SETBP1 Speech & Communication Report 2026

What 111 families shared about speech, therapy, and communication

Key Takeaways

1

Speech challenges are often **motor-based**

- **57% report Childhood Apraxia of Speech (CAS)**
- Many families report difficulty planning speech movements

2

Understanding often exceeds verbal expression

- **94% understand familiar routines**
- Many individuals understand more than they can verbally express

3

Therapy approach matters

- **79% of families reported speech therapy helped**
- Motor-based approaches were reported as most effective

4

Communication is multimodal

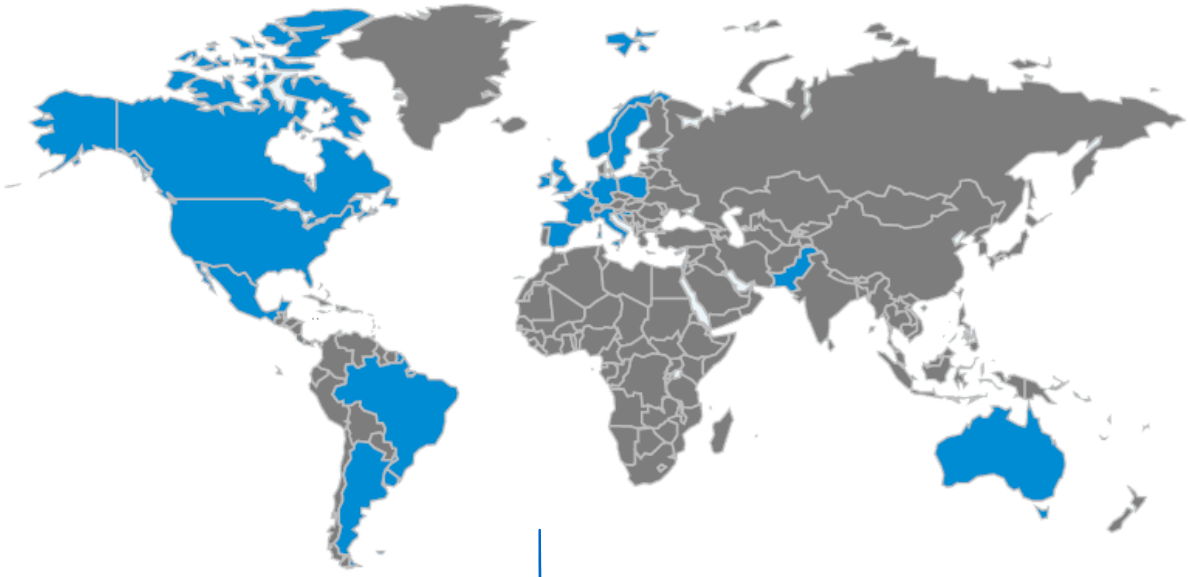
- **47% use(d) gestures and 21% use(d) AAC devices**
- Many children use approximations or combine communication supports

Who Participated

111 Total Responses

Geography

- **United States: 49%**
- **UK: 12%**
- **Netherlands: 7%**
- **Global participation across 20+ countries**



Caregivers

- **Mothers: 89%**
- **Fathers: 7%**
- **Grandparent: 2%**
- **Legal Guardian: 1%**
- **Aunt: 1%**

Area Where They Live

- **Suburban: 44%**
- **Urban: 31%**
- **Rural: 23%**
- **Other: 2%**

About the SETBP1 Bees

SETBP1 SOCIETY

Ages

- Range: **1-41 years old**
- Most common ages: **6-12 years old**
- Median age: **childhood to early teens**

Age Distribution

- Under 5 years: **14%**
- Adults (18+): **14%**

Gender

- **58%** male
- **42%** female

Disorder Classification

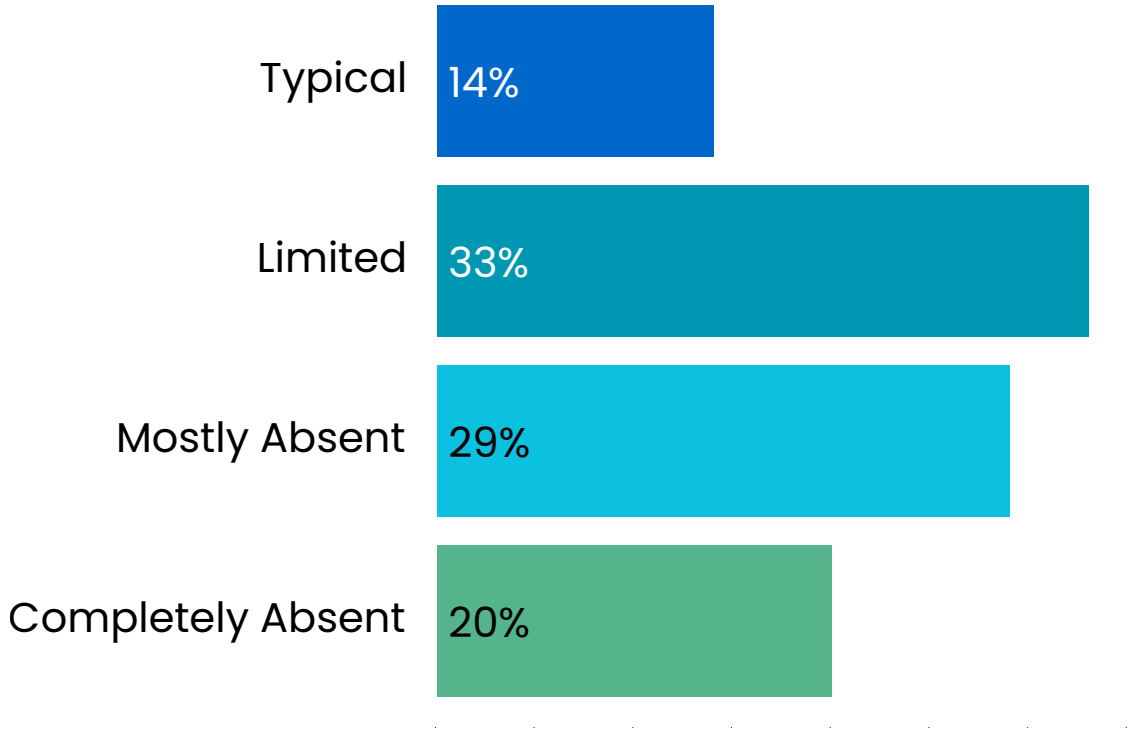
- SETBP1 haploinsufficiency disorder (SETBP1-HD): **81%**
- SETBP1-related disorders (SETBP1-RD): **14%**
- Proximal 18q- Deletion (includes SETBP1): **5%**

Primary Residence

- Lives with parent: **97%**
- Supported Living Placement: 3**%**

Early Communication Development

Babbling Before Age 1:



WHAT THIS MEANS:

- Over 80% of children showed early differences in babbling, often an early sign of motor speech differences.

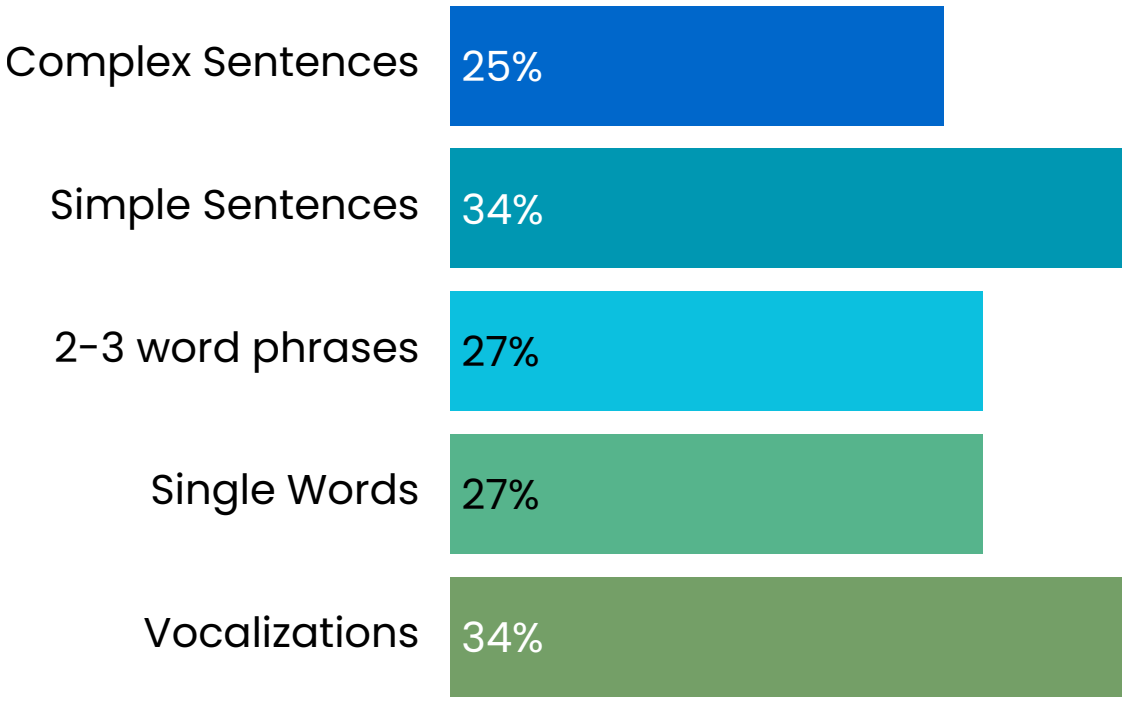
BOTTOM LINE FOR FAMILIES:

Early differences in babbling are common in SETBP1-HD/RD and may be the first sign that **speech development will follow a different path — early, targeted support** can help build a **strong foundation.**

How They Communicate

SETBP1 SOCIETY

Speech and Alternative Communication



Non-Speech Communication

Gestures
47%

Sign Language
27%

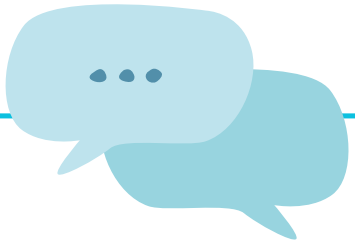
AAC Devices
21%

KEY INSIGHT:

Most individuals use **multiple communication methods simultaneously.** They may **combine sounds, gestures and Augmentative and Alternative Communication (AAC) devices.**

Speech Characteristics

How speech differences show up in SETBP1-HD/RD



What Families Report

Difficulty imitating sounds / words	**69%**
Speech clarity changes day-to-day	**38%**
Inconsistent speech errors	**37%**
Better automatic vs intentional speech	**36%**
Groping mouth movements	**34%**

⚠ WHAT THIS PATTERN SUGGESTS:

- These are common features of **motor speech disorders**
- Speech is not just" delayed"
- The brain may have difficulty **planning and coordinating movements.**

Insight from families

- Many parents report their child **knows what they want to say, but can't get the words out clearly.**

BOTTOM LINE FOR FAMILIES:

In SETBP1-HD/RD, speech differences usually come from **how the brain plans, executes, or coordinates speech movements**, not from a simple speech delay, so the type of therapy really matters.

Understanding Language

Receptive Language Skills & Challenges

Strengths

- Understand familiar routine **94%**
- Recognize names of familiar people **92%**
- Good understanding of spoken language at home **83%**

More Challenging

- Multi-step directions **41%**
- Need cues/gestures **40%**

Insight from families

- Children often understand much more than they can say or show.

What Seems to Help:

- Break directions into **smaller steps**
- Use **visuals or gestures**
- Allow **extra processing time**
- Check for understanding in different ways

Many individuals with SETBP1 **understand far more** than they are able to express verbally.

Children may be perceived as understanding less than they do due to difficulties responding or expressing themselves.

Communicating

Communication Methods

Strongest way of communicating

Speech / Verbal	71%
Using Gestures / Signs	43%
Behaviors / Actions	11%
Facial Expressions	10%
AAC Devices	5%

Strengths when communicating / interacting with others

Social Behaviors	34%
Expressive Communication	33%
Rephrasing to Clarify	27%
Social Nonverbal Cues	21%
Gestures	18%

Most helpful ways to support communication

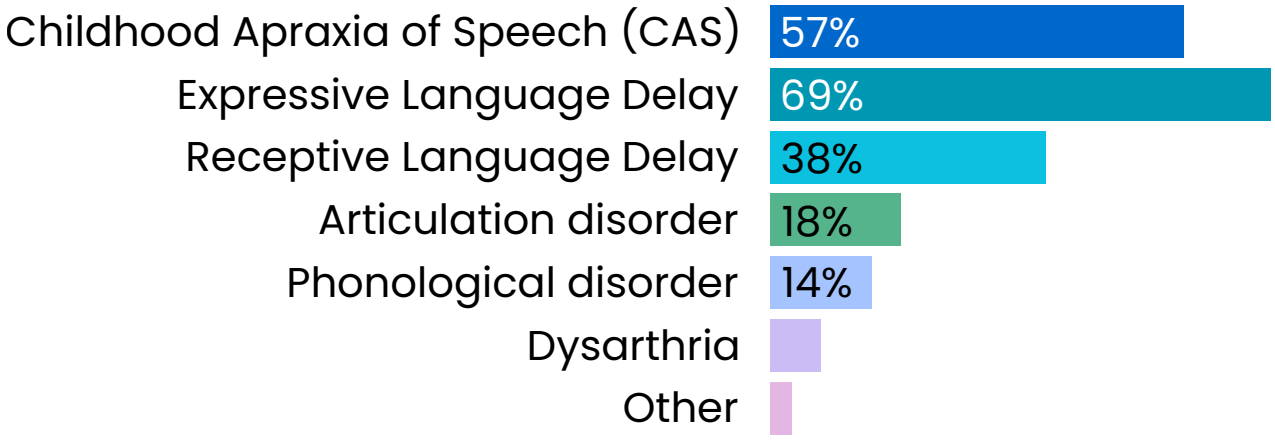
Sign Language /Gesture Support	14%
Motor Speech Approaches	20%
AAC / Visual Supports	18%
Play-based Approaches	14%
Repetition / Practice	14%

Speech is primary — but many individuals **rely on multiple communication systems.**

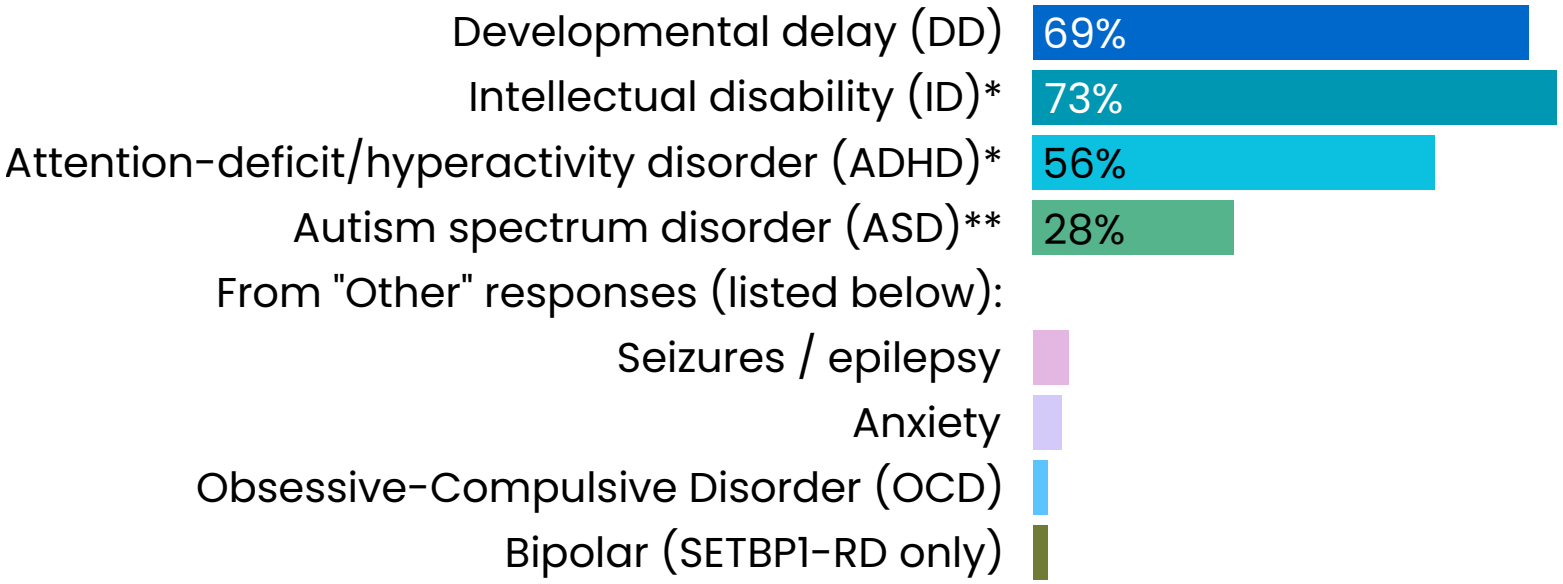
Many children are socially motivated and engaged, even when speech is limited.

Diagnoses

Communication Diagnosis



Additional Diagnosis



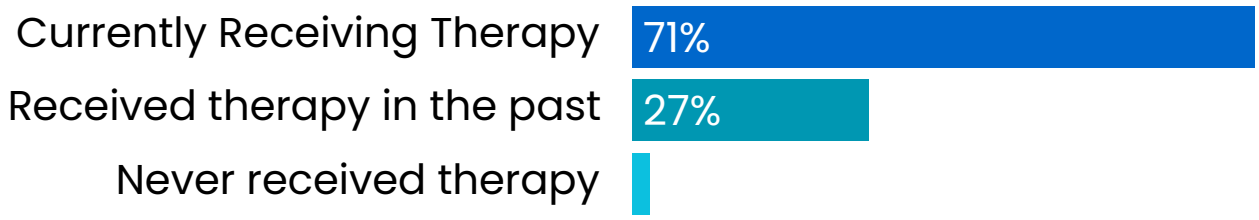
* > 5 years old ** > 2 years old

CAS and other speech challenges are central to SETBP1-HD/RD, but they occur with broader developmental needs.

Speech Therapy

Access, approaches, and what's working

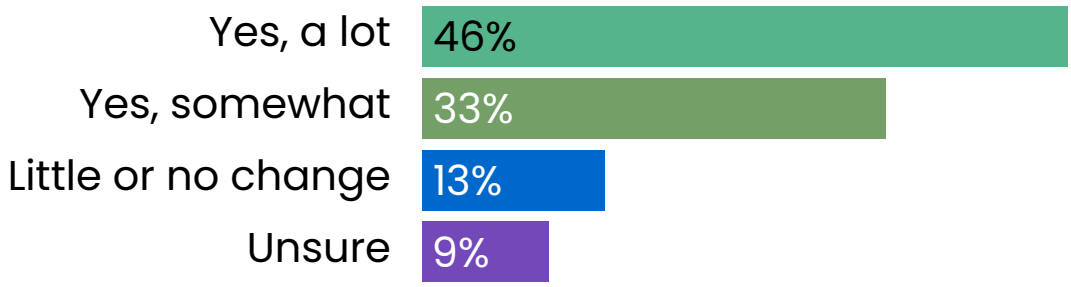
Access to Speech Therapy



When Therapy Starts?

- Most children begin between **ages 1-3**
- The latest began **as late as 10 years of age** and still progressed

Does Speech Therapy Help?



Therapy Frequency

- Most children receive **1–2 sessions per week**
- Fewer receive **3+ sessions per week**

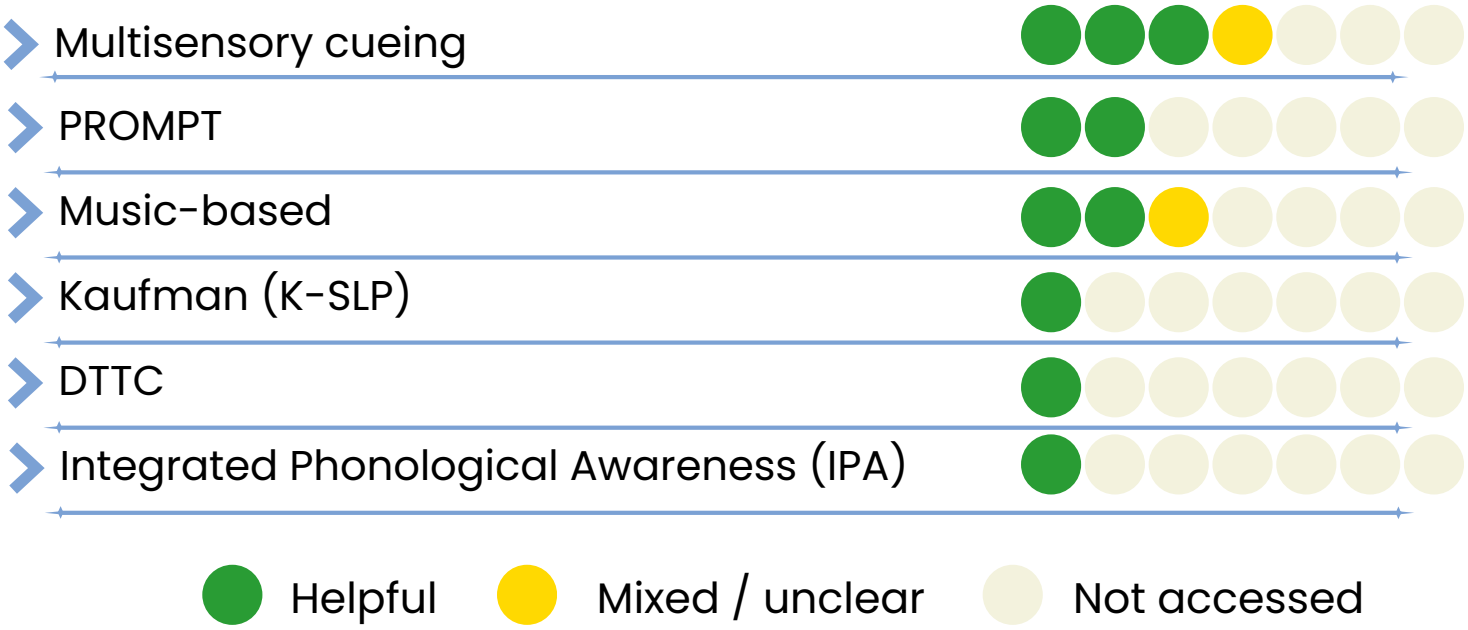
What Seems to Help:

- Repetition and consistent practice
- Use of cues (visual, tactile)
- Practicing real words and sounds
- Adjusting difficulty over time

Speech Therapy →

Access, approaches, and what's working

Speech Therapy Types / Helpfulness



Common Challenges

- Lack of progress
- **Therapy didn't meet child's needs**
- Limited access to specialists or specialized therapy
- Cost or scheduling barriers
- **Inconsistent or infrequent therapy**

BOTTOM LINE FOR FAMILIES:

The type of therapy matters as much as access

Some families reported more progress after changing therapy approaches—not just increasing frequency.

If progress is slow, consider:

- Is therapy focused on **speech movements (motor-based)**?
- Is there **enough practice and repetition**?
- Is the **approach being adjusted over time**?

Oral-Motor Skills & Sensory Experience

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Feeding, Oral-Motor, and Sensory Challenges

Oral-Motor Coordination

• Difficulty moving tongue side-to-side	45%
• Difficulty sticking tongue out on command	31%
• Difficulty licking lips	13%

Feeding & Chewing Challenges

• Difficulty chewing larger pieces of food	33%
• Difficulty managing saliva (drooling)	23%
• Food gets stuck (needs fingers to remove)	21%
• Difficulty coordinating chewing & swallowing	14%
• Difficulty keeping food in mouth	9%

Sensory & Tolerance Challenges

• Difficulty tolerating toothbrushing tools	57%
• Difficulty with inside-the-mouth touch	50%
• Difficulty cleaning around the mouth	47%
• Difficulty accepting new textures/temperatures	42%
• Difficulty with face touching	40%
• Difficulty with lip/cheek touch	30%

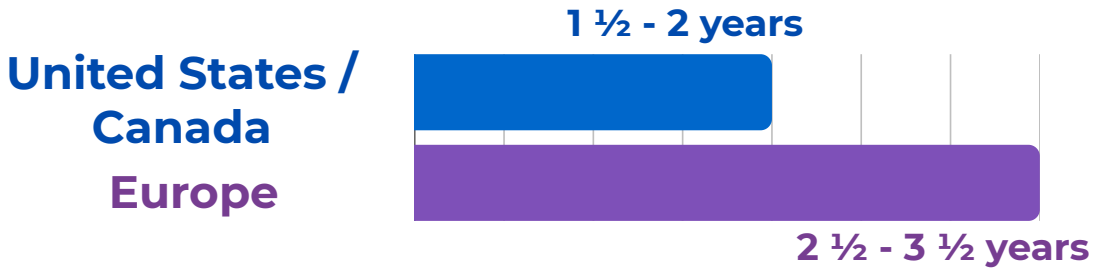
None of the listed oral-motor challenges	36%

BOTTOM LINE FOR FAMILIES:

Oral-motor and sensory differences are common in SETBP1, especially those involving tongue movement, chewing, and tolerance of oral input.

Geography, Access & Family Experience

Typical Age Therapy Starts



Different Communities, Different Experiences

Suburban	Urban	Rural
• Most consistent access • Earlier therapy start age • Access to school, early intervention (EI) and private therapy	• Greater access to specialists • Earlier referrals, especially in North America	• Later therapy start ages • Fewer specialists • More reliance on school-only therapy

These patterns were especially strong in Europe, where rural families reported the latest start ages and the fewest therapy options.

How Families Feel About Therapy

Families report higher satisfaction when they have:

- Motor-based speech therapy
- Consistent weekly sessions
- A mix of school, private and early intervention speech services

Parent Quotes

Positive Therapy Experiences

"NHS speech therapy has been very little....We are finally at 10 years of age in a financial position to pay for private speech therapy...**He is responding very well.**"

"**We switched to a clinic that specializes in apraxia**, doing 30 min sessions, 2 times a week, and we started to see lots fo progress."

"Appropriate **motor-based speech therapy has been one of the most instrumental** tools in helping my son become a verbal communicator."

Progress and Improvements

"**I've received so many compliments**...She has **progressed so much** with her speech!"

"At 4 she could barely say anything, so there has been a **massive improvement."**

"First words came just before age 3...**At 38,** we're still surprised by new words or phrases."

"**My son didn't speak until the age of six.** Since then, there **has been major improvement**."