Best Practices in Coordinated Care for Individuals Living with Intellectual Developmental Disorder (IDD) & Co-Occurring Psychiatric Disorders

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Presenter Biographies

John Siegler, Psy.D.

Dr. Siegler provides consultation to the care management team, reviews of community-based service requests, and supports children's service providers striving to provide effective and accountable treatment services to the individuals and families they serve. Dr. Siegler has extensive experience providing consultation services in educational, psychiatric, and forensic settings. He has provided staff training to behavioral health providers on a variety of topics related to clinical excellence and clinical accountability. Prior to joining Magellan, Dr. Siegler has held clinical leadership positions in psychiatric inpatient, psychiatric residential treatment, extended acute care, intensive behavioral health services, and outpatient settings.

Danielle Dolena, LCSW

Danielle Dolena is a Licensed Clinical Social Worker with over 15 years of experience working with individuals and their families living with ID/A in a variety of treatment settings. In her role as Senior Care Manager, Danielle advises the care management team, service providers, and families in their ongoing efforts to provide high quality treatment for individuals living with ID/A.

Presenters' Disclosure

John Siegler, Psy.D. and Danielle Dolena, LCSW have no relevant financial relationship commercial interest that could be reasonably construed as a conflict of interest.

Training Goal

The goal of this presentation is to provide increased understanding of best practices in coordinating care for individuals living with ID/A.

Learning Objectives

At the end of this workshop, the learner will be able to:

- Recognize prevalence of IDD and the psychiatric disorders that co-occur with IDD
- Review diverse causes of IDD
- Identify DSM-5-TR Diagnostic Criteria for Intellectual Developmental Disorder (IDD)
- Review Best Practices for Assessment to determine if a Member is living with IDD
- Review Best Practices for Treatment when IDD Co-occurs with Psychiatric Disorders
- Recognize IDD Resources and Cross System Collaboration

Prevalence of IDD

Prevalence of IDD per 1000 Children

REFERENCE	YEAR	LOCATION	AGE RANGE	MILD	SEVERE ID	ALL	COMMENTS
Bhasin et al., 2006	1996	Atlanta, GA	8 years	10.0	4.3	**15.5**	Prevalence higher in black children (22.7/1,000) than white children (9.8/1,000) and higher in boys (19.1) than girls (11.8).
Bhasin et al., 2006	2000	Atlanta, GA	8 years	7.3	3.3	**12.0**	Prevalence higher in black children (16.9/1,000) than white children (7.0/1,000) and higher in boys (14.0) than girls (9.9).
Van Naarden Braun et al., 2015	2010	Atlanta, GA	8 years	9.4	3.8	**13.6**	Prevalence of ID w/o co-occurring ASD declined from 13.0 in 1996 to 8.6 in 2010. Prevalence of ID w/ co-occurring ASD increased from 2.4 in 1996 to 5.0 in 2010.

NOTES: ASD = autism spectrum disorder; N/A = not applicable; SES = socioeconomic status. The sum of mild and severe ID prevalence may be less than the overall ID prevalence due to some cases of undetermined severity.

Maulik, P.K., Mascarenhas, M.N., Mathers, C.D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. Research in developmental disabilities, 32 2, 419-36 .

Prevalence of IDD by Severity

Severity Category	Approximate % of Cases by Severity	DSM-IV Criteria (severity based on IQ categories)	DSM-5 Criteria (severity specifier based on adaptive functioning)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.
Profound	1.5%	IQ <20	Requires 24-hour care.

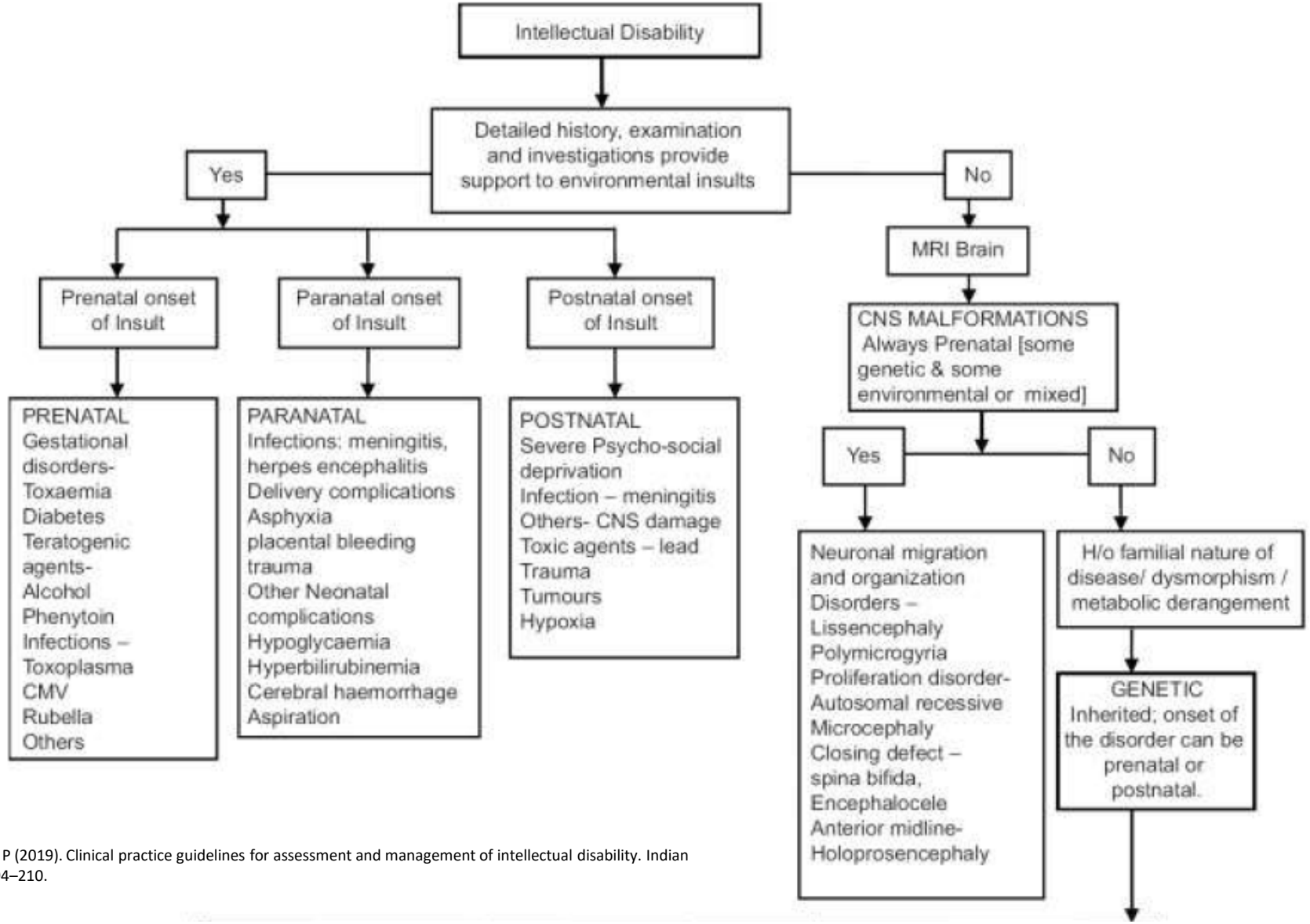
American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). Washington DC: American Psychiatric Publishing.

Etiology

A Heterogeneous Condition

- Complex interactions of
  - genetic predisposition
  - environmental insults (stressors)
  - developmental vulnerability.
- Genetic Risk Factors
  - Single-gene disorders or syndromes
  - Chromosomal or copy number variant disorders
  - Genetic variants in many genes
- Environmental risk factors
  - Prenatal
  - Perinatal
  - Postnatal

Process for Determining Causes of IDD



Kishore, MT, Udipi, GA, & Seshadri, S P (2019). Clinical practice guidelines for assessment and management of intellectual disability. Indian Journal Of Psychiatry, 61(Suppl 2), 194–210.

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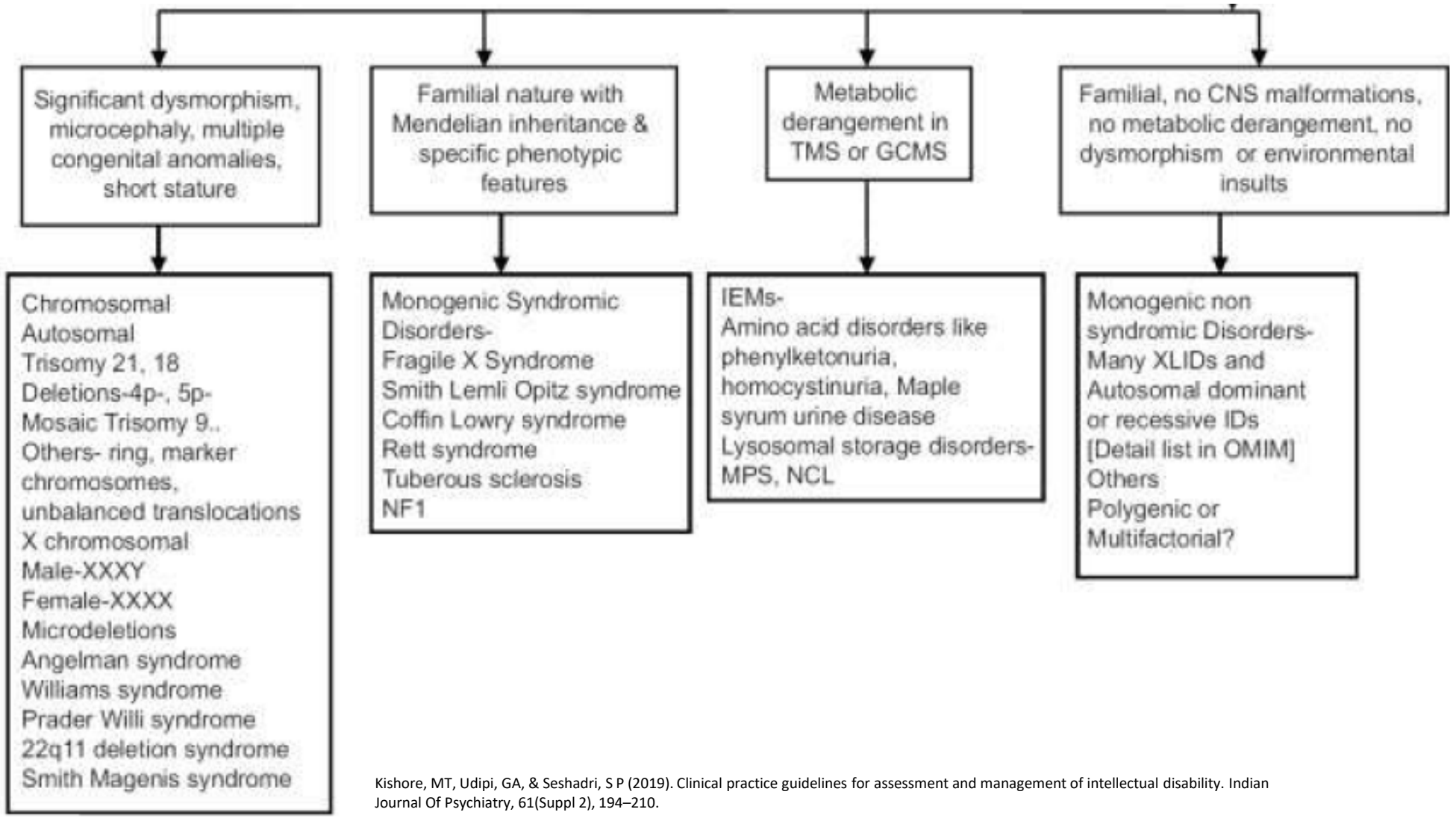
Genetic Conditions Associated with IDD



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Assessment and Diagnosis of IDD

Screening Tools for Developmental Delay

Tool	Age Range	Description	Psychometrics
Ages and Stages Questionnaire (ASQ-III)	1-66 mo.	30-Item age-specific parent report measure; Examines communication, gross motor, fine motor, problem solving, personal social, self-regulation, compliance, language, adaptive behaviors, autonomy, affect, and interaction with people	Sensitivity 0.83-0.89 Specificity 0.80-0.92 across ages
Parents' Evaluation of Developmental Status (PEDS)	1-95 mo.	10-Item parent report measure. Examines global/cognitive, expressive language, receptive language, fine motor, gross motor, self help, and social emotional	Sensitivity 0.74-0.79 Specificity 0.70-0.80 across ages
Bayley Infant Neurodevelopmental Screener (BINS)	3-24 mo.	10- to 15-min screening measure for neurological impairment or developmental delay	Interrater reliability 0.79-0.96
Denver Prescreening Developmental Questionnaire (Denver PDQ-II)	2 wk.-6 yrs.	Parent report measure. Positive results indicate need for follow-up testing with Denver-II by a professional. Examines personal and social, fine motor, gross motor, and language	Sensitivity 83% Specificity 43%
Infant/Toddler Checklist (ITC)	6-24 mo.	Population-based screener designed to identify risk for language and communication impairment	Sensitivity 0.87-0.94; Specificity 0.75-0.89

Diagnostic Criteria for Intellectual Developmental Disorder (IDD)

1. Deficits in Intellectual Functioning, confirmed by both Clinical Assessment and Standardized Intelligence Testing.
2. Deficits in Adaptive Functioning, confirmed by diagnostic interview and/or norm referenced rating scales.
3. Onset during the “developmental period.”

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Deficits in Intellectual Abilities

- Assessed with norm referenced IQ test
  - Score is reported as a “Standard Score” derived from the distribution of raw scores in a large community sample of individuals in the same age range
  - A Standard Score Distribution has a Mean of 100 and standard deviation of 15
  - A Score of 2 standard deviations below the mean (SS=70) is considered the threshold for IDD
- Wechsler Scales (WPPSI, WISC, and WAIS) influenced by speech-language abilities
- Tricky bits
  - Assess for potential barriers (psychiatric Sxs, impulsivity, speech/language, visual/hearing impairment)
  - Often, performance across tasks on the IQ test is quite variable - review the full score report
  - Check if examiner noted any concerns about scores underestimating true abilities
  - Individuals with significant receptive/expressive language deficits should be assessed with a non-verbal IQ test.

Common Intellectual Ability Assessments

Instrument	Age Range	Description
Bayley Scales of Infant and Toddler Development 4th Ed. (Bayley-4)	16 days-42 mos.	Domains: Cognitive, Language, Motor Skills, Social & Emotional Learning, and Adaptive Functioning
Stanford-Binet Intelligence-Scale 5th Ed. (SB5)	2-85 yrs.	Includes FSIQ score; Domains: Fluid Reasoning; Knowledge; Quantitative; Visual-Spatial; & Working Memory
Wechsler Preschool & Primary-Scale of Intelligence-3rd Ed.-(WPPSI-III)	2 yrs. 6 mos.-7 yrs. 3 mos.	Includes FSIQ score; 4 Domains: Verbal, Performance, Working Memory, and Processing Speed
Wechsler Intelligence Scale for-Children 5th Edition (WISC-V)	6 yrs.-16 yrs. 11mos.	Includes FSIQ score (from 7 subtests); 5 Domains: Verbal Comprehension, Visual Spatial, Fluid Reasoning, Working Memory, and Processing Speed
Wechsler Adult Intelligence Test 4th Ed. (WAIS-IV)	16 yrs.-90yrs.11 mos.	Includes FSIQ score (from 7 subtests); 4 Domains: Verbal Comprehension, Perceptual Reasoning, Working Memory, and Processing Speed
Leiter International Performance Scale -3rd Ed. (Leiter 3)	3-75 yrs.	Includes NVIQ. 2 Domains: Cognitive & Attention/Memory
Mullen Scales of Early Learning	Birth-68 mo.	Includes Early Learning Composite 5 scales: Gross Motor, Visual Reception, Fine Motor, Expression Language, Receptive Language
Comprehensive Test of Nonverbal Intelligence 2nd Ed. (CTONI 2)	6-89 yrs.	Includes NVIQ 2 Domains: Pictorial (familiar objects) & Geometric (unfamiliar shapes) ; can be administered in pantomime

Functional Impairment

3 Domains of functioning are assessed

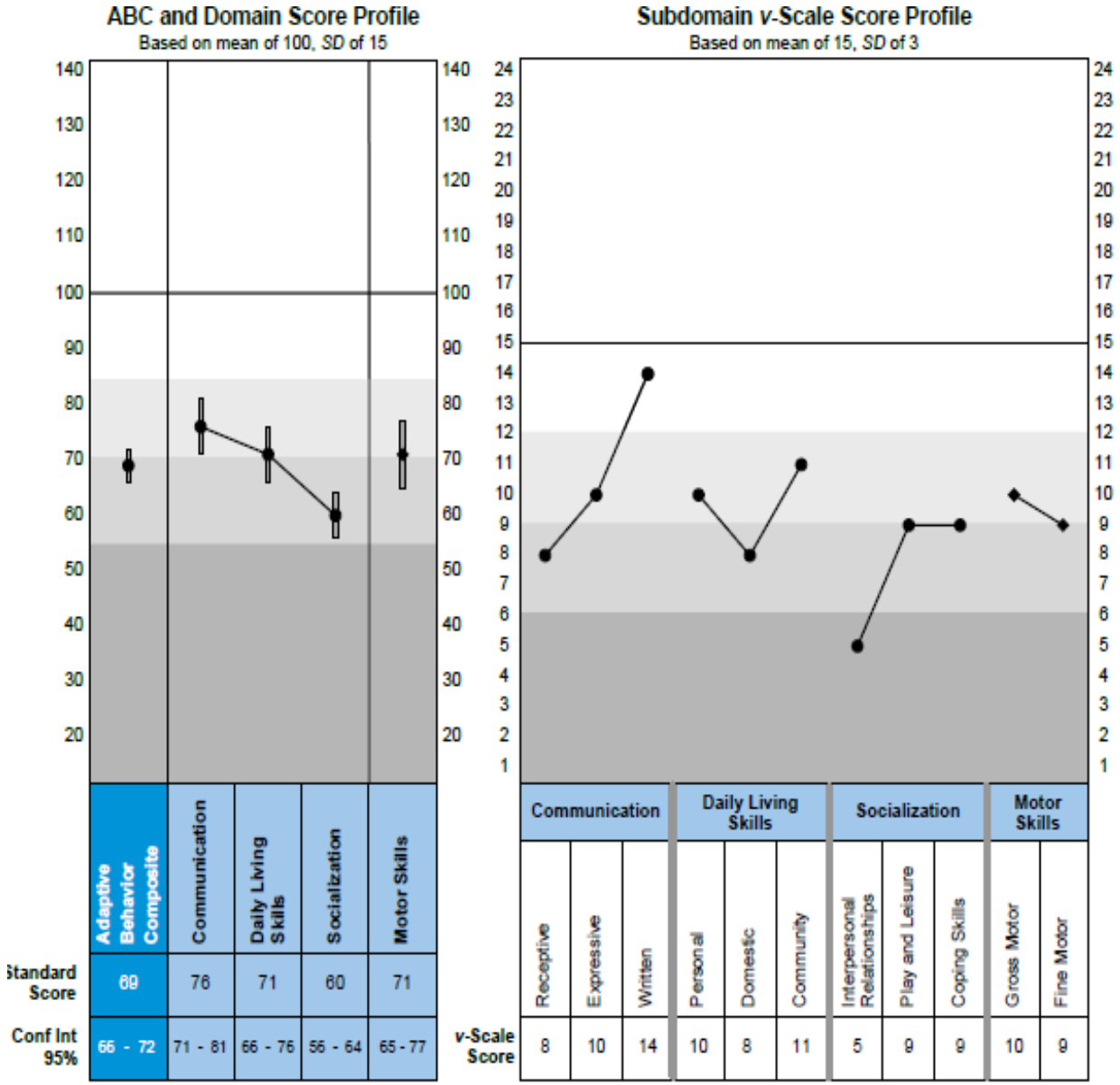
- Conceptual
- Social
- Practical

- Requires at least one domain to be “sufficiently impaired” to a degree that “ongoing support is needed for the person to perform adequately across multiple environments” (home, school, work, community)
- Assessed via observation and caregiver interview or rating scale (Vineland / ABAS)
  - Score is reported as a “Standard Score”
  - A score of 2 standard deviations below the mean score is considered the threshold for IDD
  - Often, performance across tasks, and within domains, is quite variable
  - Multiple reporters should be sought (caregiver, teachers)

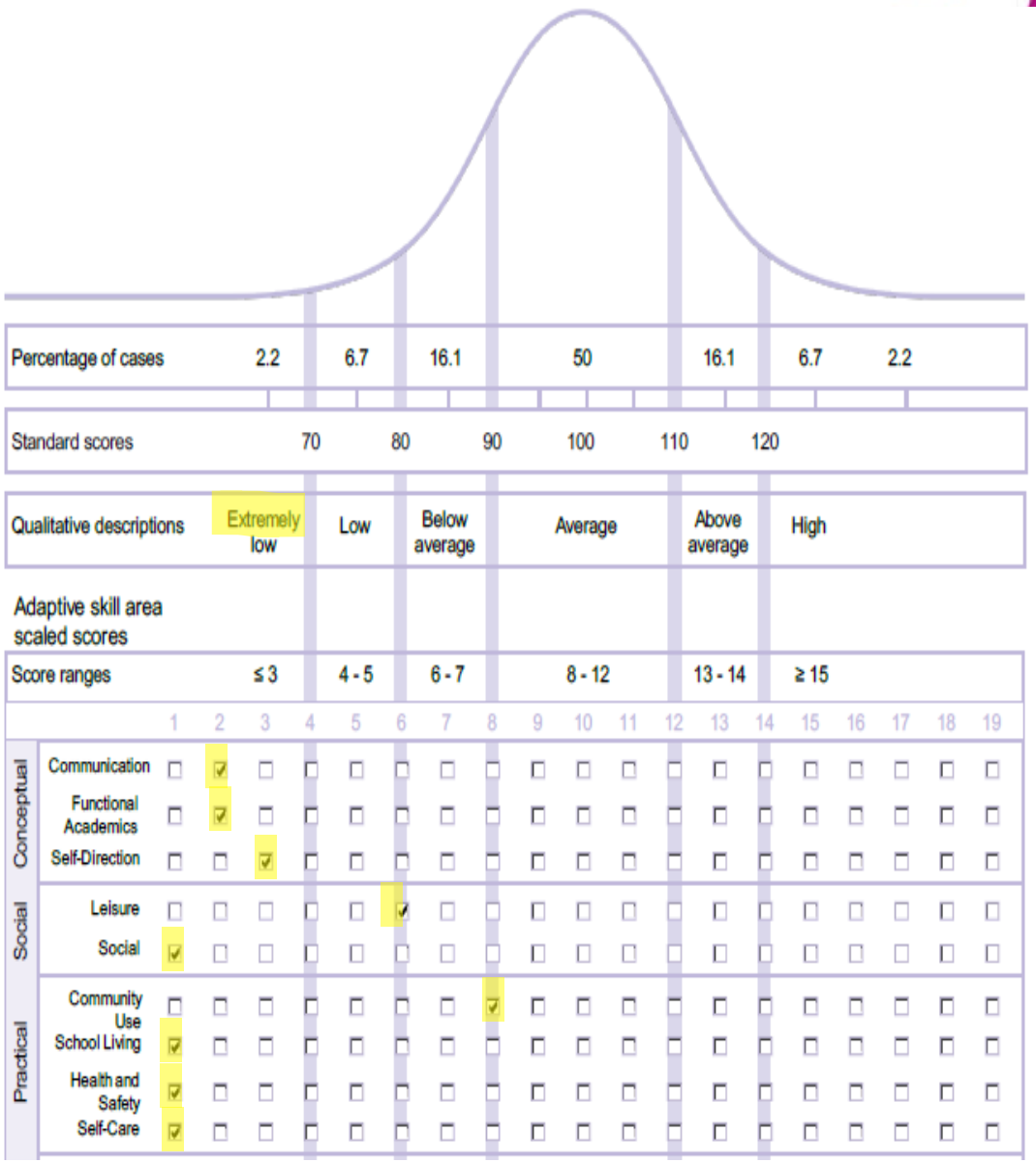
Common Adaptive Functioning Assessments

Instrument	Age Range	Description
Vineland Adaptive Behavior Scales 3rd Ed. (Vineland-3)	Birth-90 yrs.	Survey Interview & Expanded Interview Form or Parent/Caregiver & Teacher Rating Form. Assesses communication, daily living skills, socialization, motor skills, and maladaptive behaviors.
Scales of Independent Behavior-Revised	Infancy-80 yrs.	Interview or checklist. Assesses 14 areas of adaptive behavior and 8 areas of problem behavior.
Adaptive Behavior Assessment Scale 3rd Ed. (ABAS-3)	Birth-89 yrs.	Parent/Primary Caregiver form or Teacher/Daycare provider form. Assesses three domains of adaptive behavior: conceptual, social, and practical.

Vineland



ABAS



Onset during the “developmental period”

- Onset in the first two decades of life
- Identification of children with more severe ID typically occurs early in life
- Individuals with mild intellectual disability may not be recognized until early school age
- Psych Testing is often requested for “low functioning” adults
  - Need to consider how psychiatric and medical factors may interfere with performance
  - Need to interview natural supports to establish age of onset before a diagnosis of IDD can be given
  - Cannot assess Functional Impairment in an AIP setting; may be possible in an EAC or Community Based Setting.
- Age and characteristic features at onset depend on the etiology and severity of brain dysfunction

Assessment of Co-Occurring Psychiatric Disorders

- Accurate diagnosis is important because it provides a sound basis for effective treatment.
- Comprehensive Evaluation is indicated for individuals with IDD who come to clinical attention for psychiatric or behavioral symptoms.
- Assess individual's current behavior, developmental age (as opposed to chronologic age), and comparison to baseline behavior.
- Avoid pathologizing developmentally appropriate behavior. Psychiatric diagnoses consist only of symptoms that are in excess of, or are atypical for, the individual's developmental level and are causing impairment.
- Diagnostic overshadowing - when IDD symptoms are attributed to another psychiatric disorder.
- IDD often co-occurs with other neurodiverse conditions – management vs. treatment.

Structured Tools

- Measures developed with a typically developing sample may not be valid for youth with ID/IDD.
- Psychiatric assessment of neurotypical relies primarily on self-report of symptoms, feelings, and experiences.
- Neurotypical psychiatric assessment methods have limited utility for individuals with limited expressive and receptive language skills.
- Measures validated for IDD individuals can support diagnostic decisions, characterize the nature and breadth of specific symptoms, and serve as a baseline for tracking symptoms over time.
- Self-report questionnaires are frequently unreliable.
- Measures with parent and teacher versions can be more useful.

Functional Behavior Analysis

Major Emphasis on:

- Behavior as a form of communication
- Circumstances where behavioral problems occur
- Identification of how the environment rewards the problem behavior
- Identification and amelioration/accommodation of skill deficits

Treatment

Psychosocial Treatments

Cognitive Behavioral Therapy (CBT)

- Limited empirical support for effectiveness CBT of modalities in individuals with ID/IDD
- Despite the minimal evidence, some individuals with Mild IDD may benefit from CBT, with accommodations for developmental age and communication ability

Applied Behavioral Analysis

- Increasing adaptive, communication, and social skills
- Antecedent interventions
- Reinforcement strategies
- Functional communication training
- Extinction procedures
- Behavioral Parent Training

Medication Management

- NO FDA medications for use with individuals with IDD
- Medication can be helpful in managing behavior problems (attention problems/agitation)

Assessing the Need for ID/A Resources: Referrals and Linkage

Assessing the Need

- Does the individual have a diagnosis of an intellectual disability, developmental disability, and/or autism or is it suspected that they may have one of these diagnoses?

- Is the individual connected with the county office of intellectual/developmental disabilities?
  - Provide access to information, services, and supports in the community.
  - Assistance with preparing for life's transitions through childhood into adulthood.
  - May provide a range of non-medical in home and community services.

DHS Joint Bulletin – Referring Children to the County Intellectual Disability and Autism Programs, July 12, 2022:

For Referring Children to the County Intellectual Disability and Autism Programs Bulletin, please use the following links:

- **Bulletin 00-22-04** - Referring Children to the County Intellectual Disability and Autism Programs **– (Bulletin OMHSAS-22-04)**
- **Attachment 1** - Diagnostic and Eligibility Information for Services Through the County Intellectual Disability and Autism (ID/A) Program
- **Attachment 2** - Department of Human Services: Office Overview and Resources
- **Attachment 3** - Understanding the Importance of Registering with the County Intellectual Disability/Autism (ID/A) Program

Office of Intellectual/Developmental Disabilities

Determining Eligibility:

Intellectual Disabilities

- ✓Psychological evaluation documenting FSIQ of 70 or below
- ✓Evidence of onset prior to the age of 22
- ✓Evidence of three or more adaptive skills deficits

Autism Spectrum

- ✓Diagnosis of ASD, based on a standardized diagnostic tool
- ✓Evidence of diagnosis prior to the age of 22
- ✓Evidence of three or more adaptive skills deficits

❖ If the individual does not have documentation needed to assess eligibility, the county ID/A program will provide a list of resources to assist the individual/family in obtaining these documents.

Office of Intellectual/Developmental Disabilities

Montgomery County – 610-278-5666

https://www.montcopa.org/1217/Developmental-Disabilities

Bucks County – 215-444-2847

Behavioral Health/Developmental Programs | Bucks County, PA

Lehigh County – 610-782-3126

https://www.lehighcounty.org/Departments/Human-Services/Intellectual-Disabilities

Northampton County - 610-559-3270

https://www.northamptoncounty.org/HS/DP/Pages/default.aspx

Cambria County – 814-535-8531

https://www.cambriacountypa.gov/behavioral-health.aspx

Cross-System Collaboration is KEY!

Cross –System Collaboration:
A look at the “whole” person to assess supports

- ✓ Have any potential underlying medical issues been ruled out or appropriately referred out?
- ✓ Is the current diagnosis accurate? Has there been a recent evaluation?
- ✓ Is their medication management plan appropriate, based on recent assessment by a psychiatrist?
- ✓ Is a higher or lower level of care needed based on progress or lack of?
- ✓ Is the individual/family/current supports able to actively engage in the treatment and discharge planning process?
- ✓ Are any additional referrals being made to support siblings/other family members if there are concerns?
- ✓ Are basic needs being met and/or have Social Determinants of Health been considered (food insecurity, housing instability, utility needs, financial resource strain, transportation, exposure to violence, socio-demographic violence)?
- ✓ Is there coordination of care between all providers/supports involved (i.e., an ISPT meeting)?

State-Wide Resources

- **Pennsylvania Office of Developmental Programs**
  - https://www.myodp.org/
- **PA ASERT**
  - https://paautism.org/
- **State-wide Health Care Quality Units**
  - https://www.dhs.pa.gov/providers/Providers/Pages/Health-Care-Quality-Units.aspx
- **Office of Vocational Rehabilitation**
  - http://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx
- **Special Needs Unit**
  - https://www.dhs.pa.gov/HealthChoices/HC-Services/Documents/Flyer%20-%20MCO%20Special%20Needs%20Units.pdf

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