



Co-morbid Developmental Issues

Systematic early identification, culturally appropriate interventions, and removing barriers to successful services

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Child Development Occurs in Context

The same medical condition can lead to very different outcomes — depending on the supports, systems, and culture surrounding the child.



Biology + Family

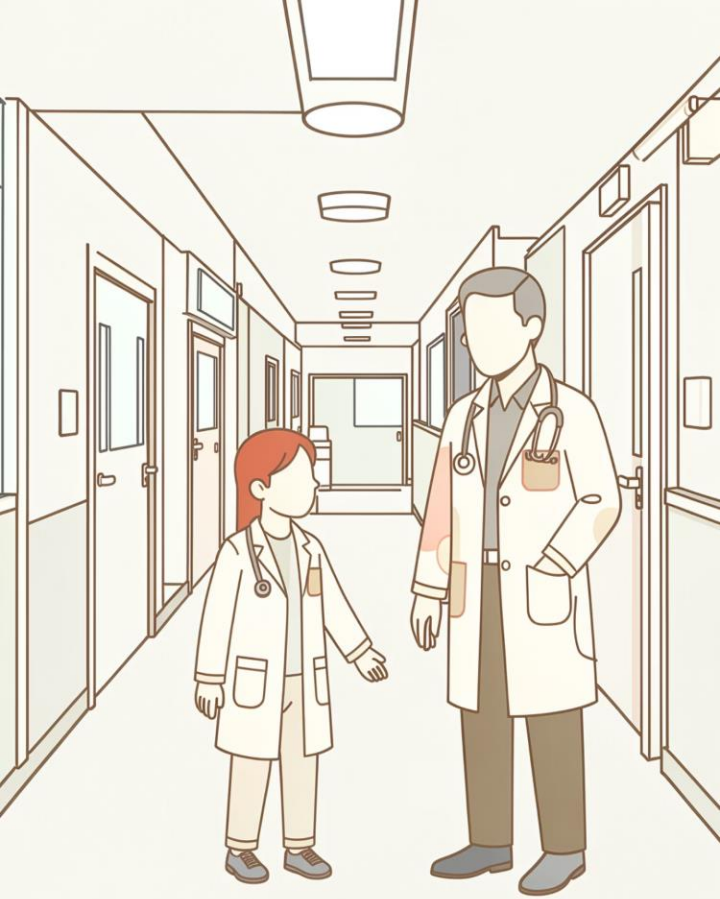
The child's innate traits shaped by those closest to them

School + Peers

Learning environments and social relationships

Culture + Community

Values, language, belonging, policies and access to resources



From Medical Survival to Long-Term Thriving

As medical outcomes improve, developmental functioning becomes the next frontier.

Visible · Immediate

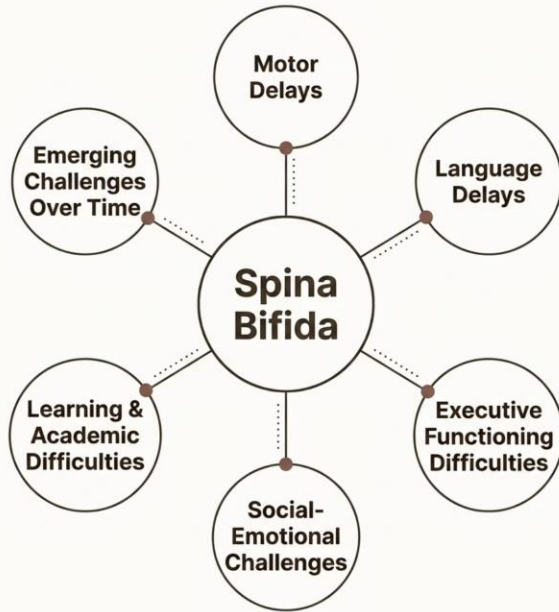
- Mobility & neurosurgical care
- Bladder/bowel management
- Shunt complications
- Acute medical monitoring

Less Visible · Long-Term

- Executive functioning
- Emotional regulation
- Language processing
- Social competence
- Academic functioning & independence

"Medical stability is not the same thing as developmental thriving."

Elevated Risk Across Multiple Domains



Risk varies substantially across children — and some challenges only emerge gradually as developmental demands increase.



Medical management alone is insufficient. Developmental monitoring is essential.

Risk ≠ Certainty

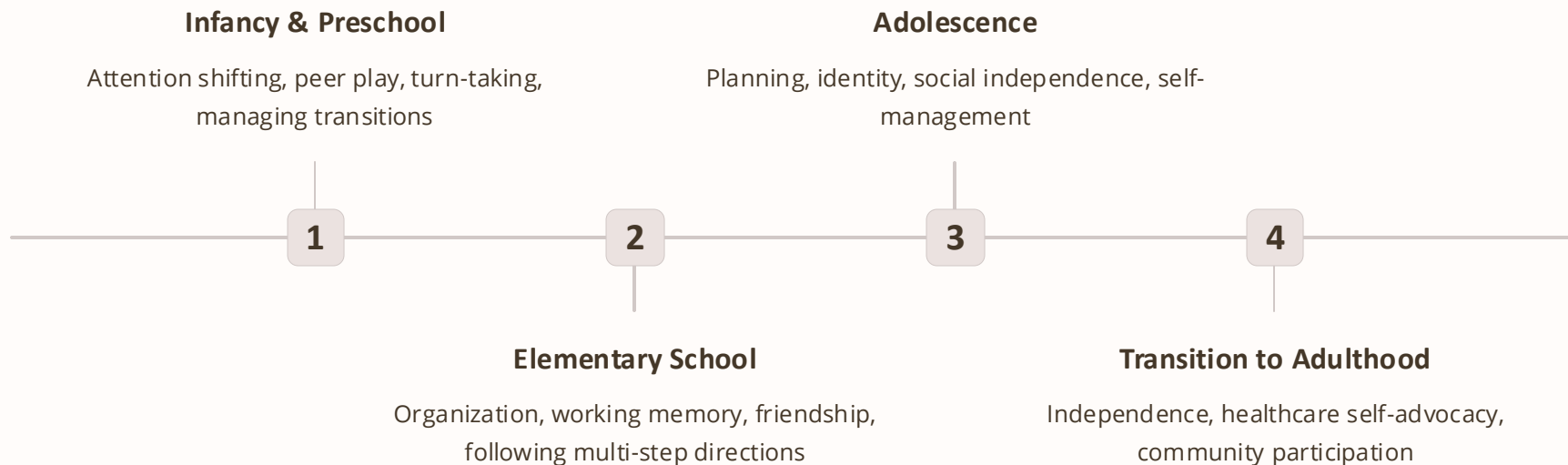
Not every child will be affected in the same way

Time Matters

Some challenges emerge only when demands increase

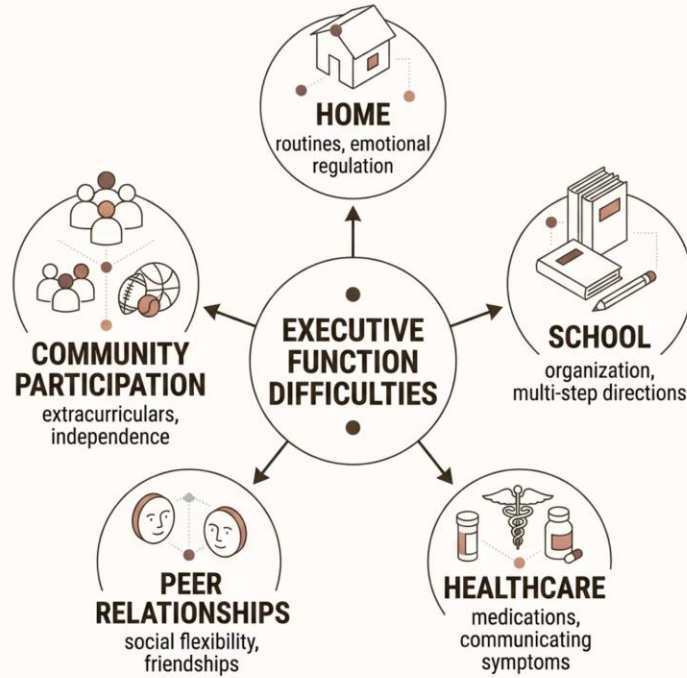
Developmental Challenges Change Over Time

New demands at each stage can reveal previously hidden vulnerabilities.



 "New developmental demands can reveal previously hidden vulnerabilities."

Developmental Challenges Ripple Across Every Setting



Home

Routines, transitions, emotional regulation

School

Organization, homework, multi-step directions

Healthcare

Managing medications, communicating symptoms

Peers & Community

Friendships, extracurriculars, independence

"Developmental success includes participation, relationships, independence, and quality of life."



The Family Experience

Families Navigate Far More Than Medical Systems



Advocates

Fighting for services, accommodations, and recognition



Coordinators

Linking healthcare, school, therapy, insurance, and transport



Interpreters

Translating clinical language for their child and community



Emotional Anchors

Holding the family together through uncertainty and change



"Many barriers are structural, not motivational."



Cultural Context

Culture Shapes Developmental Conversations

Families differ in how they understand, discuss, and act on developmental concerns.

✔ "Systems need to become easier for families to navigate."

→ Disability stigma & language barriers

→ Differing expectations for independence

→ Mistrust of systems & prior experiences

→ Uncertainty navigating services

What Families Often Need Most

Coordinated, ongoing support — not just more isolated referrals.



Understanding Patterns

Help making sense of developmental trajectories over time



Anticipatory Guidance

Preparing families for what to expect at each stage



Culturally Responsive Support

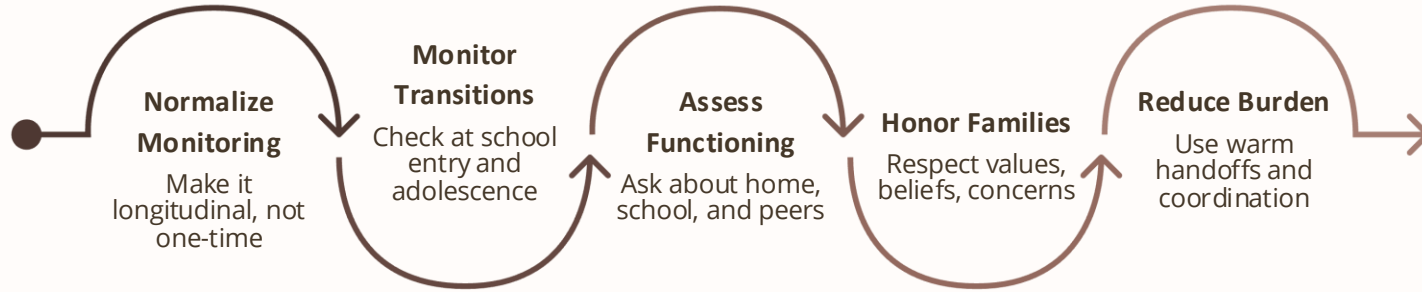
Community-based monitoring, reducing barriers, partnership-focused care



Follow-Up Across Transitions

Consistent coordination as children move through developmental stages

Small System Changes, Meaningful Outcomes



Longitudinal Monitoring

Not one-time screening



Key Transitions

School entry, upper elementary, adolescence



Family-Centered

Values, beliefs, and lived experience matter



Reduce Burden

Warm handoffs, follow-up, clear communication