

Supporting Healthy Habits With HomeGrown

March 18, 2026



Welcome!

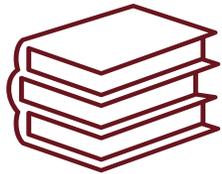
We are Recording

- Please use the chat function or the Q&A button at the bottom of the screen to ask questions.
- A Follow-up email will be sent out with additional resources and a link to the recording of today's presentation.

NDSS is creating a world where individuals with Down syndrome thrive.

NDSS Core Programs

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:



**Resources
& Support**



Research



**Advocacy
& Policy**

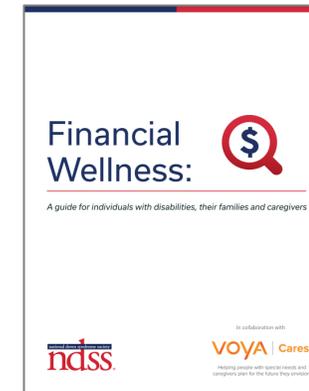
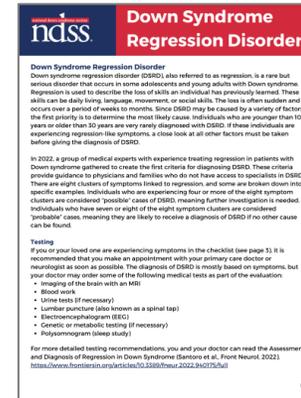


**Community
Engagement**

NDSS Core Programs

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving, and more



Upcoming Webinars



national down syndrome society
ndss.

join our
WEBINAR

Voices From the Down Syndrome Community

with James E. Valentine, Director, and Sarah L. Wicks, Associate, from Hyman, Phelps & McNamara, P.C.

April 6, 2026 | 3:00 PM ET

The poster features a dark background with a subtle grid pattern. At the top left is the NDSS logo. The text 'join our WEBINAR' is prominently displayed in the center. Below this, a blue box contains the title 'Voices From the Down Syndrome Community'. Underneath, the speakers' names and titles are listed. The date and time are shown in a bold font. At the bottom, there are two circular headshots of the speakers: a woman on the left and a man on the right.

Join Associates from Hyman, Phelps & McNamara, P.C. to learn about opportunities for participating, listening, and contributing to the upcoming NDSS-sponsored Patient-Focused Drug Development Meeting (PFDD) with the United States Food & Drug Administration (FDA) in June.



national down syndrome society
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join our
WEBINAR

Navigating an Autism Diagnosis and Services

with Dr. Melissa Hunter and Dr. Rachel Schumacher

April 15, 2026
1:00 PM ET

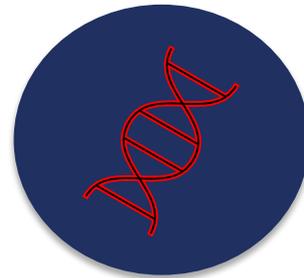
The poster features a dark background with a subtle grid pattern. At the top left is the NDSS logo. The text 'join our WEBINAR' is prominently displayed in the center. Below this, a red box contains the title 'Navigating an Autism Diagnosis and Services'. Underneath, the speakers' names and titles are listed. The date and time are shown in a bold font. At the bottom, there are two circular headshots of the speakers: a woman on the left and a woman on the right. A calendar icon is positioned to the left of the date and time.

This webinar will focus on the *practical pathway*—from first concerns to diagnosis to accessing services, specifically for individuals with Down syndrome. Participants will leave with actionable guidance, questions to ask providers, and strategies for navigating common system barriers.

NDSS Core Programs

Research

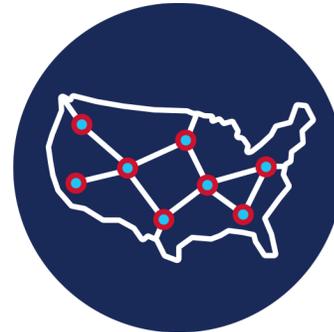
- Bridge between research and our community
- Coordinating research projects
- Preparing scientific industry companies for clinical trials
- Sharing research opportunities with families
- Expanding access to clinical trials, treatments, and diagnostics



NDSS Core Programs

Advocacy & Public Policy

- Federal, state, and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome



NDSS Core Programs

Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video Presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!



Upcoming NDSS Events



Racing For 3.21
March 21, 2026
[Virtual](#)



[Run For 3.21](#)
March 21, 2026
West Coast
Spots are filled, but
you can still support!



[Brighter Futures Conference](#)
March 27 - 28, 2026
Worcester, MA



[Down Syndrome Advocacy Conference](#)
May 11-13, 2026
Washington D.C.

Supporting Healthy Habits with



A family-centered nutrition and physical activity program for
families of children with Down syndrome

PRESENTERS: DR. ERIK WILLIS, EMMY CLARKE, DR. MICHAELA
SCHENKELBERG, STASIA MCDANIEL, MICHELLE KANG

Our Team

An interdisciplinary team of researchers, educators, medical professionals, and technology experts with diverse expertise in dietetics, physical activity, maternal and child health, communications, healthcare, statistics, and web development.



Erik Willis



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL



Emmy Clarke



Michaela
Schenkelberg
UNIVERSITY OF
Nebraska
Omaha



Michelle Kang



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL



Stasia McDaniel



Heather Wasser



THE UNIVERSITY
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at CHAPEL HILL



Seema Agrawal



Reneé Moore
 **Drexel**
UNIVERSITY



Scott Quaife



DOWN SYNDROME
INNOVATIONS



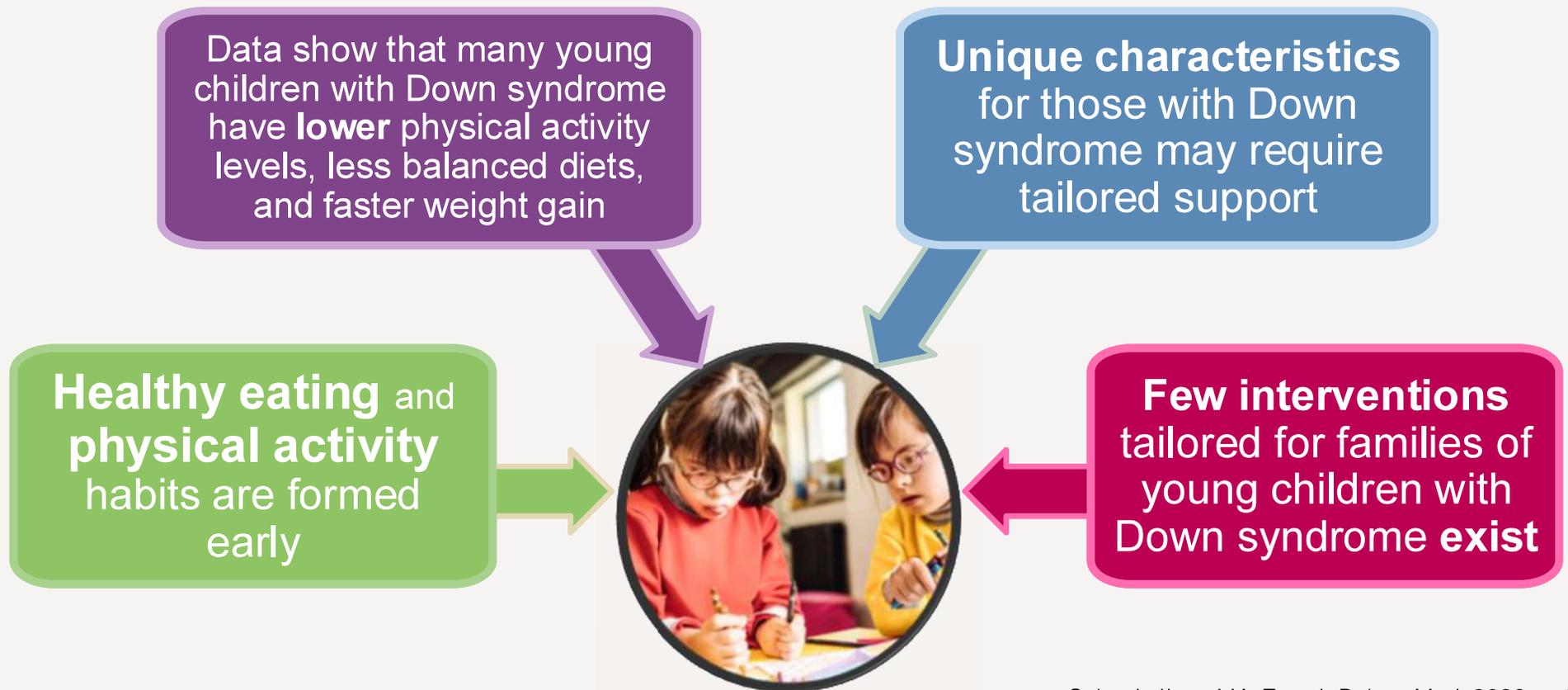
Sarah Armstrong
Duke
UNIVERSITY

Overview

- Introduction to HomeGrown
- Co-Designing HomeGrown with Families & Practitioners
- Nutrition Considerations
- Physical Activity Considerations
- HomeGrown Website Demonstration
- Joining the HomeGrown Community
- Questions & Answers



Background



Our Timeline



Healthy Homes for Children Survey

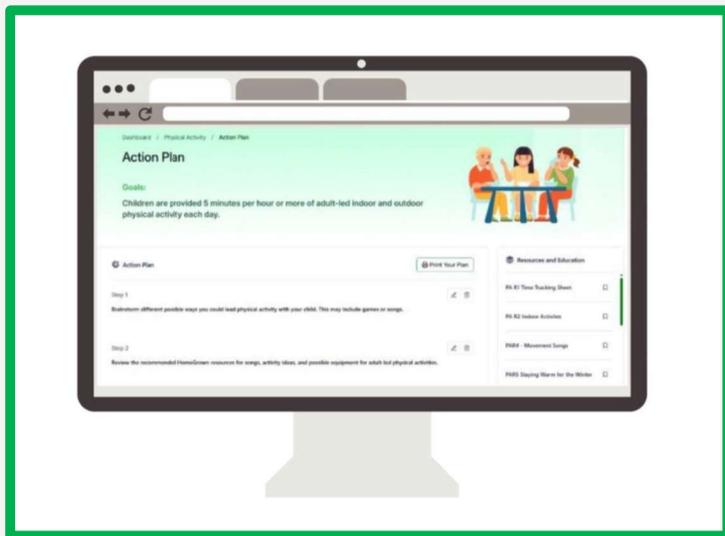
Questionnaires

- Demographics
- Health resources
- Social determinants of health
- Feeding practices

Evidence-Based Practice Content Areas

- Breast/infant feeding
- **Child nutrition**
- Farm to home
- Oral health
- Outdoor play and learning
- **Physical activity**
- Screen time

Family-Informed User Design



Guided website walkthroughs with live Q&A

Post-website survey and suggestions

Feedback provided to website developers

Family-Informed User Design



Strengths

- Educational resources and discussion forums worked well
- Profile setup was intuitive
- Felt confident using the website, did not find it difficult to use
- Modules functioned well

Areas for Improvement

- Primarily related to layout and flow
- Goal selection and action plan navigation information
- Layout and button locations on some pages
- Interest in adding progress bars

Nutrition Considerations



Children with Down syndrome should follow general nutrition recommendations

Fruits and vegetables, high fiber foods, lean protein, dairy or dairy alternatives are central

Sugar-sweetened beverages, high sugar foods, highly processed foods and snacks should be limited

Specialized strategies may be used to meet these recommendations

Example Considerations and Strategies



Celiac Disease is Common, Making Fiber Goals Difficult

Include more oats
Include more lentils
Chickpea pasta, etc.



Milk is Commonly Overconsumed

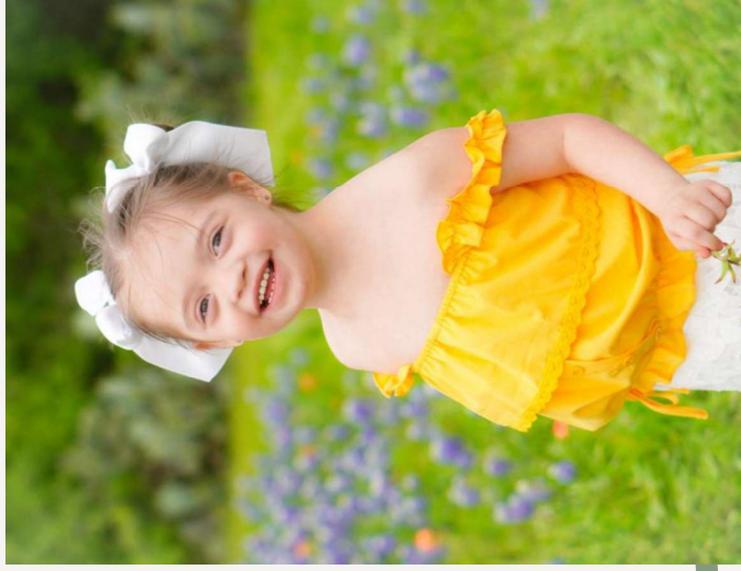
Monitor milk consumption
Discuss appropriate upper limit with physician or registered dietitian



Texture challenges makes vegetables challenging

Blend veggies into sauces
Steam, mash, puree

Concern for Weight & Appetite

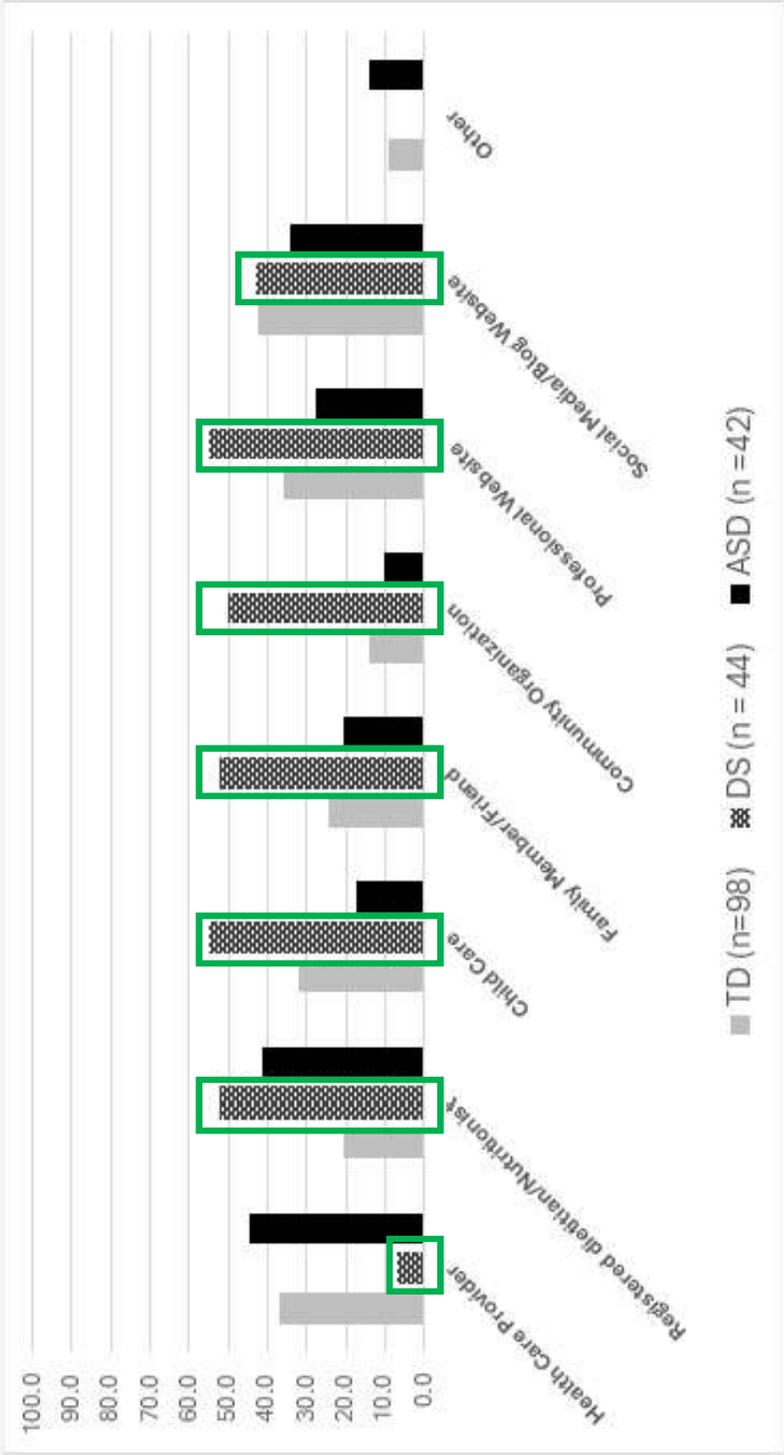


Parents of children with Down syndrome were more concerned about their child becoming overweight than other populations

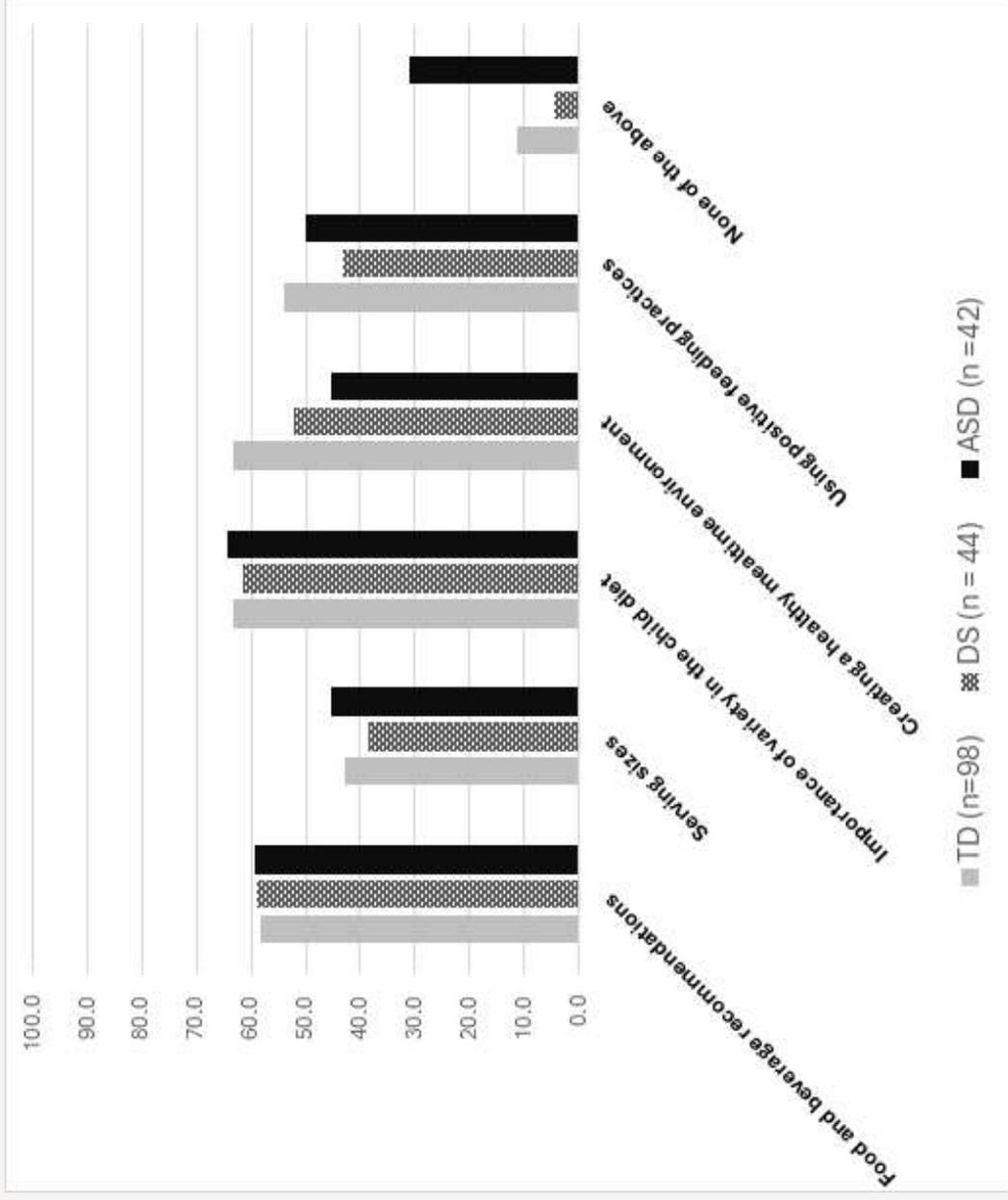
Parents of children with Down syndrome expressed feeling a greater need to regulate their child's intake

These concerns can lead to well-intended yet counterproductive practices

Percentage of caregivers reporting receipt of information from various sources



Percentage of caregivers reporting receipt of information about child nutrition topics.



Knowledge is Power!

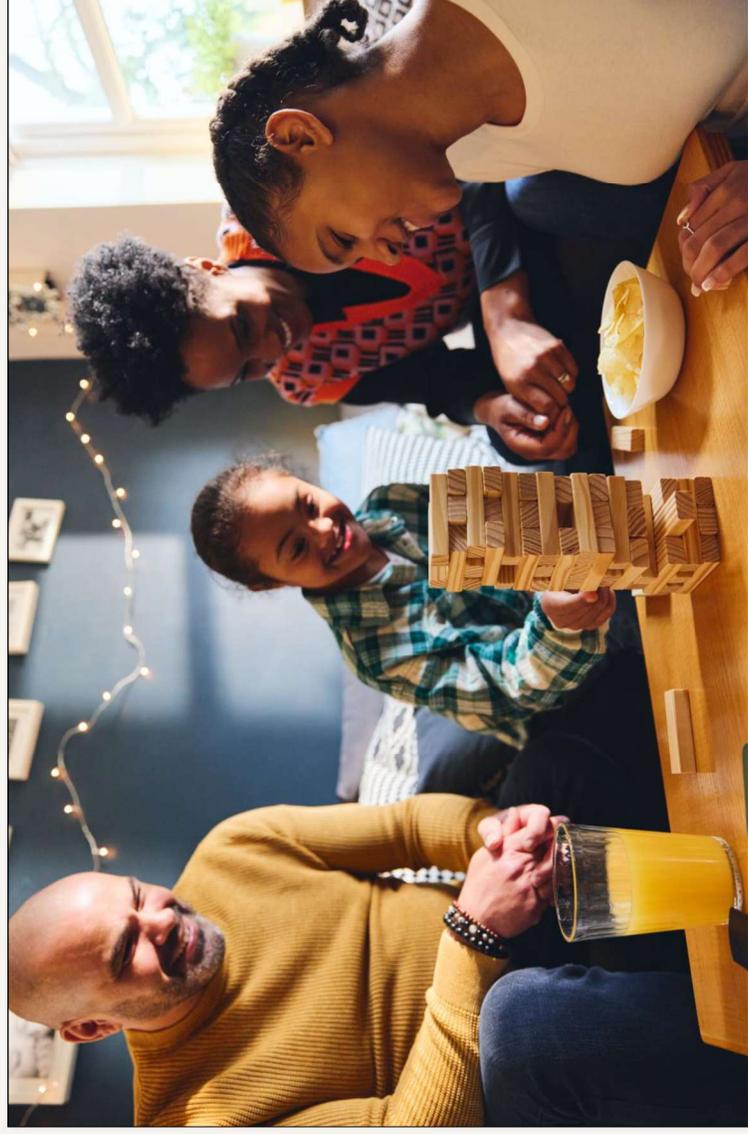


HomeGrown can help families build knowledge, skills, and confidence to minimize concerns and utilize productive nutrition practices.

Physical Activity and Children with Down Syndrome

62% of caregivers of children with Down syndrome feel like they receive **adequate health information and resources** for physical activity and play.

Compared to **84.9%** of caregivers with a child without Down syndrome



How Much Physical Activity?

Infants & Toddlers

Daily active play
Tummy time
Limit time in restrictive devices



Preschoolers (3-5 years)

15 minutes per hour (3 hours, daily)
Structured & unstructured
Various intensities



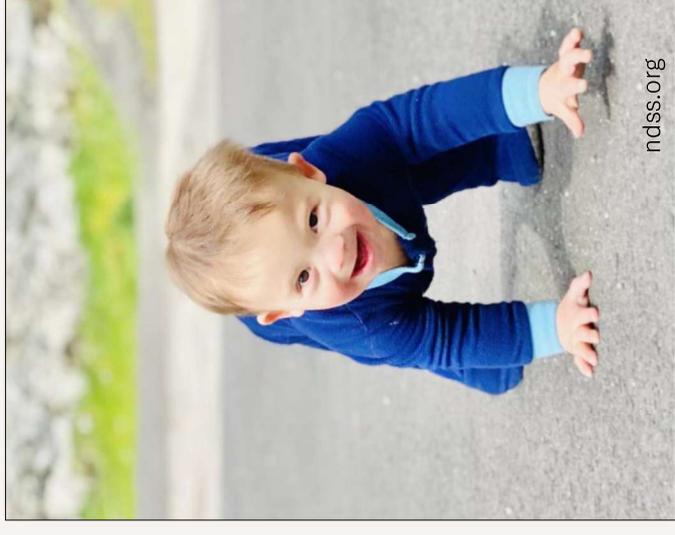
Children (6+ years)

60 minutes moderate-to-vigorous per day
3+ days of muscle and bone strengthening



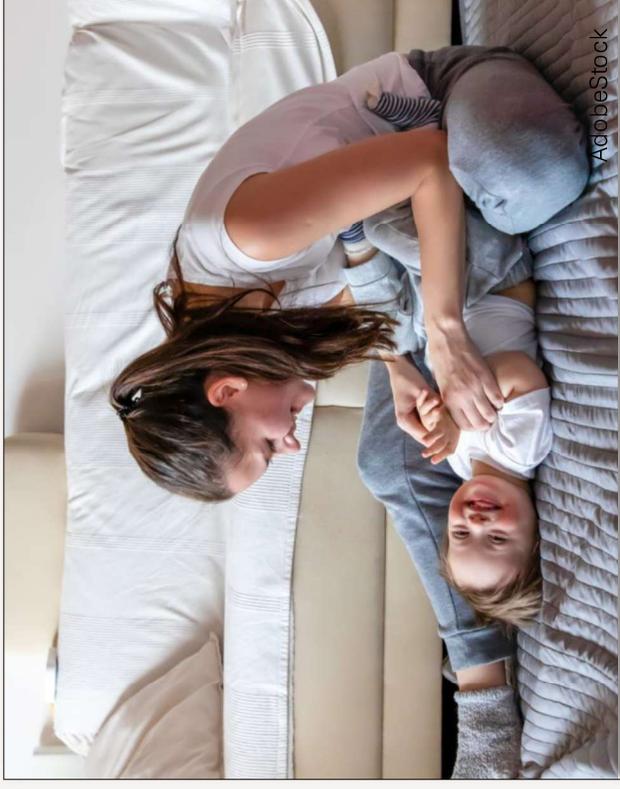
Considerations for Children with Down Syndrome

- Low muscle tone (hypotonia), postural stability, strength
- Low endurance
- Joint laxity, hyperflexibility
- Child motivation
- Comorbidities (e.g., congenital heart defects)
- Limited inclusive sports and play programming
- Developmental milestone delays



Motor Development & Physical Activity

- Encourages exploration & object manipulation
- Boosts cognitive, language, and social skills
- Establishes the foundation for more complex movements
- Supports healthy growth & development
- Encourages participation in physical activity



Healthy Habits Start at Home

Children are influenced by their environment – both physical and social.

HomeGrown equips families with strategies to create healthy home environments that support developmentally-appropriate, physically active play.



Movement Books & Toy Guides

Tips to Support Emerging Walkers

At-Home Gross Motor Activities with Adaptations

Printable Activity Cue Cards

What the 6-Month **HomeGrown** Experience Looks Like

Your 6-Month Journey in HomeGrown

HomeGrown includes **two 3-month cycles**:

- One focused on Nutrition
- One focused on Physical Activity

Each cycle follows the same simple 4-step process:

1. Assess

- Complete a guided self-assessment to reflect on your current routines.

2. Plan

- Choose 3–5 realistic goals that fit your child and family.

3. Learn & Act

- Use short videos, tools, and activity ideas to try new routines at home.

4. Keep It Up

- Revisit your assessment, celebrate progress, and adjust goals as needed.

What Participation Looks Like in Practice



Once You Begin the Intervention, You Can Expect To...



Attend an individual orientation call to get started



Complete a self-assessment at the start of each cycle



Select 3-5 goals using the HomeGrown website



Integrate small, manageable changes into everyday routines



Join twice-monthly group coaching calls for support and shared ideas



Receive supportive text reminders throughout the program



Meet individually at the end of each cycle to reflect and celebrate growth

Throughout the program, families:

Track progress

Adjust goals as needed

Build routines that support their child's development, independence, and joy

The goal isn't perfection - it's steady, sustainable progress over time.

HomeGrown Demonstration – Physical Activity Module

The screenshot displays the HomeGrown dashboard interface. At the top, there is a navigation bar with the HomeGrown logo on the left and a 'User' profile icon on the right. The main navigation menu includes 'Dashboard', 'Tools & Resources', and 'Discussion Forum'. The central area features a large green banner with the text: 'Dashboard Here's your HomeGrown activity at a glance. Your badges Earn badges for completing tasks in each module.' Below this banner are two module cards. The first card is for 'Child Nutrition' with a '0% Complete' progress indicator and a 'Start Module' button. The second card is for 'Physical Activity' with a '0% Complete' progress indicator and a 'Start Module' button. Each module card includes a list of tasks: 'Assess Pending', 'Set Goals Pending', 'Plan Pending', and 'Re-Assess Pending'.

Self-Assessment > Time Provided

Please answer the following questions about the time your family provides for outdoor play and learning.

✓ Tailoring Questions > 2 Time Provided > 3 Adult Practices

Please answer the following questions about your child's physical activity.

On a typical day how much total time is available for your child to be physically active?

- Less than 5 minutes
- 5 - 9 minutes
- 10 - 14 minutes
- 15 minutes or more

On a typical day when your child is in your care, how often is developmentally appropriate play offered to your child?

- 1 time per day or less
- 2 times per day
- 3 times per day
- 4 times per day or more

On a typical day when your child is in your care, how much of your child's time being physically active led by an adult?

- Less than 2 minutes
- 2 - 3 minutes
- 4 - 4 minutes
- 5 minutes or more

Self Assessment Result



My Physical Activity Self-Assessment Results

Your Strongest Habits

1. Children are provided 15 minutes or more per hour of indoor and outdoor physical activity each day when in your care.
2. During developmentally appropriate play and other activities, you always interact with your child to help them practice motor skills, such as lifting and turning their head, rolling over, sitting up, and/or reaching for and grasping toys.

Possible Physical Activity Goals (You can choose up to 3)

Your answer: Always

- Physically active playtime is always be supervised.**

Your answer: Sometimes

- At every opportunity, physical activity is included in your daily routine or when transitioning between activities.**

Your answer: Sometimes

- At every possible opportunity, a parent/caregiver talks with children about the importance of physical activity.**

Your answer: Rarely or never

[Return to Dashboard](#)

[Start Action Plan](#)

[Set Goals](#)

Action Plan

Goals:

Children are provided 5 minutes per hour or more of adult-led indoor and outdoor physical activity each day.



Action Plan

Print Your Plan

Step 1



Brainstorm different possible ways you could lead physical activity with your child. This may include games or songs.

Step 2



Review the recommended HomeGrown resources for songs, activity ideas, and possible equipment for adult-led physical activities.

Step 3



Share resources with family and friends, and discuss how to adjust schedules to increase time for adult-led physical activity each day.

Step 4



Purchase necessary equipment or other items needed to increase the amount of adult-led physical activity for your child.

Resources and Education

PA R1 Time Tracking Sheet

PA R2 Indoor Activities

PAR4 - Movement Songs

PAR5 Staying Warm for the Winter

PAR7 Modeling Physical Activity

Your badges



Physical Activity
Action Planning



Physical Activity
Self Assessment

[Click to view more...](#)



My Progress



75%
Complete

Action Items

| | | |
|-----------------|-------------|------------------------------|
| Self Assessment | Completed | View Results |
| View Goals | Completed | View Goals |
| Action Planning | In-Progress | View Plans |
| Re-Assess | Mar 3 | Re-Assess |

Yours Goals

Completed Goals

Children are provided 5 minutes per hour or more of adult-led indoor and outdoor physical activity each day.

Due Date: 2026-04-01

[Mark as Complete](#)

At every opportunity, physical activity is included in your daily routine or when transitioning between activities.

Due Date: 2026-04-01

[Mark as Complete](#)

Suggested Education

- [PA V1 Handout](#)
- [PA R1 Time Tracking Sheet](#)
- [PA R2 Indoor Actives](#)
- [PAR3 - Outdoor Winter Activities](#)
- [PAR4 - Movement Songs](#)



Join the **homegrown** Community!

- ❖ We are currently recruiting **38 families** of young children aged 2-6 with Down syndrome.
- ❖ Participation would include:

Baseline Data Collection

1. **Answer** questions about you, your child, and your family's home environment
2. **Report** what your child ate & drank on 3 different days
3. Have your child **wear** an activity counter for 7 days



Get Randomized

Immediately begin the 6-month HomeGrown program OR wait to start the program in 6 months



6-Month Data Collection

Repeat!

- ❖ **Develop** new habits, **connect** with other families, and **receive** compensation and HomeGrown merchandise.

- ❖ **Complete** our [interest screener](#)

[survey](#)

Go.HomeGrown@unc.edu today!



or **contact** us at

Q&A



HomeGrown
Interest Screener



Email our team!
Go.HomeGrown@unc.edu