

Adapting with integrity

Approaches to assessing clients with diverse and complex needs



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*Aboriginal people are the thought leaders on **inclusion**.*

*In traditional language there was and is **no word for disability**.*

*The focus is on what we **need to know** about that person so we can ensure they can participate in the community.*

*This is a wonderful thing in our communities – we have always been “**come as you are**”.*

- Damian Griffis

CEO, First Peoples Disability Network

Introductions

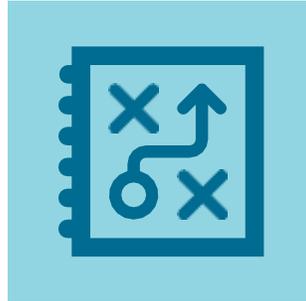
This workshop is dedicated to the students who challenged me to search for new ways of understanding them and their abilities. I am sorry I did not know then what I know now. I have been privileged get to know you and walk beside you. You inspired me to look beyond.

"Dr Hugely, even though he had been to college for like, a million years, would never be smart enough to see inside of me"

(Sharon Draper – from the novel "Out of My Mind")

Participation options

- Full participation possible without agreeing to the research
- Consent to use Mentimeter responses as part of research
- Opportunity to change your responses at the end
- Further opportunities to participate in this and future phases



Framework

Choosing the best assessment approach



Informal Assessments

Construct

Evidence

Interpretation/ formulation

Communication



Ethics

Limitations & risks

Intellectual developmental disorder/intellectual disability

- A. **Deficits in intellectual functions**, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
- B. **Deficits in adaptive functioning** that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
- C. Onset of intellectual and adaptive deficits during the **developmental period**.

**“When you read the DSM
it doesn't sound that hard to diagnose
- it's way trickier in reality.”**

Not as easy as A, B, C

English is a second language

Cultural differences

Co-occurring conditions

Appropriateness of tools
(culture/exposure)

DSM V-TR

- A. Deficits in intellectual functions
- B. Deficits in adaptive functioning
- C. Onset in developmental period

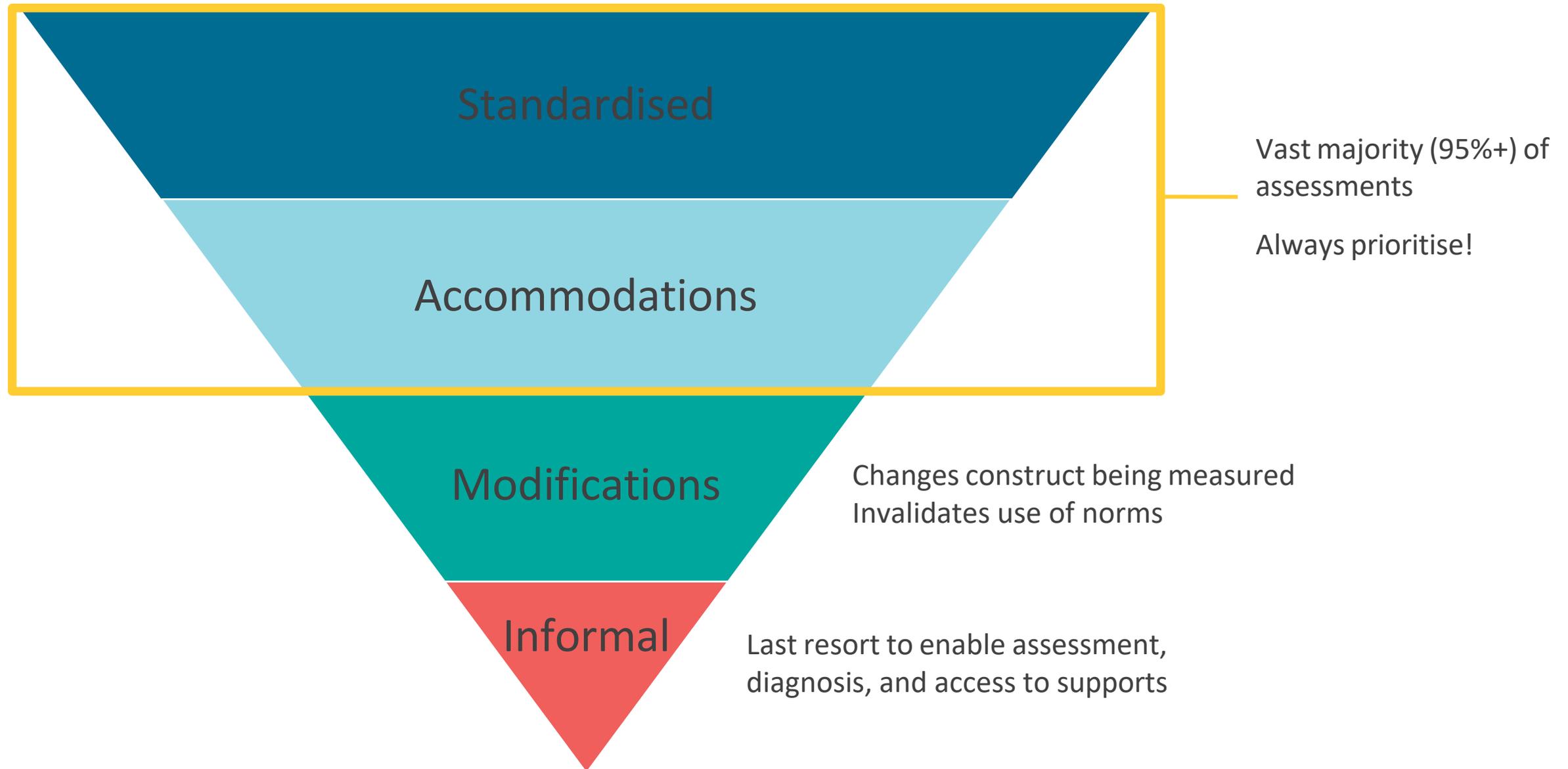
Determining severity
(other factors impact adaptive functioning)

Assessment required before age 5

Limitations of standardized IQ tests

Inflexible rules for access to services

Assessment Approach Hierarchy



Assessments

Planning

Construct

What are we measuring?



Evidence

How will we measure it?



Interpretation

How will we interpret it?

Reporting



Access Skills

Construct-irrelevant abilities necessary to participate in the test and interact with the content

VS



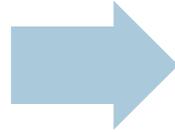
Target Skills

Representations of the construct the test is designed to measure

Assessment

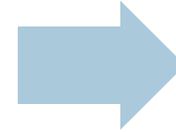
Assess access skills

- Interviews
- History
- Prior assessment reports
- Medical & allied health reports
- Observations
- Initial interactions



Consider appropriateness

- Are there any factors that should be managed or stabilised prior to assessment? E.g., sleep, instability, mental health conditions
- Consider risk



Plan for access skill limitations

- Standardised assessment not feasible

Test Adaptations

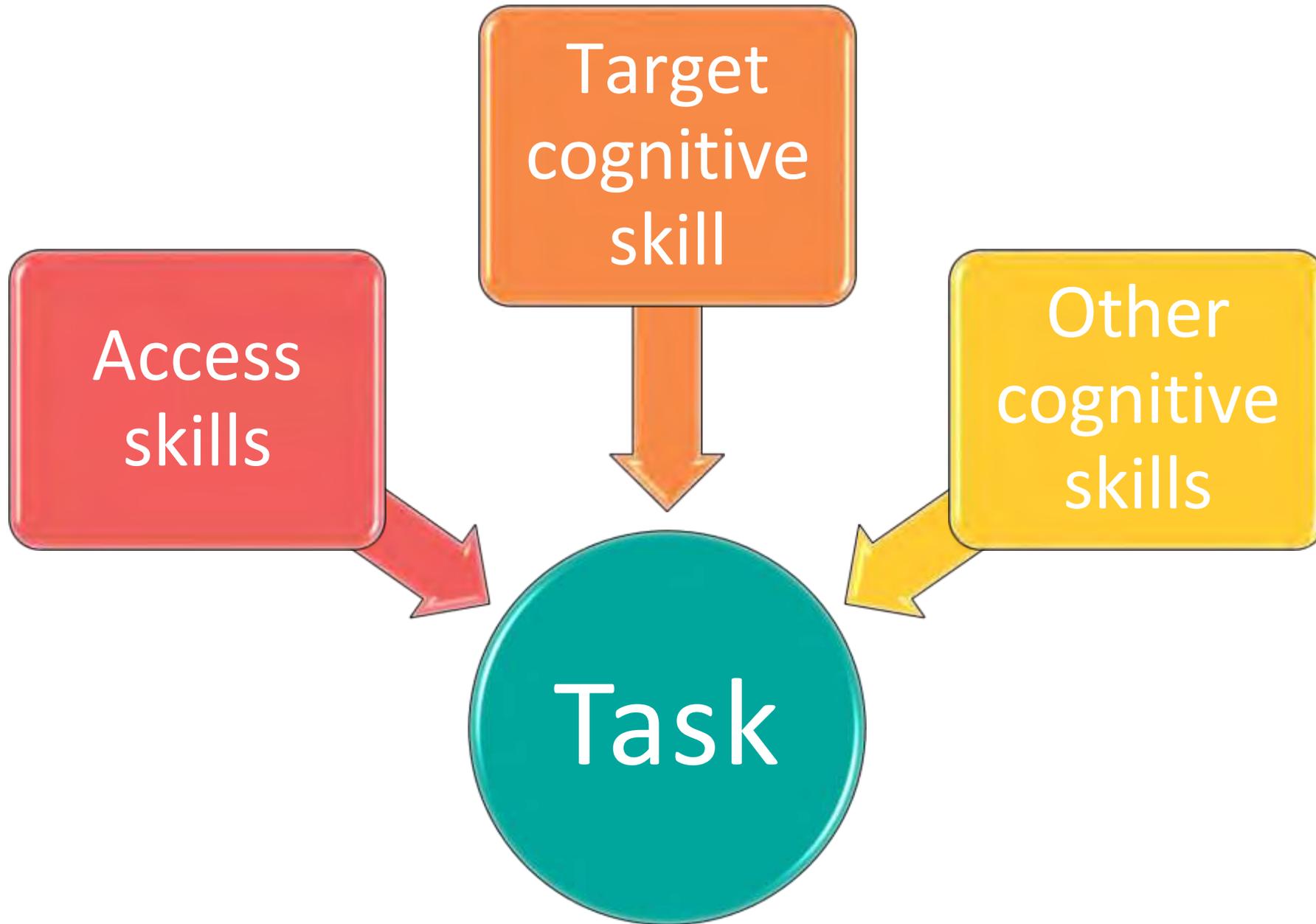
Accommodations:

“relatively minor changes to the presentation and/or format of the test, test administration, or response procedures that maintain the original construct and result in scores comparable to those on the original test” (AERA, 2014, p.58 cited in Thompson, et al., 2018)

- Enable equitable access to participating in the task and assessment
- Changing **accessibility** and NOT the **construct** or target skill being assessed

Modifications:

CHANGE the task and the construct/target skill being assessed (see Thompson, et al., 2018)

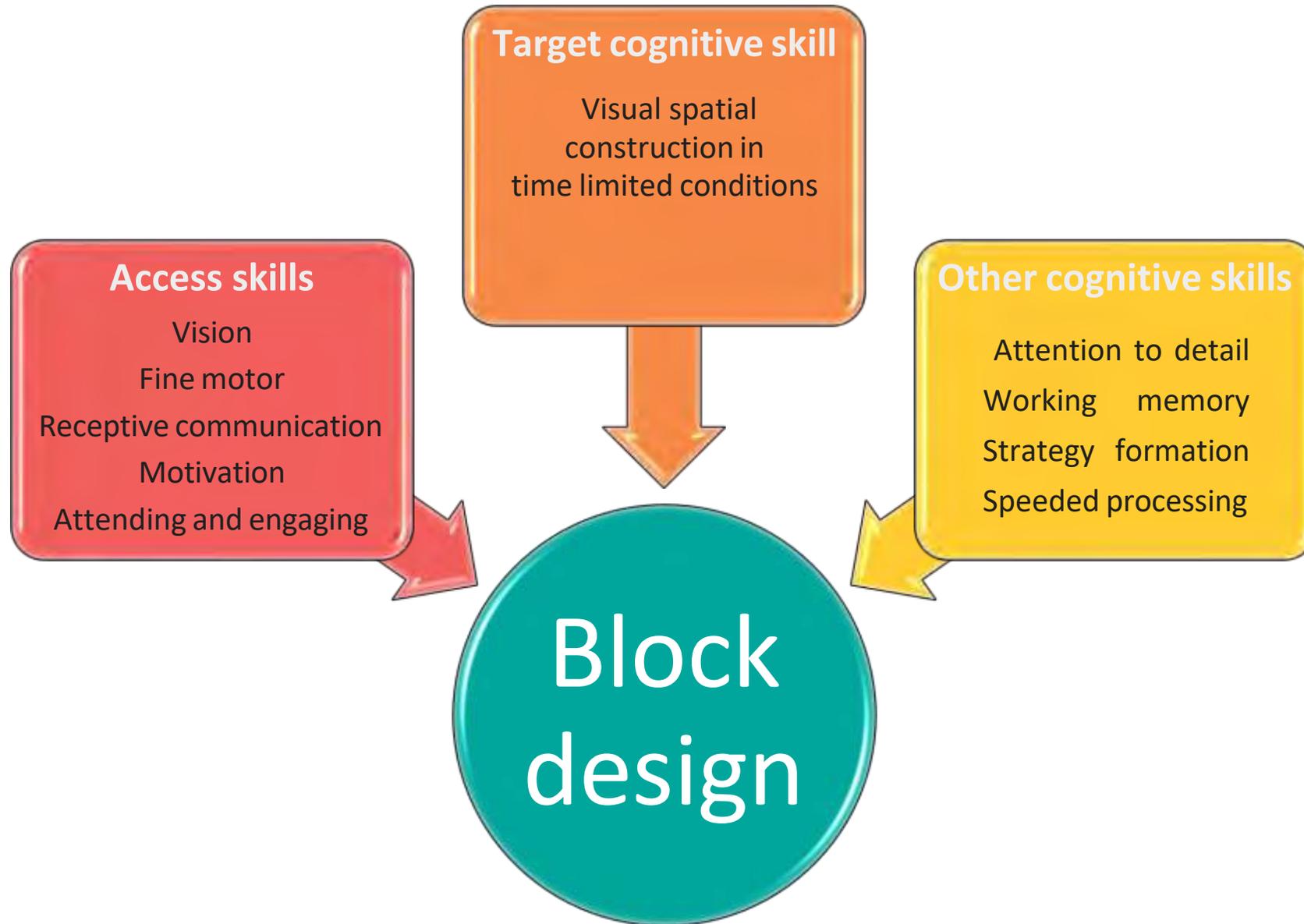


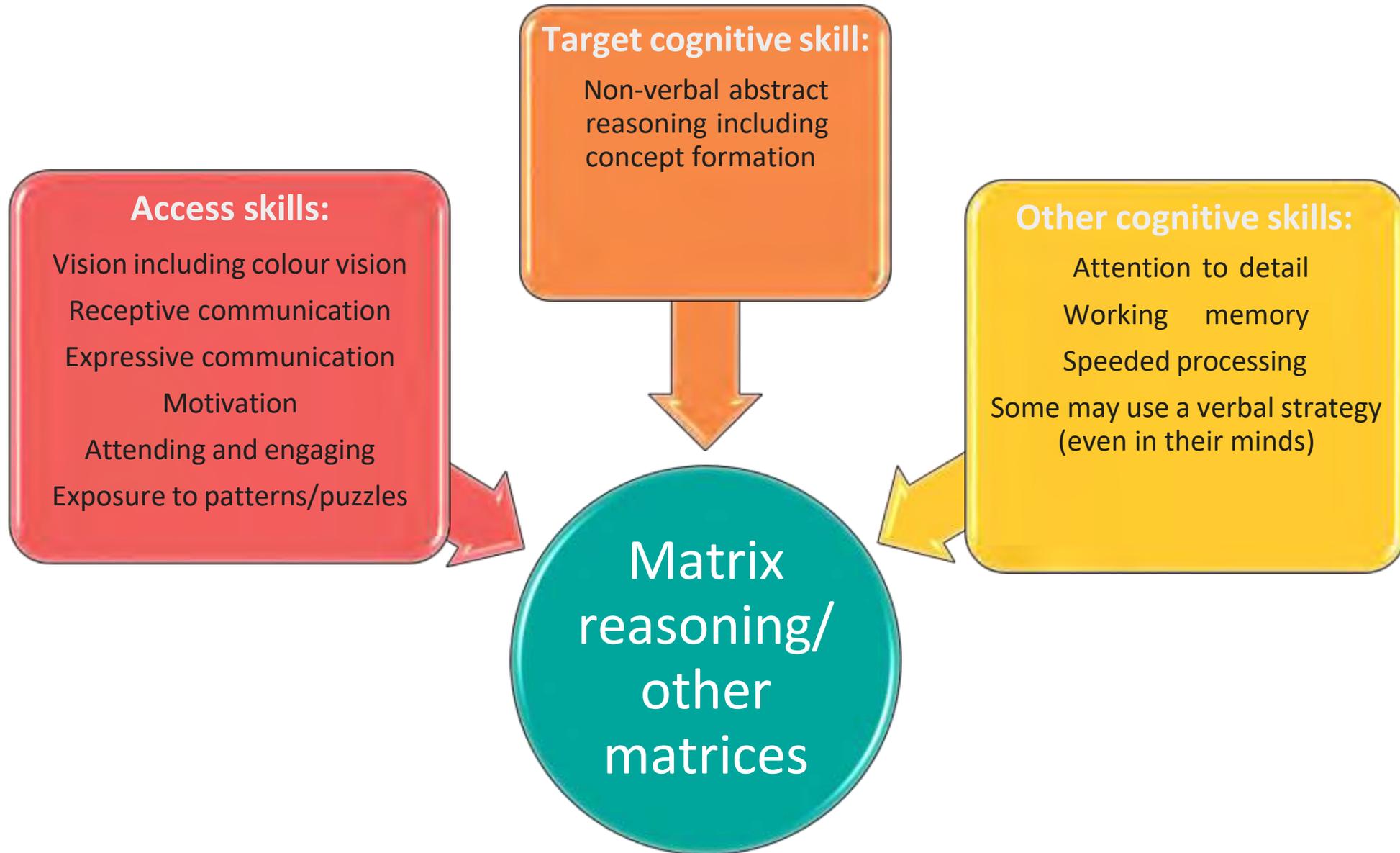
Access skills

Target cognitive skill

Other cognitive skills

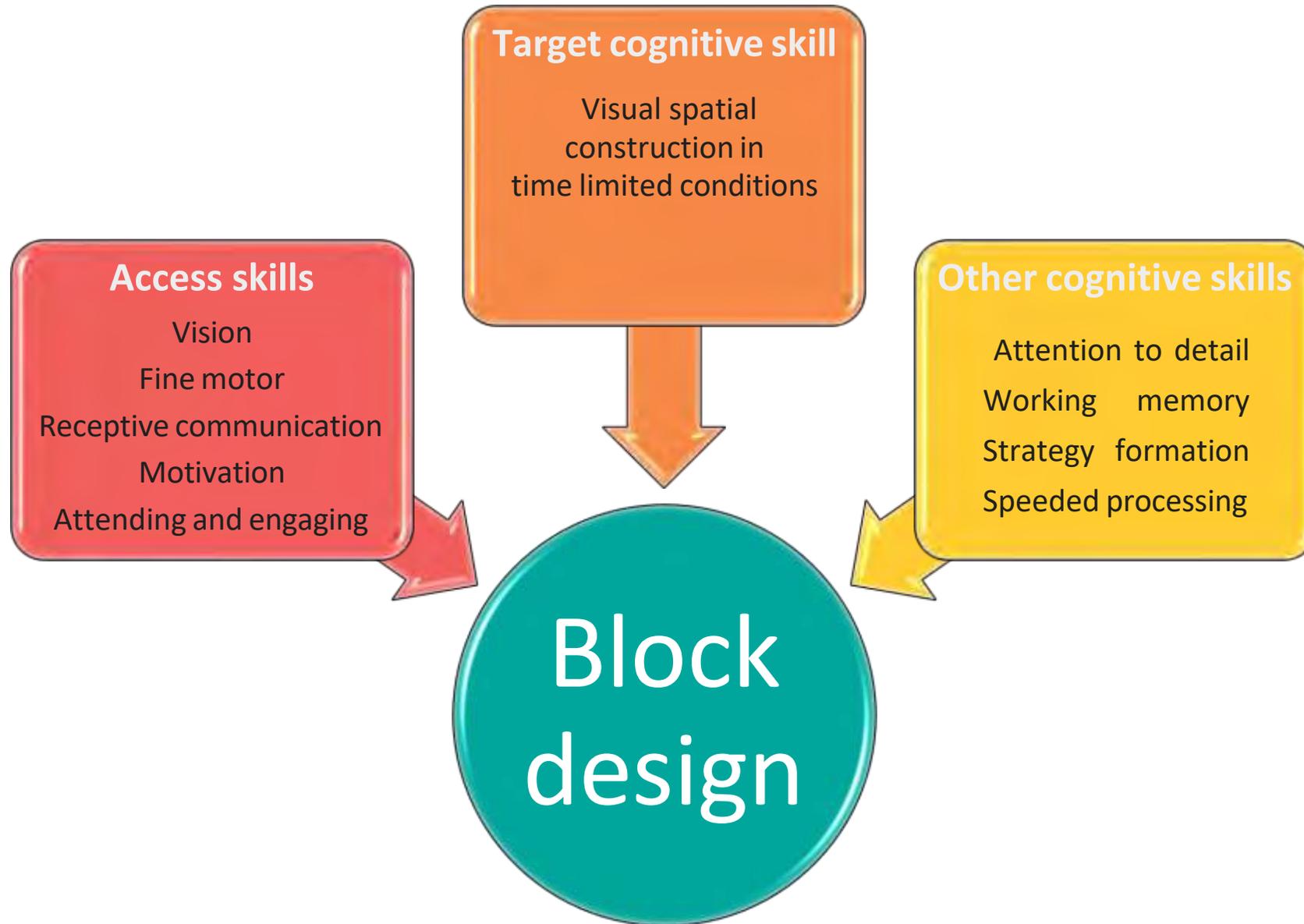
Task

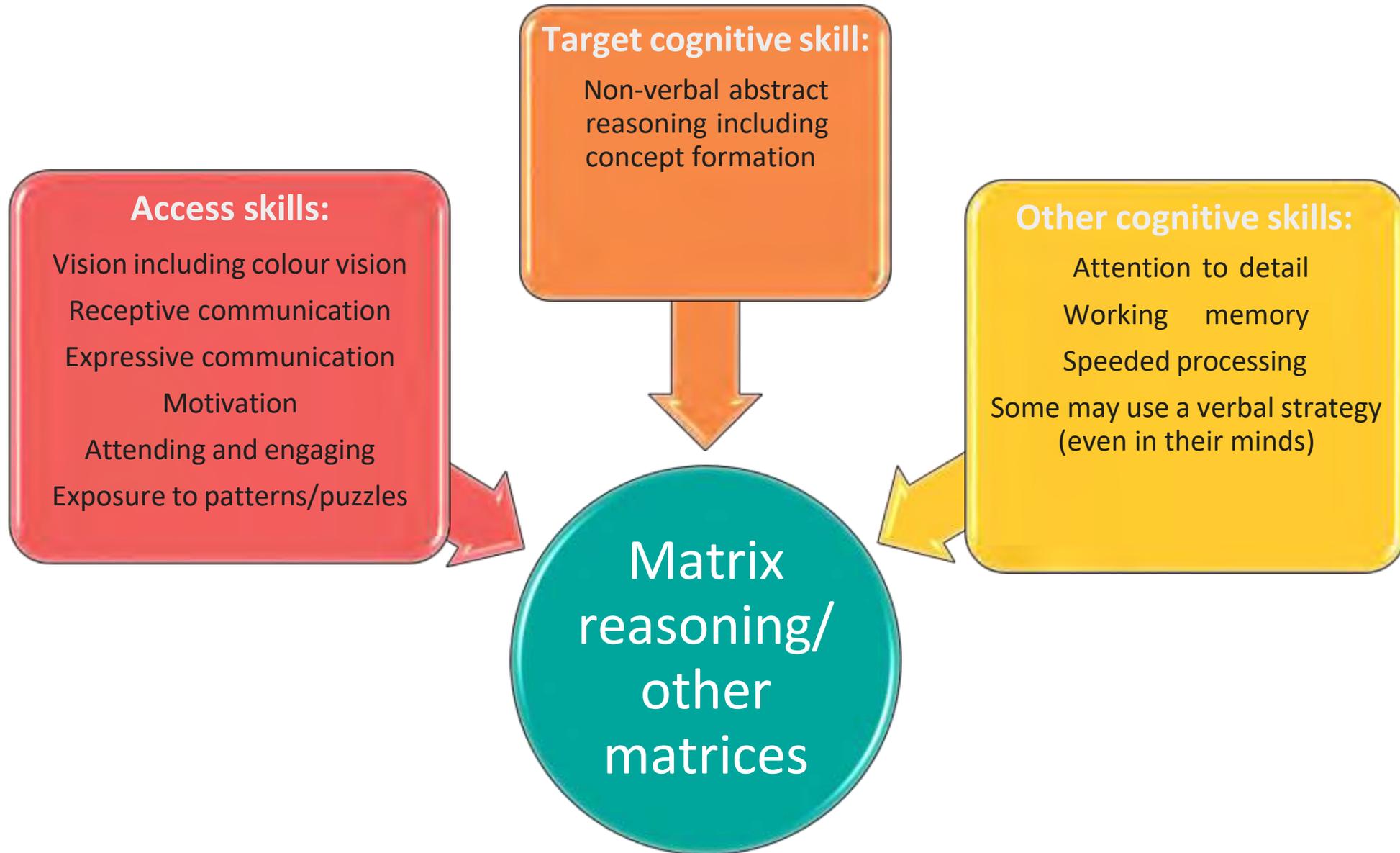




When access skills impact testing:







Accommodations

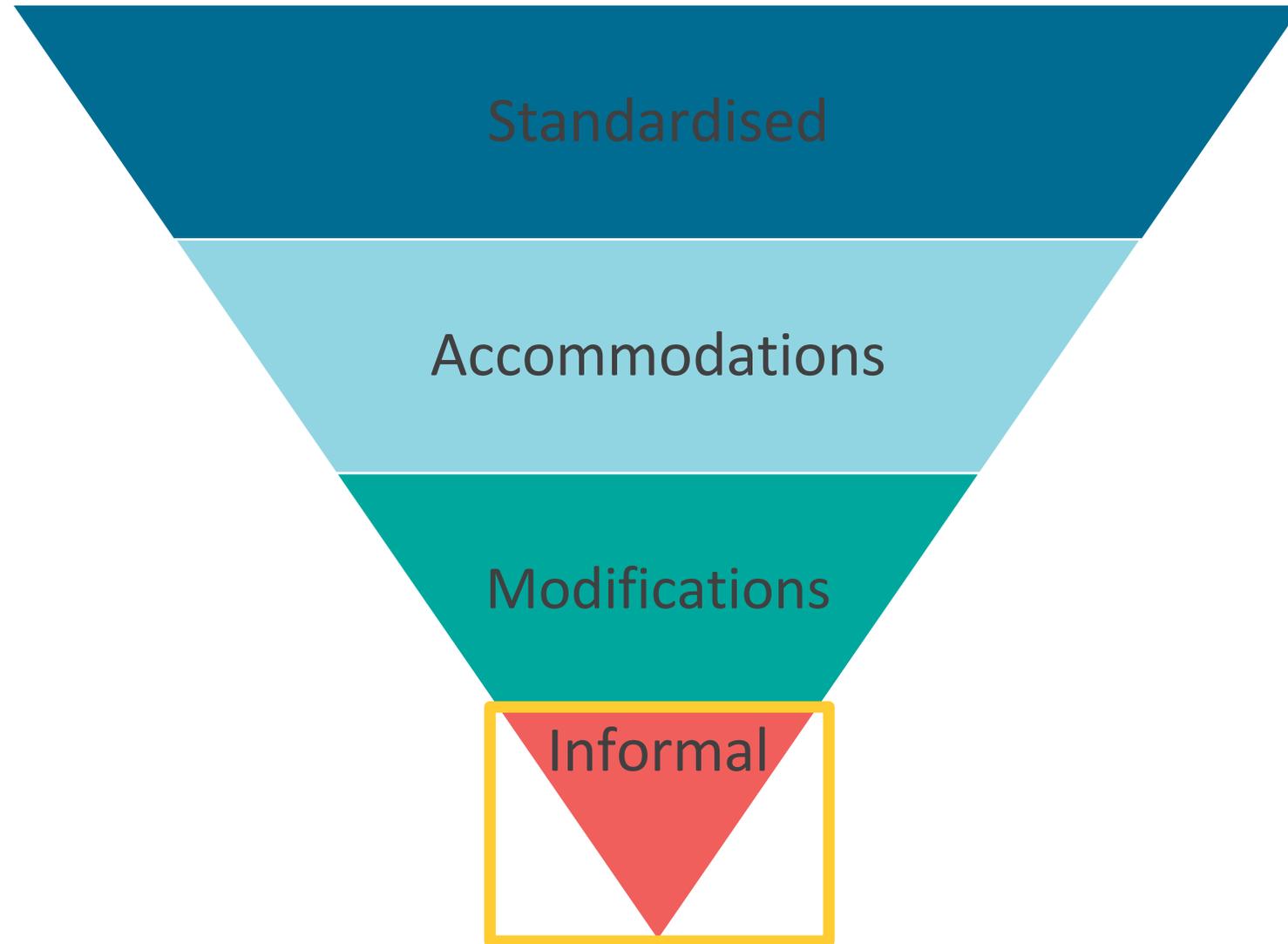
Accommodations in assessments

- Minimise the accommodations – adhere as much as possible to standardised instructions
- Before making accommodations, you MUST:
 - know the specifics of the CONSTRUCT or TARGET COGNITIVE SKILL to be assessed
 - consider the possible impacts on the construct/target cognitive skill of the accommodation

Accommodations

- Address the access skill limitations
- Not change the construct of what the individual test is assessing
- Requires thorough understanding of construct measured and impact of changes
- Document any accommodations assessments so that they can be reproduced (just like a methods section for a research study)
- Requires caution when using normative data and scores

Informal Assessment



How would you assess intellectual functioning for this client?

Age/ gender	13 years, male
Other conditions	Congenital deafblindness
Access skill Considerations	Some functional vision with a cerebral visual impairment – vision fragmented/ unpredictably functionally variable Profoundly deaf Uses bodily motion/ position/ posture/ touch to orient/ express attention focus & interest Well developed motor skills
Interests	Enjoys physical activity
Other concerns	Self regulation problems Engages in self-stimulating behaviour that escalates that can result in self-injury
Prior Assessment	Cognitive function unassessable Diagnosis: Severe intellectual disability
Reason for referral	Second opinion as teachers at school feel there is “something there”

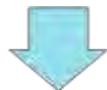
Assessments



What are we measuring?



How will we measure it?



How will we interpret it?



Ethics – to assess or not to assess....



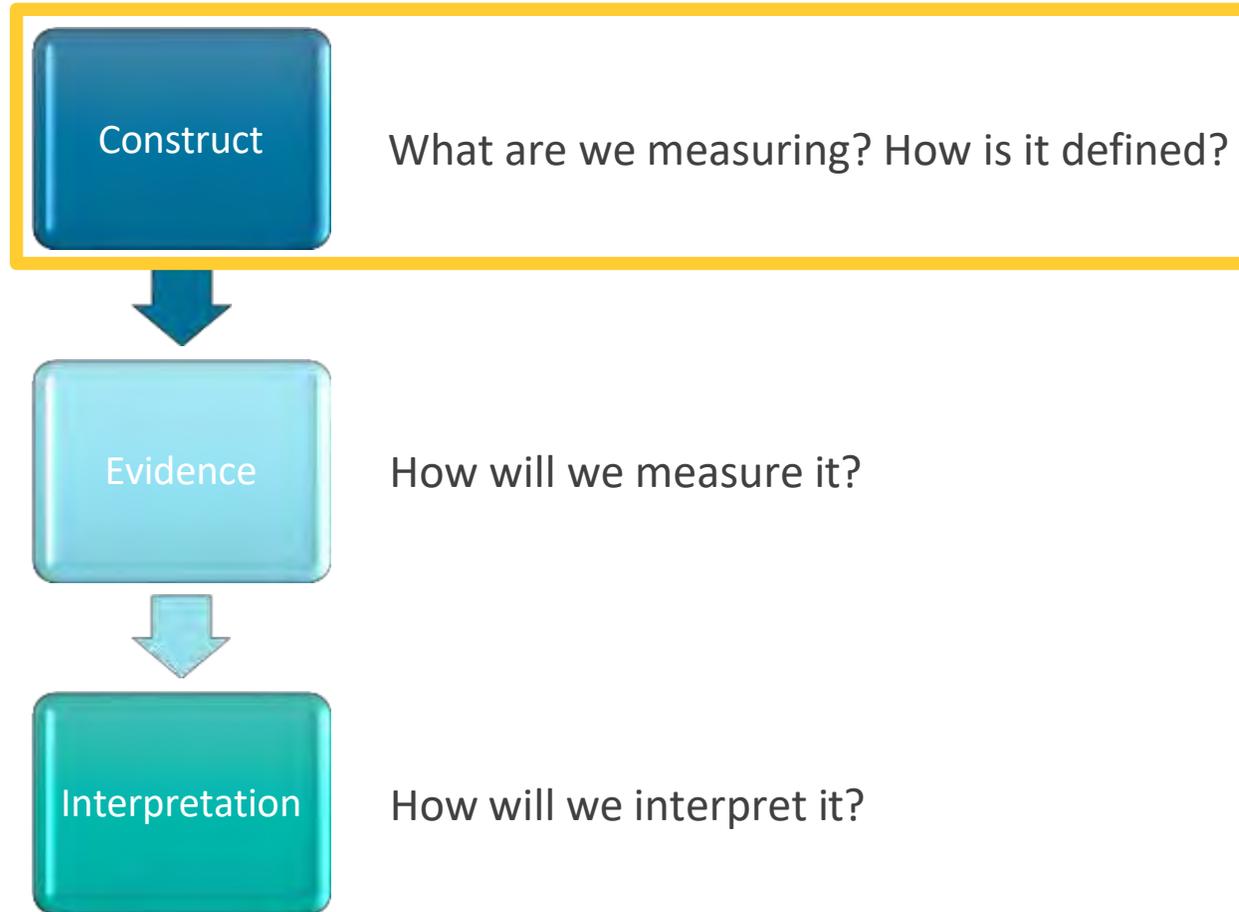
Risks of assessing
using informal
assessments



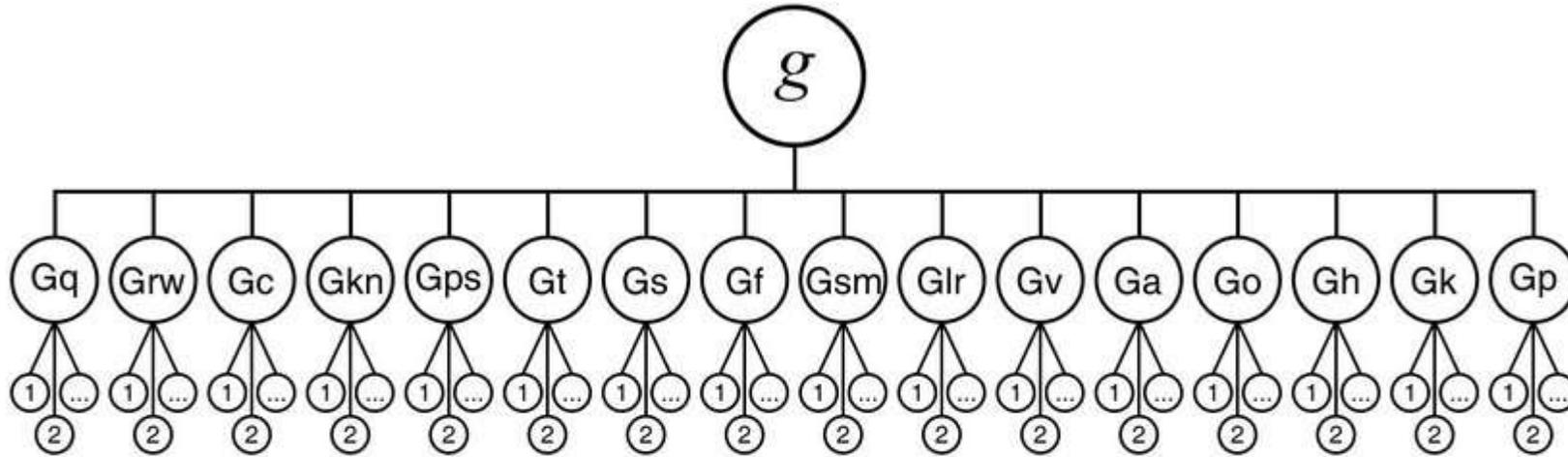
Risks of not
assessing and not
diagnosing

Does the assessment need to happen now?

Assessments



Measuring the construct of intelligence



Third-order factor:

g - General Intelligence

Second-order factors:

Gq - Quantitative Knowledge

Grw - Reading and Writing

Gc - Comprehension Knowledge

Gkn - Domain-Specific Knowledge

Gps - Psychomotor Speed

Gt - Reaction and Decision Speed

Gs - Processing Speed

Gf - Fluid Reasoning

Gsm - Short-Term Memory

Glr - Long Term Storage and Retrieval

Gv - Visual Processing

Ga - Auditory Processing

Go - Olfactory Abilities

Gh - Tactile Abilities

Gk - Kinesthetic Abilities

Gp - Psychomotor Abilities

Standardised

Informal



What are we measuring?

Intelligence/intellectual functioning
Defined – IQ/GIA/via the test

Intelligence/intellectual functioning
Defined – ??????????????



How will we measure it?

IQ/GIA/via the test

??????????????



How will we interpret it?

Scores/normative data
interpreted with context + adaptive
functioning

??????????????
with context + adaptive functioning

Criterion A: “...intellectual functions such as *reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience...confirmed by both clinical assessment and individualised, standardised testing*” (p.37)

Diagnostic features:

Also lists “**practical understanding**” (p.38) and “Critical components [of intellectual functions] include *verbal comprehension, working memory, perceptual reasoning, quantitative reasoning, abstract thought, and cognitive efficacy.*” (p.38)

“Intellectual functioning is **typically measured with individually administered and psychometrically valid, comprehensive, and culturally appropriate tests of intelligence.**”

Latent construct of intelligence

Effective application of developmentally appropriate learning and problem-solving skills to:

- detect and manage social, physical, and environmental risks
- adapt to one's strengths, limitations, and environment
- pursue goals that are meaningful to the individual and their family/community.

Adapting to
one's strengths,
limitations, and
environment

≠

Adaptive
functioning
(e.g., ABAS)
measure

What would intelligence look like for this client?

Age/ gender	13 years, male
Other conditions	Congenital deafblindness
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What would intelligence look like for this client?

Executive Function

Response inhibition
Goal directed attention
Problem solving
Working memory
Interference control
Mental flexibility

Spatial Cognition

Aspects of:

Perception
Memory
Language
Learning & problem solving
Generalisation

Why?

- Required for goal achievement in everyday life
- Evidence of higher-level cognition

Assessments

Construct

- Effective application of developmentally appropriate learning and problem-solving skills to:
- detect and manage social, physical, and environmental risks
 - adapt to one's strengths, limitations, and environment
 - pursue goals that are meaningful to the individual and their family/community.

Evidence

How will we measure it?

Interpretation

How will we interpret it?

**It takes a village to conduct an informal
assessment***



How do we measure it? Design your assessment

- Access skill limitations guide focus
- Across all settings the individual operates within
- Perspective of others from all settings the individual operates in
- Consider skills from ICD behavioural indicators

How do we measure it? Design your assessment

- Need to understand:
 - What is deemed as important/meaningful goals for the individual AND the community/family
 - What is deemed as functioning well/adaptively within the context of the family and community
 - What the person has been exposed to

Safety

Crossing the road

Knowing who is safe

Community participation

Accessing materials/devices

Finding ways to avoid!

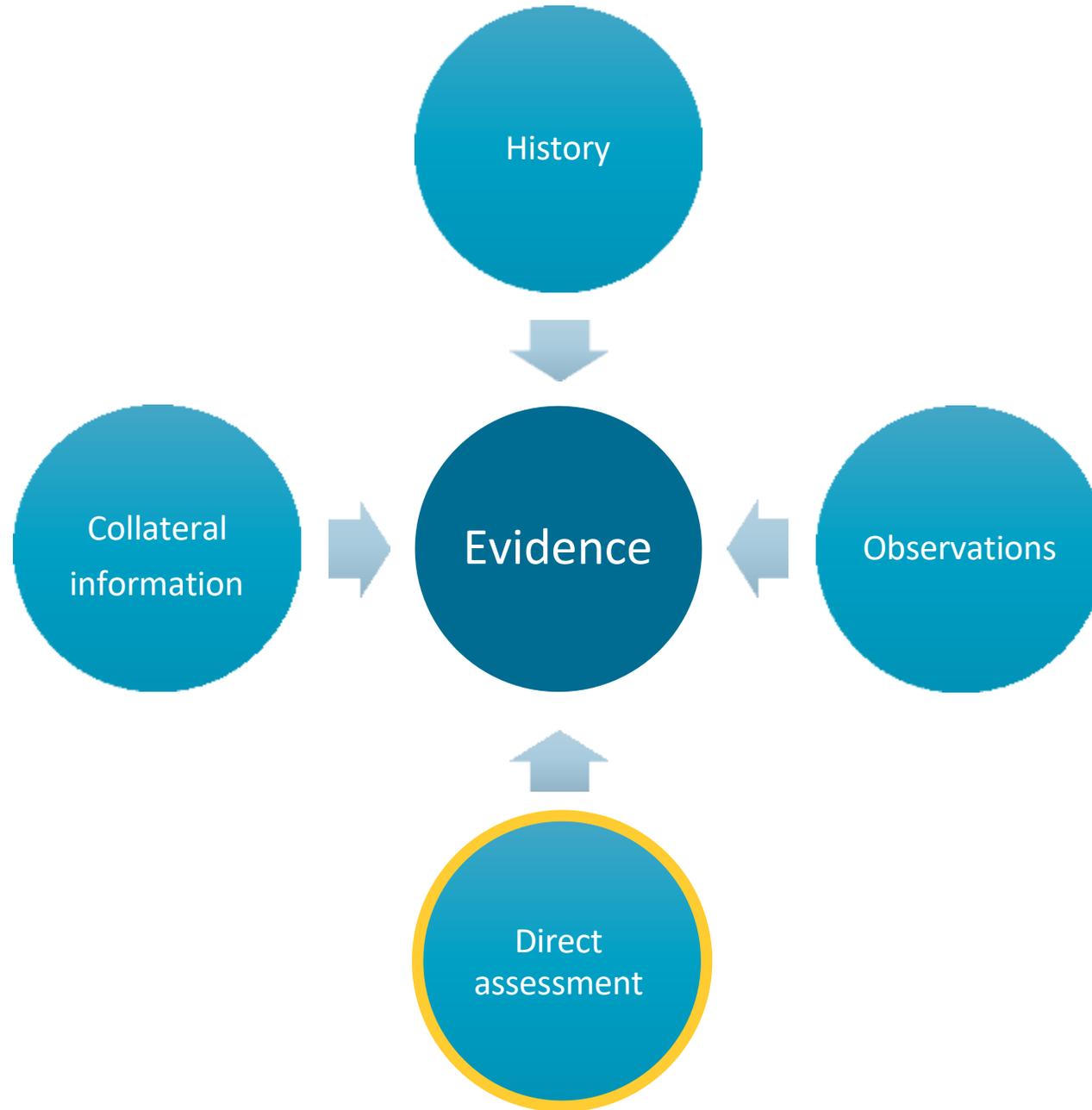
Age appropriately caring
for others

Finding “work arounds” for physical
impairments

Learning from intervention

Negotiating with peers

Engagement in age appropriate
activities



Picking useful assessment activities

- ✓ The activity is within the client's capabilities
- ✓ Client interested and willing to engage
- ✓ Elicits easily observable action and reaction
- ✓ Requires higher level mental processing (not reflex response)
- ✓ Demands are meaningfully adjustable
- ✓ Requires adaptation of skills to novel task
- ✓ Clear goals and integrates meaningful feedback
- ✓ Include tasks others think are important

How would you gather evidence of this client's intelligence?

Age/ gender	13 years, male
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Reason for referral	Second opinion as teachers at school feel there is “something there”

How did they gather evidence of this client's intelligence?



Assessments

Construct

- Effective application of developmentally appropriate curiosity and learning and problem-solving skills to:
- detect and manage social, physical, and environmental risks
 - adapt to one's strengths, limitations, and environment
 - pursue goals that are meaningful to the individual and their family/community.

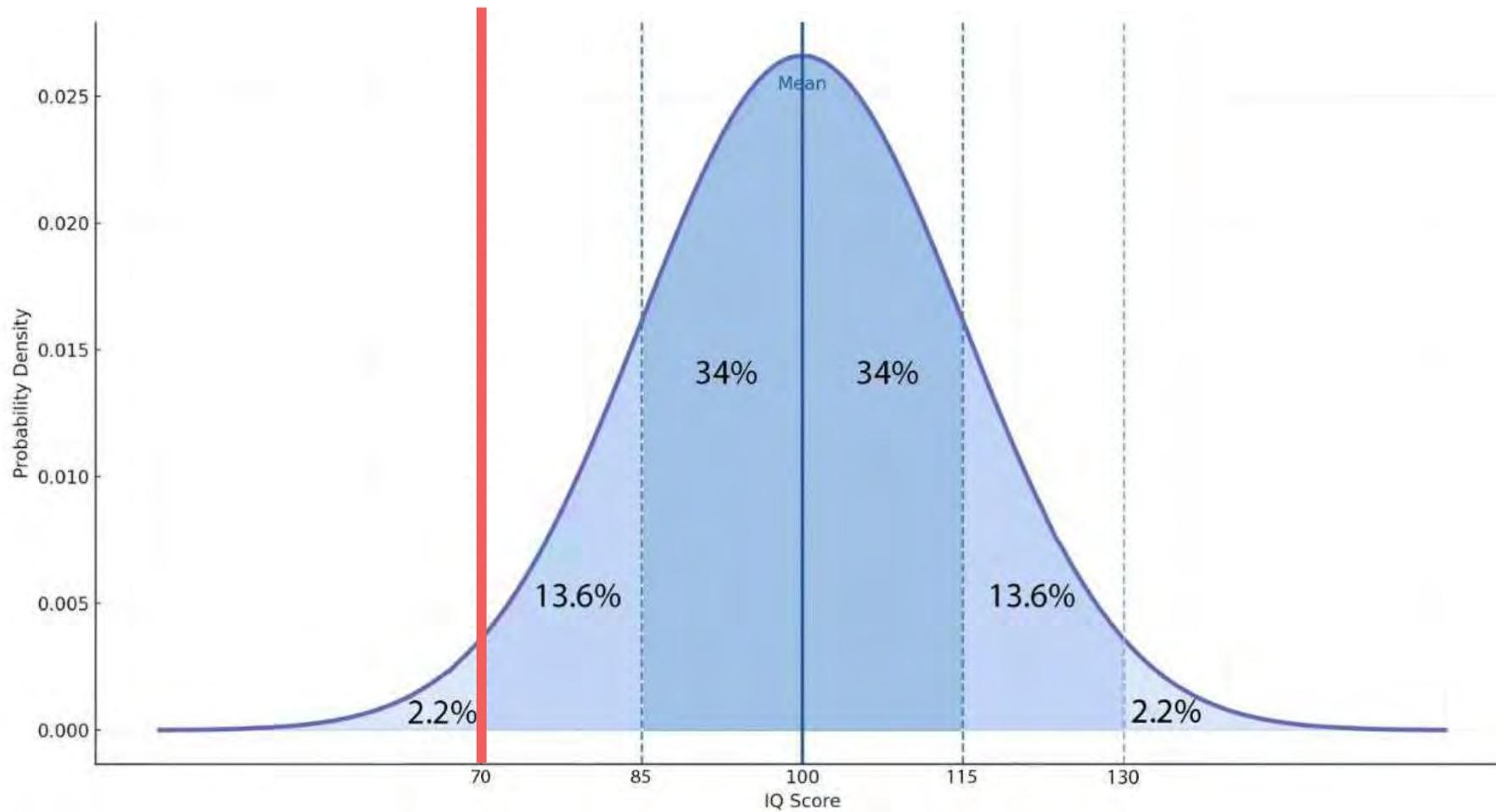
Evidence

Design and conduct assessment based on what is meaningful to the individual, their family, community
Use observation, interaction, activities, interviews
In the contexts the individual lives and operates
Involve MDT & carers

Interpretation

How will we interpret it?

IDD Diagnosis Threshold



Is this person's intellectual functioning substantially below expected?

Develop a Prototype

From informants/ a meaningful comparator group

- What is developmentally within expectations:
 - given access skill limitations / co-occurring conditions
 - culturally
- What is substantially below this?

Resources to draw on:

- ICD-11 behavioural indicators
- See hand out

One prototype does not fit all!

How would you interpret evidence of this client's intelligence?

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How did they interpret evidence of this client's intelligence?

Observational cues	Interpretation	Cognitive function
Harness of shoulder	I know where this goes	Executive function
Problem solving	Where do I need to put my feet	Executive function
Pushing rope to come down	I understand how this works	Spatial cognition Executive function
Looking towards the wall after carer sign wall, responding		Spatial cognition
Takes carabiner to the right place on harness	I know where this goes	Executive function
Feeling the rope with his mouth	Bodily tactile exploration	Bodily tactile cognition

What stage of intellectual development does this indicate?
How might sensory limitations have impacted opportunity to develop?

Planning

Assess access skills
Prioritise standardised assessments, use accommodations
Informal assessment a last resort
Consider ethics of informal assessment (timing, risks)

Construct

Effective application of developmentally appropriate learning and problem-solving skills to:

- detect and manage social, physical, and environmental risks
- adapt to one's strengths, limitations, and environment
- pursue goals that are meaningful to the individual and their family/community.

Evidence

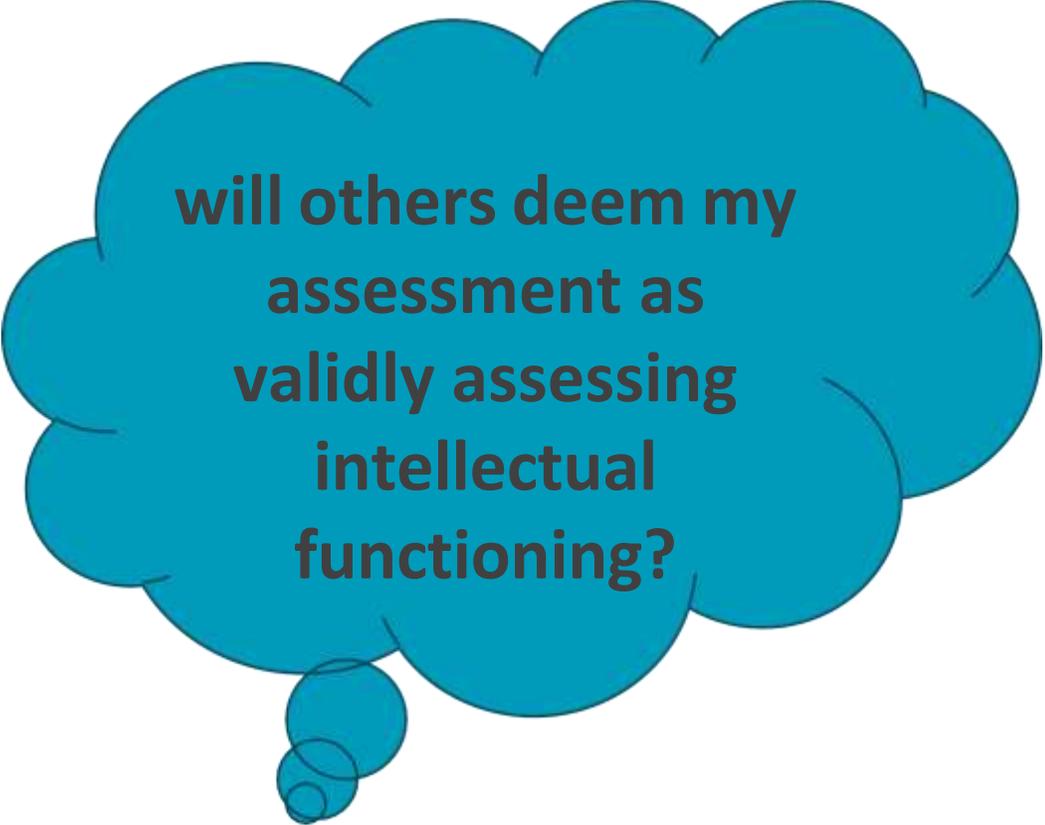
Design and conduct assessment based on what is meaningful to the individual, their family, community
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Interpretation

"Prototypes" (contextual/cultural developmental expectations given co-occurring conditions)
Appropriate comparators
Consistency of presentation across settings and time

Reporting

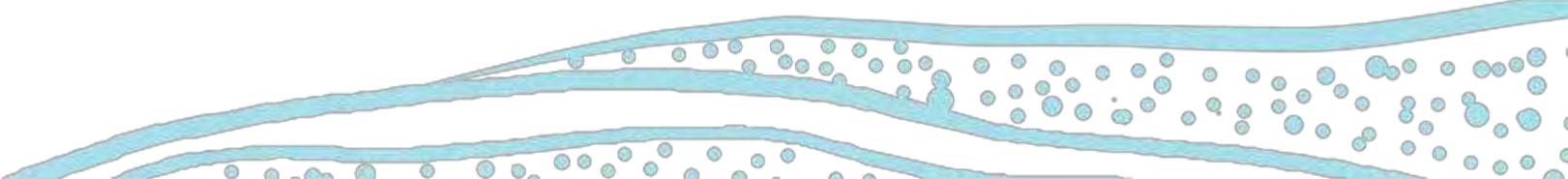
Validity and reliability challenges



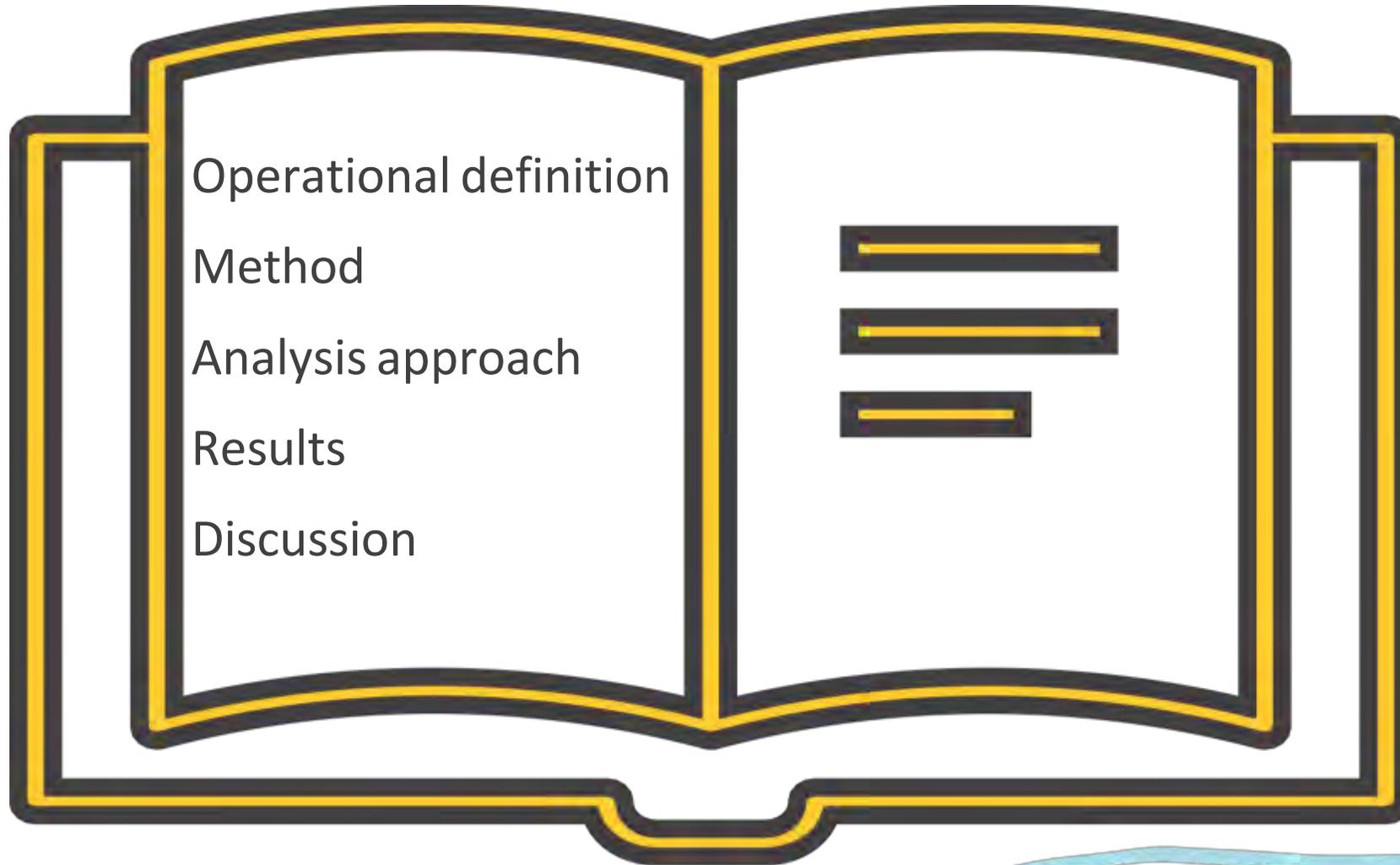
**will others deem my
assessment as
validly assessing
intellectual
functioning?**



**could my
assessment be
replicated?**



Validity and reliability: scientist practitioner!



Operational definition

Method

Analysis approach

Results

Discussion



Planning

Assess access skills
Prioritise standardised assessments, use accommodations
Informal assessment a last resort
Consider ethics of informal assessment (timing, risks)

Construct

Effective application of developmentally appropriate learning and problem-solving skills to:

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Evidence

Design and conduct assessment based on what is meaningful to the individual, their family, community
Use observation, interaction, activities, interviews
In the contexts the individual lives and operates
Involve MDT & carers

Interpretation

"Prototypes" (contextual/cultural developmental expectations given co-occurring conditions)
Appropriate comparators
Consistency of presentation across settings and time
Collaborate with peers and get supervision

Reporting

Demonstrate validity through documentation
Write up like a research report – explicit rationale, replicable method, and clear justification of prototypes and interpretation/ conclusions

With the people around you discuss:

- One new thing you learnt today
- One thing you want to explore further
- One thing you will integrate into your practice

Key References

Ask Larsen, F., & Damen, S. (Eds). (2014). *Guidelines for assessment of cognition in relation to congenital deafblindness*. Nordic Centre for Welfare and Social Issues. <https://nordicwelfare.org/en/publikationer/guidelines-for-assessment-of-cognition-in-relation-to-congenital-deafblindness/>

Damen, S., Costain, K., Hart, P., & Nicholas, J. (Eds). (2020). *Revealing hidden potentials – Assessing cognition in individuals with congenital deafblindness*. Nordic Welfare Centre. <https://urn.kb.se/resolve?urn=urn:nbn:se:norden:org:diva-6006>

Nordic Welfare Centre. (2021, June 30). *Climbing the wall: Assessment of cognition through video analysis* [Video recording]. <https://www.youtube.com/watch?v=Mg5Ytgu76Ck>

Prigge, M.B.D., Bigler, E.D., Lange, N. *et al.* (2022). Longitudinal stability of intellectual functioning in autism spectrum disorder: From age 3 through mid-adulthood. *Journal of Autism and Developmental Disorders*, **52**, 4490–4504. <https://doi.org/10.1007/s10803-021-05227-x>

Thompson, T., Coleman, J.M., Riley, K., Snider, L.A., Howard, L.J., Sansone, S.M., & Hessler, D. (2018). Standardized assessment accommodations for individuals with intellectual disability. *Contemporary School Psychology*, **22**, 443-457. <https://doi.org/10.1007/s40688-018-0171-4>

World Health Organization. (2024). *Clinical descriptions and diagnostic requirements for ICD-11 mental, behavioural and neurodevelopmental disorders*. <https://iris.who.int/handle/10665/375767>