

DO YOU HAVE AN IDEA FOR YOUR PROJECT YET?



NO, I'M WAITING FOR INSPIRATION.

YOU CAN'T JUST TURN ON CREATIVITY LIKE A FAUCET. YOU HAVE TO BE IN THE RIGHT MOOD.



WHAT MOOD IS THAT?

LAST-MINUTE PANIC.

Transitioning to Adulthood:
A subjective topic (adulthood that is)
also a little bit about neuropsychology

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Neuropsychological evaluation

Goes by many names, but in the end it's a cognitive evaluation that is sensitive to the factors associated with the diagnosis that may have a role in cognitive development/function.

Intelligence, Memory,
Language,
Visuospatial/Visuoperceptual,
Fine Motor, Executive
Functioning, Attention and
Behavior/Mood

Used for determining academic needs, help with obtaining resources (Social Security, State services, etc.)

How does CKiD affect the brain?

- Neuroimaging in adults shows structural abnormalities including cerebral atrophy, white matter hyperintensities, cerebral microbleeds, cerebral infarcts, and dialysis-associated cerebral density changes.
- In children, cross-sectional studies have shown cerebral atrophy, cortical infarcts and periventricular WM lesions. A newer study (2018) concluded that CKD in children and adults may be associated with lower gray matter and higher white matter volumes in some specific areas (ROIs).

Cognitive changes noted

- This data is from the NiCK study and one of the variables assessed was eGFR (estimated glomerular filtration rate).
- eGFR in the CKD patients vs. Control was significantly lower (<0.001) but had no meaningful relationship with neurocognitive performance or structural findings.
- Neurocognitive performance in the CKD group was not associated with ROI volumes.

Is there a CKiD Cognitive Phenotype?

YES

and

NO

These are all possible factors affecting cognitive functioning in CKiD

Anemia

Blood pressure

Genomic Variation

Lead exposure

Sleep

Mineral bone disease

Stroke

Depression

Some Findings

- Hypertension is associated with lower FSIQ and Nonverbal IQ.
- Hypertension is also associated with executive functioning difficulties.
- Hypertension also increases the risk of stroke.
- Anemia affects development (chronic hypoxic effect reduces oxygen to developing neural structures and pathways).
- Genomic variants are associated with lower IQ

Chronic Kidney Disease in Children (CKiD) Study

- Found that in general “median cognitive function was within the range of normal values; however 21% to 40% scored at least 1 standard deviation below the normative mean on measures of IQ, achievement, attention and executive functions.”
- What does that mean for life in the real world?

What are the needs?

- Determination for eligibility for resources
 - Social Security will probably (more than likely) ask for a current evaluation of cognitive ability
 - Will they need a guardian?
- Types of assistance they are getting already vs. types of assistance they may need in the future
- Are they going to go to college? Will they need accommodations? Many schools will offer accommodations but not all do. It will be necessary to maintain high school records of any assistance that was given to the student. Especially if they need accommodations for testing. The parent will need to provide that information to the school.

Needs (continued)

- How independent is the individual?
 - Activities of daily living
 - Dressing
 - Food preparation
 - Medication
 - Self-care
 - Financial management
 - Transportation
 - Self-advocacy
 - Have they ever had a job? Do they know about work etiquette and work ethic?

Moving into the adult world

Do they need a current assessment? Level of functioning?

What other services are they going to need?

If college bound, what types of accommodations would be helpful? What do parents need to know about transitioning accommodations/modifications from an IEP/504 into college?

Will the college provide accommodations?

Can this person live/work independently?

Ongoing Health Issues...including Mental Health

Real World Problems

- Lower level of cognitive ability probably means low pay if a job is a possibility.
- Lower cognitive ability is likely to translate to organizational difficulties.
- Poor organizational skills affect daily living, appointments, etc.
- There may be issues with understanding the consequences of medical procedures if comprehension, reading, and processing are issues.
- The ability to accurately communicate needs may not be present
- Driving/Transportation

Non-monetary resources

- State vocational services-Vocational Rehabilitation-can help with finding a placement, testing for vocational skills, etc. This could be an important resource.
- Board of Developmental Disabilities-can help with programs for young and older adults. Paperwork will be required.
- (Ohio specific) Opportunities for Ohioans with Disabilities (ood.ohio.gov)

What Do The Parents (main caregivers) Need to Know?

- Don't depress them, but there's more work to do...
- Find out what they are thinking (guardianship, group home, etc.)
- This will really shape the information that they will be asking you for.
- Depending on the state they are living in, they may be eligible for services through a number of resources and depending on their goals there are state services that may be available to them.

Conclusions

- The good news is that it looks like identifying and treating CKD in children is having a positive effect, but the fight continues...the statistics I have are old but indicate that early intervention has a positive effect on development and growth.
- Support is important and identifying support systems that are sustainable (likely to be around in 10 years) if possible is the ideal.



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I CAN'T IMAGINE
MASTERING THE SKILLS
INVOLVED HERE
WITHOUT A CLEARER
UNDERSTANDING OF
WHO'S GOING TO BE
IMPRESSED.



WITSON

The End

Thank you

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