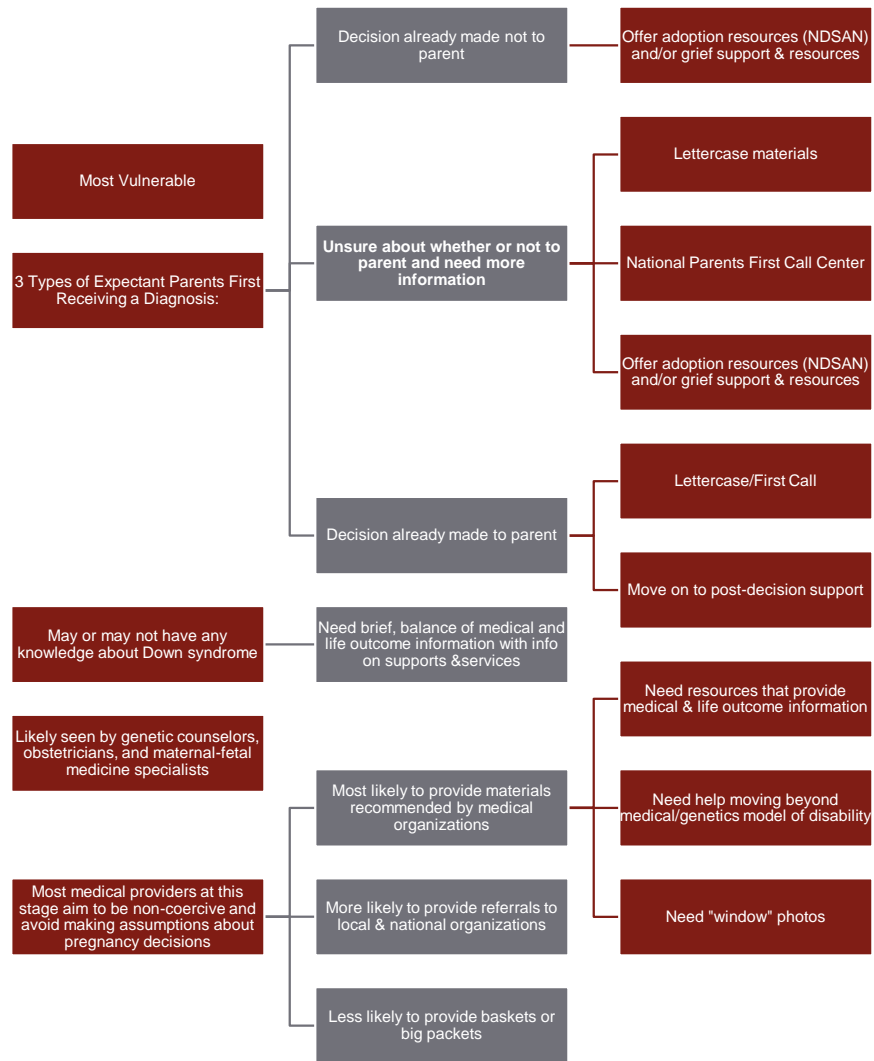


NEW PARENTS



FAMILIES AND
INDIVIDUALS WITH
DOWN SYNDROME

Understanding the Audience: Layers of Support



Pre-Decision Expectant Parents

Decision already made not to parent

Offer adoption resources (NDSAN) and/or grief support & resources

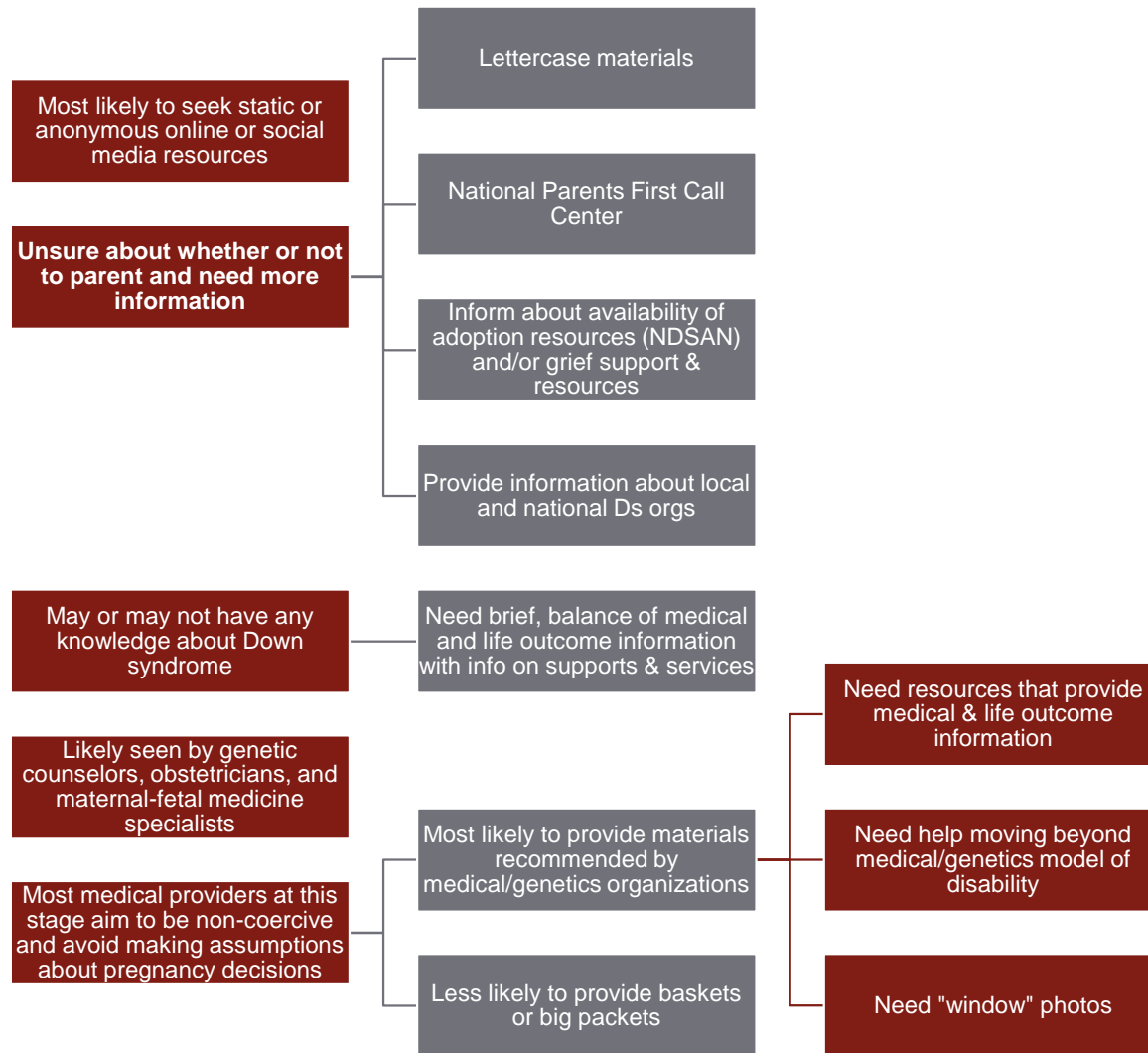
Offer Lettercase materials

National Parents First Call Center

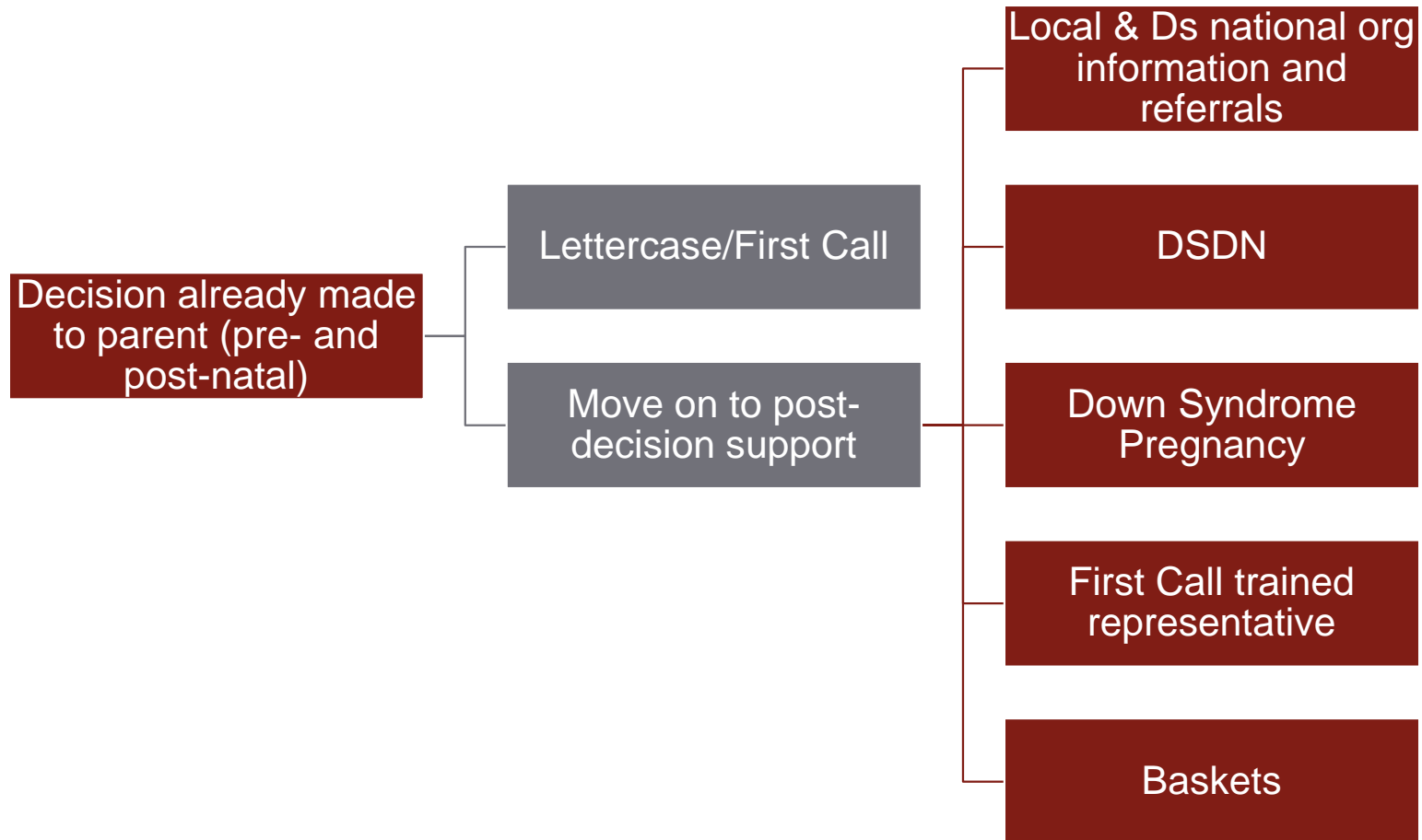
May or may not have any knowledge about Down syndrome

May need brief, balance of medical and life outcome information with info on supports & services

**Scenario:
Decision
already
made not to
parent**



**Scenario:
Unsure
about
whether or
not to parent
and need
more
information**



**Scenario:
Decision
already
made to
parent**

Prenatal Outreach Representative Training

(<https://www.lettercase.org/education/advocacy-organizations/>)



“Understanding a Down Syndrome Diagnosis” booklet

(<https://resources.lettercase.org>)



Accurate, Up-to-Date, Balanced Information

Available free online and print on request at lettercase.org at the University of Kentucky's Human Development Institute in multiple languages.

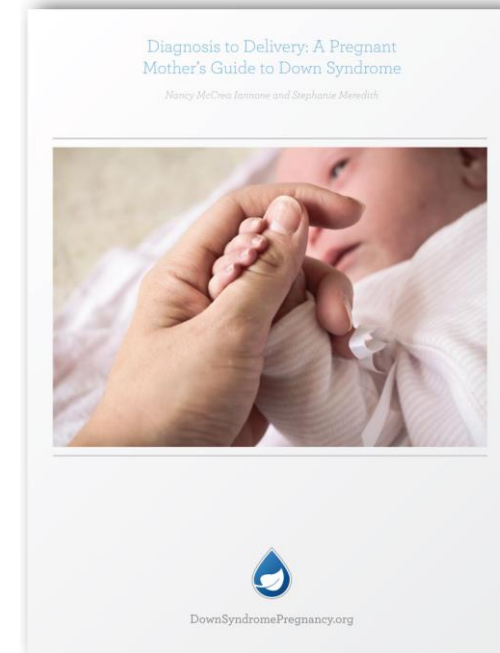
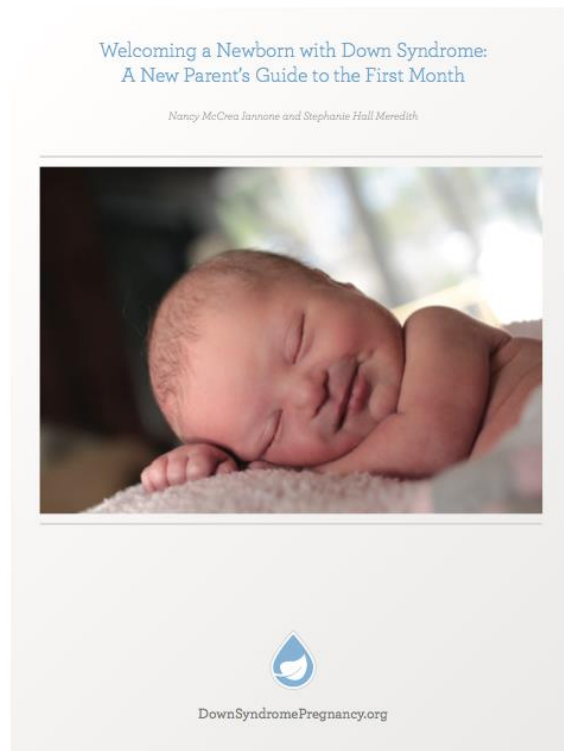
Diagnosis materials reviewed by Genetic Conditions Consensus Groups which includes representatives from ACOG, AAP, NSGC, ACMG, Association of University Centers on Disabilities, and national patient advocacy groups.



Recommended by ACOG,
ACMG, and NSGC.

Materials cited in AJOG,
Prenatal Diagnosis, Genetics
in Medicine, Am Journal of
Med Genetics, Obstetrics &
Gynecology, Journal of
Genetic Counseling, Ped in
Review, etc.

Funding provided by the
Joseph P. Kennedy, Jr.
Foundation and HDI Fund
for Excellence




**“Diagnosis to Delivery: A Pregnant Mother’s Guide to DS” &
“Welcoming a Newborn with DS” English and Spanish books (2020)
(<http://downsyndromepregnancy.org>)**

National Center/ Lettercase

(<https://resources.lettercase.org>)

Parents learning about a prenatal diagnosis for various genetic conditions:



Understanding a Turner Syndrome Diagnosis
(English & Spanish)
PRINTED BI-FOLDS WITH FULL VERSIONS ONLINE

PRINT ONLINE

lettercase.org



Understanding a Jacobsen Syndrome Diagnosis
PRINTED BI-FOLDS WITH FULL VERSIONS ONLINE


PRINT ONLINE

lettercase.org

Accurate, balanced, and up-to-date information about genetic conditions for medical professionals and new and expectant parents.

Materials offer accurate, balanced, and up-to-date information that has been reviewed by genetic and disability experts to include information about available services and support, legal issues, medical issues, and more. Our materials are recommended in various medical journals, including the National Society of Genetic Counselors, the American College of Obstetrics and Gynecologists, and the American Society of Human Genetics and Genomics.

For patients immediately following a confirmed prenatal diagnosis or results indicating high chances for Down syndrome:



Understanding a Down Syndrome Diagnosis
English and Spanish in one book

PRINT ONLINE

Also available as bi-folds in English, Spanish, Chinese, Korean, Japanese, Vietnamese, Somali, Canadian French, Arabic & Russian
PRINTED BI-FOLDS WITH FULL VERSIONS ONLINE

lettercase.org

How to Order:

All resources are available free online, and medical professionals and expectant parents can request complimentary samples of Lettercase materials. Additional printed resources can be ordered from lettercase.hdi.uky.edu. All proceeds are used to provide for the ongoing support of this university program.

This work is generously supported and funded by the Joseph P. Kennedy, Jr. Foundation & the Human Development Institute.



©
lettercase.org

NATIONAL CENTER
FOR PRENATAL AND
POSTNATAL RESOURCES
at the University of Kentucky's
Human Development Institute

National Parents First Call Center



NATIONAL PARENTS FIRST CALL CENTER

a program of the



nationalfirstcall@mdsc.org

National Down Syndrome Adoption Network



National
Down Syndrome
Adoption Network
planning for a loving future

**A Loving Choice...
Adoption as an Option**

A PROGRAM OF THE DOWN SYNDROME ASSOCIATION OF GREATER CINCINNATI

Down Syndrome Diagnosis Network

A Layer of Support
When You Need It Most



Real Time Parent Connections
Through our private, moderated online pregnancy and birth clubs, DSDN members can connect 24/7 with other parents at the same point in the journey.



Topical Support
DSDN provides 50+ additional groups for parents to more deeply and hear other parents' experiences. Groups include: pregnancy, heart conditions, single parenting, Spanish-speaking, and more!



Local Resources
While DSDN focuses online, we know how critical local connections are for a lifetime of support. Our team works to connect new parents to the local Down syndrome organizations and supports in their area.




Parent-Focused Programs and Services
DSDN hosts annual Rockin' Mom™ and Dad™ Retreats that allow for parents to connect and recharge. The DSDN Rockin' Family Fund enables us to provide parents with welcome gifts, scholarships, memorials, and adoption grants.



CONNECT TODAY
@THE DSDN www.DSDIAGNOSISNETWORK.ORG #DSDN



Discussing a Diagnosis
Trisomy 21 (Down syndrome)



Support for Medical Providers
Unexpected news can be difficult to share with patients. The American Academy of Pediatrics (AAP) recommends the following for physicians discussing a Down syndrome diagnosis.

Helpful discussion will include:

- Up-to-date, accurate information on personal opinions rather than relying on personal opinions and experience (syndrome)
- Person first language (child with Down syndrome)
- Connection to other parents and resource groups
- Discussion of life potentials for people with Down syndrome


Helpful discussion will include:

- Many families find it important to have the diagnosis confirmed before they can consider what it will mean to their infant and their family

At the time of diagnosis:

- Congratulate the family
- When possible, have infant present; refer to infant by name
- Use a respectful bedside manner
- Time discussion after labor is complete and as soon as a diagnosis is suspected
- Have a support person present for parent
- Use a cohesive, physician-led team approach

CONNECT TODAY
@THE DSDN www.DSDIAGNOSISNETWORK.ORG #DSDN



BULL M3, TROTTER T, SANTORO SL, ET AL; AAP COUNCIL ON GENETICS. HEALTH SUPERVISION FOR CHILDREN AND ADOLESCENTS WITH DOWN SYNDROME. PEDIATRICS. 2022;149(5):E2022057010

**Bad Diagnosis
Experiences**

**Concerns:
Advocacy Community**

Bad Diagnosis Experiences

- Providing resources, support, and training for clinicians can improve diagnosis experiences for families.

Reproductive Decisions & Impact on Community

**Addressing Concerns:
Advocacy Community**

1

**Fully Funding
Prenatally and
Postnatally
Diagnosed
Awareness Act**

2

**Access to Genetic
Counselor
Services Act**

3

**Disability
Designation as
Minority
Underserved
Populations**

4

**Required Disability
Competency
Training for
Medical
Professionals**

Policy Initiatives



DOWN SYNDROME COLLABORATIVE

For New and Expectant Parent Support

DOWN SYNDROME COLLABORATIVE



Down Syndrome Diagnosis Network (DSDN)
Christy Cooper
Christy@dsdiagnosisnetwork.org

National Center for Prenatal and Postnatal Resources
Stephanie Meredith, MA
Stephanie.Meredith@uky.edu

National Down Syndrome Adoption Network
Stephanie Thompson
stephanie@ndsan.org

National Parents First Call Center
Sarah Cullen
Scullen@mdsc.org