Beyond the WISC: Psychological assessment of cognitive functioning in special populations

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Contents

About the author

Jennifer Engle is a registered psychologist living in Vancouver, British Columbia. She has been working at BC Children's Hospital and Sunny Hill Health Centre for Children since 2009. Dr. Engle's primary work is conducting neuropsychological assessments in children with complex neurological and medical conditions. She also works for the Vision Inter-Professional Assessment Team at Sunny Hill Health Centre for Children. Dr. Engle has previously worked in various programs including the Provincial Autism Resource Centre, the Neuromotor Program, and the Deaf and Hard of Hearing program. Dr. Engle received her PhD from the University of Victoria's Clinical Neuropsychology program, and did her pre-doctoral residency at the Hospital for Sick Children in Toronto. She is Board Certified in pediatric neuropsychology through the American Academy of Pediatric Neuropsychology. Dr. Engle is passionate about supporting psychologists in providing high-quality cognitive/developmental and neuropsychological assessments.

Introduction

I wrote this book to help support psychologists in their goal to provide accurate and meaningful cognitive assessments for children with multiple and severe disabilities. What do we do when a child is not able to use their hands to manipulate blocks? Or when a child is not able to use words to answer any of our questions? What about children who are not able to participate in any standardized measures of intelligence, even with adaptations? How do we get an accurate picture of the child's capabilities? How can we make the assessment meaningful for the child, family, and team? Some people have described these children as "un-testable". While it is true that some children will not be able to complete a standardized measure of intelligence, the limits of our clinical skills do not end with an IQ score. What you will see throughout this book is encouraging the reader to turn the focus away from "test results" and to focus instead on "assessment results."

This book assumes that the reader is competent in conducting psycho-educational (cognitive) assessments. Readers of this book will find information on how to apply their knowledge of psycho-educational assessments to a specialized population – children with multiple, severe disabilities. The specialized assessment skills presented include adaptations for motor, communication, visual, and hearing impairments. Thus, much of the information in this book will also be applicable to children who have specific (singular) impairments in one of these areas.

This book provides many suggestions for further education on the topics presented. If you are reading a print version of this book, you may wish to access the electronic version of the book in order to have a direct link to online resources, videos, and articles. You can find the book (available for free) at the following website: https://pressbooks.bccampus.ca/jengle/.

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1. Introduction to neuromotor disorders

Learning Objectives

- Describe the different features of motor dysfunction in children with neuromotor disorders.
- Be aware of basic seizure safety protocols.

Introduction to neuromotor disorders

A neuromotor disorder is a developmental or acquired condition that typically affects movement, gross motor ability, posture, and fine motor ability. Neuromotor disorders are caused by damage to the central nervous system. This could be due to problems with development or injury to the developing motor pathways in the cortex, basal ganglia, thalamus, cerebellum, brainstem, or spinal cord. The most common neuromotor disorders in childhood include cerebral palsy, muscular dystrophy, and spina bifida. The impairment may be static (not getting worse) or progressive. Children may present with a combination of problems including weakness, problems with muscle tone, muscle contractures, sensory impairments, cognitive difficulties, and other medical conditions. There is a great amount of variability between the different disorders, and also great variability in the presenting characteristics among individuals with a given diagnosis.

The NIH-funded Taskforce on Childhood Motor Disorders[1] provided definitions related to terminology associated with childhood movement disorders:

- Hypertonia – increased resistance of the muscle to movement. It may be caused by spasticity, dystonia, rigidity, or a combination of the two.
- Spasticity – resistance of the muscle is variable depending on the velocity of movement.
- Rigidity – frequently occurs in Parkinson's Disease in adults, but rarely occurs in children.
- Dystonia – a movement disorder in which involuntary muscle contractions cause

twisting and repetitive movements, abnormal postures, or both. Dystonia frequently co-occurs with athetosis, problems with manual dexterity, problems with oromotor function, and abnormalities of eye movement.

Seizure safety

Epilepsy is common in children with neuromotor disorders, particularly those with cerebral palsy where the rate is about 40% [2] Thus, it is important that you are aware of basic seizure safety protocols (see Resources for Further Education below).

Key Takeaways

- Neuromotor disorders are caused by damage to the central nervous system.
- Neuromotor disorders typically impact muscle tone.
- Neuromotor disorders often co-occur with other medical conditions and learning challenges. Seizures disorders are common.

Resources for Further Learning

Movement disorders

- Sunny Hill Movement Disorders e-learning course (free & available to the general public)

Epilepsy

- Epilepsy and Seizures 101 by Dr. Linda Huh
- Types of seizure disorders with video examples
- What to do if a child has a seizure: Seizure Types & First Aid from BC Epilepsy Society
- Seizure first aid video from Epilepsy Toronto.

Notes

1. Sanger, T.D.,Delgado, M.R., Gaebler-Spira, D.,Hallett, M., & Mink, J.W., (2003). Classification and Definition of Disorders Causing Hypertonia in Childhood, Pediatrics, 111(1), e89-e97.
2. Christensen, D., Van Naarden Braun, K., Doernberg, N. S., et. al. (2014). Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning – Autism and Developmental Disabilities Monitoring Network, USA, 2008. Developmental Medicine and Child Neurology, 56(1), 59–65.

2. Introduction to cerebral palsy

Learning Objectives

- Understand the types and causes of cerebral palsy.
- Understand the terminology used to describe motor impairments in individuals with cerebral palsy.

Introduction to Cerebral Palsy (CP)

Cerebral Palsy (CP) is the most common neuromotor disorder in childhood. Prevalence of CP in the USA is about 2.6 – 3.1 per 1000[1,2]. CP is an umbrella term that denotes a disorder of movement and posture caused by a non-progressive abnormality of the developing brain, usually originating in the prenatal or perinatal period. CP may be due to complications during pregnancy (e.g., stroke in the brain of the fetus), congenital malformation in the brain, birth trauma, or complications of premature birth (e.g., brain hemorrhage). It can also be caused by damage in the early developmental years (i.e., 0-2 years).

Subtypes of CP

- Spastic CP is the most common type of CP. It is caused by damage to the part of the brain that controls motor movements (the motor cortex) or the motor pathways as they descend down to the spinal cord. In this type of CP, muscles appear stiff, and movements may be stiff or jerky.
- Dyskinetic or dystonic CP is caused by damage to the basal ganglia or associated pathways. In this type of CP, you see involuntary movements.
- Ataxic CP is caused by damage to the cerebellum. In this type of CP, you see unsteady, imprecise movements and balance difficulties.

Understanding terminology in CP

- Weakness (hemiparesis) or paralysis (hemiplegia) on one side of the body is caused by damage to the opposite side of the cortex, or the same side of the cerebellum. It may affect the entire side of the body, or only part (e.g., only the arm). Individuals with hemiparesis or hemiplegia have varying amounts of ability to use their affected limbs.
- Diplegia describes paralysis or weakness which affects symmetrical parts of the body (both legs or both arms) and suggests damage to both sides of the brain.
- Quadriplegia describes paralysis or weakness which affects all four limbs.
- Gross Motor Function Classification System – Expanded & Revised (GMFCS – E&R) is a system that classifies the level of gross motor movement capabilities in individuals with CP[3].

Learning and development in CP

- About 45% of individuals with CP have an Intellectual Disability (ID).
- Many of those who have CP without ID have some learning differences.
- As a group, those with hemiplegia (paralysis on one side of the body) or spastic diplegia (paralysis of both corresponding limbs, usually legs) tend to be less cognitively impacted than those who have all 4 limbs involved[4].

Key Takeaways

- Cerebral Palsy (CP) is the most common motor disorder in childhood.
- Cerebral palsy is non-progressive, and is caused by abnormal development or damage to the fetal or infant brain.
- Individuals with CP can present with a variety of motor and cognitive issues depending on the part of the brain affected, the severity of the brain damage, and the time of the injury in development.

Resources for Further Learning

- Krigger, K.W. (2006). Cerebral Palsy: An Overview. University of Louisville School of Medicine, American Family Physician, American Family Physician, 73(1):91-100.

Notes

1. Christensen, D., Van Naarden Braun, K., Doernberg, N. S., et. al. (2014). Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning – Autism and Developmental Disabilities Monitoring Network, USA, 2008. Developmental Medicine and Child Neurology, 56(1), 59–65.
2. Maenner, M. J., Blumberg, S. J., Kogan, M. D., Christensen, D., Yeargin-Allsopp, M., & Schieve, L. A. (2016). Prevalence of cerebral palsy and intellectual disability among children identified in two U.S. National Surveys, 2011–2013. Annals of Epidemiology, 26(3), 222–226.
3. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 39(4), 214-23.
4. Reid, S. M., Meehan, E. M., Arnup, S. J. and Reddihough, D. S. (2018). Intellectual disability in cerebral palsy: A population-based retrospective study. Dev Med Child Neurology, 60, 687-694.

3. Child characteristics to consider in assessment planning

Learning Objectives

- Identify potential child factors that need special consideration in the assessment setting.
- Understand how to appropriately support children's needs in order to maximize the potential for successful engagement in the assessment.

As with all assessments, it will be very important to thoroughly review the child's history and records, interview caregivers and teachers, and if possible observe the child in a familiar environment prior to your assessment. Through this process, you will learn about the child's communication methods, interests, and interaction style. Some things to consider when evaluating children with multiple, severe disabilities are as follows:

Many children with neuromotor conditions are easily fatigued. For some children, they are expending significant effort on tasks that for many others come with little or no effort. This includes things like maintaining upright posture, listening, walking, and talking. Therefore, consider whether you need to offer:

- Multiple short sessions
- Frequent breaks
- Appropriate seating support
- Materials presented in an ergonomically appropriate manner

It is common for children with neuromotor conditions to take longer to understand and respond (slow processing speed). To support these children, consider the need to:

- Pause to wait for the child's responses
- Allow more time for the assessment

Children with neuromotor conditions may show a limited attention span and therefore may benefit from the following:

- Table free of distractions
- Presentation of only one thing at a time
- Brief, frequent “rewards”

New situations and new people may be stressful. If possible:

- Visit with the child prior to the day of the assessment or send a photo of yourself and the assessment room ahead of time
- Have a parent or other familiar caregiver in the room
- Ask about the child’s interests ahead of time so that you can have objects or toys of interest available
- Visit the child in a familiar environment, or request a video of them in a familiar environment

Some children with neuromotor conditions have special needs for personal care or accessibility which may mean you need to:

- Accommodate breaks for toileting, tube feeding, medications, or suction
- Have a caregiver present during the assessment to support medical needs
- Offer a later start time depending on the morning routine
- Have a wheelchair accessible office, table, and washroom. Your table should be tall enough so the wheelchair’s arms can fit underneath, and be at the right height for the person to work comfortably. If your table is not set up to have the arms of the wheelchair fit underneath, ask the family to bring a tray that attaches to the wheelchair. More information on this can be found in the next chapter.

Key Takeaways

- Understanding a child’s particular needs in terms of energy levels, attention, processing speed, and comfort in new situations is essential to assessment planning.
- Pay attention to wheelchair accessibility in your office (and particularly the work surface).

4. Choose your approach: Plans A, B, and C

Learning Objectives

- Understand the various approaches to psychological assessment in children with severe disabilities.

In advance of your assessment, once you have learned about the child, make an initial plan for direct assessment. It is always best to *not make any presumptions* about what the child can do. That is, presume that the child in front of you will be able to demonstrate their skills and abilities when given appropriate accommodations for their motor and sensory impairments. When we approach a child in this way, they are most likely to show us the full measure of their ability. Use Plan A (standardized assessment tools) whenever possible and as a first choice in most cases. Be ready to flexibly move between plans during your assessment as you learn about the child. Details on Plans A, B, & C are available in the upcoming chapters.

Plan A: Standardized assessment tools: Standardized IQ tests are designed to compare children to a normative group of their same aged peers. For children with severe disabilities, their scores may be near the "floor" of the test. Thus, the IQ test will not necessarily identify the personal strengths and challenges of children with severe disabilities. However, IQ tests have a role to play, primarily as they are often required in order to support the child's access to appropriate supports and services at school or in the community. Plan A assessments with children with multiple, severe disabilities involve carefully evaluating the test requirements and matching those to the child's capabilities. The following sections will discuss various tests. Plan A assessments may include accommodations which do not change the underlying concept being measured.

Plan B: Out of age range measures: Sometimes it is appropriate to choose a measure which is developmentally appropriate but not age-appropriate for the child. For example, this would include using a measure of early childhood development (e.g., Bayley-4) in an older child with severe disabilities. When using out of age range measures, raw scores can be translated into age equivalent scores which can sometimes be helpful as a component of

your broader assessment. The limitations of age equivalent scores are discussed along with the use of out of age range measures in a separate chapter.

Plan C: Non-standardized assessment/observation: Taking a different approach to assessment may be necessary when a child is not capable of participation in standardized measures, even those designed for younger children. Moreover, non-standardized assessment can be a useful addition to your regular assessment tools (Plans A and B), particularly for identifying strengths and next steps in development.

Often, some combination of the above is the most appropriate.

Key Takeaways

- Do not make presumptions ahead of time of what a child is capable of. Use Plan A (standardized assessment) whenever possible.
- For some children, it may be appropriate to also consider using out of age range measures (Plan B) or non-standardized assessment techniques (Plan C) in order to provide a meaningful assessment.
- In many cases, use of a combination of approaches is most appropriate.

5. Plan A: Standardized measures of IQ and development

Learning Objectives

- Understand factors to consider when choosing a test of IQ in special populations
- Describe the benefits and drawbacks of various tests of IQ and development

Considerations for test selection

When there is a query of intellectual disability, a standardized measure of IQ, along with a standardized measure of adaptive functioning are essential assessment tools. When deciding which test of cognitive/developmental functioning to administer, there are a number of factors to consider. In addition to the things you usually look for in a test, there other factors you should consider in children with motor, sensory, and communication differences.

Test characteristics: For children whose developmental level is likely to be highly discrepant from their chronological age, it is helpful to look for tests (or subtests within tests) that span a large age range so that the test is appropriate for both the child's chronological and developmental age. For example, the Stanford-Binet 5 spans the age range from 2 to 85. It is also important that the test have an appropriate sampling of easier item content to minimize the floor effect. It can be beneficial to use tests which build in extended opportunity for teaching the task for children who need extra time to learn *how* to do the task. For example, the DAS-II has extended opportunity to teach the subtests via corrective feedback. For those children who are not able to complete a full IQ test due to extremely limited attention and energy, it can be helpful to choose a test which has a built in brief Full Scale IQ score.

Match between test and child: When evaluating the appropriateness of a specific test for a specific child, look carefully at the motor, visual, and oral language demands of the test. Are they a good fit for the child? Does the test introduce construct irrelevant

bias? For example, some tests of verbal intelligence require motor responses which would be inappropriate for a child who communicates through spoken language but cannot manipulate objects with their hands. Other verbal intelligence tests require that child to see and respond to pictures, which would be inappropriate for a child who cannot see.

Is it possible to make necessary adaptations without changing the nature of the task? Some tests are not easily adapted for the specific child's motor, sensory, or language abilities, and thus should not be administered. If a child does not have sufficient motor control to move small blocks, and you move the blocks for the student, that is a modification of the test which changes the nature of the task. If you choose to administer a test with modifications, it would be appropriate to interpret the results qualitatively and not quantitatively.

Sometimes it is appropriate to administer a nonverbal test of intelligence. *Nonverbal* refers to the method of administration and responses of the examinee, not what is being measured, nor the strategies used to arrive at solutions to questions. In nonverbal tests, children do not need to speak. Sometimes, instructions are also provided completely nonverbally using gestures and facial expression.

Review of IQ/developmental tests in special populations

Commonly used measures of intelligence

- Wechsler Intelligence Scale for Children – 5
- Differential Abilities Scale – II
- Stanford Binet – 5
- Kaufman Assessment Battery for Children – 2
- Reynolds Intellectual Assessment Scales – 2
- Woodcock Johnson Tests of Cognitive Abilities – 4

Nonverbal measures of intelligence

- Wechsler Nonverbal Scales of Ability
- Leiter International Performance Scale – 3
- Universal Nonverbal Intelligence Test – 2
- Comprehensive Test of Nonverbal Intelligence – 2
- Other nonverbal, single domain tests

Measures of early cognitive development

- Bayley Scales of Infant and Toddler Development – 4
- Batelle Developmental Inventory -2
- Mullen Scales of Early Learning

General intelligence tests

Wechsler Intelligence Scale for Children -5th Edition (WISC-V), 2014 & WISC-V Integrated, 2015

- Age range 6:0 to 16:11
- Benefits:
    - Most common test of IQ in children; is well known.
    - Most subtests can be completed without motor manipulation of items.
    - Has a Nonverbal Index (but this requires the motor ability to do Coding).
    - Q-interactive (iPad administration) makes administration and scoring simple and quick.
    - WISC-V Integrated can be used in conjunction with the WISC-V in order to "break down" the task demands of WISC-5 subtests. WISC-5 Integrated is designed to identify the underlying cognitive processes that may be impairing performance on the WISC-V (e.g., what happens when the child is given extra time, or given multiple choice instead of needing to generate responses).
- Potential drawbacks/considerations:
    - Children with developmental level below 5 or 6 years may have difficulty understanding the task demands of some subtests on the WISC.
    - Only a few subtests are appropriate for children who are completely nonverbal and who do not have use of their hands (Matrix Reasoning, Figure Weights, Visual Puzzles and possibly Picture Span). These subtests would require some adaptation depending on the child's communication strategies (e.g., use of gestures, eye gaze, etc.)
    - WISC-V Integrated subtests should not be interpreted as measures of IQ. In some cases, it may be appropriate to administer a WISC-V Integrated subtest without first administering the corresponding WISC-5 subtests. For example, if a child is not able to speak, but is able to point or otherwise indicate choices, the verbal multiple choice subtests will give you an idea about the child's language based knowledge and reasoning. However, WISC-V Integrated scores should never be interpreted as a measure of a child's intelligence.

Differential Abilities Scale, 2nd Edition (DAS-II), 2007

- Age range 2:6 to 17:11.
- Early years record form: 2:6 to 6:11, out-of-level normative data available for up to age 8:11.
- School-age record form: age 7:0 and up.
- Benefits:
    - Extended opportunities for teaching the tasks.
    - Abbreviated testing time due to special rules for start and stop points.
    - Out-of-level normative data can be very useful for children ages 7 and 8 as they can be administered the young child battery.
    - Some core subtests (Pattern Construction, Matrices, Recall of Digits) as well as quite a few Diagnostic subtests span the entire age range (2:6 to 17:11).
    - For the most part, the DAS does not require motor skills (except for early items on Verbal Comprehension, Copying and Pattern Construction). Other subtests can be easily adapted to give oral responses instead of motor responses (e.g., Picture Similarities).
    - Special Nonverbal Composite (SNC) is a 4 subtest composite, but is not appropriate for children with limited motor function. There is a 2 subtest Nonverbal Reasoning Index that is appropriate for children with limited motor functioning (Upper Level Early Years and School Age).
    - Includes signed nonverbal subtest administration instructions for children who use American Sign Language.
- Potential drawbacks/considerations:
    - Early Years Verbal subtests are inappropriate for children with significant visual impairments, and at the earliest level, inappropriate for children with significant motor impairments.
    - No Canadian normative data.

Stanford Binet – 5th Edition (SB-5), 2003

- Age range 2:0-85+ within a single series of subtests.
- Five areas (Fluid Reasoning, Knowledge, Quantitative Reasoning, Visual Spatial, and Working Memory) are assessed in both the Verbal and the Nonverbal domains.
- Benefits:
    - The fact that all subtests are given to all ages (at the appropriate level) makes this an excellent test for evaluating children whose developmental level is 2+, but whose cognitive functioning is highly discrepant from their age level.
    - Nonverbal routing subtest starts with manipulatives which can be helpful for children who do not understand concepts on paper (such as bigger/smaller).

    - Extensive guidance is provided in the manual on the use of SB-5 in hearing impaired individuals.
- Potential drawbacks/considerations:
    - "Nonverbal" tasks require a fair bit of receptive and expressive language.
    - Some nonverbal tasks cannot be easily modified for individuals with motor impairments.
    - Early verbal tasks require visual inspection of pictures and visual manipulation of objects. Therefore, this limits the utility of this test in children with visual impairments. Adaptations can be made for motor impairments.
    - More difficult to administer than many other standard IQ tests.
    - Age equivalent scores are only available if you give both verbal and nonverbal portions of a domain and for the abbreviated battery.
    - No Canadian normative data.

Kaufman Assessment Battery for Children, 2nd Edition (2004), Normative Update (2018) (KABC-II NU, 2018)

- Ages 3:0 – 18:11
- Benefits:
    - Comprehensive measure of intellectual functioning designed to minimize verbal instructions and responses and limit "cultural content".
    - Many subtests span the age range: Atlantis, Face Recognition, Number Recall, Gestalt Closure, Rover, Expressive Vocab, Verbal Knowledge, Rebus, Triangles, Word Order, Hand movements, Riddles.
    - In addition, out of age range norms are available for some ages (e.g.,. a 7 year old can be administered the 5 or 6 year old battery).
    - Extensive teaching is available.
    - Nonverbal scale available at each age point.
    - Most subtests have a sample item plus two teaching items (for children at the youngest age).
- Potential drawbacks/considerations:
    - Most nonverbal subtests require pointing. Some can be adapted with use of a grid (to label response options) but other subtests are not easily adapted in this way.
    - No Canadian normative data.

Reynolds Intellectual Assessment Scales, 2nd Edition (RIAS-2, 2015)

- Ages 3-94
- 4 core intelligence subtests (2 verbal, 2 nonverbal), 2 processing speed (verbal/

nonverbal), optional verbal + nonverbal memory subtests

- Benefits:
  - Short administration time.
  - Minimizes need for motor skills.
- Potential drawbacks/considerations:
  - Supplemental subtests are different by age.
  - No Canadian normative data.

Woodcock Johnson Tests of Cognitive Abilities, 4th Edition, (WJ–IV Cognitive)

- Ages 2 +
- 10 core intelligence tests
- Benefits:
  - Low floor.
  - 3 subtest Brief Intellectual Ability score.
  - Co-normed with Woodcock Johnson's tests of Oral Language and Achievement.
  - Braille & Large Print versions available through American Printing House for the Blind.
- Potential drawbacks/considerations:
  - No Canadian normative data.

Nonverbal scales of intelligence

Wechsler Nonverbal Scales of Ability (WNV), 2006

- Age range – 4:0-21:11
- Ages 4:0-7:11: Matrices, Coding, Object Assembly, Recognition
- Ages 8:0-21:11: Matrices, Coding, Spatial Span, Picture Arrangement
- Benefits:
  - Primarily pictorial/gestural instructions. Can be entirely nonverbal, but verbal instructions are provided.
  - Translations of verbal instructions (and prompts) are provided in 6 languages.
  - Completely nonverbal response format available.
  - There are Canadian norms available.
  - 2 subtest abbreviated scale option.
- Potential drawbacks/considerations:
  - Only 1 of the 4 scales spans the age range, meaning that for the other subtests,

there is the issue of floor effects.
    - As an abbreviated measure, it has limited coverage of cognitive abilities.
    - Only 2 subtests (Matrices, Recognition) are easily adapted for those with serious motor disability.

Leiter International Performance Scale, 3rd Edition (Leiter-3), 2013

- Ages 3 to 75
- 4 Cognitive subtests, 4 attention/memory/processing speed subtests
- Benefits:
    - Completely nonverbal assessment. All instructions are conveyed via picture, gesture, and demonstration. There are no oral responses required.
    - All subtests span the age range.
    - The cognitive subtests are untimed and do not require careful placement of cards/ blocks so that children with mild motor impairments may be fully capable of completing the tasks.
- Potential drawbacks/considerations:
    - Takes time to learn how to administer the Leiter correctly. There is a training DVD available.
    - The examinee responds by moving small cards or blocks to indicate a response. Some children with severe motor impairments will not be able to do this.
    - In our clinic, we have had the experience that the Leiter-3 sometimes over-estimates a child's true capabilities. Therefore, we recommend the Leiter should always be administered in conjunction with another IQ test.
    - No Canadian normative data available.

Universal Nonverbal Intelligence Test, 2nd Edition (Unit-2), 2016

- Age 5:0-21:11
- 6 subtests: Symbolic Memory, Nonsymbolic Quantity, Analogic Reasoning, Spatial Memory, Numerical Series, and Cube Design.
- Benefits:
    - Entirely nonverbal administration and response format.
    - Has a 2 subtest brief IQ score available.
    - Attempts to limit cultural content.
- Potential drawbacks/considerations:
    - 3 of the 6 subtests require the child to manipulate task materials.
    - One subtest (Cube Design) is timed, with no option for an untimed administration.

This subtest is not appropriate for those with severe motor impairments.
    - All other subtests require pointing to the correct response or moving tiles. This could be adapted to place letters/numbers below the responses for those who cannot point.
    - Some subtests are reliant on the child understanding written numbers and having a basic understanding of numbers (e.g., counting by 5s).

Comprehensive Test of Nonverbal Intelligence, 2nd Edition (C-TONI-2), 2009

- Ages 6:0-89-11
- 6 subtests: Pictorial Analogies, Geometric Analogies, Pictorial Categories, Geometric Categories, Pictorial Sequences, Geometric Sequences.
- Benefits:
    - Can be entirely nonverbal administration, but verbal instructions are also provided.
    - Response format does not require any verbal output.
    - No manipulation of objects required.
    - Completely untimed.
- Potential drawbacks/considerations:
    - All subtests require pointing to the correct response. This could be adapted to place letters/numbers below the responses for those who cannot point.
    - No measurement of short term or working memory.

Single domain nonverbal tests

These are single domain tests of intelligence. Although they are quick and easy to administer, they are not generally appropriate as stand-alone diagnostic tests of IQ. They may be appropriately used in conjunction with another IQ test.

- Raven's Progressive Matrices (Various). Child/Adult.
- Naglieri Nonverbal Ability Test (2003). Age 5:0-17:11.
- Test of Nonverbal Intelligence–4th Ed. (2010). Age 6:0-89.

Developmental Measures

These are standardized measures which provide information about a child's developmental status by assessing specific developmental milestones. Use of a developmental measure

in an older child can be a good way to provide a structure to your assessment of developmental level.

Bayley Scales of Infant and Toddler Development, Fourth Edition (Bayley-4, 2019)

- Ages: 1 to 42 months (3 years, 6 months)
- Three scales administered with child interaction – cognitive, motor, language. Two scales conducted with parent questionnaires – social-emotional, adaptive behavior.
- Cognitive scale benefits:
    - Play-based test with natural type interactions.
    - Administration manual discusses accommodations/modifications.
    - Allows for some items to be scored based on parent report.
- Cognitive scale potential drawbacks/considerations:
    - Takes some time to learn to administer.
    - Starting from 13 months – requires the child to follow verbal instructions.
    - Requires some motor coordination from child (cannot modify some items for lack of hand use).
    - No Canadian normative data.

Batelle Developmental Inventory -2nd Ed., Normative Update (Batell-2-NU; for the 2015 US census)

- Tests 5 global developmental domains and 13 subdomains: Adaptive behaviour, personal and social skills, motor skills, communication skills, and cognitive.
- Ages 0 – 7:11
- Benefits:
    - Wide age range for a developmental measure
    - Play-based test with natural type interactions.
- Potential drawbacks/considerations:
    - Challenging to learn and to administer
    - No Canadian normative data

Mullen Scales of Early Learning – 1995

- Birth to 68 months
- Benefits:
    - Play-based test with natural type interactions.
- Potential drawbacks/considerations:

- Challenging to learn and to administer
- No Canadian normative data
- Older normative data

Recommendations

How do you choose which measure of intelligence or development to use in an assessment? You are looking for the best match between the child's capabilities and the tests' ability to capture those capabilities. The Wechsler scales (WPPSI, WISC, WAIS) may be a perfectly appropriate measure to use with children who have moderate (and sometimes even severe intellectual disabilities). However, what if the child does not understand the tasks, or is not able to respond due to motor limitations? The first choice would be to choose a measure that is both developmentally AND age appropriate. For children who are developmentally 3 or over, the DAS-2 or the KABC-II are excellent choices as they are comprehensive measures where each subtest has relatively discrete demands. However, for younger children, the motor and visual demands on the verbal subtests of the DAS may make it inappropriate. For those children (with adequate vision and hearing) who are are able to complete developmental tasks at the age 2 to 3 year old level , the Stanford Binet-5 is an excellent option.

When you have a child who shows some capability to do standardized testing but who has extremely limited ability to participate due to limited attention, energy, etc., the following are some options for abbreviated scores which can provide an estimate of IQ:

- SB-5 two subtest abbreviated IQ
- WNV two subtest abbreviated IQ
- Peabody Picture Vocabulary Test (PPVT) as estimate of IQ

Although important for addressing the diagnostic question of an intellectual disability, the results of a standardized test for children with severe disabilities can be of limited functional value. For a 14 year old who is functioning on a test at a 2 year old level or less, your standard scores, even for those tests with "low floors" will be at the "floor" of the test... so what to do? Document the low score – it may be necessary for access to services. Next, describe what the child "can do." For example, *Sammy was able to objects match by shape or color, but did not understand simple pattern reasoning (e.g., XOXO?).* For those children who appear to be under approximately age 2 developmentally, consider doing a developmental assessment of functioning (e.g., Bayley-4) to get a more objective measure of their developmental level. Interpret age equivalent (AE) scores, but see caution.

Key Takeaways

Summary of recommendations for test selection:

- The first option is to use standard measures of IQ (e.g., WISC, DAS, KABC) with appropriate adaptations to accommodate the child's motor, hearing, and visual capabilities.
- It is generally best to choose a measure that is appropriate both for the child's chronological age and their developmental level. Some measures (e.g., DAS, KABC, WJ, SB) span a larger age range than the Wechsler scales.
- The SB is an excellent option for children who are able to complete developmental tasks at the 2 to 3 year old level. But, note that the SB is not appropriate for those with significant visual impairment or hearing/communication difficulties.
- For children who are not able to understand or respond to verbal questions, a nonverbal measure of intelligence would be appropriate. When possible, it is helpful to complement a nonverbal measure of intelligence with a standard measure of intelligence.
- If a child is not able to complete a full measure of intelligence due to fatigue or attention issues, it is helpful to choose a measure that provides a "brief" IQ score.
- For those children who are not able respond to a standard IQ test (typically those children who are under about age 2 developmentally), consider doing a developmental assessment of functioning (e.g., Bayley-4) to get an objective measure of their developmental level. Calculate age equivalent (AE) scores, but see caution. Interpret AE scores only in the overall context of the assessment results.

Resources for Further Education

Drevon, D.D., Knight, R.M. & Bradley-Johnson, S. (2017). Nonverbal and Language-Reduced Measures of Cognitive Ability: a Review and Evaluation. Contemporary School Psychology, 21: 255-266.

6. Plan B: Out of age range assessments and age equivalent scores

Learning Objectives

- Describe the benefits and drawbacks of using a developmental assessment measure in older children with severe disabilities.
- Understand the limitations of age equivalent scores.

Developmental assessments in older children

Some children will not be able to complete standardized, age-appropriate measures, even when using tests with "low floors," and with appropriate accommodations. This is often the case for children who's developmental level is below approximately age 3. For these children, one way of conducting a structured assessment of developmental level is to use one of the infant (developmental) assessment measures such as the Bayley-4. These measures are designed to directly measure developmental level through a series of interactive activities. Doing a developmental assessment allows for documentation of functioning through developmentally appropriate assessment materials.

However, developmental assessments are designed for children with typical motor and sensory functioning. For children with multiple, severe disabilities, you may only be able to complete certain parts of a developmental assessment (e.g., if a child has significant motor or sensory dysfunction). For example, the Bayley-4 Cognitive asks children to place blocks in a cup, which would be impossible for some children with severe motor disabilities. Also, if there is a query of Autism, self-directed behaviour may interfere with the child's ability to follow directions and thus results could under-estimate capabilities.

Using a developmental measure, you will get valuable direct observations of the child's developmental capabilities. For example, do they have object permanence? Do they

understand simple cause and effect reasoning? What level of play skills do they demonstrate? If you are able to complete a full measure, you can also calculate age equivalent scores. An age equivalent (AE) score indicates the age at which a given raw score is equal to the median (or mean) raw score for a particular age level.

Limitations of age equivalent scores

- AE scores are an ordinal, not a ratio or an interval scale of measurement. They cannot be added, subtracted, or averaged. Being ordinal, a 3 month difference at age 4 can be very different than a 3 month difference at age 14.
- AEs do not take into account the range of normal performance. A child age 8:0 with an AE of 6:10 on WISC-5 Vocabulary may appear to be impaired based on the AE, but this is equivalent to a Standard Score of 8 (Average).
- AEs are not comparable across subtests (even on the same test). For example, you may see an AE score on the WIAT Word Reading subtest which is lower than the AE score on WIAT Numerical Operations subtest, even though Word Reading has a higher standard score compared to Numerical Operations.
- A 14 year old who scores at the 12 month old level on the Bayley-4 has a very different developmental experience than a typical 12 month old infant. It is unlikely that they function like a typical 12 month old child.

So what to do? Be aware of the limitation of AE scores. Use AEs when they are useful, but interpret with caution and **only in the context of a broader assessment of the child**.

Key Takeaways

- Using a structured developmental assessment (such as the Bayley-4), can be a useful way of gathering information about a child's developmental level in a child who cannot complete a standardized measure of IQ.
- Developmental assessments were not designed for children with motor or sensory impairments, and thus may be difficult to administer and interpret in this population.
- For children who can complete a developmental assessment, an age equivalent score can provide information which can be incorporated into your broader assessment of the child. Age equivalent scores have significant psychometric limitations and should be interpreted with caution, only in the context of the broader assessment.

Resources for Further Education

- Maloney, E.S. & Larrivee, L.S. (2007) Limitations of Age-Equivalent Scores in Reporting the Results of Norm-Referenced Tests. Contemporary Issues in Communication Science and Disorders, 34, 86-93.

7. Plan C: Non-standardized assessment

Learning Objectives

- Learn ways of evaluating developmental level and aspects of cognitive functioning when it is not possible to complete a standardized measure.
- Understand the importance of communication evaluation in children with multiple, severe disabilities.

Creative approaches to non-standardized assessment

Some children are not able to participate in a standardized measure of intelligence or a standardized measurement of developmental level.

> Susan is a 14 year old girl with a spastic quadriplegia. She has never developed spoken language. She communicates primarily through vocal tone and gestures such as turning her head away or reaching for something of interest. She has limited voluntary control of her limbs. She can use her right arm for large movements such as holding down an object on the table. She cannot independently grasp items or release a grasp. She was not able to complete any age-appropriate standardized measures of IQ as she did not understand the concept of choosing the correct picture from an array. She cannot complete a measure such as the Bayley-4 due to her extremely limited motor functioning.

For children like Susan, it would be appropriate to take a different approach to assessment. This could include using individual items from developmental assessment measures (e.g., the Bayley-4), play-based interactions to evaluate discrete cognitive functions, structured or unstructured observation, and interview. This type of “non-standardized” assessment can be used when no standardized assessment is possible, or can be used to augment a standardized assessment.

Below I describe two approaches which are useful as models of how to evaluate a child's learning processes rather than evaluate discrete cognitive skills. These models are also very useful for helping support children in their development (next steps).

- **Child Guided Assessment** by Jan van Dijk was originally designed for working with children who are Deafblind. This approach encourages the examiner to look at the processes through which the child learns, rather than evaluate discrete skills. The foundation of the assessment relies on the assessor establishing a relationship with the child. The child's interests and abilities determine what materials are used to promote the child's engagement. The focus of the report/feedback is on identifying strengths and next steps in development. Child-guided strategies are "conversational." Establishing an interactive routine is important. To do this, the assessor may imitate what the child is doing, then add new information. Communicative signals are elicited by stopping the routine and waiting for a signal from the child indicating a desire for continuation. Excellent video examples of this approach are available in the Resources for Further Education section below.
- **Sensori-motor learning** by Millie Smith is designed to help learners move through hierarchical states/stages. This model recognizes that some children spend periods of time in what Smith calls "extended states" where they are sleepy or agitated. The goal would be to help them achieve and maintain focus on objects to promote learning. There are a series of objects available which help stimulate the child's various senses to see what they respond to. The next goal would be to help the child explore objects through their available senses. This would then move to understanding the function of objects and then learning to label objects. The goal is developing "Coherence" – the feeling that you understand what is going on in your environment.
- **Active learning** by Lili Nielsen is an approach for assessment and curriculum for children with multiple, severe disabilities. The Functional Scheme Assessment provides a structure to evaluate functioning across areas in order to develop an appropriate learning plan.

The models above can be complemented with an evaluation of the child's developmental functioning in various domains. The remainder of this chapter is devoted to discussing how to do this in a child who cannot complete a standardized test. Evaluation of socio-emotional development and behaviour will be discussed in a separate chapter.

Communication

Communication is often THE most important area to address for children with severe

disabilities. It is essential for quality of life: choice making, social relationships, reducing frustrated behaviour, etc. If you are lucky enough to have a speech and language pathologist as part of your team, their assessment will provide an in depth look at communication. When you are looking at communication, look both for the goal of the communication, and the mode of communication (see the table below). To learn more about assessing and supporting children with complex communication needs, see the Communication Matrix, a free online tool available at https://communicationmatrix.org/.

Goal of communication	Modes of communication
• Seeking attention • Protesting • Requesting objects/activities • Making a choice • Greetings • Asking and answering questions • Labeling • Commenting	• Gestures • Head turning • Body/head movements • Eye movements • Actions (e.g., banging) • Facial expression • Sounds • Tone of voice • Signs • Word approximations • Words/sentences

Assessment of communication

- Is the child able to communicate essential needs such as hunger, thirst, and pain?
- Is the child able to make choices when provided with 2 or more options? For example, would they consistently "choose" what is clearly the preferred choice (e.g., favorite TV show or favorite food)?
- Can they reliably respond yes and no, and in what mode?
- Do they understand or use any gestures (e.g., point to indicate desire, arms up to request "up")?
- Do they have finger/hand use sufficient for basic sign language use? Try to teach a simple sign (e.g., "more" in relation to requesting food).
- Does the child recognize any visual communication symbols such as symbols or signs (e.g., recognize McDonalds arches, sign for bus stop).
- Can they discriminate between different drawings or photos of objects? If they cannot do either, they may need real objects to make choices (basketball to symbolize the gym).
- Can the child follow a one step instruction in a routine situation (e.g., "put your arms up" when dressing)? Can they follow a one step instruction when outside of a familiar routine (e.g., saying "put your arms up" during the assessment)? Do they need a visual prompt or can they follow a request with a verbal prompt only? In order to directly

assess this, try incorporating commands into play or natural conversation. Be careful to observe what cues the child uses such as watching your eye movements or reading gestures. For example, you could ask, “Please put your napkin in the garbage.”

General cognitive functions

- Can you elicit object permanence? Do they look for an object placed out of sight or dropped on the floor?
- Can the child understand cause/effect reasoning. Simple cause and effect reasoning would be something like – press a button to make a toy pop up, flip on a light switch and watch the light turn on.
- Does the child understand the function of common objects? For example, puts spoon in mouth, puts hat on head.
- Do you observe imitation/attempted imitation? For example, introduce a novel toy and show how it works. Are they able to reproduce this? Put a toy on your head, do they copy you?
- What kind of problem solving can the child demonstrate? For example – puts together a 2 piece puzzle, gets something out of a container, stacks cups, takes something out of a bag.
- Play skills: level of play provides insight into developmental level. A broad developmental trajectory would be mouthing, banging, throwing/dropping, shaking, functional play (play with a toy as it is intended), parallel play, make believe play, cooperative play. However, be aware that children with severe motor or sensory disorders have had a different developmental experience than typical children. They may be less interested in, or less experienced with play.

Learning/Memory

- Is the child able to show habituation to repeated/familiar stimuli?
- What do they show memory for? Familiar people, places, objects? Get examples from everyday life. Do they react differently to familiar vs unfamiliar people? Having a favorite toy would be an example of memory for an object.
- Can the child predict what will happen if you repeat the same action multiple times? For example, do they know what to expect next in their familiar daily routines? If they go to the bus stop, do they get excited because they know they will be getting on the bus? Do they react to a mismatch to expectations? One fun way to test this is to put an object like a doll on your head and pretend to “sneeze” with a slow lead up to a big “achoo” where the doll flies off your head. Does the child start to predict this will

happen and get excited?

- You can use things from a backpack that the child recognizes: present the items, remove, hide them etc.
- Learning from experience (trying something new). For example, find something new and teach it, and see if they remember it later. Many children have difficulty putting together two small triangles to make a large triangle on the Stanford Binet-5 puzzle. Teach them, then present it again later. Follow up – Will they apply their learning to new situations?
- Can the child hold information in mind briefly ("short term memory")? For example, hide a toy of interest or food under a cup. Increase the difficulty level by using multiple cups, move the toy/food to a new cup (visible displacement – "look I'm moving it here"), or switch the location by moving cups while toy/food is hidden (hidden displacement). There is a series like this on the Bayley-III.

Early academic assessment – reading. Is the child able to:

- Recognize any signs and symbols in the community (e.g., McDonalds; boys vs girls washroom)?
- Listen attentively to a short story?
- Recognize that a book is held a certain way.
- Recognize that words on the page are associated with spoken words.
- Recognize rhymes (do they enjoy rhyming songs, word plays?).
- Provide rhymes for words, e.g., fly, star.
- Recognize letters (i.e., which one is the "A"?). For many children, most likely they would recognize the first letter of their name.
- Name letters (presented one by one vs. in the context of a word or sentence).
- Name letter sounds.
- Recognize own first name written (provide choice of 3, can they point to it?) May want to try with printing three/four names on individual pieces of paper and ask them to pick up their name.
- Recognize sight words (may use enlarged version or whiteboard).

Early academic assessment – writing. Is the child able to:

- Hold a writing utensil (can they use a pencil/pen or do they need a marker?).
- Scribble purposefully.

- Connect dots; trace shapes.
- Copy shapes from model (line, circle, triangle) – may want to try doing the Beery VMI.
- Trace letters (e.g., of their first name).
- Copy first name from a model.
- Write letters or words to dictation.
- Speak clearly enough to use speech-to-text technology?

Early academic assessment – math. Is the child able to:

- Match by shape or colour.
- Recognize (point to) shapes/colours, name shapes/colours.
- Understand patterns using real objects XOXO pattern? (2 step, 3 step).
- Understand printed patterns XOXO..?
- Understand concepts such as more/less, up/down, empty/full, longest/shortest, same/different.
- Recognize written numbers.
- Able to answer questions about number concepts (e.g., how many brothers do you have? If we were setting the table for everyone in your family, how many plates would you need?).
- Count aloud; Count concrete objects aloud with 1:1 correspondence moving one at a time; concrete objects without moving them; count objects drawn on paper.
- Identify which group has a certain number of items.
- Understand concept of “1 more” (concrete, abstract).

Creative assessment requires creative tools! Here are some ideas:

- 2 or 3 large plastic cups to hide object under (e.g., from SB-5).
- 3 piece puzzle (e.g., triangle, square, circle from the SB-5 to assess visual spatial skills and problem solving).
- Toy cookie making set (to assess play skills, numeracy, ability to follow directions, social skills).
- Toys that assess cause and effect reasoning (press a button, something happens) especially those that light up or make sound.
- Large portable white board & marker (to assess letter recognition, name recognition, simple math).

- Shapes of different colors (to assess color/shape recognition and pattern recognition, “let’s put away all the yellow ones!”).
- A few items to assess recognition (e.g., spoon, pencil, ball, cup).
- Soft, squishy, easy to catch ball (to assess play skills, following directions, coordination).
- Snacks/treats and favorite objects brought from child’s home to use as motivation.
- Printed pictures/photos of objects/actions.
- Toys that promote creative play (e.g., dolls, figures, house cars).
- Objects/toys that involve sensory stimulation (make noise, have lights/shiny things, vibrate).
- Wiki sticks, thick crayons, triangular pencil, heavy black pen, thick lined paper.
- Balls of different textures, bounciness, weight and shape (e.g., white Styrofoam cube).
- Large magnetic letters plus magnet board.
- Developmental assessment kits (e.g., Bayley-4) have a lot of good items to use.

Key Takeaways

- Non-standardized assessment is appropriate when a child is not able to complete any standardized measures. It can also be used to supplement standardized assessment.
- Non-standardized assessment may include:
    - Administration of individual items from standardized measures (e.g., SB-5 puzzle, items from the Bayley-4).
    - Play-based structured interactions.
    - Directly attempting to engage the child in demonstrating specific skills.
    - Observation of the child.

Resources for Further Education

- Child Guided Assessment:
    - Nelson, C., Dijk, J. McDonnell, A.P. & Thompson, K. (2002). A Framework for Understanding Young Children with Severe Multiple Disabilities: The Van Dijk Approach to Assessment. Research and Practice for Persons with Severe Disabilities, 27(2), 97-111.
    - For an excellent case-based example of how to use this approach in assessment see this article.
    - CD-ROM: Child-Guided Strategies for Assessing Children who are Deafblind or have Multiple Disabilities, sold by the American Printing House for the Blind ($60).
    - A 30 minute video summary can be found for free here: http://www.perkinselearning.org/videos/webcast/child-guided-assessment
- Sensori-motor learning: Free video with Millie Smith: “Strategies for Assessing and Teaching Students with Visual and Multiple Disabilities” http://www.perkinselearning.org/videos/webcast/strategies-assessing-and-teaching-students-visual-and-multiple-disabilities
- Active learning: http://www.activelearningspace.org/ has a series of free online courses on this approach.

8. Evaluating devepmental level

Learning Objectives

- Identify the importance of evaluating developmental level.

All psycho-educational assessments must address diagnostic questions such as whether or not a child has an Intellectual Disability or a Specific Learning Disorder. These diagnostic evaluations are also important for children with multiple, severe disabilities. An additional essential component of the evaluation should be to provide an estimate of the child's level of developmental functioning in various areas. Estimating a child's developmental level involves synthesizing results of direct testing, observation, parent report, teacher report, and adaptive functioning measures. All of these things must be considered in the context of typical and atypical development. Having a firm grasp on early child development is essential. In particular, understanding typical development between birth and age 3 is important. You need to further understand the impact of sensory and motor impairments on development. According to Piaget's theory of development, learning begins with the acquisition of sensory input (sensori-motor stage). Children with motor and sensory impairments may experience limited sensory input, limited ability to explore their environment, reduced opportunities for incidental learning, and reduced experiential learning. Furthermore, physical needs (e.g., toileting, dressing) may take up a relatively large part of their day, leaving less time in the day for typical learning/developmental experiences. In addition, you may see aspects of learned helplessness, for example as parents learn to anticipate child's needs without the child making requests.

Identifying a child's developmental level will help you to provide recommendations to tailor a child's educational programming to their developmental functioning. Understanding a child's current level of functioning is also important to help identify the next steps in development and what is needed to get there.

9 year old Shary was able to scribble randomly on the page using a fisted grip. This suggests that Shary's next goal should be to work on coloring in the lines of drawings, followed by drawing simple shapes such as lines and circles. Once she is drawing some controlled, meaningful shapes, then it would be time to work on letter writing. Her school was having her practice hand over hand writing of her name multiple times per day which was not helping her progress towards independent writing.

10 year old Phillip's school team is helping him understand and predict his daily activities by using a visual schedule. The schedule uses "clip art" (line drawings) of various activities, as Phillip does not recognize letters or words. In your assessment, you identify that Phillip's overall developmental level is in the range of 9-15 months. He does not yet have symbolic understanding that pictures represent actions or objects, which is not unexpected given his developmental level. He is able to identify familiar objects (e.g., "where is the spoon?). Based on this, you recommend that Phillip's team consider using actual physical objects to symbolize activities (e.g., basketball for gym, drum for music).

When a child scores low on standardized tests, it tells us about what they *cannot* do, not what they *can* do. As part of the assessment, make sure to look for what the child is capable of doing. Incorporating non-standardized adaptive assessment can be helpful to quickly evaluate a specific skill. For example, when using this approach, start where you think the child is, and adapt the difficulty level of the skills you are assessing up or down based on the child's responses. This will get you to the child's developmental level quickly.

12 year old Joey is not able to answer any simple math problems (e.g., 1+2), orally or on paper. You offer him a set of 5 blocks and ask him to count how many blocks are present. He is able to count the objects with 1:1 correspondence by moving the blocks as he counts them. He cannot, however, reliably count objects printed on a page as he loses count of which ones he has counted. When he has counted the blocks, you give him 5 more and ask him to tell you "how many blocks are there if you add 2 blocks to your 5 blocks?" Joey is able to add 2 blocks, and count the total of 7. You now know that Joey understands basic numeracy and can count real objects up to at least 7. He needs manipulatives to be successful.

Key Takeaways

- It is important to have a firm grasp on typical development, particularly for the birth to 3 age range.
- Identifying a child's developmental level can help you make specific recommendations for interventions to help the child make developmental progress.

Resources for further information

- CDC's Developmental Milestones
- Pediatrics in Review: Developmental Milestones (2016)
- Dosman, C.F., Andrews, D. Goulden, K.J. (2012) Evidence-based milestone ages as a framework for developmental surveillance, Pediatric Child Health, 17 (10), 561-568.

9. Assessment of adaptive functioning in children with complex conditions

Learning Objectives

- Understand the complexities and best practices in evaluating adaptive functioning in children with multiple, severe disabilities.

Adaptive functioning & Intellectual Disability

A diagnosis of Intellectual Disability according to the Diagnostic & Statistical Manual of Mental Disorders, Version 5 (DSM-5) requires that the child must have one or more domains of adaptive functioning impaired (Conceptual, Social, or Practical). The DSM-5 recognizes that scores are not the only consideration in evaluating adaptive functioning: "Adaptive functioning is assessed using both clinical evaluation and individualized, culturally appropriate, psychometrically sound measures... Additional sources of information include educational, developmental, medical, and mental health evaluations. Scores from standardized measures and interview sources must be interpreted using clinical judgment" (DSM-5, p.37). Furthermore, a DSM diagnosis of intellectual disability requires a relationship between the cognitive and adaptive deficits: "To meet diagnostic criteria for intellectual disability, the deficits in adaptive functioning must be directly related to the intellectual impairments described in Criterion A" (DSM-5, p.38).

However, standardized measures of adaptive functioning (e.g., ABAS, VABS) are not designed to differentiate between limitations in functioning arising from cognitive impairments from those arising from the impact of motor or sensory impairments. What do we need to consider when evaluating adaptive functioning in children with multiple, severe disabilities?

- When evaluating young children with complex disabilities, it is wise to be cautious about diagnosing intellectual disability. Due to their very different developmental experiences, we need to be cautious in predicting their developmental trajectory. For example, a child who is blind will need to learn special skills to identify coins and keep track of different denominations of money. Thus, they are likely to learn this skill at an older age than a sighted child. A child with severe motor impairments will not have had the same opportunities to learn and practice independence skills compared to their peers. Overall, when we see children in their teenage years, we can be more confident in making a diagnosis when it is appropriate.
- Adaptive functioning is best evaluated through interview format (e.g., VABS interview). If adaptive functioning is done in an interview format, you will better be able to understand which supports are in place due to motor or sensory impairments. Further, an adaptive functioning interview is helpful as it can be depressing and frustrating for parents to fill out forms where questions do not apply to their children, and where they have to fill out "zero after zero".
- Many questions on adaptive functioning forms will be inappropriate for children with motor or sensory impairments (e.g., "carries dishes to the sink" for those without the physical ability to lift dishes; "uses spoon without spilling" in a child who is tube fed, "stays on sidewalk" in a child who is pushed in a wheelchair). Guidance from the measures themselves suggest that if a child is not capable of doing something due to a physical condition, the item must be scored as "0" but that you should take this into account in your interpretation.
- Do allow for a child's use of sign language, braille, or adaptive equipment to communicate (if used independently and unprompted). This includes listening to audiobooks and screen readers for those with visual impairments (VABS-3 Manual, p.45). The ABAS manual does not discuss this topic, but a similar approach between the tests would be appropriate.
- If you are finding the question of a possible intellectual disability to be a tricky one in a particular child, it will be important to do a detailed examination of individual items on adaptive functioning measures. For children with severe motor impairments, some subdomains of adaptive functioning are very low due to the motor impairments (e.g., for a child who can not dress or toilet independently). If that is the case, it is helpful to look particularly at the level of independence in the social and leisure domains, or the communication domain if language is not severely impaired. It is essential that you look at the scores in the context of the child's experiences, opportunities, and current functioning. Observations and interviews are essential compliments to adaptive functioning forms.
- Be very cautious about interpreting age equivalents which may be calculated as part of adaptive functioning measures, particularly for children with sensory and motor

impairments where you often see a lot of intra-subtest variability. See the section on age equivalents for more information on this topic.

- For discussion of evaluating the level of intellectual disability (mild, moderate, severe, profound, please see the next section – here.)

Key Takeaways

- Evaluating adaptive functioning in children with sensory and motor impairments is complex and is best done using an interview format.
- It is important to understand that children with motor or sensory disabilities are expected to have an altered development trajectory (e.g., they may develop certain skills at later ages, or some skills may not develop at all).
- Some subdomains of adaptive functioning are less impacted by motor impairments. For many children with motor impairments, it can be helpful to look at the Social, Communication, and Leisure subdomains of adaptive functioning. It is often important to look at individual items on adaptive functioning measures.

10. Evaluating level of Intellectual Disability

Learning Objectives

- Understand the complexities in evaluating level of Intellectual Disability

Diagnosing level of disability (mild, moderate, severe, profound)

Why is it important? Under the British Columbia (BC) Ministry of Education Special Needs Categories, the designation of Mild Intellectual Disabilities ("K") is funded through School-based funding. It does not bring extra funding to the district, while Moderate to Profound Intellectual Disabilities ("C") does bring extra funding to the district. The level of disability may also be relevant to the child's classroom placement. Thus, if you think the child has a moderate or more severe disability it is essential to be explicit in the level of disability. In contrast, the level of intellectual disability is irrelevant for access to community services in British Columbia outside of the schools.

What is the challenge? Standardized IQ and adaptive functioning tests do not differentiate well between moderate, severe and profound intellectual disabilities. The DSM-5 is the go-to place to find descriptions of the levels of disability. However, outside of the Conceptual domain, level of disability is mostly described in terms of adult-attained competency. Level of disability is more difficult to evaluate in children who are still developing. Further, the level of disability may vary in an individual over time. In addition to the DSM-5, Tasse and colleagues (2019[1]) elaborate on the DSM-5 criteria for levels of intellectual disability. They list what individuals at each level of disability can typically do "by the end of the developmental period." Also helpful is the work of Schalock & Luckasson (2015[2]).

Thus, while we need to be very clear about the distinction of intellectual disability versus *not* intellectual disability, it is OK to state "moderate to severe range" or "severe to profound

range." For those under age 5 who have multiple disabilities, a DSM-5 diagnosis of Global Developmental Delay (GDD) may be most appropriate. A formal diagnosis of GDD allows a child to access Children and Youth with Special Needs (CYSN) in BC. To continue to receive CYSN services past age 7, the child must be re-evaluated. DSM-5 also allows for "Unspecified Intellectual Disability" for "individuals over the age of 5 years when assessment of the degree of intellectual disability (intellectual developmental disorder) by means of locally available procedures is rendered difficult or impossible because of associated sensory or physical impairments, as in blindness or prelingual deafness; locomotor disability; or presence of severe problem behaviours or co-occurring mental disorder… Requires reassessment after a period of time." If you use this category, be sure to state (if appropriate) that the individual clearly has an Intellectual Disability (& meets DSM-5 criteria) and whether you think re-assessment is necessary. Under current regulations, BC's community services (CYSN and CLBC) will accept a diagnosis of "Unspecified Intellectual Disability."

Key Takeaways

- IQ tests and measures of adaptive functioning do not differentiate well between moderate, severe, and profound Intellectual Disabilities.
- The DSM-5 is a great resource for descriptions of the various levels of disability.

Notes

1. Tasse et al (2019). Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development. Journal of Intellectual Disability Research, 63(5): 386-407.
2. Schalock & Luckasson (2015). A Systematic Approach to Subgroup Classification in Intellectual Disability. Intellectual and Developmental Disabilities, 53(5): 358-366.

11. Assessment of socio-emotional and behavioural functioning

Learning Objectives

- Describe the essential areas to address when interviewing regarding socio-emotional functioning and behaivour.
- Understand the limitations of standardized measures of socio-emotional functioning and behaviour in this population.

Children with neuromotor disorders have a higher risk for mental health problems compared to the general population. This may include difficulties with behaviour (including aggression or self-injurious behaviour), anxiety, mood, or attention. Socio-emotional functioning may also be complicated by related factors including problems with sleep, pain, constipation, swallowing, and difficulty with communication. Our standardized questionnaires are often not very useful in this population as many of the questions are inappropriate. This makes an interview format the most appropriate way of assessing functioning.

Socio-emotional functioning interview

- What are the child's likes and dislikes? What motivates them? Do certain experiences cause the child distress (e.g., changes in routine/caregivers, sensory overload)? What calms and comforts, is there a calming routine?
- Document issues with pain and ask about pain on the day of the assessment. Is the child able to communicate when and where they are in pain or uncomfortable?
- Interaction with peers (e.g., watches from a distance, waits to be approached, makes social overtures, has favored peers).
- What activities does the child do for pleasure? Are there ways to increase independence with leisure activities?

Safety issues/Behaviour interview

- Ability to judge personal safety (choking risk, stranger safety, wandering off, falling, unbuckling seat belt, etc.).
- Aggression towards self (self-injurious behaviour).
- Aggression towards others.
- Are there behaviours that are getting in the way of social functioning or learning?

Questionnaires

Behavioural and socio-emotional questionnaires (e.g., BASC, BRIEF, autism questionnaires) are typically not appropriate for this population. For example, here are some items from the BASC-3:

- "Says 'I hate myself'" (does not talk)
- "Is organized" (the person who is nonverbal with quadriplegia may never have had the opportunity to try organizing materials)
- "Is a picky eater" (tube fed)
- "Avoids eye contact" (cannot see unless close up)
- "Listens to directions" (not able to follow commands)
- "Cleans up after self" (very limited use of hands)
- The same problems can be found in everyday executive functioning and autism questionnaires in this population!

The Maladaptive Behavior Domain of the Vineland-3 is brief and targeted to evaluate internalizing, externalizing and critical behavioural problems. While some questions may be inappropriate for this population, most are applicable. In addition, the Developmental Behavior Checklist – Version 2 (available online through WPS) was designed specifically to evaluate behavioural, social, and emotional problems of individuals with an intellectual disability, ages 4 and older.

Key Takeaways

- Assessment of socio-emotional functioning and behaviour is best evaluated through interview.
- Standardized measures of socio-emotional functioning and behaviour are not usually appropriate for children with multiple, severe disabilities. Two that may be appropriate are the Maladaptive Behavior Domain of the Vineland and the Developmental Behavior Checklist-2.

12. Adaptations for motor and communication impairments

Learning Objectives

- Understand how to optimally adjust the physical testing space.
- Be aware of various alternative response options for children who have difficulty with motor control or communication.

Children with cerebral palsy or other neuromotor conditions present with a wide spectrum of motor involvement. Some children's motor involvement may be barely noticeable by a novel observer, and will not have any impact on the assessment situation. At the other extreme end, some children will present with almost no voluntary motor control. It is up to the assessor to learn about the individual child's capabilities, and then set up the testing environment and choose testing materials and adaptations that maximize the child's ability to demonstrate their knowledge.

Adaptations/modifications and validity of data

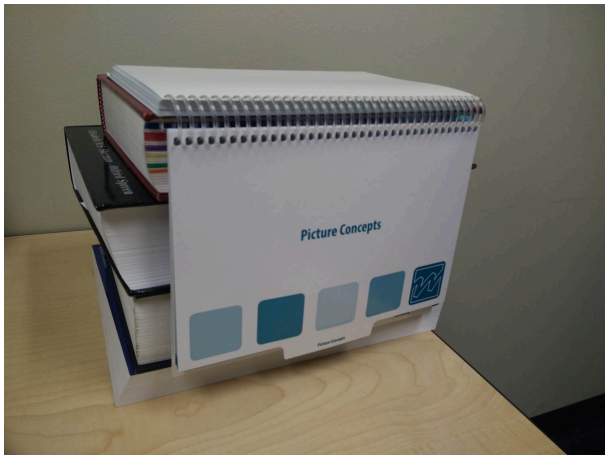
All adaptations and modifications to standard testing practices must be carefully documented and considered for their potential impact on test results. Some adaptations are unlikely to have any impact on test results (e.g., allowing the use of a felt pen rather than a pencil for writing, allowing the child to make a response with their voice rather than point on an untimed multiple choice test). When the adaptations or modifications make a change to the demands of the task, it may not be appropriate to interpret the test results using normative data. For example, allowing a child to dictate an essay fundamentally changes the writing demands and makes the task a measure of oral expression rather than written expression. When modifications fundamentally change the way a test is administered, it would most likely be appropriate to interpret the results qualitatively. However, comparison to normative data may also be instructive. For example, for a child who will never be able to write by hand or type due to a motor disability, it would be

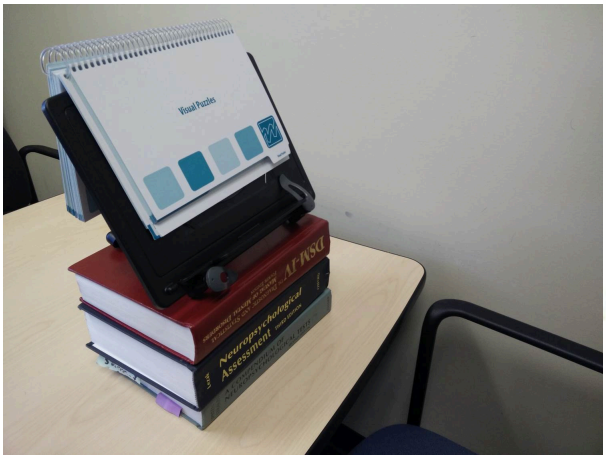
appropriate to evaluate how the child's only means of written output (dictation) compares to their peers' written expression.

Setting up the test materials

For children in a wheelchair, it is important to present materials in a location convenient for the child to see and manipulate. If your table does not change height, you may need another way to present information at the appropriate height. One option is use of a tray that attaches to the child's wheelchair. This is something the family may be able to bring from home.

Another option is to raise the test materials above the height of the testing table and bring them closer to the child's eyes. This could involve use of a slant board (also called a "book stand" or "book holder"). This option is especially useful for children who have visual difficulties, or who have difficulty with head or trunk control. Some children may be seated in a harness in their wheelchair to keep them upright which would also keep them from positioning themselves closer to the test material. If you do not have a book stand, you can improvise using books or boxes (e.g., see photos below). You can also raise the height of your slant board by placing it top of books:





Alternate response options for multiple choice tests

For children who have limited or no spoken language, or who have limited or no use of their hands, we need to consider alternate ways the child can make responses during the assessment. In general, the first choice should be to utilize the child's main mode of communication (gesture, point, words, adaptive equipment). Possible adaptations may include:

- Allow the child to state the number/letter of the response option rather than point. If no number or letter is present, you can create an overlay using clear paper (avoiding glare) or a border cut-out with drawn on numbers. This is typically not appropriate for tasks where speed is important or where it changes the demands of the task. For example, this method of response would be entirely appropriate to use on WISC Matrix Reasoning. On this test, the child has unlimited time to consider the stimulus and possible responses, which are all presented on the same page. However, for a test

like WISC Picture Span (where the child is asked to remember a series of picture and point to them in order on the next page), requiring the child to attend to and read the letters associated with each picture increases the cognitive demands of the task. It may be worth attempting, but this adaptation means the results should be interpreted cautiously, as a minimum estimate of capability. Another alternative for Picture Span would be to allow the child to state the names of the objects rather than point. However, this requires that the child is able to name the objects (which is not a requirement of the test), and therefore this also changes the demands of the task.

- If the child is not able to identify numbers or letters (or does not have a way of communicating them to you), you may need to point to each response in turn and ask for a yes/no response. If using this strategy, it is important to keep your facial expression and movements neutral. The best way to do this is to try not to pay attention to what is the correct answer.
- If the child is not able to show consistent use of any communication strategy to respond to the test questions, you may need to consider using a different type of assessment (see non-standardized assessment chapter).

Motor adaptations: Writing

- A pencil can be difficult to use if the child does not exert sufficient pressure (or exerts too much pressure). Regular pens can be difficult because you have to hold them at a specific angle. In this case, a thin felt tip marker can be a good alternative.
- For children with hemiplegia, you may observe that the child does not hold down the paper with their non-dominant hand when writing. If that is the case, you can assist by reminding the child to use their other hand, holding the paper down for them, or taping the paper to the desk.
- To evaluate spelling or written expression, you may choose to allow typing or dictation, especially if that is how the child normally writes. For typing, open a word document, and turn off spell and grammar check. Of course this is a departure from standardized procedures, and thus interpret results with caution. When a child is dictating to you, make sure they can watch you writing in order to get the visual feedback, and have the opportunity to self-correct.

Reading tests with reduced motor or spoken language demands

- Woodcock Johnson – IV (WJ:4)
    - Reading Comprehension has a nice way of sampling early reading skills (match word or words to picture, match outline of picture to detailed picture. For children with verbal responses or who can write, this test proceeds to single word responses using fill in the blank (while reading to yourself).
    - Sentence Reading Fluency – Answer Yes or No to indicate whether sentences are true or false for 3 minutes (e.g., "A banana is blue" – No). An adaptation for motor impairment would be for the child to state Yes or No aloud (or using gestures) while the examiner marks the response.
    - Word Reading Fluency – mark two words that go together in each row in 3 minutes. The same adaptation can be used as for Sentence Reading Fluency.
    - Woodcock Johnson also has a braille and large print version available through American Printing House for the Blind.
- Kaufman Test of Educational Achievement – 3 (KTEA-3)
    - Silent Reading Fluency: The student silently reads simple sentences and marks yes or no in the Response Booklet to indicate whether the statement is true or false, completing as many items as possible within a two-minute time limit. An adaptation for motor impairment would be for the child to state Yes or No aloud while the examiner marks the response.
    - Reading comprehension – early items involve matching a word to a picture then doing an action described in what was read.
    - Reading Vocabulary – point to one of 3 words that goes with a given picture. Later read a sentence and point to the word or sentence that has the same meaning. An adaptation could be oral or gestural responses.
- Wechsler Individual Achievement Test -III (WIAT-III) Early Reading Skills subtest has a few items where the person reads the word and points to the matching picture (low level only).
- Bracken Basic Concept Scale – 3 Receptive version asks child to point to colors, letters, letter sounds, numbers, sizes, shapes, etc.

WISC-V and motor/communication adaptations

- Even with limited hand use, many people can do Block Design (though they may have

difficulty lining up the blocks and may take extra time). The DAS-II test has an option for an untimed version of block design (Pattern Construction).

- WISC-5 Coding/Symbol Search can be problematic as these tests are heavily dependent on motor speed and vision/visual tracking.
- WISC-5 Arithmetic is a good way look at mental math when a child is not able to work out problems on paper.
- The WISC-5 Integrated has versions of the verbal WISC subtests which are multiple choice. This may have a place in your assessment, but never as a replacement for regular WISC subtests as the task demands are entirely different from the WISC-5 subtests.

Attention & memory and motor/communication adaptations

- The Child and Adolescent Memory Profile (CHAMP) has non-motor response options for the visual memory subtests.
- For verbal memory subtests, if the child is nonverbal or minimally verbal, you can use the multiple choice recognition format to assess comprehension (skipping free recall). As this would be administering the subtest in a non-standardized manner, describe results rather than compare to the normative sample.

Communication

- Receptive language/listening comprehension is an essential skill to assess in children with severe motor and communication disabilities. At a minimum, this would include the ability to hold in mind and follow directions (e.g., NEPSY Comprehension of Instructions if able to use visual/ motor response route or WIAT Listening Comprehension if using auditory/oral response route).

Use of eye gaze for communication in assessments

Children who have limited use of their body, but who have volitional movement of their eyes may use eye gaze for communication. An E-tran (“eye transfer”) board is a low-tech communication system which allows someone to make choices with their eyes. An E-tran consists of a clear acrylic board with a cut-out in the middle. Responses can be Velcro’d or clipped to the corners. The examiner places their face in the middle of the

board in order to watch where the person directs their eye gaze. The child would look at the intended response, then look back at the examiner, who speaks the answer aloud. A simple communication system would involve choices between yes/no, with the words YES and NO placed opposite each other. For children who have learned to spell, they may use a system which allows for letter-by-letter selections. It is often helpful to have a second examiner in the room who can note down the child's responses. Newer, high-tech eye gaze technology uses a camera which tracks a person's eye gaze across a screen. For many individuals, learning to use eye gaze for communication takes time and lots of practice including training in visual tracking. For some individuals using this type of communication can be very physically demanding and may require multiple short sessions.

Key Takeaways

- It is important to adjust the physical space so that test material is presented at an optimal location for the individual.
- Adaptations should be tailored to the child's individual motor and communication needs and should be carefully noted in the report.
- It is important to evaluate if adaptations or modifications change the fundamental demands on the task. If they do, it may not be appropriate to use the normative data.

Resources for Further Education

- Hill-Briggs, F., Dial, J.G., Morere, D.A., & Joyce (2007). A. Neuropsychological assessment of persons with physical disability, visual impairment or blindness, and hearing impairment or deafness, *Archives of Clinical Neuropsychology*, 22(3:1) 389–404.

13. Strength-based report writing - The "integrated report format"

Learning Objectives

- Describe one method of translating a strength-based assessment approach into a strength-based report.

Integrated report format

If you are looking for a way to write reports which fits with the approach presented in this book, consider using what I call the “integrated report format”. In this format, you include all of the same information you would in any assessment report, but organized in a different way, integrating the assessment findings across sources. This format recognizes that your assessment is not just based on test results, but rather on the integration of multiple sources of information. It also has the benefit of lending itself very easily to discussing strengths and what a child is able to do. It is quick to write and easy to read. Using an integrated report format, you would include:

1. Reason for referral.
2. List sources of information including tests administered.
3. Relevant background information. Note here that many children with multiple, severe, disabilities have very extensive medical histories, including complicated birth histories, multiple surgeries, a list of medical diagnoses, etc. For children who are well cared for by medical teams who know them well, there is no need to summarize all of their history. Rather, note the key points that are essential to your case conceptualization.
4. General observations/adaptations/structure of the assessment. In this section, discuss general alertness, cooperation, and overall presentation of the child. Also discuss the format of the assessment (e.g., play based, combination of standardized measures + observation), any adaptations or modifications provided, anyone else who was present for the assessment and the role they played.

5. Results section. This is where the flexible report format may be very different from your standard report. The results section may be broken down into domains of functioning, similar to other formats. In each domain, integrate parent report of current functioning, your observations, adaptive functioning report, teacher report of functioning, and standardized test data. Domains may include Communication (sometimes broken up by expressive/receptive), Behaviour, Socio-emotional/play skills, Physical/motor/sensory, Learning/Cognitive, Pre-academic (or combined with cognitive), Self-help skills (not covered elsewhere). In each section, say what the child can do, while acknowledging what limitations are present.
6. Very brief "Summary/impressions section" which ties it all together. "Julia is a child who…". Be clear and definite about diagnoses (i.e., do not say "appears to meet criteria for").
7. Recommendations & Resources – keep this to the essentials.
8. Data table with standard scores. I suggest including adaptive functioning standard scores (with 95% confidence interval) as community services are sometimes based on these numbers. If there is no contraindication to doing so, I would also suggest including the 95% confidence interval for the Full Scale IQ (or whatever IQ score you are using), particularly at the mild to moderate borderline of functioning.

Results Section – Examples

Note: All names and identifying details have been changed for confidentiality purposes.

Observations and overview of assessment: This assessment is based on direct observation of Susie in the presence of her mother, an interview with her mother, and a telephone interview with her teacher. Susie uses very few words, has minimal use of her hands and arms due to spasticity, and had very limited interaction with me during the assessment. Thus, formal, direct testing was not possible. The direct portion of the assessment utilized a functional approach attempting to engage Susie with play materials and social games. The report below incorporates direct observations with parent and teacher report in order to give a picture of her typical level of functioning. According to her mother, Susie's presentation during the assessment was typical. This, in addition to the well-informed report from the adults who know her best means that this assessment is believed to be an accurate reflection of Susie's current functioning. Please see the appendix for adaptive functioning scores.

Social skills, play, and behaviour: Susie's mother and teacher both described her as a very happy young girl, except when she is in pain or tired. There are no concerns with self-harm or harm towards others. During the assessment, Susie smiled in response to games (e.g., peek a boo) and laughed

easily when her mother playfully interacted with her. She enjoys listening to music, looking at books, playing in water, and watching children play. She demonstrates her interest by becoming quiet, and making eye contact. At home and at school, while she responds to playfulness, she does not initiate/ request games such as peek a boo.

Motor skills: Due to spasticity, Susie's arms and hands are tightly clenched and she does not use them for any fine movements such as grasping or pointing. She uses a head switch successfully, and has at times been successful with using her forearm to press a large button. She receives botox for spasticity and her ability to use her arms fluctuates depending on the currently level of spasticity. Other things Susie is able to do include reaching for objects placed in water, flipping something off her wrist, and knocking things off her lap. She will assist with dressing by raising her arms.

Academics: Jill is working at a pre-Kindergarten level in academics. When writing, she used her left hand with an awkward pencil grip. She did not direct her gaze at her writing. She was able to spell her first and last name aloud, but she was not able to write anything legible. She was able to produce scribbles. She demonstrated emerging pre-literacy skills including knowing the sounds that (most) individual letters make, the ability to rhyme simple words, and the ability to orally blend sounds into words. Jill correctly named colours, and some shapes (circle, square), but could not name a triangle. She did not understand the concept of more/less (on paper, or using real objects). Jill was able to count objects with 1:1 correspondence, at least up to 10 by moving each object in turn. In oral math, she could do +1 problems. She did not understand the concept of "take away" or "minus," even when using real objects.

Everyday living skills: Adaptive functioning, or skills for everyday living, were evaluated using an interview with Joe's parents (VABS-2) and a comprehensive questionnaire completed by his Learning Support Teacher (VABS-2). In some areas, Joe requires help and support due to his physical disability and visual impairment. For example he needs help dressing and undressing, and with toileting. He is able to feed himself using a spoon or his hands. He enjoys being helpful around the house (setting out placemats, returning his dishes to the kitchen). Overall, Joe needs a lot more help and support in all areas of everyday functioning, well above what would be expected based on his physical and visual impairments. Ratings by both his school and family place him overall within the moderate to severe range of intellectual disability.

Expressive language: According to his parents, at home Steve will point to objects that he wants that

are out of reach (while making eye contact), or take parents by the hand and lead them where he wants to go, placing their hands on what he wants. He will sometimes wave “bye”, but not when requested. He will make a choice between 3 DVDs, but this is the only type of choice he makes in this way. He does not copy gestures, facial expressions, or word sounds, even when requested. He will sometimes copy other children’s play. At school, Steve has trialed an iPad with Proloquo2Go which use visuals for choice making and verbalizes the choice. However, he has not had success thus far. Various other augmentative communication devices and picture communication systems have been trialed, with varying success depending on his interest at the time. At a previous school, he apparently successfully used a card with 4 pictures and could point to the one he wanted. Currently he has words for Yes and No printed on his wheelchair. His EA believes he does not understand these choices and at this time they are rarely used. Like at home, his primary mode of communication at school is taking an adult by the hand and placing their hand on what he wants. During the assessment, Steve frequently made noises to indicate pleasure or displeasure. No word approximates or signs were observed. He indicated his desires quite clearly by pushing things away, grabbing things, putting an adult’s hand on what he wanted, or attempting to leave the room. He gave high-5’s when requested.

Cognition: During this assessment, Peter demonstrated knowledge of object permanence (when something is out of sight, it continues to exist), and basic cause and effect reasoning(e.g., press a button and something happens). Of note, he was only able to focus on one thing at a time. For example, when given a second block, he would drop the first. He did not show coordination of use between his two hands. Rather, he tended to use just one hand at a time. He was able to briefly hold in mind a location (where something was hidden), but he was not able to keep track of location when the hiding place was changed within his sight.

Summary/Impressions Section – Examples

Peter is a happy, social 12 year old boy. He has a history of learning difficulties, ataxia (difficulty coordinating movements), and epilepsy which has been difficult to control with medication. There are known differences in the white matter of his brain. His parents have done a wonderful job of getting Peter involved in engaging activities outside the home. At school, he receives full time 1:1 support. Peter is nonverbal, and communicates through eye contact, facial expression, tone of voice, and a few simple gestures such as clapping. He can follow familiar, simple instructions when provided with encouragement and gestures. He is dependent on others for all aspects of daily living.

He enjoys simple social games, physical interaction with objects, music, and using his gross motor skills. Fine motor skills are very limited. He is familiar with his routines and gets upset when they are altered. When he is able to predict what is going to happen, he is a generally a happy, easygoing boy. Results of the current psychology assessment found that in general, Peter demonstrates cognitive, communication, and social skills at approximately the 10-12 month old level. He meets DSM-5 criteria for an Intellectual Disability in the profound range.

Andy is a social, friendly, enthusiastic grade 4 student with a history of spastic dystonic cerebral palsy secondary to premature birth. Andy uses a wheelchair for mobility, and has limited use of his hands (right better than left). He has a long history of services, interventions, and therapies to support his development. He is involved in many supported community activities, and has an incredibly enriched, encouraging, and supportive home environment. Andy is best able to focus when he is presented with one thing at a time, and when he is given sufficient processing time. He does best with short, focused learning sessions. It is wonderful to see that Andy is developing some nice early literacy skills. He is starting to sound out words, and is able to read short sentences using sight words, at the early Grade 1 level. Math concepts, on the other hand, have been extremely challenging for him. He has difficulty with pre-Kindergarten skills such as counting objects and naming shapes. Andy's difficulty with pre-math skills is consistent with his very significant difficulty with visual processing and reasoning in general. He has difficulty making sense of visual patterns and thinking logically through problems. He also has difficulty with demonstrating his knowledge and reasoning through language. However, Andy is able to understand and remember more than he is able to express in words. With cues or prompts (such as a multiple choice format), he is able to show that he knows much more than he is able to express on his own. Overall, Andy is an easy-going, friendly, adaptable boy who meets DSM-5 criteria for a mild intellectual disability.

Acknowledging and building on strengths

When children's standardized scores are all below the 1st percentile, it can be helpful to identify personal areas of strengths which likely lie outside of the formal test results. Examples of strengths may include:

- Motivated by social connections, friendly, cheerful, eager to please others
- Sense of humor, playful
- Engagement with learning, curious, agreeable to trying new things
- Motivated by special personal interests
- Loves animals

- Loves music/singing/dancing
- Easy-going nature, patient, able to stay calm when frustrated
- Exuberant, high energy, strong, energetic
- Thrives with routine/adaptable to change
- Learns through repetition, learns by watching others
- Responds well to encouragement, proud of successes
- Persistent, likes to try to do things for self
- Able to use communication strategies when frustrated (e.g., looks away from book rather than throwing book when does not want to read book)

It is especially helpful if you can tie the child's personal strengths to recommendations.

> Sally is very socially motivated. Thus, she would benefit from learning through interactions with peers.

Important areas to address in recommendations

- Building communication skills is often an important areas for development in children with multiple, severe disabilities.
- Are there factors in the child's presentation that are impeding development or the ability to function to their greatest personal capacity? (e.g., sleep issues, undiagnosed Autism, safety or behavioural issues).
- What accommodations/supports/interventions would be helpful?
- What opportunities/activities would enrich the child's life?
- What community supports and services would the child/family qualify for?
- Can we help the child to have a voice in decision making? Helping the child develop choice making skills is important.

Key Takeaways

- The “Integrated report format” discussed in this chapter describes an alternative format for writing strength-based reports.
- The essential component of this format, is that the in the “Results” section, your assessment findings (from various sources) are integrated. For example, the section on Communication integrates your observations and direct testing results with reports from teachers and parents. The results section focuses on what the child can do, rather than comparing them to their same aged peers.
- The Summary/Impressions section should be brief and include only the key features from the results section. Diagnoses should be made explicit.

14. Assessment in children who are blind or visually impaired

Learning Objectives

- Be familiar with common visual conditions in children with neuromotor disorders and what impact they may have on assessment.
- Understand options for adaptations in the assessment to support children with visual impairments.
- Understand issues in interpretation of assessment results in children with visual impairments and know where to go for further education on this topic.
- Know where to go for further information on this topic.

Cautionary note: It is important to highlight that competency in assessment with children who have visual impairments involves much more than making adaptations to tests. Specialized training in vision is important to understand the impact of vision on development, provide the appropriate adaptations, interpret results, and make appropriate diagnoses and recommendations. This chapter is designed to be an introduction to visual impairments for psychologists who are interested in learning about assessments with children who are blind or partially sighted. Extensive resources for further learning are provided for those clinicians who are interested in developing competency in this area. Children in British Columbia, the Yukon, or the Northwest Territories, Canada with visual impairments may be referred by their medical doctor to the Sunny Hill Visual Impairment Program.

Development and assessment of vision in children

In early childhood, vision is still developing. Maturity in vision usually occurs around age 6 to 8. An ophthalmologist uses a fundoscopic evaluation to examine the anterior visual pathway (from the eye to the lateral geniculate nucleus of the thalamus). This type of evaluation can identify about 60% of visual impairments. The posterior pathway includes the optic radiations and the occipital cortex of the brain. Problems in the posterior pathway

rarely occur in isolation. They often occur with anterior pathway problems or other developmental issues.

Visual conditions

Various vision conditions are common in children with neuromotor disorders and multiple, severe disabilities. For a list of visual conditions and their potential impact on education, see here. Following are some common categories of visual impairment:

- Problems with visual acuity, or sharpness of vision, may be present. Children who have visual acuity of 20/70 or poorer (with correction) qualify for the designation of "visual impairment" for special education purposes. For context, 20/200 (with correction) is considered "legally blind." Children with visual acuity difficulties need material brought closer or enlarged. Children with acuity of 20/80 in general need information presented 4 times larger, or 4 times closer, than someone with 20/20 vision.
- Strabismus is a condition where the eyes look in two different directions. The misaligned eye may look inward (esotropia), or outward (exotropia). Untreated, it can lead to amblyopia (sometimes called "lazy eye") and severe visual impairment in the affected eye.
- Cortical Visual Impairment (CVI) can result from damage to the occipital lobe or pathways between the eye and the occipital lobe. Children with CVI have an abnormal response or reduced response to visual input. CVI tends to improve with development. Children with CVI benefit from reduced visual clutter, and use of high contrast materials.
- Visual field loss can occur due to damage to the visual pathways in the brain. This can include specific field cuts (e.g., upper left field cut), or a reduced field of vision (e.g., loss of peripheral vision in both eyes). Hemianopia (also called hemianopsia) is the loss of half of the field of vision and can result from brain damage to the optic tract or occipital lobe. This can impact one or both eyes. Commonly, you will see "homonymous hemianopia." More details on assessment in children with homonymous hemianopia can be found in the next chapter.
- Difficulty with control of eye movements can impact functional use of vision.
- Problems with depth perception "stereopsis" are common in children with multiple, severe disabilities, but this should not impact typical psycho-educational testing.

General set up, optimizing vision & adaptations

- For children with visual impairments, it is often mentally draining to engage in visually-demanding tasks. Furthermore, the ability to see over the course of a day varies with level of fatigue, attention, familiarity, and lighting conditions. Eye movement issues, esotropia, exotropia, nystagmus, may become more impairing as the child fatigues. For this reason, it is helpful to alternate visual and verbal tasks and to provide lots of breaks.
- Pay attention to lighting, glare, and shadows. Some children need low light, while others need bright light. It can be helpful to have a table lamp available instead of (or in addition to) overhead lights. Watch for glare off of materials. Baseball caps can be good for glare and light sensitivity. Watch for shadows on the work area (a slant board can help with this).
- For visual items, consider placing the material on a book stand to bring the material closer to the child. You could also prop it up on a pile of boxes or books (see photo). The material should be at eye level of the child. This is to bring the material closer to the eye without producing neck strain. Use caution when turning the pages so that you do not hit the child in the face.
- I like to start off by telling children that I am not trying to test their eyesight. If they have difficulty seeing ANYTHING during the assessment, it is important that they let me know. However, some children cannot or will not tell you if they are having difficulty seeing. If you have concerns about the child's ability to see details correctly, it is important to check with the child. When the discontinue is met, go back to an item where they made an error, and ask the child to describe exactly what they see. Ask the child to describe what they see rather than ask, "can you see this?". Pay attention to possible problems with color vision, mislabeling, missing details, etc. When tests are challenging for the child to see (when they can see but it is effortful), consider whether these tests are necessary to administer. Realize that they may not be a measuring what the test was designed to measure. For example, the WISC Processing Speed tests may not be a good measure of mental processing speed if the child has difficulty seeing the shapes. However, a score on these tests can give you a measure of how fast a child is likely to finish visually challenging written worksheets in the classroom compared to their peers.
- Observe how the child scans the page, do they scan in an organized manner; are they missing parts of the page? Some children with visual difficulties have difficulty with visual attention and visual search strategies. They may need support/reminders to attend to all aspects of the page ("look here, look here").
- Many children with visual impairments (particularly children with cortical visual impairment) benefit from increasing contrast. Consider using a black contrast mat

("desk blotter") to increase the contrast between test materials and the table. This also helps to focus visual attention on the testing materials. Pay attention to contrast on other test materials and how this may impact the assessment. For example, an early item on WPPSI Block Design asks the child to look at a picture of white blocks on a white background. Also, the Stanford Binet three-hole puzzle has no contrast in the puzzle pieces space. You could consider using a black "inset" in the puzzle to increase the contrast.

- When a task is "visually crowded" (e.g., the last page of the Visual subtest on the Beery VMI) consider isolating individual items by covering up irrelevant parts.
- For children with visual impairments, it is still important to assess visual learning and reasoning. For some children with visual impairments, vision may still be their strongest learning channel. However, if a child with visual impairments has difficulty on tests with high visual demands, we must consider the results a minimum estimate of their functioning.
- In addition to the typical areas of functioning, be sure to assess listening comprehension as this is an important skill for children with visual impairments who rely heavily on their listening skills.
- Using an enlarger, such as a magnifier, increases the working memory demands of the task as the child has to integrate multiple "parts" into a whole. Rather than being able to see and "take in" the whole of the picture, they must look at each part separately and then mentally integrate the parts. This inherently makes most visual tasks more challenging and this should be taken into account when interpreting your findings. Similarly, children who see only through a small visual field (or who have spots of loss such as in scotoma) will need to work harder to integrate the things that they see.
- For children with visual impairment, it is important to be aware of the impact of sensory loss on development. Children with limited vision have reduced access to incidental learning. Be aware of how sensory (and motor) impairments may have limited an individual's exposure to certain concepts/pictures. For example, someone who is blind may not have had the experience of using something like chalk, an item with which most North American children would be familiar. Thus, asking how chalk and a marker are alike would present an unfair challenge.
- Children with visual field loss may show specific errors on testing related to their visual condition. For example, on WISC Picture Span, the child is asked to memorize a series of drawings of objects. Examination of the child's pattern of errors may show that a child with left field loss does not recall the item on the far left.

Academic testing

- Be aware that for braille learners, the expected progression of numeracy, reading, and writing, are not the same as the progression of the same skills in sighted peers.
- Be aware that reading, for individuals with a visual impairment, is likely to be slower. Reading enlarged materials takes more time. Reading small text takes more effort, and therefore more time. If a child with visual impairments has no difficulty with accuracy and reading comprehension, slow reading speed should not be considered a learning disability, but rather should be considered secondary to the visual impairment. Even experienced braille readers are typically slower than print readers. They will require extra reading time for tests due to their visual impairment.
- If needed, enlarge reading materials ahead of time of. Be sure that the copies have high contrast (you can adjust the contrast to the highest possible on the photocopier). With photocopies, make sure you present only one page at a time, so that there is no interference from text showing through from the page underneath.
- Right (compared to left) homonymous hemianopia has a stronger impact on reading as the person is not able to preview the upcoming letters, particularly impacting reading beyond the single word stage and causing a decrease in reading speed. Left homonymous hemianopia can also impact reading by causing difficulty finding the next line of text and causing word reading errors as the first letters of the word may be missed.
- To support children who have low vision when writing during an assessment, it is appropriate to provide the child with whatever adaptations they normally use for writing. You may want to use paper with thick black lines (free printable pdfs are available online). There is also paper with raised black lines available for purchase. Give the person a dark thin pen or marker to write with to increase contrast.

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Key Takeaways

- Various types of visual impairments, including problems with seeing clearly, and visual field loss are common in children with multiple, severe disabilities.
- Specific adaptations to assessment materials are sometimes necessary including enlargement of reading material, raising of test materials close to the eyes, and attention to lighting.
- In order to appropriately interpret assessment results, it is essential to understand the impact of visual impairments on development, and understand the impact of visual impairments on the assessment results.

Resources for Further Education

Impact of visual impairment on development

- Impact of Visual Impairment on Development by Chris Strickling, Texas School for the Blind and Visually Impaired.
- Free e-learning course through the Provincial Health Services Authority: Development and Assessment of Children with Visual Impairments.

Vision and assessment

- American Printing House for the Blind, position paper: Intelligence Testing of Individuals Who Are Blind or Visually Impaired; especially issues 8 (Direct Observation), 9 (Qualitative Observation) and 10 (Reporting Results).
- Psychoeducational Assessment of Students Who Have Visual Impairment by Carol Anne Evans
- Making Evaluations Meaningful, determining appropriate instructional strategies for blind and visually impaired students, by Marnee Loftin, Texas School for the Blind and Visually Impaired.
- Clinical Practice Guideline: Report of the recommendations – Vision impairment assessment and intervention for young children (age 0-3 years), NY State Department of Health.
- Atkins, S. (2012). Assessing the ability of blind and partially sighted people: are psychometric tests fair? RNIB Centre for Accessible Information, Birmingham.
- Hill-Briggs, F., Dial, J.G., Morere, D.A., & Joyce (2007). A. Neuropsychological assessment of persons

with physical disability, visual impairment or blindness, and hearing impairment or deafness, *Archives of Clinical Neuropsychology*, 22(3:1) 389–404.

Vision and education

- Visual Field Loss in Children – an excellent article on the impact of field loss on reading.
- Canadian National Standards for the Education of Children and Youth Who are Blind or Visually Impaired, Including Those with Additional Disabilities
- The Expanded Core Curriculum. Nine essential skill areas directly impacted by visual impairment.
- 6 minute YouTube video "The Role of the Teacher of the Visually Impaired in British Columbia".
- UEB, Accessible Braille Training, online braille training: https://uebonline.org/

General visual impairment resources

- How to Interact with a Person Who is Blind or Visually Impaired, by the Associated Services for the Blind and Visually Impaired.
- Sighted guide techniques, video series from the Canadian National Institute for the Blind.
- American Foundation for the Bind e-learning series.
- Extensive list of eye conditions, includes educational implications, from the Provincial Resource Centre for the Visually Impaired.
- Free e-learning course through the Provincial Health Services Authority: Development and Assessment of Children with Visual Impairments.
- Guide for developing technology skills for children who are blind or visually impaired by the Royal Institute for the Deaf and Blind.
- An Introduction to Cerebral Visual Impairment by Professor Gordon Dutton.
- Perkins eLearning resources: https://www.perkinselearning.org/
- Perkins eLearning podcast: https://perkinsvision.podbean.com/

15. Visual field loss and psychology assessments

Definition/cause: Loss of vision in part of the field of vision may be due to traumatic brain injury, tumor, surgery, or infarct in the posterior cerebral artery. Field loss can affect different parts of the field of vision depending on what part of the system is affected. When the same half of the visual field is affected in both eyes, it is called homonymous hemianopia (HH). Many children with HH will also have weakness or paralysis on the same side of the body as the vision loss.

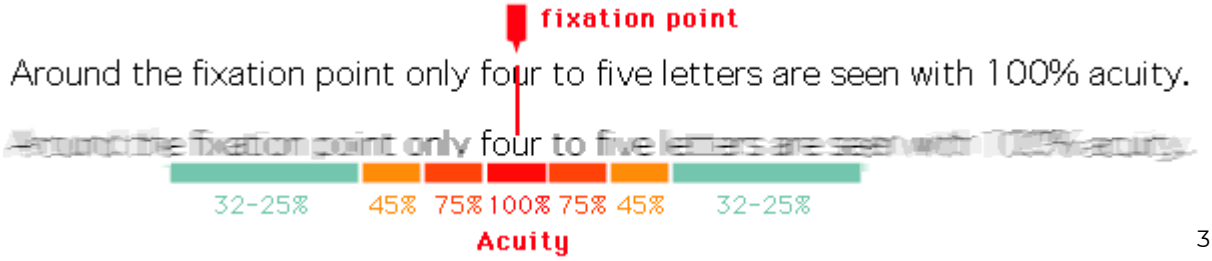
Field loss in right HH:[1]

What someone with left homonymous hemianopia would see[2]:

Course: In some cases, a new field loss can resolve on its own within a few months after the injury. In general, however, it is a permanent loss. It is not reversible with therapy. The person with field loss may learn to use special scanning techniques (e.g., when reading). Children who have HH from a young age may not be aware that their vision is different than other children.

Functional impact on reading: When we read, our eyes make rapid eye movements (saccades) between fixations. We are using our central vision to see the small amount of letters which are in focus during the fixation (see image below). The central area is only about 5% of our visual field. When reading a longer word, the child with HH would not see half of the word and would need to scan to see it, creating an extra step. The area outside central vision is called the parafoveal region. When we are reading, we use this surrounding region to preview what is coming up and see what was previously read. When reading left to right, our perceptual span (how many letters we can see) extends about 4 letters to the left and up to 15 letters to the right. This is like a "preview" of upcoming words and helps your eyes plan where to land the next time they move. Thus, with languages which are written from left to right, right HH has a stronger impact on reading than left HH as the person is not able to preview the upcoming words. HH particularly impacts reading beyond the single word stage, and can cause a decrease in reading speed. Left HH can also

impact reading by causing difficulty finding the next line of text and causing reading errors as the first letters of the word may be missed. HH can make reading slow, frustrating, and tiring.



3

Other functional impacts:

- The individual with HH may miss information on the affected side. They may bump into things, have difficulty with stairs, or miss self-care on one side of body. In physical education class or on the playground, the child may not see children running or a ball approaching. They would not see a car approaching from their blind side.
- Driving can be dangerous.
- Children may adapt to field loss by moving their eyes or head to maximize their vision.

Recommendations during assessment:

- During the assessment, place yourself on the child's "good side."
- Place your materials slightly off centre to take advantage of the child's intact visual field.
- Watch how the child scans pages to ensure they are looking at all options. Remind the child to scan the whole page, using your finger to point to each part if needed. Make sure you are giving consistent reminders and not ONLY when the child makes a mistake.
- Observe: Do they lose their place when reading? Miss the ends or beginnings of words?

Recommendations for school/home:

- It is important that the child is made aware of their condition for safety, particularly street safety. The individual must be taught to actively scan their blind side. It would also be appropriate to walk down the hallway with the wall to the affected side. Orientation and Mobility Instruction within the school and community is suggested.
- Teaching compensatory strategies for reading is important. For children with right HH, this would include teaching children to scan to the end of each word, and to the end

of each line. For children with left HH, this would include strategies such as using a ruler to keep place, and a line down the left side of the page to help orient to the start of the text. Some children would benefit from smaller text (so that more text is within their central vision), or text written diagonally. Students should have support from the Vision teacher at school to implement these strategies and supports.

- In the classroom, children should be seated with their intact visual fields facing the teacher and the classroom (blind side to the wall).
- Children should be approached from the side with intact vision.
- It can be helpful in the classroom to leave furniture in place throughout the year.
- Children must be allowed extra time to read.

Resources for further information

- The Brain Recovery Project of the Childhood Epilepsy Surgery Foundation.
    - Excellent visuals and descriptions of HH on their website. The same information is also presented in an easy to access pdf for Educators.
    - Videos which demonstrate what it is like to see with this condition.
    - A webinar by M. Jones from the Brain Recovery Project on Perkins Learning.
- Schett, S., Heywood, C.A., Kentridge, R.W., & Zihl, J. (2008). The significance of visual information processing in reading: Insights from hemianopic dyslexia. Neuropsychologia, 46(10):2445-62.
- http://www.hemianopsia.net/

Notes

1. The original uploader was Nunh-huh at English Wikipedia. - Transferred from en.wikipedia to Commons by Roberta F. using CommonsHelper., CC BY-SA 3.0, https://commons.wikimedia.org/w/index.php?curid=5866899
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16. Assessment in children who are Deaf or hard of hearing

Learning Objectives

- Be aware of the factors that are important to consider when conducting psycho-educational assessments in children who are Deaf or hard of hearing.
- Understand important factors in assessing children with mild or unilateral hearing loss.
- Know where to go for further education on this topic.

Cautionary note: It is important to highlight that competency in assessment with children who are Deaf or who are hard of hearing involves much more than making adaptations to tests or choosing the right test. Specialized training in hearing loss is important to understand the impact of hearing on development, provide the appropriate adaptations, interpret results, and make appropriate diagnoses and recommendations. When working in this population, it is also important to have an understanding of Deaf culture and American Sign language. Given that the development of spoken language and reading can be expected to be different in children who are Deaf, there are special considerations in making diagnoses of a Language Disorder or Dyslexia. This chapter is designed to be a very preliminary introduction to hearing impairments for psychologists who are doing assessments with children who have multiple disabilities which includes hearing loss. Extensive resources for further learning are provided for those clinicians who are interested in developing competency in this area. A review of nonverbal tests of intelligence can be found in a separate chapter. Children in British Columbia, the Yukon, and the Northwest Territories with bilateral moderate to profound hearing loss may be referred by their medical doctor for multi-disciplinary assessments through the Sunny Hill Deaf and Hard of Hearing program.

Hearing loss and the neuromotor population: Hearing loss is much more common in children with neuromotor and multiple, severe disabilities compared to the general population. Children with hearing loss may present with bilateral hearing loss or unilateral hearing loss. You may also see mild to profound loss. Some children with neuromotor conditions may use a few “personal” signs to communicate. For those children, using an ASL interpreter is not necessarily appropriate.

Mild and unilateral (one sided) hearing loss

When you are testing someone with mild or unilateral hearing loss, it is important to use a room without auditory distractions. Noises coming from outside the room will make it much more difficult for the child to hear.

When talking with the child, face them so that they can use visual cues as well as oral cues (look at your lips and facial expression). It is not necessary to sit to the side of a child with unilateral hearing loss. However, if you must sit to the side, sit on the side where they have better hearing.

Talk in a normal speaking voice, being alert to keeping up a normal volume. Be sure to pronounce words very clearly, especially the last sound in the word, which can sometimes get dropped. This is especially important on a task like list learning, where you read a list of words aloud. It would be normal for someone with mild hearing loss to mishear similar words (e.g., “eyes” for “ice”).

When looking at the group level, overall children with mild and unilateral hearing loss have more educational, social, and behavioural challenges than their peers.[1] However, this is complicated by the various etiologies of hearing loss, which can themselves impact functioning. This may including premature birth, meningitis or infection.[2]

Regardless of the etiology of the hearing loss, these children have to work harder than other children to listen. In the classroom, this can lead to fatigue or what looks like problems with attention or acting out.

Assessment with someone who is Speechreading (“lip reading”)[3]

- Speak at a normal rate and with normal articulation.
- Keep your hands very still while talking.
- If you want to show something while talking, silently show first, then explain, and possibly show a second time.
- Never speak while not facing the person.

Assessment with an American Sign Language (ASL) interpreter

- If you are new to working with an ASL interpreter in an assessment setting, you should seek out consultation.
- When working with an ASL interpreter, allow more time for the assessment.
- Meet with an interpreter for 10-15 minutes before starting the assessment so you can talk about the process of the assessment. It is helpful to mention that you want to know the child's level of language, therefore you want to know if they are using incorrect grammar, or if signs are signed incorrectly.
- Introduce the interpreter to the child and explain their role. Children may not be used to having interpreters.
- According to the professional code of sign language interpreters, they will interpret everything that occurs in the room (sounds, private conversations, phone calls).
- Generally, it is best to sit next to the sign language interpreter, opposite the child. Thus, the client can easily shift from looking at you to looking at the interpreter. Make sure there is no distracting background (e.g., venetian blinds) that could make it taxing to see the interpreter's hands.
- Address the client directly, and maintain eye contact with the client rather than with the interpreter.
- In general, wait to begin speaking until the interpreter is finished signing.
- Do not give visual instructions (pointing, demonstrating) at the same time as you are talking (or the interpreter is signing).
- Allow a brief silent time for reading if you hand out written material. Wait until the Deaf person looks up before you start to speak again.
- The process of reading or writing printed English for someone who communicates via ASL is called transliteration. The interpreter who is assisting with transliteration is having to pair the printed English word with their vocabulary of ASL signs. You may wish to ask the interpreter if it is best for you to read the text aloud or have them read it themselves (e.g., on a consent form).

Specific testing tips for the child who uses ASL

- It is important to understand that ASL is another language. Sentence structure is Object/Subject/Verb commonly (In spoken English, Subject/Verb/Object is most common). Further, verbs are tough to translate into a single ASL sign. The verb is usually communicated together with the sign for the subject or the sign for the

object. There are signs for most nouns, but specific signs are often fingerspelled (spelled letter by letter). Thus for spelling tests this is an important clarification – some spoken words may be difficult to translate into a single sign.

- With a test of word reading, try to get children to provide a single sign if one exists (the interpreter can tell you).
- For paragraph reading, it is likely best to choose a test which allows for silent reading (e.g., WIAT) rather than reading aloud (e.g., GORT).
- When giving a measure of adaptive functioning, have parents think about child's communication in ASL or spoken language. The child should get "credit" for accomplishing something using either sign or spoken language. However, as with spoken language, independence of behaviour is important. For example, if the child is prompted (reminded) to use the sign for "thank you", that is not independent behaviour.

Resources for Further Education

Explanation of different types of hearing loss:

- Includes examples of what various hearing losses sound like – Provincial Health Services Authority: http://www.phsa.ca/health-info/hearing-loss-early-language/hearing-loss

Relationship between hearing impairments and development:

- Knoors, H. & Marschark, M. (2014). *Teaching Deaf Learners: Psychological and Developmental Foundations.* Oxford University Press.
- Lederberg, A. R., Schick, B., & Spencer, P. E. (2013). Language and literacy development of Deaf and Hard-of-Hearing Children: Successes and Challenges. *Developmental Psychology. 49*(1):15-30

Psychology assessments in the Deaf & Hard of Hearing population

- Cromwell, J. (2005). Deafness and the art of psychometric testing. The Psychologist, 18,12, 738–740.
- Hill-Briggs, F., Dial, J.G., Morere, D.A., & Joyce (2007). A. Neuropsychological assessment of persons with physical disability, visual impairment or blindness, and hearing impairment or deafness, *Archives of Clinical Neuropsychology*, 22(3:1) 389–404.
- Miller, M.S., Thomas-Presswood, R.N. (2016). Psychological and Psychoeducational Assessment of Deaf and Hard of Hearing Children and Adolescents, Washington. DC: Gallaudet University Press.
- Reesman J.H., Day L.A., Szymanski C.A., Hughes-Wheatland R., Witkin G.A., Kalback S.R., Brice P.J. (2014). Review of intellectual assessment measures for children who are deaf or hard of hearing. Rehabilitation Psychology, 59 (1) 99-106.
- WISC-V Technical Report #2 "Testing Children Who Are Deaf of Hard of Hearing" (Day et al., 2015) and Technical Report #4 "WISC-V Special Group Study: Children with Hearing Differences Who Utilize Spoken Language and Have Assistive Technology" (Adams et al., 2016).

- Wood, N. & Dockrell, J. (2010). Psychological assessment procedures for assessing deaf or hard-of-hearing children. Educational and Child Psychology, 27, 11-22.

Nonverbal measures of intelligence

- Drevon, D.D., Knight, R.M. & Bradley-Johnson, S. (2017). Nonverbal and Language-Reduced Measures of Cognitive Ability: a Review and Evaluation. Contemporary School Psychology, 21: 255-266.
- See also the separate chapter on standardized assessment measures.

Notes

1. Tharpe A. M. (2008). Unilateral and mild bilateral hearing loss in children: past and current perspectives. Trends in amplification, 12(1), 7–15.
2. Tharpe, A. M., & Sladen, D. P. (2008). Causation of permanent unilateral and mild bilateral hearing loss in children. Trends in amplification, 12(1), 17–25.
3. Cromwell, J. (2005). Deafness and the art of psychometric testing. The Psychologist, 18,12, 738–740.

17. Autism in children with multiple, severe disabilities

Learning Objectives

- Understand special considerations in considering a diagnosis of autism in this population of children.

Autism (Contributing Author: Dr. Armansa Glodjo)

Autism has a higher prevalence in individuals with CP (about 7%) compared to the general population[1]. It is likely that both under and over diagnosis of autism is common in children with severe disabilities. Evaluating the question of autism in children with multiple, severe disabilities takes special consideration. Evaluation by someone with expertise in developmental expectations of children with severe disabilities is essential. Children in British Columbia with a question of an autism spectrum disorder can be referred for assessment to the British Columbia Autism Assessment Network.

Standardized tools used in autism assessments were not developed for children with sensory impairments, severe intellectual disabilities, or multiple disabilities. Thus, these tests must be used with caution. Questionnaires may include many items which are inappropriate for the child (e.g., asking about eye contact or use of gestures in a child with a visual impairment). Furthermore, the "youngest" module from the Autism Diagnostic Observation Schedule (ADOS) is designed for children with a "nonverbal mental age" of at least 12 months. For children with developmental skills under 12 months, ADOS results may be misleading. Clinical impressions are thus much more important in guiding diagnosis than test scores.

For children with severe disabilities, whose cognitive functioning is well below their age level, repetitive behaviours may be present and be consistent with the child's developmental level. Therefore, when considering a diagnosis of Autism, less emphasis should be placed on the presence of these behaviours. Rather, more emphasis should

be placed on social communication skills. When children have motor and/or sensory impairments, one way to do this is to look for evidence of capacity of a skill, but not using that skill for social communication, for example:

- Able to use a point to activate a button, but not pointing to draw a person's attention.
- Auditory attention to a musical toy, but not to one's own name being called.
- Visual attention to an object, but not to faces.
- Self-directed but not other-directed play.

Key Takeaways

- There are special considerations in considering a diagnosis of autism in children with low developmental level, sensory impairments, or motor impairments.
- Evidence of reduced social communication despite the physical capacity to engage in social communication is an important factor.

Resources for Further Learning

- Childhood vision impairment, hearing loss and co-occurring autism spectrum disorder
- Autism Spectrum Disorders (ASD) in Blind Children: Very High Prevalence, Potentially Better Outlook
- Szarkowski, A., Flynn, S., & Clark, T. (2014). Dually diagnosed: A retrospective study of the process of diagnosing autism spectrum disorders in children who are deaf and hard of hearing. In *Seminars in Speech and Language* 35(4), 301-308.
- Szymanski, C. A., Brice, P. J., Lam, K. H., & Hotto, S. A. (2012). Deaf children with autism spectrum disorders. *Journal of autism and developmental disorders*, *42*(10), 2027-2037.
- Mood, D., & Shield, A.M. (2014). Clinical use of the autism diagnostic observation schedule-second edition with children who are deaf. *Seminars in speech and language, 35 (4)*, 288-300.

Notes

1. Christensen, D., Van Naarden Braun, K., Doernberg, N. S., et. al. (2014). Prevalence of cerebral palsy,

co-occurring autism spectrum disorders, and motor functioning – Autism and Developmental Disabilities Monitoring Network, USA, 2008. Developmental Medicine and Child Neurology, 56(1), 59–65.

18. British Columbia Services Supports - Government, Hospital, Community and School

British Columbia & Canadian Federal government services/ supports

- Children and Youth with Special Needs (CYSN): Provides a number of services including funding for respite care, youth workers, and behavioural support. Requires a psychologist's DSM-5 diagnosis of Intellectual Disability or Global Developmental Delay.
- At Home Program: Provides all the benefits of CYSN + medical benefits (including equipment and supplies) and/or funding for school aged therapy (speech and language therapy, occupational therapy, physiotherapy). Physician referral required. To qualify, the child must be assessed by the program as dependent in at least three of the four activities of daily living (eating, dressing, toileting and washing).
- Community Living BC (CLBC): Provides residential, inclusion, respite, behavioural, and employment support to adults (19+) with intellectual disabilities. Requires a DSM-5 intellectual disability which was present before age 18. Or, for the Personal Supports Initiative, a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) or Autism Spectrum Disorder (ASD) + overall adaptive functioning 3 standard deviations below the mean. CLBC legislation currently REQUIRES IQ below 70 (+/- confidence interval) on "standardized intelligence tests." When you are not able to present a formal IQ score, provide a formal DSM-5 diagnosis of Intellectual Disability with explanation:
    - Say what you tried.
    - Say why it did or did not work.
    - Give whatever scores you have, even if they are based on raw scores of zero.
    - A developmental assessment is "better than nothing" in terms of CLBC eligibility, and if a formal developmental assessment is not possible, classroom observation and notes on developmental capabilities would be appropriate.
    - Provide relevant history of development and current everyday functioning skills.
- Services to Adults with Developmental Disabilities (STADD): Offers Navigator services for youth transitioning to adult services and their families in 116 communities across B.C. Navigators act as the primary point of contact for individuals in coordinating

transition planning and access to supports and services through the transition period of 16-24 years old.

- Choice in Supports for Independent Living (CSIL –pronounced SEE-sul): CSIL is a self-directed option for eligible adult home support clients. CSIL clients receive funds directly from their local health authority to purchase their own home support services. The BC Cerebral Palsy Association offers a series of workshops on CSIL.
- Home Adaptations For Independence (HAFI): Provides financial assistance for home modifications for eligible low-income British Columbians with mobility or health issues.
- Child Disability Tax Credit (CDTC): There are different ways to qualify for the Canadian federal Disability Tax Credit. Application can be completed by a Registered Psychologist for individuals with an Intellectual Disability. Other applications require a medical or other professional.
- Registered Disability Savings Plan (RDSP): A RDSP is a Canadian federal savings plan to help parents and others save for the long-term financial security of a person who is eligible for the disability tax credit. Contact any participating financial institution for more information once the Disability Tax Credit is approved.

BC Ministry of Education Provincial programs

- Inclusion Outreach (previously "PISP") provides child specific strategies to maximize learning for students who have multiple disabilities (physical, sensory, neurological) combined with severely impaired cognitive functioning. Most students are non-verbal. See the Curriculum and Strategies section of the Inclusion Outreach website for a wealth of educational resources.
- SET-BC (Special Education Technology-BC) lends assistive technologies to the school district (reading, writing & communication tools) to ensure students' access to educational programs. The program also assists school districts in training students & educators to use these technologies. Districts are allotted a certain number of SET-BC spots per year, and must request the service. When providing technology, SET-BC includes 1 year of intensive training to the team + 4 years of equipment only support. Their website has a wealth of information on special technology (e.g., how to use speech to text programs)..
- Provincial Outreach Program for Autism and Related Disorders (POPARD) provides consultation, training and support services to public and independent schools across the province of British Columbia with a primary focus on increasing the capacity of school district staff to support students with an autism spectrum disorder (ASD). POPARD can provide short-term intensive intervention to students with significant

behaviour difficulties which are beyond the current skill levels of District staff.
- Provincial Outreach Program – Deaf and Hard of Hearing (POPDHH) collaborates with school districts in meeting the needs of all Deaf and Hard of Hearing learners.
- Provincial Resource Centre for the Visually Impaired (PRCVI) provides schools with alternate formats of provincially recommended learning resources and with specialized equipment to support the educational needs of students with visual impairments. It also provides consultations to schools.

Health/Mental Health Services

- Developmental Disabilities Mental Health Services (DDMHS) provides individualized assessment, treatment and education for adolescents (12+) and adults with developmental disabilities and complex mental health needs. Referral may be needed through CYSN. The diagnosis of intellectual disability must be formalized.
- Sunny Hill Health Centre, provides inpatient acute rehabilitation and respite care as well as outpatient services including Assistive Technology, Developmental Coordination Disorder diagnostic clinic, Feeding & Nutrition, Hearing Loss, Positioning & Mobility, Therapeutic Recreation, Tone Management, Visual Impairment, Neuromotor, Autism, Complex Developmental Behavioural Conditions (CDBC), and Gait Assessment.
- ACCESS Clinic at BC Women's Hospital & Health Centre offers cervical cancer screening (Pap tests) to adolescents and women with disabilities, or who have had difficulties with routine screening at their health care provider's clinic. They aim to help any woman who has experienced barriers to cervical cancer screening, menstrual management, or who requires specialized contraception counselling. Referral is not required.
- The BC Children's Hospital Orthopaedic Cerebral Palsy Clinic cares for children with cerebral palsy and similar neuromotor conditions. Referral is required.

Community Services/supports

- The Developmental Disabilities Association provides community-based programs and services for children, youth, and adults with intellectual disabilities.
- Family Support BC provides support to individuals with disabilities and their families. They provide family support, have a database of support workers, provide webinars on estate planning, and more.

Community funding sources for children to participate in sports activities

- KidSport: http://www.kidsportcanada.ca/ provides funding for sports programs for low income families.
- Athletics for kids: https://www.a4k.ca/ funding for sports programs for low income families.
- Jump Start: http://jumpstart.canadiantire.ca/content/microsites/jumpstart/en/apply.html funding for sports programs for low income families.

Community funding sources for equipment, therapies, education, and entertainment

- Access2 Card: https://access2card.ca/ is a program that provides free access to entertainment and recreational opportunities for a support person of a person with a physical disability.
- BC Cerebral Palsy Association: http://bccerebralpalsy.com financial support to individuals and families of children with CP through Summer Camperships, Tanabe Bursaries for post-secondary students, and Assistive Devices and Equipment Subsidies.
- BC Epilepsy Society: http://www.bcepilepsy.com/ has scholarships available for post-secondary students who have a diagnosis of epilepsy.
- BC Rehab: http://www.bcrehab.com/content/individual-grant-programs funding for equipment and therapy based on financial need.
- CKNW Kid's Fund: https://www.cknwkidsfund.com/ for equipment, therapy, or special education bursary.
- Jennifer and Gregory Louie Foundation for Cerebral Palsy http://www.jglfoundation.com grants for children with cerebral palsy who live in BC.
- Jordan's Principal: www.canada.ca/jordans-principle support with access to education, healthcare, therapy and equipment for First Nation's children.
- Maple Ridge Lions Club: http://www.mapleridgelionsclub.org/Support.html for equipment or funding for services for children in Maple Ridge.
- March of Dimes of Canada: https://www.marchofdimes.ca funding for equipment or devices for adults with physical disabilities and financial need.
- Military Police Fund for Blind child: http://www.mpfbc.com funding for children and young adults to age 21 with visual impairments.

- President's Choice Charity http://www.presidentschoice.ca/.
- Rick Hansen Foundation: https://www.rickhansen.com/ funding for organizations to improve accessibility to a building or site for people with disabilities.
- Shriners: https://www.bcshriners.com/ for "medically necessary equipment"
- Spina Bifida and Hydrocephalus Association of British Columbia http://www.sbhabc.org/ Funding for recreational programs, education, equipment, drivers assessments, and transportation for medical appointments.
- Vancouver Island Bear Essentials: https://islandkidsfirst.com/bear-essentials/ funding for travel costs for health care, equipment, and therapeutic resources for children who live on Vancouver Island or the Gulf Islands.
- Variety: http://www.variety.bc.ca/ grants for therapy, equipment, orthotics and learning disability tutoring for low income families.
- Western Society for Children: http://wsfc.ca/ direct support to families and children with disabilities including financial support for therapies.

19. Conclusion

I hope this book has helped the reader appreciate not just the complexity, but also the simple beauty of seeing the unique development of each child who happens to have multiple, severe disabilities. Working with this group of children and their families can be extremely rewarding both professionally and personally.

I plan for this book to be a living document, as I find that I am constantly learning and adapting as I gain new knowledge and experience from the children and families I see in my practice. I welcome your comments and suggestions. Please feel free to contact me at jengle@cw.bc.ca. Please also visit https://pressbooks.bccampus.ca/jengle/ where you can read and download the newest version of this book.

Resources for continuing education

Guidance on searching for more information

- "Multiple and severe" or "profound and complex" disabilities are the terminology which are likely to be most helpful when searching for more information.
- A lot of good work for children with multiple and severe disabilities has come out of the field of professions who work with children who are Deafblind.
- Much of the "assessment" work in this population is classroom assessment or curricular-based assessment. This type of work provides excellent models for "creative" or non-standardized psychology assessments.

Highly recommended resources for further education

- Set BC hosts online webinars (open to all), school district training, and has an extensive list of self-directed trainings online for free: http://www.setbc.org/
- POPARD has an extensive video training library: https://www.autismoutreach.ca/
- Curriculum and Strategies section of the Inclusion Outreach website has a range of helpful resources and videos: http://www.inclusionoutreach.ca
    - For example, how to teach the sign "more": http://www.inclusionoutreach.ca/content/cs/Communication/Developing%20aRequest%20for%20More.pdf
- The United Kingdom Department of Education has a series of 16 online modules, available for free, entitled: Training materials for teachers of learners with severe, profound and complex learning difficulties. http://complexneeds.org.uk/

Assessment in individuals with multiple, severe disabilities

- Guidelines for Assessment of and Intervention With Persons With Disabilities: http://www.apa.org/pi/disability/resources/assessment-disabilities.aspx
- Horn, E. M., & Kang, J. (2012). Supporting Young Children With Multiple Disabilities: What Do We Know and What Do We Still Need To Learn? Topics in Early Childhood

Special Education, 31(4), 241–248. http://doi.org/10.1177/02711214111426487
- Assessing Communication and Learning in Young Children Who are Deafblind or Who Have Multiple Disabilities, Edited by Charity Rowland, Ph.D. and published in 2009 by Design to Learn Projects of Oregon Health & Science University. Available free here: https://www.designtolearn.com/uploaded/pdf/DeafBlindAssessmentGuide.pdf

Parent perspective

- Stronger Every Day Podcast – http://www.portlandrootsmedia.com/strongerpodcast: Episode 8: Going through an autism evaluation, and Episode 197: what it feels like to hear difficult things about your child, even if you know those things already. What is helpful to hear from a professional.
- Also, this article provides a parent's frustration with the clinician's focus on what their child cannot do: "I Have a Question for the Person Evaluating My Child With Special Needs" by the person behind the Stronger Every Day podcast: https://themighty.com/2015/02/evaluating-a-special-needs-child-cant-be-multiple-choice/