Seizure Disorders and Individuals with Developmental Disabilities

NM START Program Learning Forum

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START Model

The START (**S**ystemic-**T**herapeutic-**A**ssessment-**R**esources-**T**reatment) model is an evidence-informed model of integrated community crisis prevention & intervention services for individuals ages 6 and older with intellectual and developmental disabilities and mental health needs.

START was first developed in 1988 by Dr. Joan B. Beasley and was cited as a best practice in the 2002 US Surgeon General's report and by the National Academy of Sciences in 2016.

The **National Center for START Services** at the UNH Institute on Disability oversees the development, measurement and quality of START programs across the country.

Objectives

- Discuss seizure disorders and the various types of seizures.
- Review current prevalence of seizure disorders amongst IDD populations.
- Discuss the mental health effects associated with seizure disorders.
- Describe how parents and caregivers can support the diagnostic process for seizure disorders.
- Describe different treatments for seizure disorders. Investigate the treatment challenges related to the management of both behavioral and medical comorbidities in individuals with seizure disorders

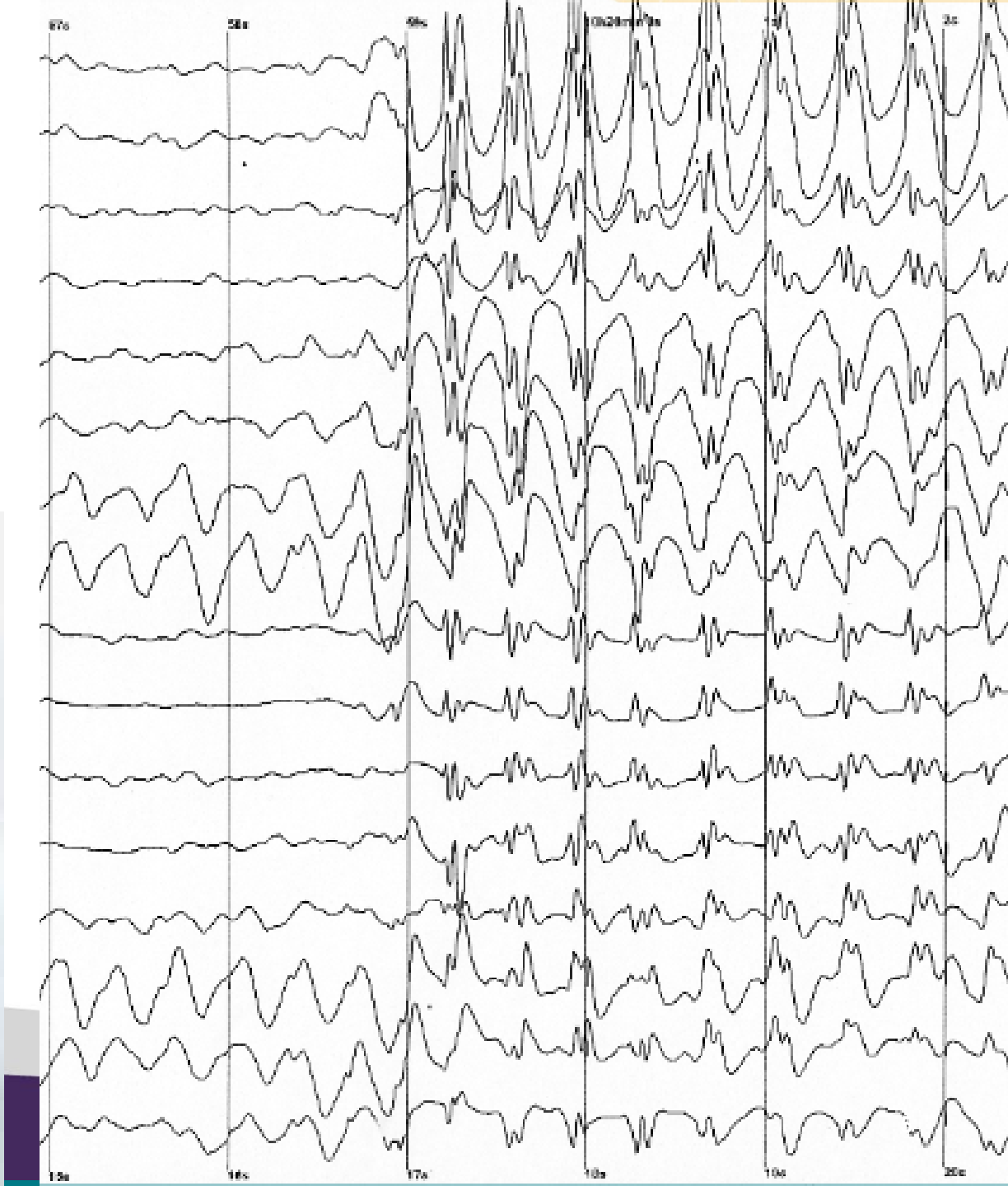
Neurons

Electrically excitable nerve cells in the brain.
They function in collaboration with neurotransmitters in a neural circuit.
There are an estimated 100 billion neurons in the human brain.

The Arc
Chemung-Schuyler
New York

Measuring Brain Activity

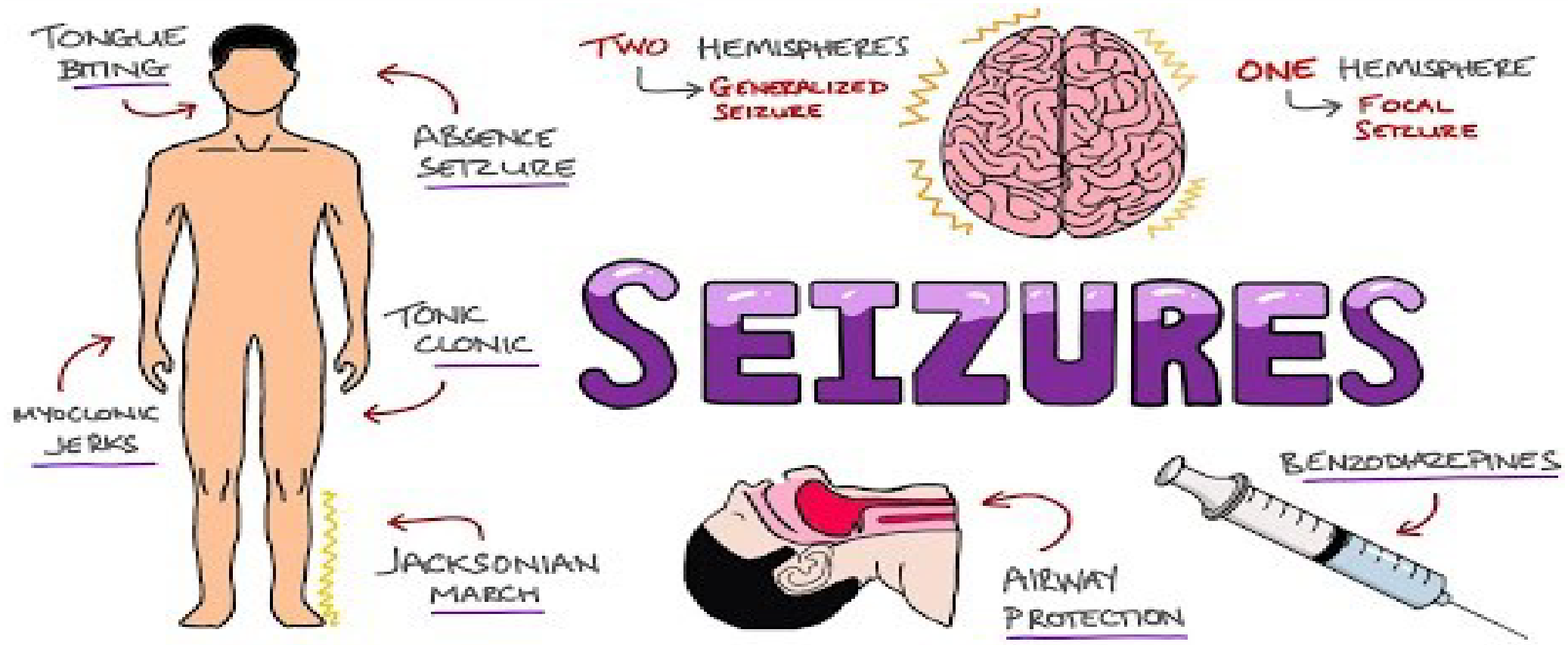
An electroencephalogram (EEG) is a test that measures electrical brain activity using electrodes attached to the scalp.



What are seizures?

An excessive discharge of electrical activity in the brain that alters one or more of the following:

- Movement
- Sensation
- Behavior
- Awareness


TONGUE BITING
ABSENCE SEIZURE
TWO HEMISPHERES
GENERALIZED SEIZURE
ONE HEMISPHERE
FOCAL SEIZURE
SEIZURES
TONIC CLONIC
MYOCLONIC JERKS
JACKSONIAN MARCH
AIRWAY PROTECTION
BENZODIAZEPINES

What are seizures?

Seizures, Epilepsy, Seizure-like events, Pseudoseizures, Psychogenic seizures, PNES “Spells”, “Episodes”, and more.

- What are different types of seizures?
  - Epileptic
  - Non-epileptic
  - Other Movements or Episodic Behaviors:
    - Tics
    - Fidgeting
    - Repetitive movements
    - Dystonia, Dyskinesia, or Akathisia
- Where to go next if you have concerns about seizures?
- How can Caregivers support the diagnostic process?

What are seizures? Epilepsy

Epileptic Seizures are **uncontrolled electrical bursts** among **Neurons** in the brain that **disrupts** the function of the **Brain**.

- Neurons
- Brain
- Sensations, Cognition and Behaviors

- **Generalized** or **Focal** Epileptic Seizures
- "**Tonic**", "**Clonic**", and "**Grand-Mal**" Seizures
- **Absence Seizures** - "Petit-Mal Seizure", "Staring Spells"
- Rare Genetic Syndromes, Provoked Seizures, and others.

What are seizures? "Non-Epileptic"

Psychogenic Non-Epileptic Seizures (PNES)

- "Non-Epileptic Seizures"
- "Psychogenic Seizures"
- "Functional Seizures"

Epileptic-appearing* episodes **without** the abnormal electrical activity.

- Some subtle differences.

Complex and Psychiatric in nature, a widespread "**Dysfunction**" of the brain activity.

- Not "made-up" or "faking"
- A type of **Functional Neurologic Symptom Disorder**

Can have both Epileptic and Non-Epileptic Seizures in one individual!

What are seizures? Other Events

Other motor movements or behaviors that can look like Seizures.

- Motor Tics and Vocal Tics, aka “Tourette’s Syndrome”
- Dystonia, Dyskinesia, or Akathisia
- Breath-holding Spells, Vaso-vagal Syndrome, Syncope, and “Fainting”.
- Autism related Repetitive Movements
- Attention: Fatigue, “Zoning out”, daydreaming, etc.
- Hyperactivity, Fidgeting, Anxiety, or Panic Attacks

Seizure Disorders and IDD Populations

- Prevalence in general population is 0.6-1%
- Systematic Reviews Reviewed (Robertson et. al., 2015; Liu et. Al., 2022)
  - 2015 study reviewed 48 studies; 2022 reviewed 66 studies
  - 2015 study: In general population: 0.63% vs People with Intellectual Disabilities pooled estimate 22.2%
  - 2022 study: People with Autism pooled estimate in adults 19%, children was 7%
  - Prevalence increased with increasing level of intellectual disability
- Epilepsy is more common in people with intellectual disabilities than in the general population.
- PNES – Non-Epileptic Seizures are also common in ID and Non-ID.
  - Estimated average of 9% in ID (and non-ID individuals)
  - Common to have Both PNES and Epilepsy, estimates of 22% w/ Epilepsy also have PNES.

Epilepsy and Neurodevelopmental Disorders

- ~ 10% of individuals with mild IDD have seizures
- ~ 20% of all individuals with severe intellectual disability
- Up to 12.4% in Down syndrome (increases with age)
- Up to 39% in Autism Spectrum Disorder
- More in those with genetic syndrome (50% prevalence X chromosome linked syndromes – Fragile X, Tuberous sclerosis, Lesch Nyhan, Cornelia de Lange, MELAS, etc.)
- Approximately half of seizures are idiopathic (unknown cause)

You Have Concerns for Seizures?

Where do I go First?

- See **your** General Physician, Pediatrician, or Psychiatrist.
  - "I want to schedule an appointment to talk about my concerns for …"
- May lead to a **Neurologist** Specialist.
  - Referral to Clinic Eval
  - In-Hospital Consult
  - Collaborative Care
- **Testing** may be indicated:
  - EEG – ElectroEncephaloGram
  - Brain Imagining – MRI
  - Genetic Testing

In an Emergency:

How you(parent, caregiver, partner) can support the diagnostic process?

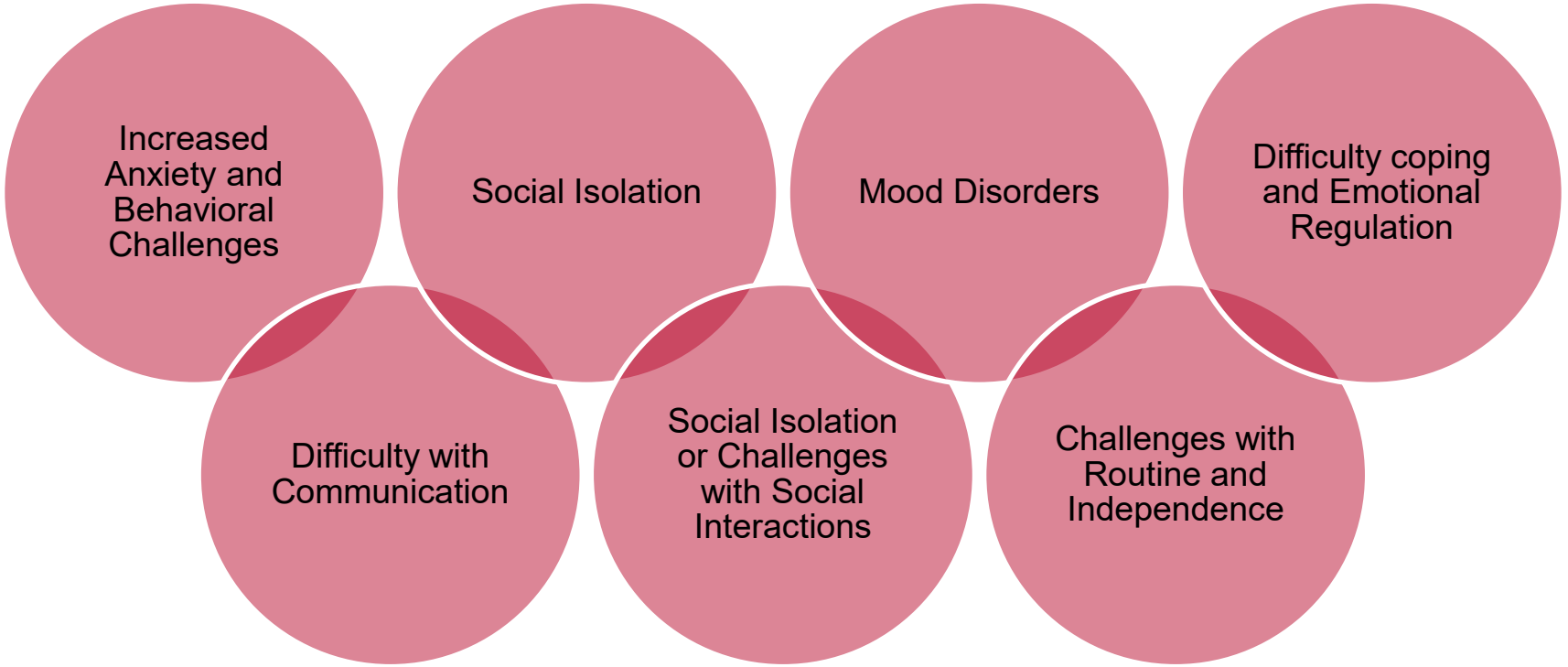
- After Episode Care – "*Staying Calm is Easier Said than Done*"
  - Knowing and teaching "**Seizure First Aid**"
  - "**Post Ictal State**" After-Episode **Confusion**, **Grogginess**, **Fatigue** or **Irritability** for minutes to hour.
  - Above all, be there for each other and stay safe.

- Document your concerns:
  - Camera-phone Videos
  - Debrief Notes

- Chart patterns, triggers, and changes.
  - Any info is helpful.

- Prepare for Appointment.

Mental Health Effects

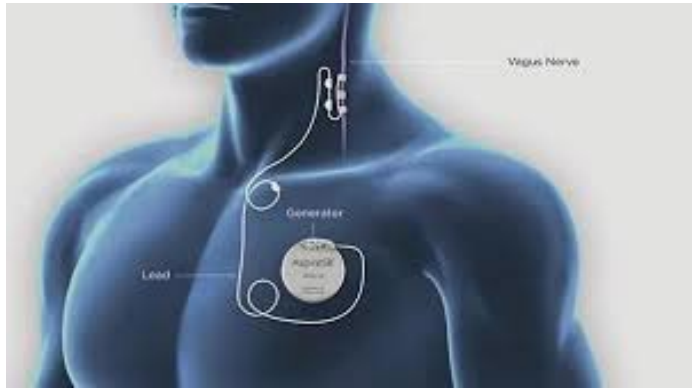


Treatment for Seizure Disorders

- Medication
  - Anticonvulsants (e.g. Depakote, Lamictal, Tegretol, Keppra)
  - 70% respond favorably to medication

Treatment for Seizures- Nerve Stimulators

- Vagus Nerve Stimulator (VNS)
  - Treats focal or partial seizures that do not respond to medications.
  - Device is implanted under the skin in the left chest. A connecting electrode wire is attached around the vagus nerve in the neck.
  - Device is programmed to deliver pulses or stimulation at regular intervals.
  - If a person is aware of when a seizure happens, a magnet can be swiped over the device to send an extra burst of stimulation to the brain. This may help stop seizures.



Treatment- Nerve Stimulators

- Responsive Neurostimulation
  - A device is placed in the bone covering the brain. Tiny wires are placed on top of the brain where seizure activity begins.
  - The system can give small pulses or bursts of stimulation to the brain when anything unusual is detected. This can stop seizure activity before the actual seizure begins. Or it could stop seizure activity from spreading from a small focal seizure to a generalized seizure.

Treatment for Seizures- Surgery

1. Resection: Removal of part of the brain where seizures start
   a) Laminectomy: Removes a lesion or mass that causes the seizures.
   b) Lobectomy: Removes a part of the brain where seizures begin.

2. Disconnection: Cutting the nerves that send seizure impulses in the brain.

Keto Diet?

Some thin evidence for Ketogenic Diet in children

- Difficult to study therefore few studies with limited sample sizes
  - In the studies available, there are promising findings (up to 50% seizure reduction)

How Does Keto Diet Work?

- A diet that is low enough in carbohydrates that the brain becomes starved of sugar. This triggers the production of ketones and metabolic changes leading to a state of ketosis. Ketosis results in the body using fat for energy rather than glucose.
- Still unclear what the actual mechanism is. Some theories:
  - Ketones may affect the activity of neurotransmitters.
  - Altered antioxidant activity reducing inflammation in the brain.

Questions for Discussion

- How can caregivers and healthcare providers improve communication with individuals who have IDD or ASD to better understand the emotional and mental health impact of seizures?
- What are some key barriers to effective treatment for individuals with both seizure disorders and mental health conditions, and how can these barriers be overcome?
- What are the potential underlying causes of aggression in individuals with IDD who have seizures, and how can caregivers and professionals effectively manage these behaviors during or after a seizure episode?
- How can professionals ensure parents feel empowered and equipped with tools to handle the complexities of managing multiple conditions, especially when their child's aggression may be influenced by a combination of seizures, mood disorders, and developmental challenges?

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