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How many clients do you have living with chronic illness or neurological conditions?

- How many clients are living with chronic illness?
- How many clients have significant health challenges?
- How many clients are neurodiverse?
- How do you determine which clients have chronic illness or neurological conditions? Do you even know?

The Graying of America

- Prevalence of chronic illness escalates with advancing age
  – Aging clients face many similar issues to those living with chronic illness,
  – The number of clients requiring the planning is significant and growing
- Similar health issues span across the aging and chronically ill populations, highlighting the need for practitioner awareness.
- 2030 Projection: An estimated 20% of Americans will be 65+ by 2030, signaling a demographic shift.
- There is a marked increase in the need for specialized planning for this demographic.
- Addressing the health concerns of the elderly and chronically ill is becoming an essential part of all health practitioners' roles.

Chronic Illness – What Is It?

Chronic illness refers to a health condition that is persistent or long-lasting, often for several months or more, and typically cannot be completely cured, requiring ongoing management and care.

- Chronic diseases affect millions globally.

- Symptoms and visibility can differ widely.

- Long-term management focused on sustained treatment plans and lifestyle adjustments.

- Importance of holistic support integrating medical, emotional, and social support.

Chronic Illness:
A Prevalent Reality

- About 157 million Americans were estimated to be living with chronic illnesses
  - 60% of those living with chronic illness are between the ages of 18 and 64
  - 26% have lifestyles markedly altered by illness.
  - Roughly 50% experience some form of cognitive decline
- Chronic illness affects all ages, not just the elderly
  - Studies suggest 2 to 5% of all people with MS have a history of symptom onset before age 18
  - In the US, 8,000-10,000 children have MS
  - 5-10% of people with Parkinson's disease are under the age of 45 (Young Onset Parkinson's disease, or "YOPD").

Unseen Chronic Illness

- 96% of chronic conditions may not be outwardly visible
- Neurologic symptoms are often subtle: Fatigue, cognitive issues, and sensory disturbances
- Clients may avoid discussing their hidden symptoms
- Clients often unaware of practitioners' ability to assist
- Fear of stigma can deter clients from sharing their illness

Visible Disabilities

Mobility Impairments
(i.e., use of wheelchair or walker)
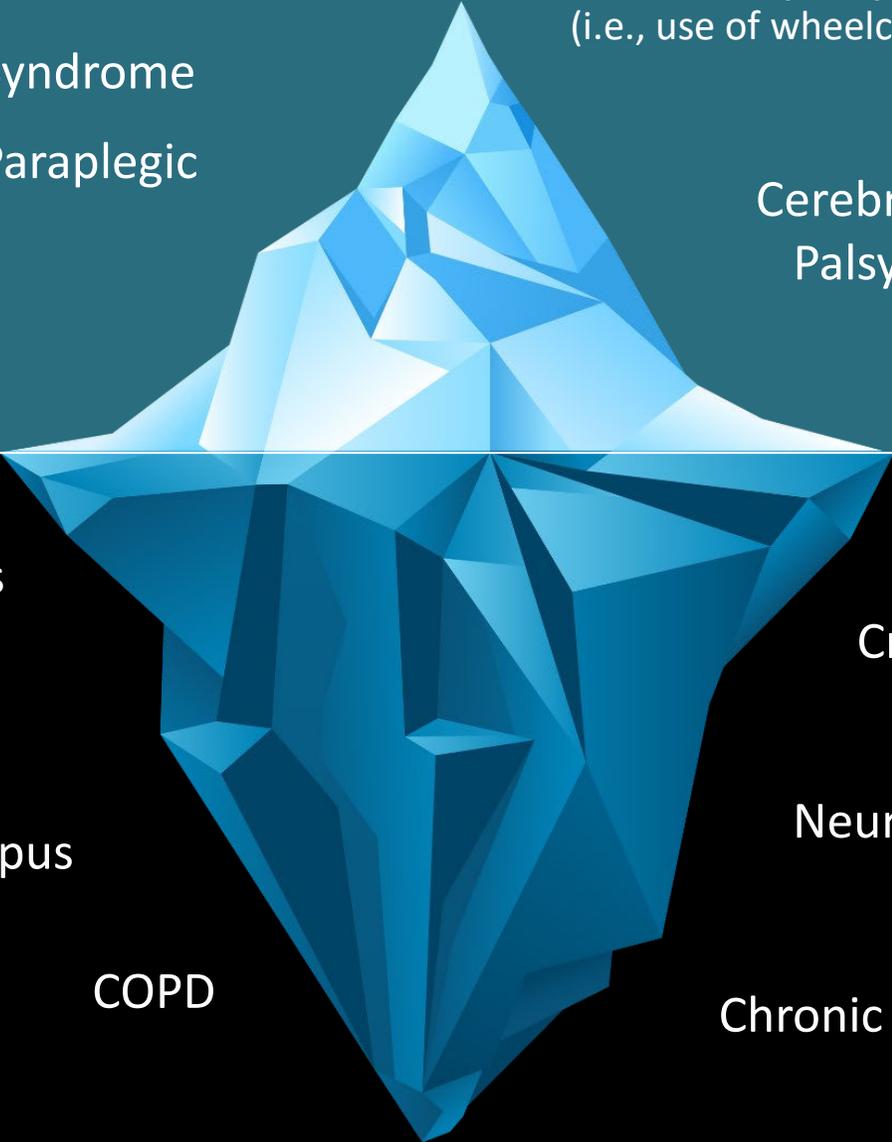
Down Syndrome

Amputee

Alzheimer's
(later stages)

Paraplegic

Neurodiversity

Cerebral
Palsy

COPD
(advanced stages may require
supportive equipment)

Deafness or
Hearing Loss

Multiple Sclerosis
(as it progresses)

Multiple Sclerosis
(early stage or mild)

Fibromyalgia

Crohn's Disease

Alzheimer's
(early stages)

Neurodiversity

Lupus

COPD

Chronic Fatigue Syndrome

Invisible Disabilities

Challenging Assumptions About Disability

Visibility Misconceptions:

Challenging the belief that disabilities must be visible to be valid.

Neurological Differences:

Recognizing neurological variances are not inherently disabilities

Stereotype Impact:

Examining our biases of what is 'normal' vs 'a-typical' expression and behavior.

Alzheimer's Disease

A progressive neurological disorder that leads to the shrinkage (atrophy) of the brain and death of brain cells. It is the most common cause of dementia, resulting in a continuous decline in thinking, behavioral, and social skills that disrupts a person's ability to function independently.

- 10% of adults over 65 have dementia, with increasing incidence.
- Women live approximately 4.6 years after an Alzheimer's diagnosis; men live 4.1 years.
- Earlier diagnosis typically results in a longer post-diagnosis lifespan.
- The practical window for planning is often brief due to progressive cognitive decline.
- Establishing a care and support framework is vital for managing Alzheimer's.

Multiple Sclerosis (MS)

A chronic autoimmune disease in which the immune system attacks the protective sheath (myelin) that covers nerve fibers, causing communication problems between the brain and the rest of the body. This can lead to nerve deterioration or damage. Symptoms vary widely and can include fatigue, difficulty walking, numbness, and muscle weakness

- Approximately 1 million people in the U.S. affected.
- Most commonly diagnosed between ages 20 to 50.
- Can present as relapsing-remitting or steadily progressive.
- Symptoms vary, including fatigue, mobility challenges, numbness, cognitive changes.
- Management strategies aim to slow progression, alleviate symptoms

Case-Study: Living with MS

- Experiences fluctuating daily fatigue, impacting job performance.
- Left the workforce prematurely due to fatigue's toll.
- Diagnosed at 32, necessitating an intensified savings approach for early retirement.
- Despite MS, maintains significant cognitive function; long-term impact uncertain.
- Has set up special powers of attorney to prepare for unexpected exacerbations.
- Carries disability insurance, yet lacks long-term care coverage.
- A single woman, representative of the majority gender affected by MS

COPD:
Chronic Obstructive Pulmonary Disease

COPD, or Chronic Obstructive Pulmonary Disease, is a group of lung conditions that cause breathing difficulties, including emphysema and chronic bronchitis, usually developing due to long-term damage to the lungs from irritants.

- Often presents with a chronic cough and difficulty exhaling.
- Long-term exposure to lung irritants, like smoking and pollutants, increases risk.
- Significant contributor to global morbidity and healthcare burden.
- Management includes medication, pulmonary rehabilitation, and oxygen therapy.
- Proactive lifestyle adjustments, such as smoking cessation, are key to management.
- Ongoing research focuses on improving treatment and quality of life for patients.

Neurodiversity

A term used to refer to variations in brain functioning, processing and cognition that affect different ways people experience and interact with the world.

Cognitive spectrum	Natural variations	Innate differences

- Term coined by Judy Singer in 1998, an autistic sociologist
- Originally referred to autism, but now includes all neurological differences
- Recognizing the unique strengths and challenges of neurodiverse individuals
    – Like differences in physical appearance, there are natural variations in our brains
    – "Neurotypical" is what is considered "normal" within dominant societal standard
- Normal or neurotypical is not a prerequisite to success

Neurodiversity is more common than you think

15% to 25%

of the population is considered
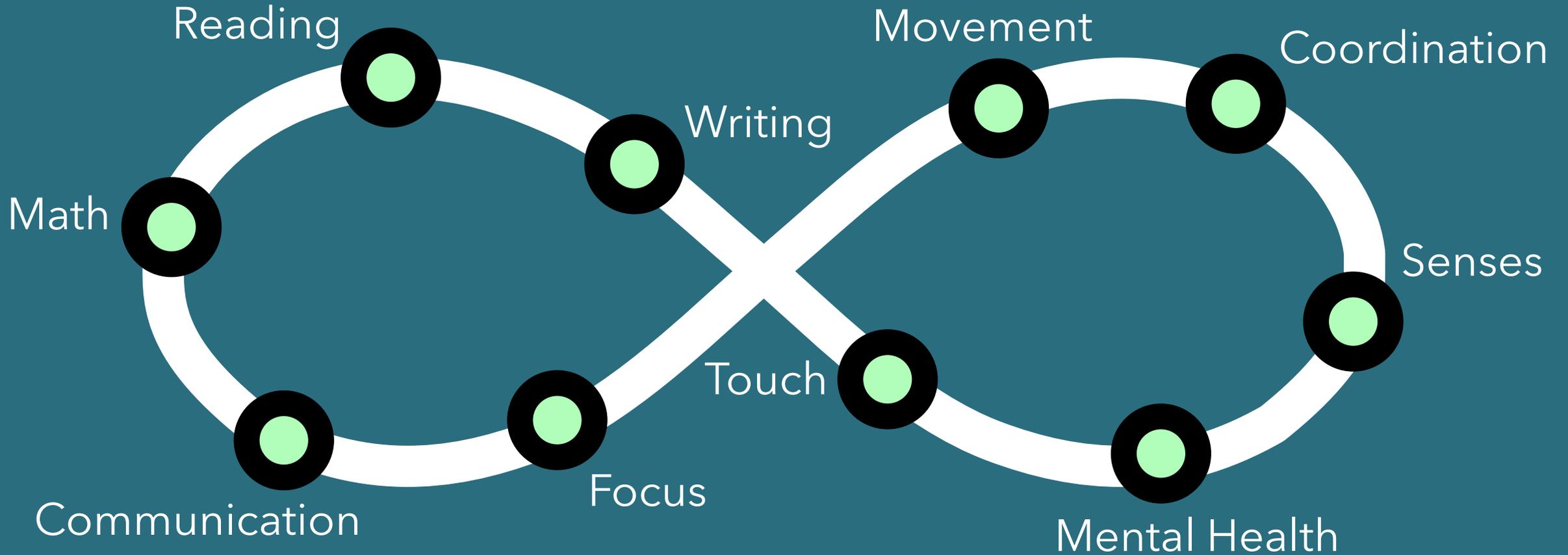to be neurodivergent
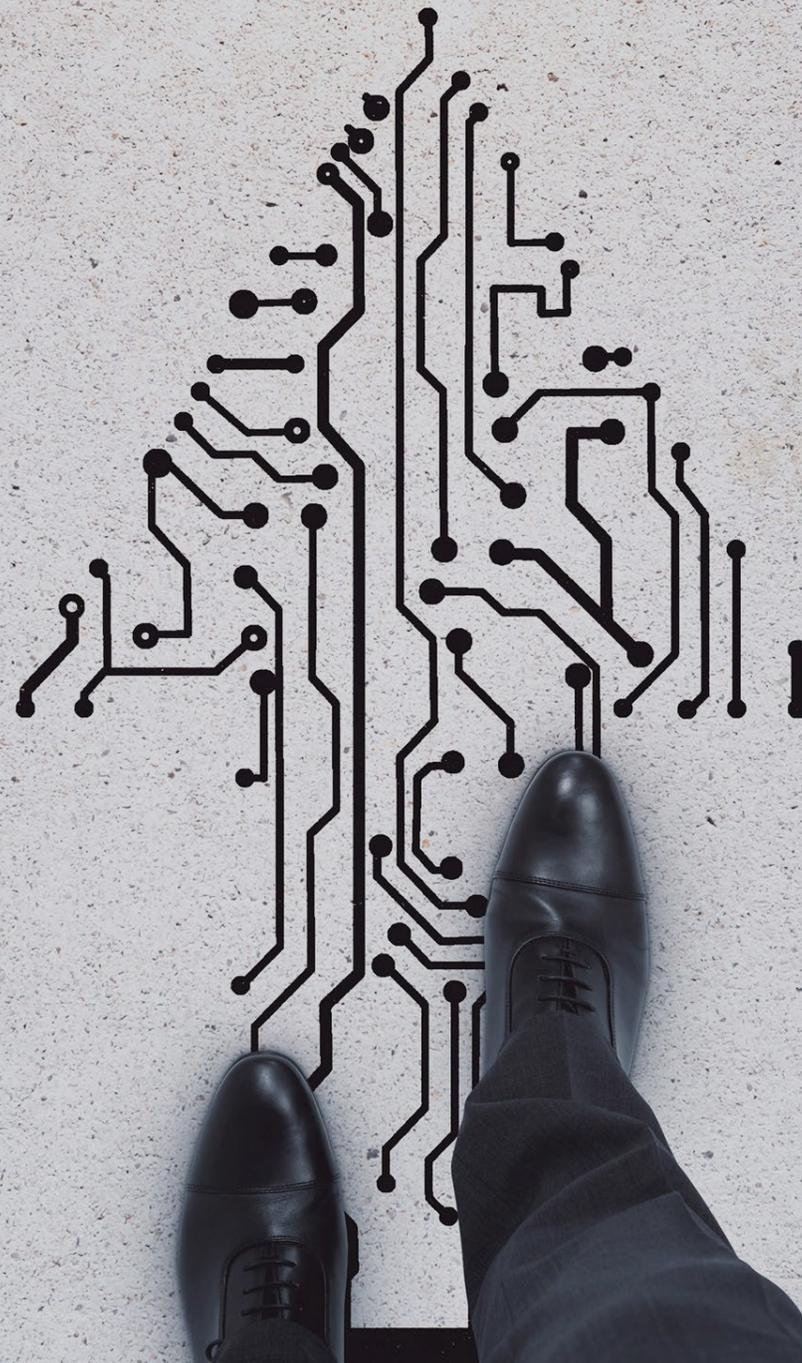
Understanding Neurodivergence

- "Neurodivergent" is a non-medical term
- A neurodivergent person has one or more ways in which their brain functions outside the "typical" way
- The term does not intend to diminish or disregard struggles or challenges of neurodivergent people
- Different models for classification:
- Medical model – set of symptoms to be cured
- Social model – a person is "disabled" when society cannot accommodate their needs
- Neurodiversity model –
  - differences are not deficits that need to be fixed or viewed as weaknesses
  - differences are part of the richness and depth of the very fabric of life

The Spectrum of Neurodiversity©

Reading

Movement

Coordination

Math

Writing

Senses

Touch

Communication

Focus

Mental Health

Common Types of Neurodiversity

Dyslexia
Difficulty reading due to problems identifying speech sounds and learning how they relate to letters and words

ADHD
(Attention-deficit hyperactivity disorder) Difficulty with focusing, restlessness and/or impulsivity

Dysgraphia
Difficulty forming letters, spelling words or both

Tourette Syndrome
(Also known as Tourette's Disorder). A type of tic disorder. Tics are involuntary, repetitive movements or vocalizations.

Autism Spectrum Disorder (ASD)
Range of conditions affecting how people communicate and interact with others and the world around them

Dyscalculia
Ability to understand number-based information and math

DCD/Dyspraxia
(Developmental coordination disorder). Difficulty with movement and coordination

OCD
Type of anxiety disorder characterized by recurring obsessions or compulsions

Neurodiversity Myths, Assumptions & Stereotypes

- Neurodiverse conditions are frequently classed as disabilities which can lead to stigmatization, discrimination and marginalization
- Neurodiverse employees cannot perform at the same level as neurotypical employees
- Neurodiversity is rare
- Accommodations and supports are expensive
- Workplace impacts:
  - Neurodiverse employees can be difficult to manage
  - Stressful, fast-paced or high-pressure situations are more difficult for neurodiverse people

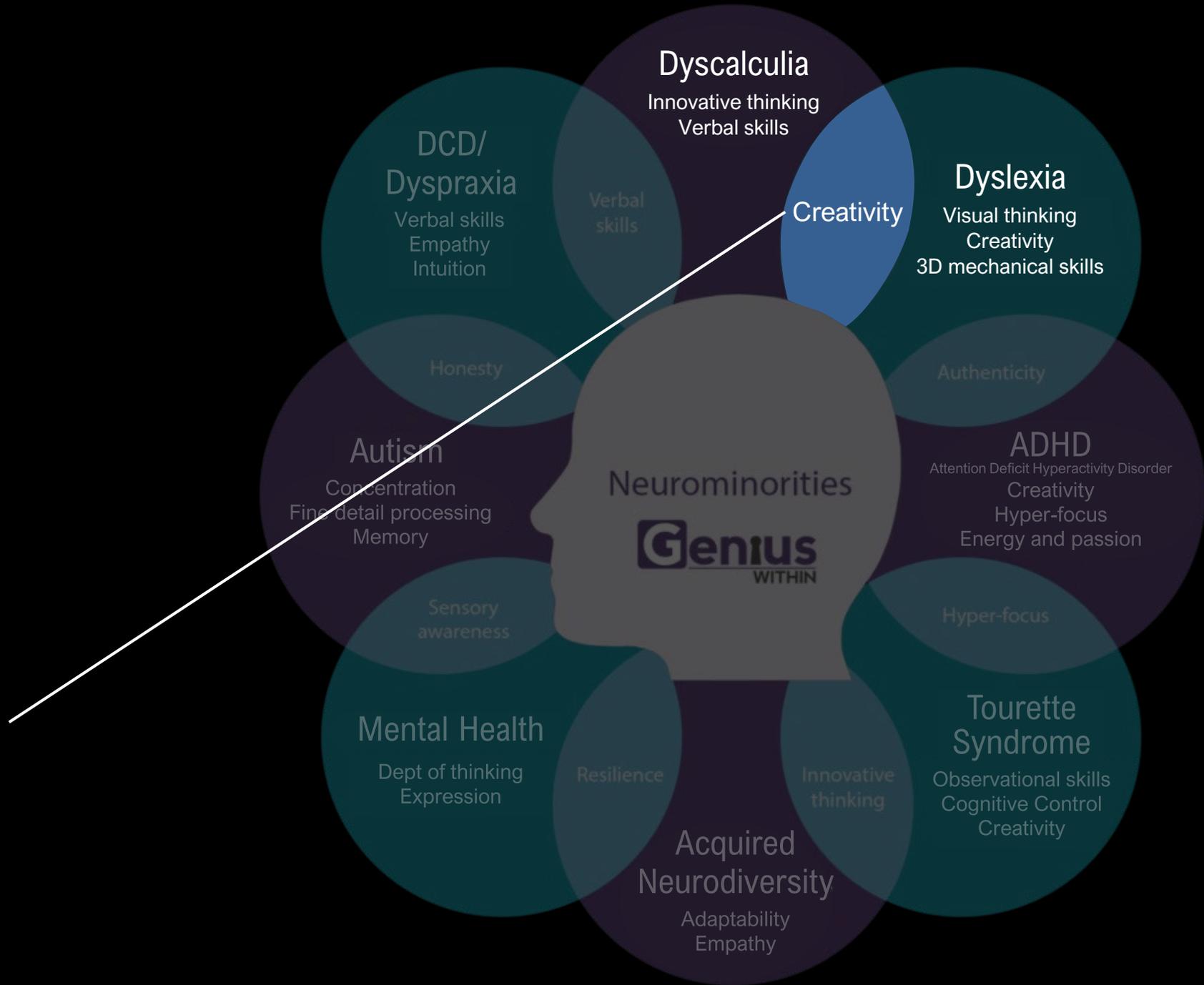Overlapping Strengths of Neurodiversity
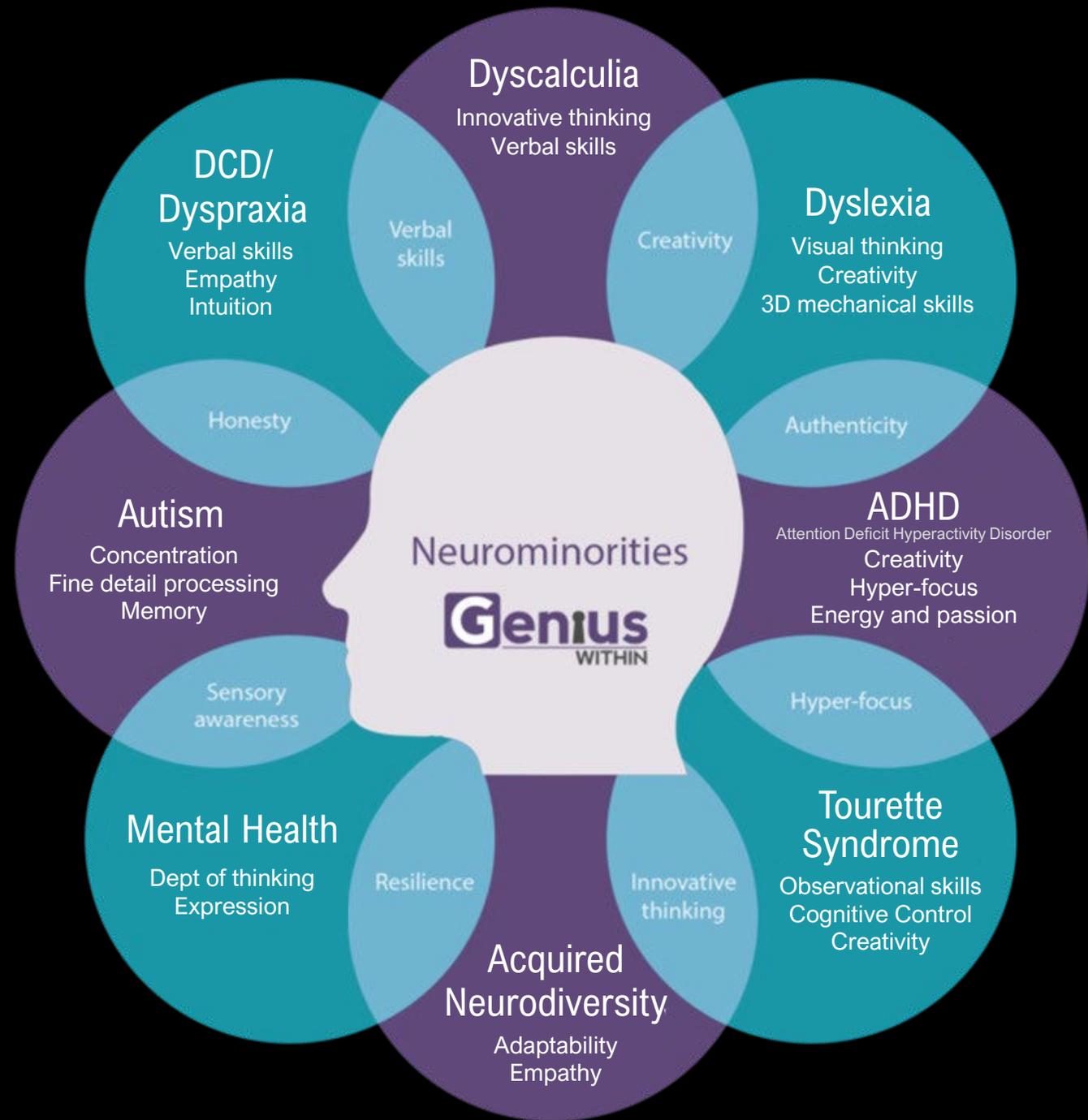
Dyscalculia:
Problem solving
Qualitative reasoning

+

Dyslexia:
Visual-Spatial Abilities
Storytelling

=

Creativity

Dyscalculia
Innovative thinking
Verbal skills

DCD/Dyspraxia
Verbal skills
Empathy
Intuition

Verbal skills

Creativity

Dyslexia
Visual thinking
Creativity
3D mechanical skills

Honesty

Authenticity

Autism
Concentration
Fine detail processing
Memory

Neurominorities

Genius
WITHIN

ADHD
Attention Deficit Hyperactivity Disorder
Creativity
Hyper-focus
Energy and passion

Sensory awareness

Hyper-focus

Mental Health
Dept of thinking
Expression

Resilience

Innovative thinking

Tourette Syndrome
Observational skills
Cognitive Control
Creativity

Acquired Neurodiversity
Adaptability
Empathy

Dyspraxia:
Straightforward
Empathy

+

Autism:
Respect for rules
Reliability

=
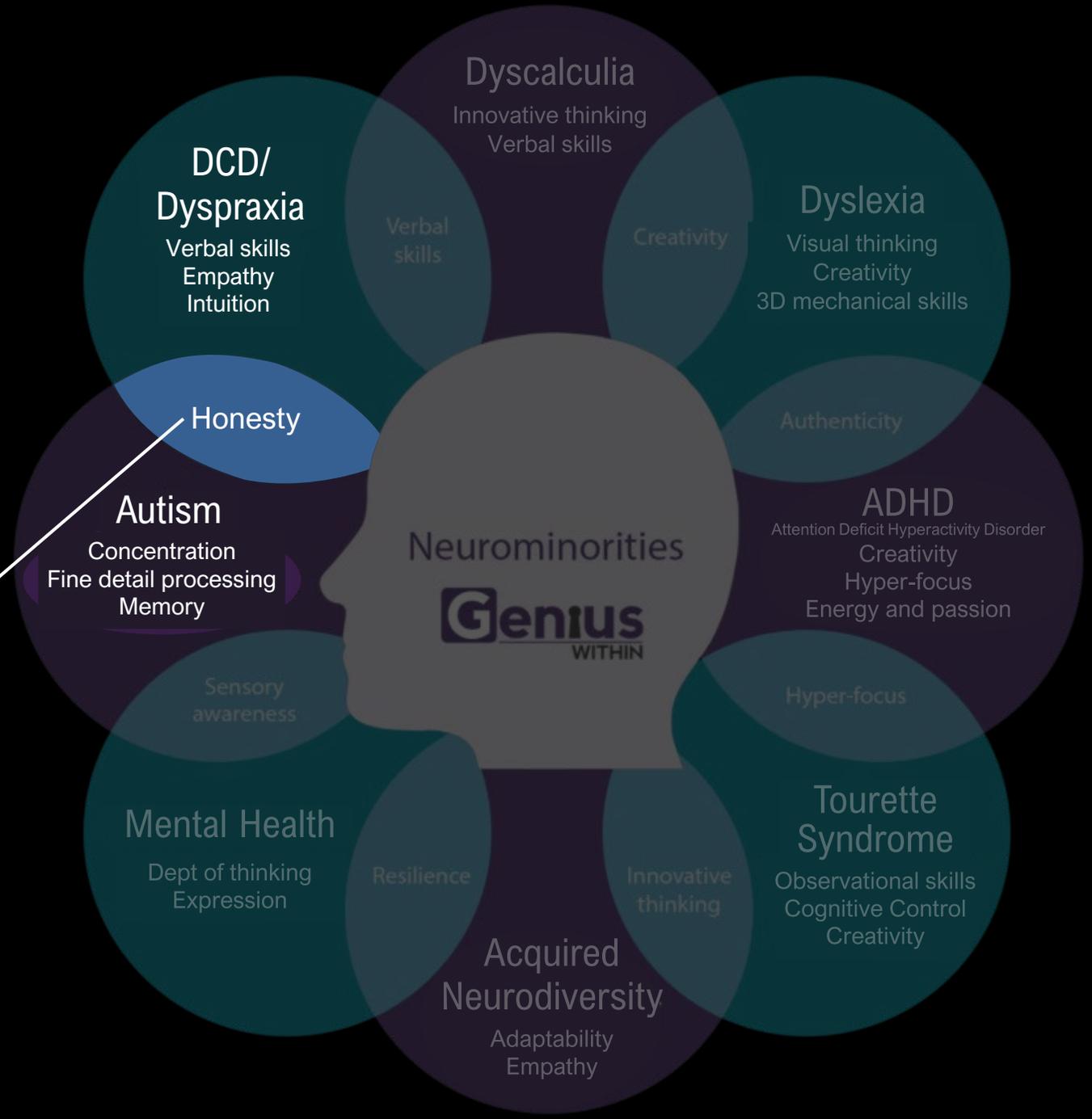
Honesty
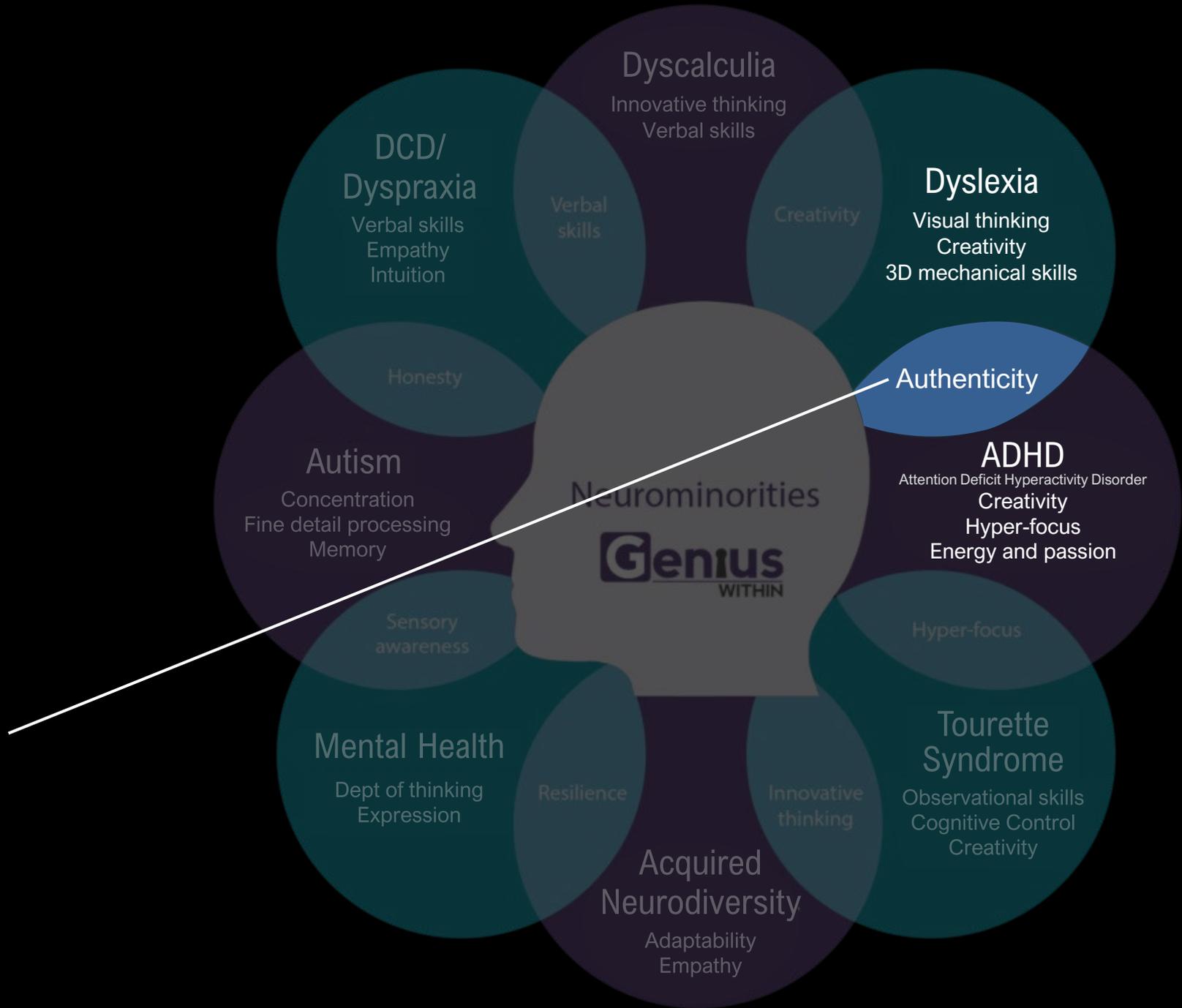
Understanding Cognitive Impairment

- Cognitive status can vary widely among individuals.
- Changes can occur gradually or suddenly due to health events.
- Diseases like Parkinson's have diverse effects on cognition.

Assessing Capacity

- Determine current cognitive status for informed decisions.
- Engage in targeted questioning to uncover cognitive challenges.
- Utilize care managers to observe and report on daily functioning.
- Regular assessments can reveal changes due to health events.
- Situational capacity varies with task complexity and decision gravity

Validating Competency

- Substantiate capacity legally for client directives and actions.
- Compile evidence from medical evaluations, professional observations, client statements.
- Match competency level to the potential impact of decisions.
- Incorporate tangible evidence, like medical letters, for validation, task complexity and decision gravity

The Aging Mind:
Tracking Cognitive Health

- Recognize increased risk of cognitive impairment with age.
- Prioritize regular cognitive evaluations in aging clients.
- Understand Parkinson's progression: dementia onset can be delayed.
- Emphasize annual meetings for proactive cognitive health management.
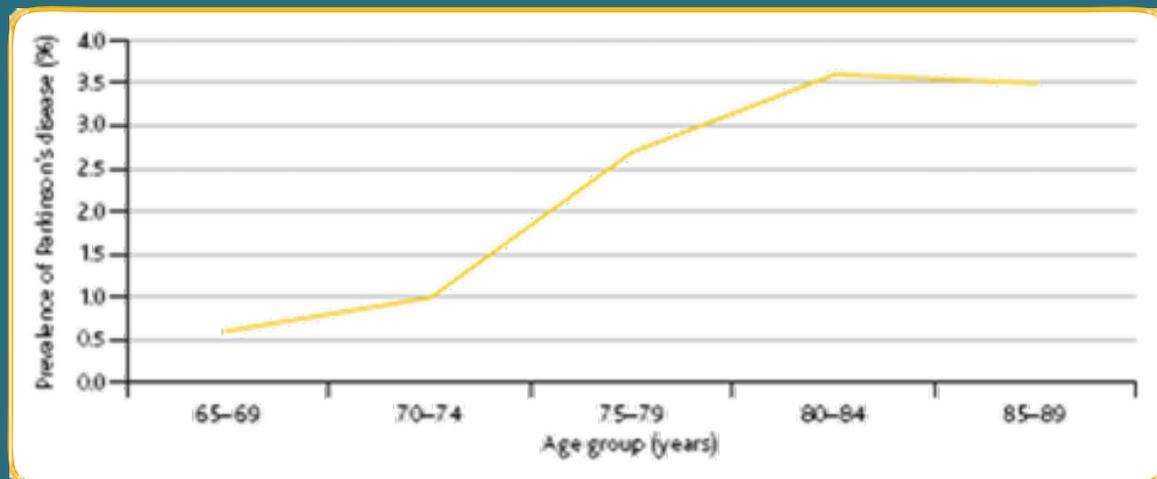
One Example: Cognitive Impact of Parkinson's Disease

20% of people with Parkinson's will go on to develop dementia an average of 10 to 15 years later

General Considerations

- Web vs In-Person: Choosing the format based on client comfort and accessibility.
- Meeting Length: Balancing shorter sessions with comprehensive coverage.
- Agenda Structure: Providing clear outlines or bullet points for guidance.
- Breaks: Integrating breaks to maintain focus and comfort.

Kübler-Ross, E. (1969) On Death and Dying, Routledge, ISBN 0415040159

Neurodiversity Considerations

- Information Processing: Recognizing how neurodivergence affects information intake.
- Summarizing Key Points: Offering high-level overviews before detailed discussion.
- Use of Stories and Examples: Aiding understanding through real-life contexts.
- Interaction Styles: Adjusting to varied communication needs, especially in Autism Spectrum Disorder.
- Virtual Meeting Enhancements: Utilizing closed captioning, avoiding chat distractions, and being adaptable with platform choices.

Virtual Meeting Considerations

- Font and Background Choices:
  – Using san serif fonts
  – Darker backgrounds for readability
- Visual Aids:
  – Employing illustrations
  – Minimal text for clarity.

Effective Communication

- Ensuring Understanding: Regular comprehension checks.
- Meeting Recordings and Transcriptions: Providing multiple formats for review.
- Support Person Involvement: Encouraging a companion for assistance.
- Meeting Summaries: Concluding with clear, actionable points.
- Note-Taking Alternatives: Offering solutions for clients facing challenges in note-taking.
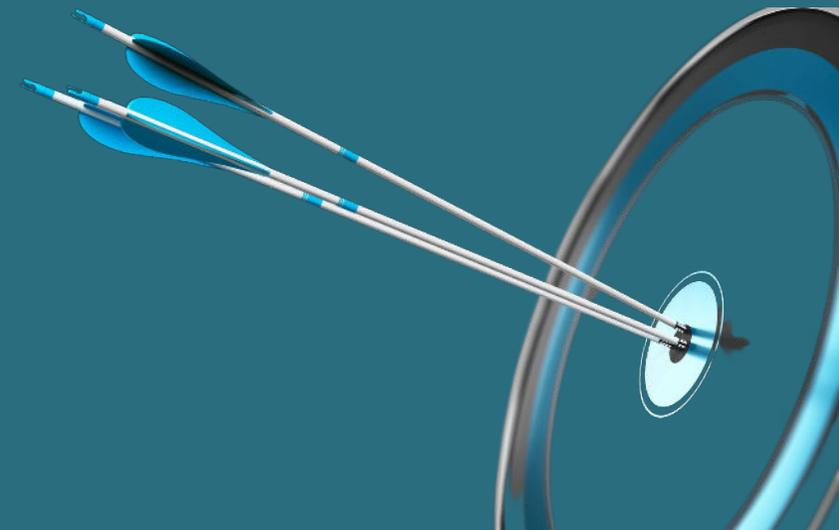
Client-Focused Follow-Up

- Actionable Takeaways: Providing a concise list of to-do items post-meeting.
- Client-Centric Formats: Tailoring follow-up material to suit client's specific needs and challenges.

Final Thoughts

Asking is Compassionate

- Addressing the implications of chronic illness is not only the compassionate, but it's also good business
- Don't be uncomfortable to ask
  - Not addressing these issues is far more difficult for the client than addressing them
  - You don't have to be an expert
- Awareness will facilitate communication, engagement and planning
- Empathy not sympathy is the attitude that will facilitate planning
  - Empathy is understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another
  - Sympathy is feeling bad or sorry for the experiences of another

Final Thoughts

Empathy & Creativity

- Don't assume – ask about individual preferences or needs
- Avoid sarcasm, jargon, euphemisms and implied messages
- Allow additional time to process information
- Provide options for different communication styles
- Be patient
- Consider organization wide changes to minimizes or eliminates the need to self-disclose or request accommodations
- Avoid text-heavy emails, documentation or presentations

Questions?

Thank you!

Jina Etienne, CPA, CGMA, CDE®

Etienne Consulting, LLC

jina@etienneconsulting.com
etienneconsulting.com

Martin Shenkman, CPA, MBA, AEP, PFS, JD

Shenkman Law

shenkman@shenkmanlaw.com
shenkmanlaw.com