



Okur-Chung Neurodevelopmental Syndrome (OCNDS) and Educational Support

A Guide for Educators

Prepared by the CSNK2A1 Foundation Parent Advisory Board with collaboration from Deanna Heuring, Ed.S.

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Legal Disclaimer:

The information provided in these slides is for **informational purposes only** and is not intended as legal advice. Every child's educational needs and Individualized Education Program (IEP) process are unique, and laws and regulations may vary by state and school district.

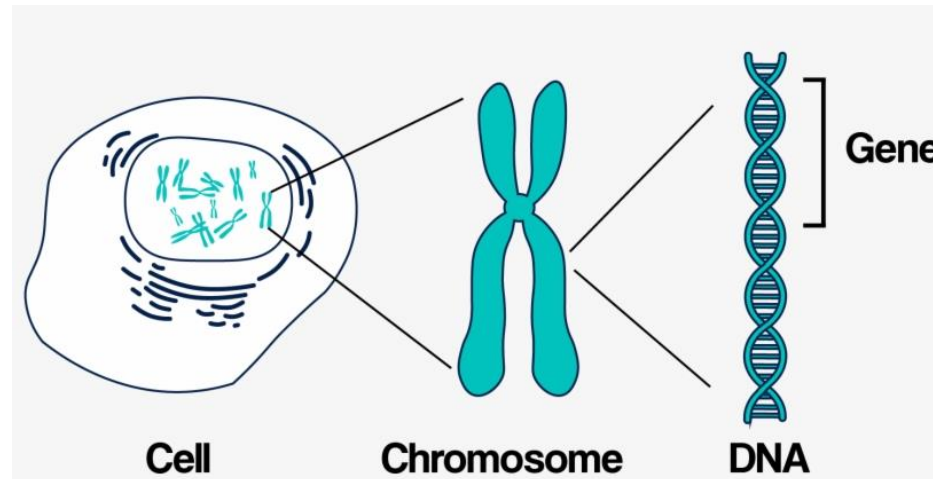
We encourage parents and caregivers to consult with a qualified **special education attorney or advocate** to better understand their rights and options under the Individuals with Disabilities Education Act (IDEA) and other applicable laws.

The CSNK2A1 Foundation does not provide legal representation or advice but is committed to empowering families with knowledge and resources to advocate for their children effectively.

Okur-Chung Neurodevelopmental Syndrome (OCNDS)



An ultra-rare genetic syndrome first identified in 2016.



Caused by mutations in the **CSNK2A1** gene on chromosome 20.

The gene **CSNK2A1** produces a protein called **CK2**.

The CK2 Protein is found in every cell of the body and plays a crucial role in development.

Individuals with a mutation in this gene have Okur-Chung Neurodevelopmental Syndrome.



- Currently there are about 407* individuals diagnosed with **OCNDS** in the world.
- **Not everyone with OCNDS will present in the same way or to the same degree, from mild to severe.**

BRAIN

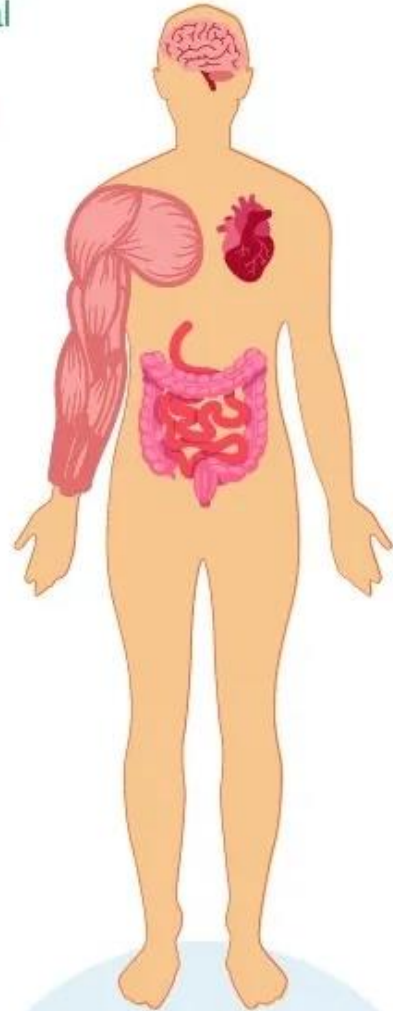
- Developmental delay/intellectual disability
- Speech delay/inability to speak
- Brain MRI abnormalities
- Sleep issues
- Microcephaly (smaller head)
- Seizures (~25% of individuals)
- Learning disabilities
- Sensory challenges

MUSCLE

- Hypotonia (decreased muscle tone, mobility issues)
- Musculoskeletal findings (loose/hyperextensible joints, scoliosis, kyphosis)
- Ataxia / gait difficulties / poor coordination

GI

- Difficulty feeding
- Difficulty gaining weight
- Constipation



FACE

- Dysmorphic facial features

EYE

- Vision difficulties (strabismus, refractive error)

ORAL

- Misaligned teeth
- Cavities

HEART

- Congenital heart defects

OTHER

- Behavioral issues (autism, stereotypic movements, aggression, ADHD)
- Postnatal short stature

Clinical Features

[Gene Reviews](#)

Children with OCNDS benefit from:

Speech/Language
Therapy



Early Intervention



Vision Therapy



Physical
Therapy



Occupational
Therapy



THERAPIES



Assistive Communication
Technology



Behavior Therapy



Equine Therapy



Music Therapy

***Please note this is not an exhaustive list. Each individual will have their own therapeutic needs.**

Overarching Goals the Family has for the Team:

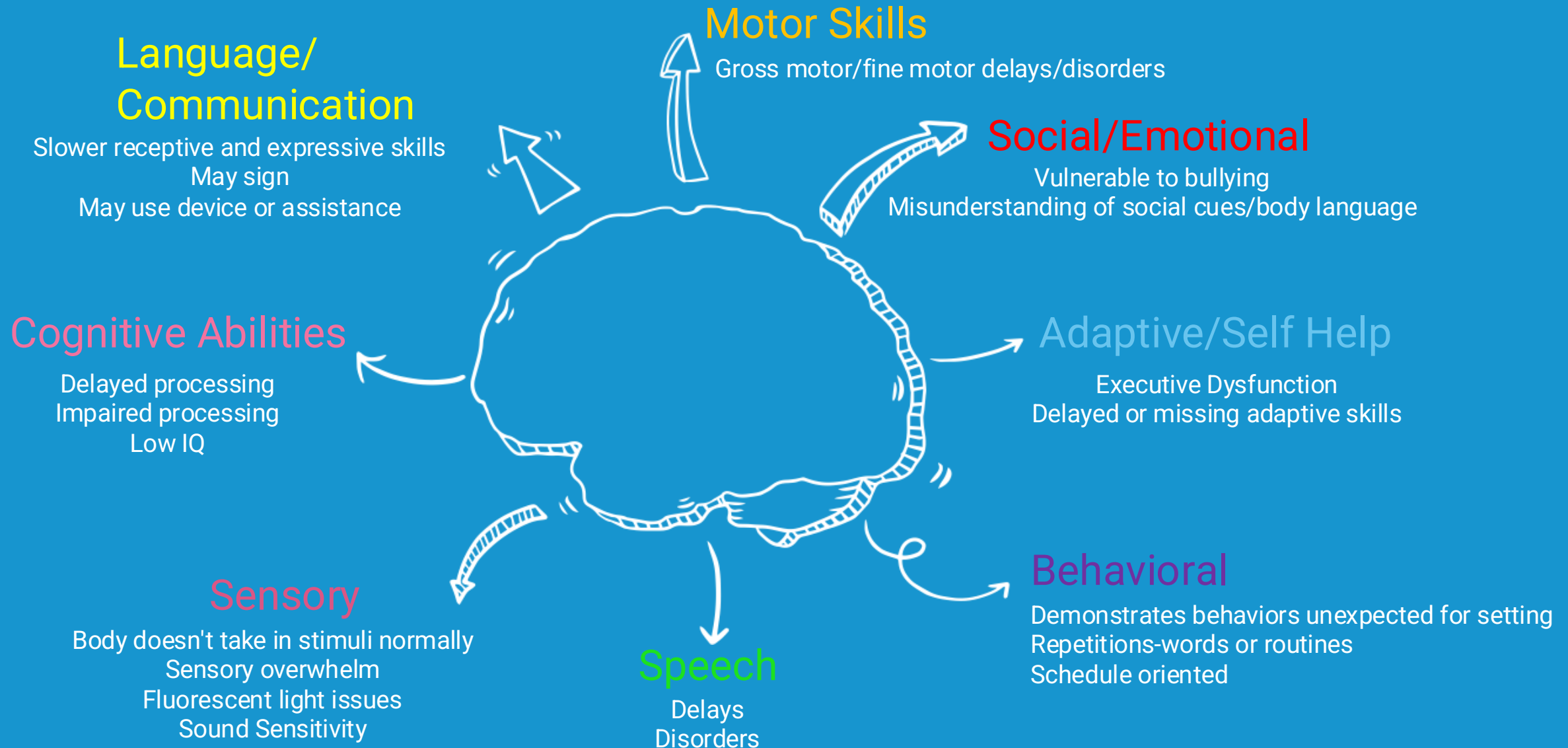
- **MINDSET.** Maintain the mindset everyone is working in the best interest of the student
- **MEETING BEFORE SCHOOL:** A team meeting before the school year to set student up for success.
- **COMMON METHODS:** Having common methods between home and school (i.e. phrases, behavior expectations, independence)
- **COMMUNICATION BETWEEN HOME & SCHOOL:** Ways to communicate regularly such as a notebook or daily chart that can go between home and school to maintain expectation consistency
- **DATA SHARING:** Sharing data between home and school therapists
- Big picture goals and the path to them. (i.e. use Charting the Life Course Trajectory)

Background information about OCNDS Caregivers:

- At any given time, Caregivers are juggling therapies, medical appointments, and phone calls for insurance coverage.
- Caregivers are valuable resources about their child and may know reasons for behaviors that don't seem obvious.
- If Caregivers get short or upset, it's not personal. Caring for a child with complex needs can be mentally, physically, and emotionally exhausting. Every day often comes with its own set of challenges.
- In new settings, certain behaviors may seem new to educators but are actually familiar patterns for the child. Caregivers can share context from past experiences to help address and reduce these behaviors effectively.
- Caregivers often feel unheard and misunderstood. As noted, there are only 319 individuals currently diagnosed with this condition. The closest support in a similar situation is hundreds of miles away.
- Many children with OCNDS have severe sleep disruption, meaning difficulty falling asleep or staying asleep, or they wake 4-5 times per night interrupting Caregiver sleep, leading Caregivers to be short on restful sleep.



Categories for IEP Teams to Consider



CSNK2A1 Foundation as a Resource

- Website www.csnk2a1foundation.org
- [What is Okur-Chung Neurodevelopmental Syndrome - CSNK2A1 Foundation information page](#)
- [General Session Day 2 | Developing Social and Pragmatic Skills in School Age Children & Discussion](#)

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THANK YOU

for all you do educating children of all abilities!