Child-neurology is more than cerebral palsy: an overview beyond epilepsy

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Disclosure Statement

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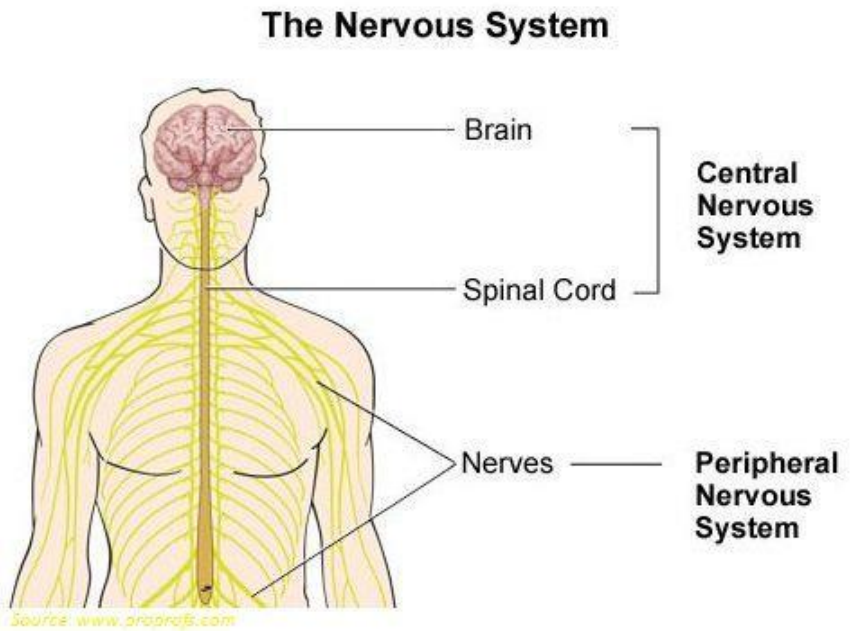
The Nervous System



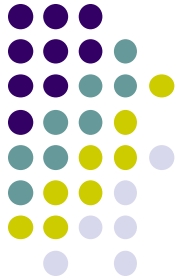
- Includes diseases of the **central** and **peripheral** nervous system.
- Damage may arise from:
  - ✓ Trauma
  - ✓ Infections
  - ✓ Degeneration
  - ✓ Structural defects
  - ✓ Tumors
  - ✓ Blood flow disruption
  - ✓ Autoimmune disorders
  - ✓ Inborn genetic or metabolic problems
  - ✓ Toxic/drug exposures
  - ✓ Lifestyle or environmental health problems

Neurological disorders are characterized by dysfunction in any part of the nervous system

One in three people globally will develop a neurological disorder at some point in their lifetime, many of which are preventable and treatable.

Lancet Neurol, 2022

Definitions & Background (1):



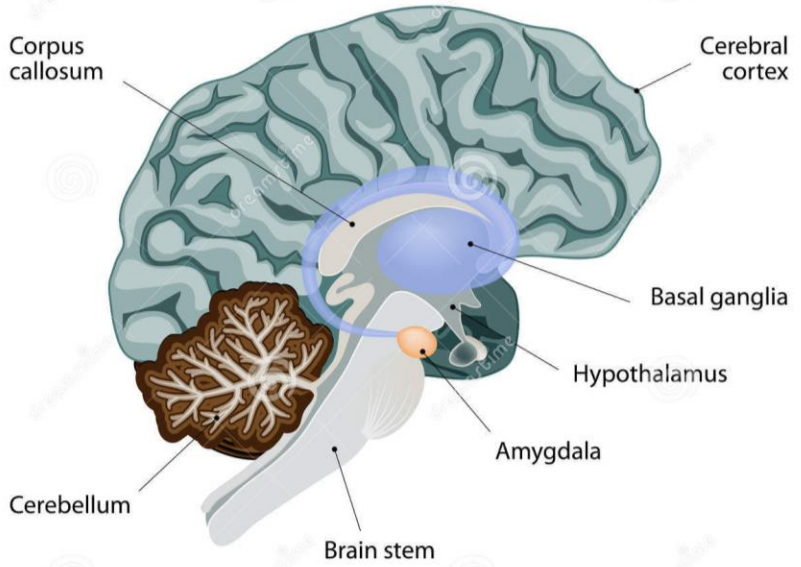
- Neuro-developmental disorders (NDDs) are identified as one of the greatest threats to global public health (*WHO,2006*).

- What are NDDs ?

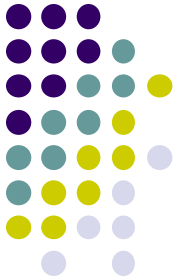
  $\rightarrow$Diverse group of chronic conditions, often severe, that originate during neurological development and typically persist throughout life of an affected individual.

Neuro Developmental Disorders:

- Due to mental and/or physical impairments.
- Affect brain, special senses & neuromuscular systems.
- Begin at any point in development up to 22 years of age.
- Impairments often last throughout a child's lifetime.



Definitions & Background (2):



- What is their etiology?

  →Limited data ??? multi-factorial causes including genetic diseases, neurotoxins, hypoxia, infections, and injuries, environmental (pre-natal, natal, post natal) & miscellaneous contributors.

- NDDs etiology may be:

  → **Congenital**.

  → **Acquired**-thru accidents, trauma or infections during early life.

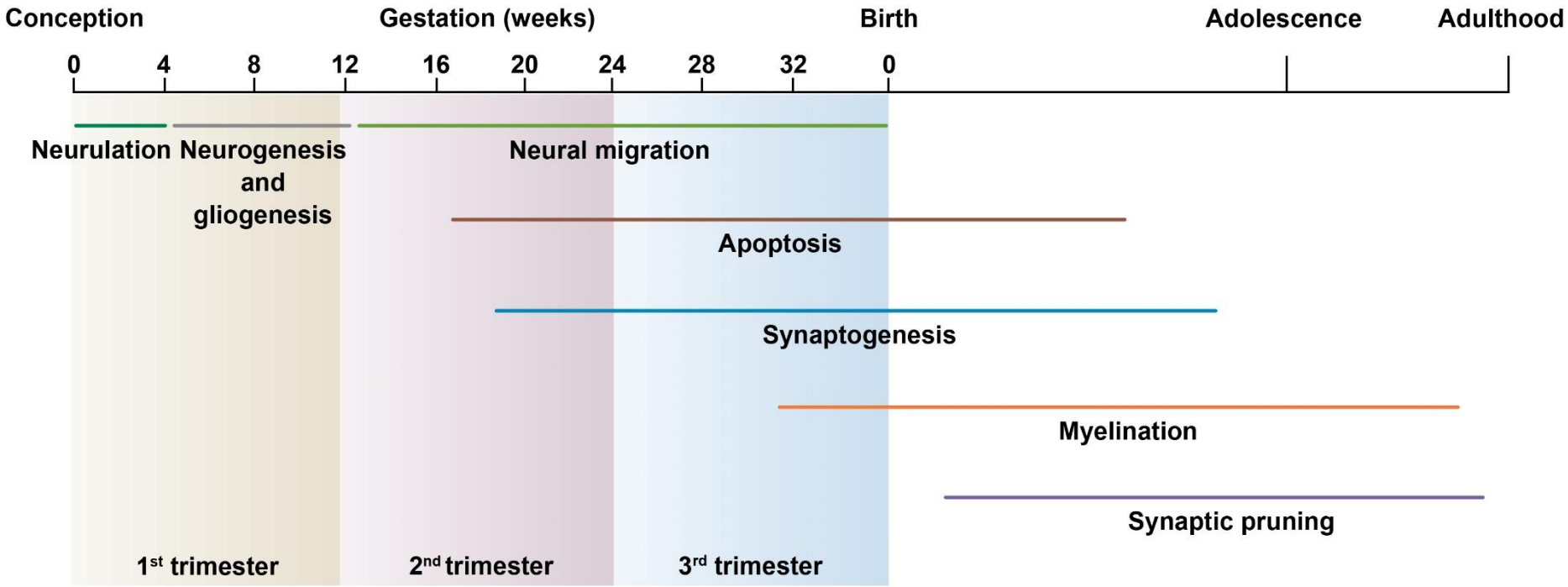
Major risk factors

In resource-poor countries, lack of obstetric care, adverse perinatal conditions, poverty, infection, ignorance, insufficient immunization, malnutrition, and poor living conditions considered main risk factors.

Obi JO et al, 1984; De Myer W, 2003; Burton KJ et al, 2003;Newton CR, 2018

The timeline of human brain development

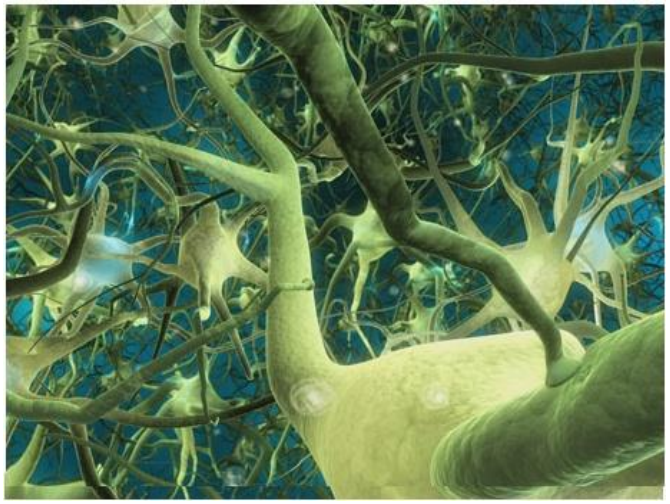
"sensitive windows"



The developing brain is particular sensitive to early life environmental factors

Microbial pathogen infections

Increase risk for neurodevelopmental disorders

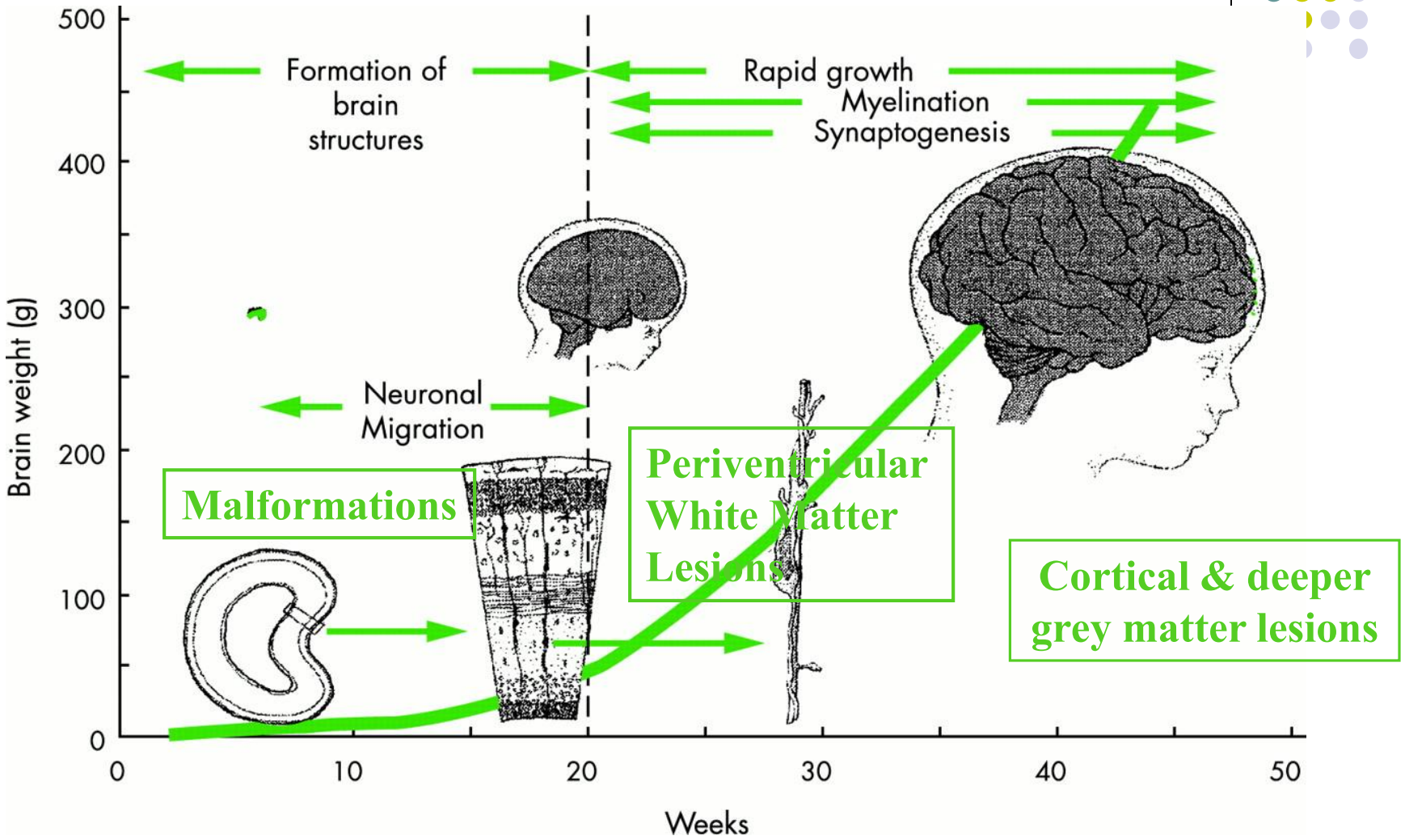


Perinatal brain development

e.g., autism, cerebral palsy , schizophrenia

Bilbo et al. Behav Neurosci (2005); Goehler et al. Brain Behav Immun (2008); Sullivan et al. Dev Psychobiol (2006)

Brain development during gestation and early postnatal life.



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Jean-Pierre Lin J Neurol Neurosurg Psychiatry 2003;74:i23-i29

JNNP

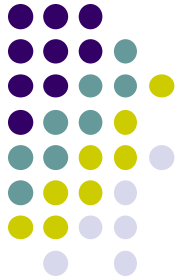
Definitions & Background (3):

- Common NDDs that lead to severe impairment with resultant personal and public cost include:

1. Autistic Spectrum Disorders (ASD).
2. Intellectual Impairment (ID).
3. Cerebral Palsy (CP).
4. Attention Deficit Hyperactivity Disorder (ADHD).
5. Epilepsy
6. Speech & Language disorders.
7. Hearing impairment.
8. Visual impairment.

1. The case of Autism Spectrum Disorders

What are Autism spectrum disorders?

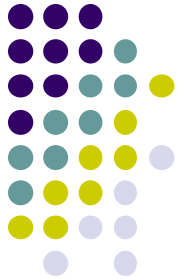


- Represents a heterogeneous group of NDDs characterized by a clinical dyad of
  - impaired social communication function
  - presence of a restricted, repetitive pattern of behaviour or interests

- Studies in Asia, Europe, and North America have identified individuals with ASD with an average prevalence of 1%-2%.

DSM-5, American Psychiatric Association, 2013; CDC, 2016;

Identifying Autism Spectrum Disorder



- Early identification important because early intervention services may be more effective in children with ASD than with other NDDs.

- A 2-level approach to autism screening and diagnosis is recommended.

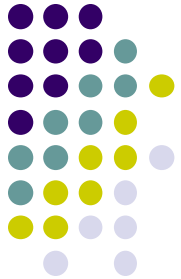
- Children who fail specific autism screening, referral for a formal evaluation by an experienced clinician is recommended.

Filipek, PA et al, 1999; Lipkin PH et al, 1996

Examples of some Autism-Specific Screening Tools

Screening Tool	Characteristics
Checklist for Autism in Toddlers (CHAT)	For use in children aged 18 mo; 14 items, 9 derived from parent history and 5 from direct observation; specificity 98%, sensitivity 38%; does not discriminate well between children with autism and children with mental retardation
Social Communication Questionnaire (formerly called Autism Screening Questionnaire)	For use in children aged ≥4 y
Modified Checklist for Autism in Toddlers (M-CHAT)	For use in children aged 24 mo; 23 items, all based on parental report; specificity 87%, sensitivity 99%; efficient for use in a primary care setting

Tumaini Child Health Project (TUCH)



- Developed an assessment tool and conducted pilot screening for NDDs use in Uganda.

- Generated preliminary data on the prevalence and descriptive epidemiology of NDD’s in Uganda.

TUCH 23 Q Screener

TUMAINI CHILD HEALTH PROJECT

Initial Screening Form

Child ID number: _____ Assessment Date, Month, and Year: _____

Age _____yrs_____months Assessment Performed By: _____

Sex *(circle one)* M F Respondent's relationship to Child: _____

Mother=1; Father=2; Grandparent=3; Sibling=4; other relative=5; other=6

Failed Screener? (circle one) Yes No

Please circle the respondent's answer following each question.

1. Compared with other children, did the child have any serious delay in sitting, standing, or walking?	YES*	No	DK	N/A
2. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?	YES*	No	DK	N/A
3. Compared with other children, does the child have difficulty seeing either in the day time or at night?	YES*	No	DK	N/A
4. In school going children ask: Does the child read well what is written on the blackboard when sitting at the back of the class?	YES	No*	DK	N/A
5. Does the child appear to have difficulty hearing?	YES*	No	DK	N/A
6. Does the child often ask you to repeat what you have said?	YES*	No	DK	N/A
7. When you tell the child to do something, does he/she seem to understand what you are saying?	YES	No*	DK	N/A
8. Does the child learn to do things like other children his/her age?	YES	No*	DK	N/A
9. Compared with other children of his/her age, does the child appear in any way mentally backward, dull, or slow?	YES*	No	DK	N/A
10. Does the child sometimes have fits, become rigid, or lose consciousness?	YES*	No	DK	N/A
11. Does the child have episodes of staring when you can not get their attention by talking to them or touching them lightly?	YES*	No	DK	N/A
12. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words?	YES	No*	DK	N/A
13. a.For 3-9 year-olds ask: Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family?	YES*	No	DK	N/A
b.For 2 year-olds ask: Can he/she name at least one object (for example: an animal, a toy, a cup, a spoon)?	YES	No*	DK	N/A

14. Does the child have difficulty making and maintaining eye contact?	YES*	No	DK	N/A
15. Does the child cry or get upset if you do not do particular routines the same way every day like using the same plate/cup to serve his/her food/drink, letting him/her sit on a particular stool/chair in the house?	YES*	No	DK	N/A
16. Does the child take an interest in playing with other children?	YES	No*	DK	N/A
17. Does the child usually turn to look at you when you call his/her name?	YES	No*	DK	N/A
18. Does the child repeat phrases over and over exactly as they were said or heard from someone (or on the radio)?	YES*	No	DK	N/A
Additional questions for children <5 years of age				
19. Does the child engage in pretend play like 'Mama ne Tata', driving, cooking?	YES	No*	DK	N/A
20. Does the child usually use his/her index finger to point, to indicate interest in something?	YES	No*	DK	N/A
21. Does the child often bring objects over to you (parent) to show you something?	YES	No*	DK	N/A
22. Does the child imitate you? (e.g., if you make a face, will the child imitate it?)	YES	No*	DK	N/A
23. If you point at a toy or a person across the room, does the child look at it?	YES	No*	DK	N/A

Screening result is positive if any one or more of the responses with an asterisk (*) is circled.

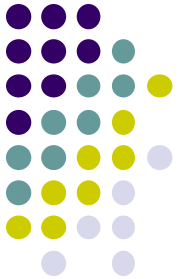
The TQ screening tool

- The instrument adapted was the Ten Questions screen (TQ). (*Durkin et al, 1994*)
- Originally constructed to investigate
  - cognitive & motor disabilities,
  - seizure disorders,
  - serious hearing & visual disorders,
  - speech and language disorders
- BUT not Autism Spectrum Disorders or behaviorally defined disorders.

The TQ screening tool (Cont).

- Age range is from 2-9 years.
- Administered by non-professional community members.
- Asks mother/caregiver to compare her/his child to others of same age & cultural setting.
- Answers given in a yes/no response format.

Development of the adapted 23 Questionnaire



- Five ASD questions were added for all children 2-9 years of age.
- Five additional ASD questions for children less than 5 years of age.
- Three questions were also added to try to increase screening capability for visual, hearing, and seizure disorders.
- The 23Q, locally translated and pilot tested before use.

Study setting:

- The study was conducted in two districts of Uganda.
- Selection based on the extensive experience of the Ugandan investigators.
- Geared to represent urban and rural communities.

Study setting 1:

- Kampala District, the only urban district in the country based on census criteria, & houses the capital city of the country.
- Population of ~1.2 million residents living in >300,000 households.

Study setting 2:

- Wakiso District is a primarily rural district adjacent to Kampala.
- Population of more than 900,000 residents in >218 households.

Study population:

- Target population included children 2-9 years of age in randomly selected parishes of the two districts.
- Families had to be resident in the study area for the previous six months prior to study commencement.

Screening Questions

- Examples of questions specific for **Autism Spectrum Disorder** were:

15. Does the child have difficulty making and maintaining eye contact? YES* No DK

17. Does the child take an interest in playing with other children? YES No * DK

Additional Questions for < 5 years

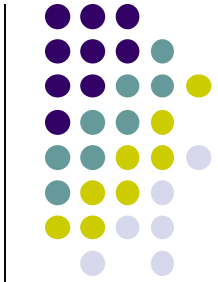
21. Does the child usually use his/her index finger to point, to indicate interest in something? YES No* DK

22. Does the child often bring objects over to you (parent) to show you something? YES No* DK

Stage I: Screening:

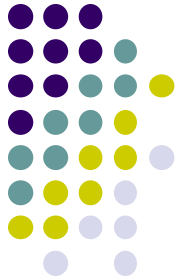
- For those children who registered a response with an asterisk (*) to any of the questions, a referral for further assessment was made.

Stage II: Comprehensive Clinical Assessment.



- Medical Officer Examinations (MOE) were conducted by two certified medical officers specifically trained for the project.

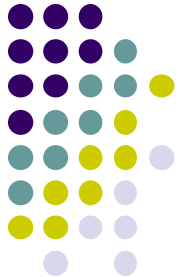
Conducting the medical assessments



- All children scheduled to attend the MOE picked from a central location of the parish with their caregivers.

- At the end of the assessments; those children that required specialist referrals were given appointments.

Stage III: Confirmatory Clinical Diagnosis.



- Conducted by a Psychiatrist based at Mulago National Referral Hospital.

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Autism Spectrum Disorders:

- A total of Fifteen children were assessed for autistic spectrum disorders using the DSM-IV-R criteria.
- Of these Eight (53.3%) qualified to be classified on the spectrum.
  - Pervasive developmental disorder.
  - Autistic disorder.
  - Pervasive developmental disorder- NOS
- This yielded an estimated adjusted prevalence of 1.2/100 –- 1.3 /100 children in this population.

Kakooza-Mwesige et al, 2013

Other related study findings

- Parents/caregivers and the whole community with low awareness of ASD's.
- Lack of supportive services to handle the special needs of these children.
- No research infrastructure in general, in place for ASD's.
- Shortage of human resource in managing these patients.
- Lack of supportive medications and other health supplies

Kakooza-Mwesige et al, 2013

For more detailed information

Autism
http://aut.sagepub.com/

Adaptation of the 'ten questions' to screen for autism and other neuro-developmental disorders in Uganda

Angelina Kakooza-Mwesige, Keron Ssebyala, Charles Karamagi, Sarah Kiguli, Karen Smith, Meredith C Anderson, Lisa A Croen, Edwin Trevathan, Robin Hansen, Daniel Smith and Judith K Grether

Autism published online 27 March 2013
DOI: 10.1177/1362361313475848

The online version of this article can be found at:
http://aut.sagepub.com/content/early/2013/03/26/1362361313475848

Autism Specific Diagnostic Tools:

Instrument	Characteristics
Autism Diagnostic Interview-Revised (ADI-R)*	Semistructured interview that is reliable, valid, and differentiates autism from other developmental disorders; takes 1½ h to administer, limiting clinical use
Autism Diagnostic Observation Schedule-Generic (ADOS-G)*	Reliable, valid, direct assessment that helps to differentiate ASDs from other developmental disorders; requires specific training; takes 30 min to administer, making it practical for clinical use
Gilliam Autism Rating Scale	Checklist that may be used by parents and teachers and other professionals to quantify autism symptoms
Childhood Autism Rating Scale	Structured interview and observational tool designed to be used by experienced clinicians or other professionals to identify symptoms consistent with ASDs

Abbreviation: ASDs, autistic spectrum disorders.
*Neither the ADI-R nor the ADOS-G is sufficient to enable a diagnosis of autism. The diagnosis depends on assessment by an experienced clinician.

Diagnosis of ASD

- Made by an experienced clinician, using a combination of

  - parent report
  - direct examination of the child
  - standardized developmental and behavioural testing when needed

Diagnosis of ASD:

- A clinical dyad of:
  - impaired social interaction and communication
  - presence of a restricted, repetitive pattern of behaviour or interests

Evidence-based types of ASD therapies to date (1)

Non pharmacological-

1.Applied behaviour Analysis (ABA)

- Aims to teach the absent child skills through the introduction of these skills in stages.
- Usually, each one of the skills is individually showed, presenting it coupled with an indication or instruction

2.Picture Exchange Communication System (PECS)

- enables non-verbal children to communicate by using figures.
- PECS can be used at home, in the classroom or in several others environments

Warren et al, 2011; Ganz et al, 2012

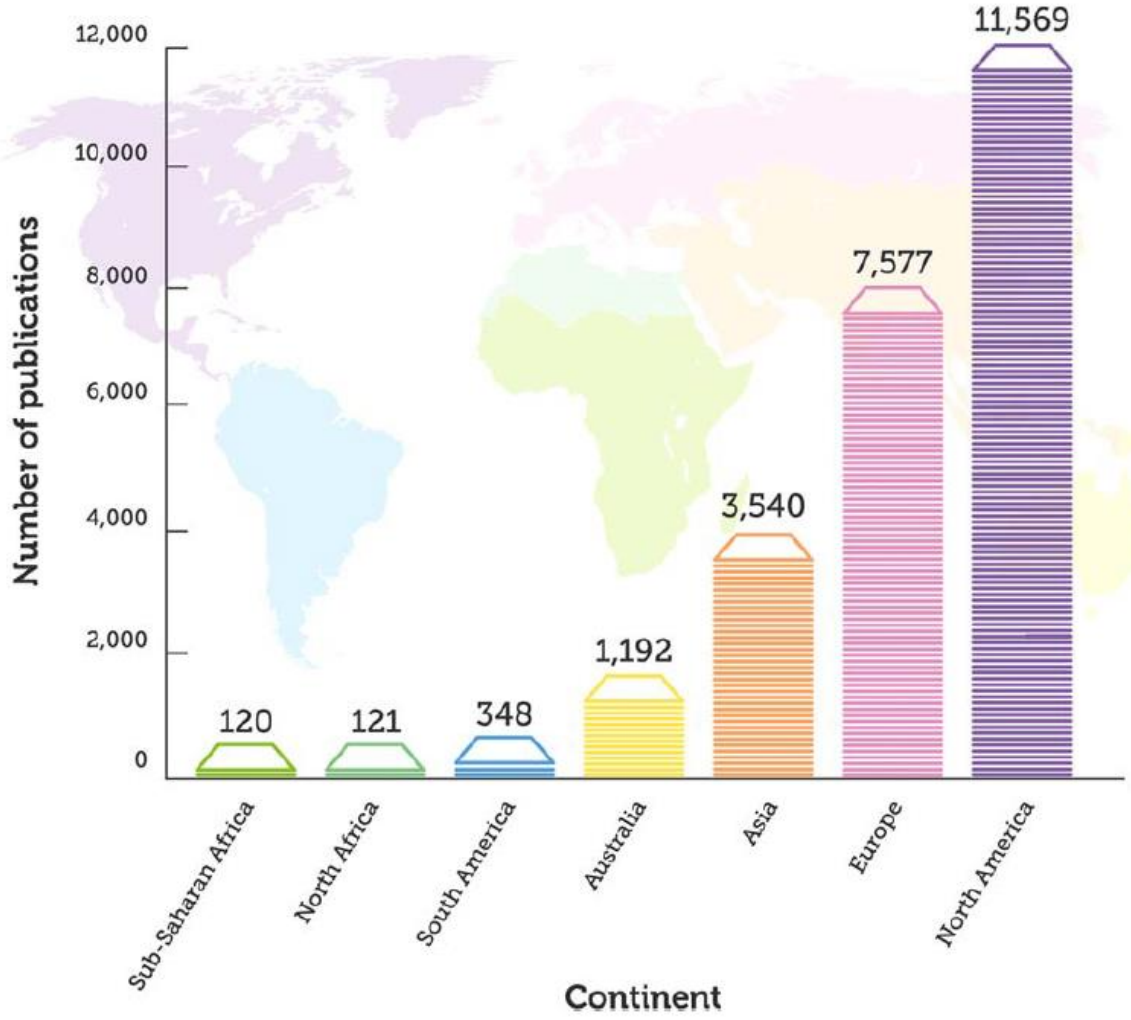
Evidence-based types of ASD therapies to date (2)

Pharmacological-

	CORE SYMPTOMS	MEDICATIONS
1.	Aggressiveness, Irritability, Self Injury, Other disruptive behaviours	Risperidone Aripiprazole Valproic Acid
2.	Hyperactivity, Inattention	Risperidone Aripiprazole Methylphenidate
3.	Repetitive behaviour, Stereotypies	Risperidone Aripiprazole Valproic Acid
4.	Sleep disorders	Melatonin

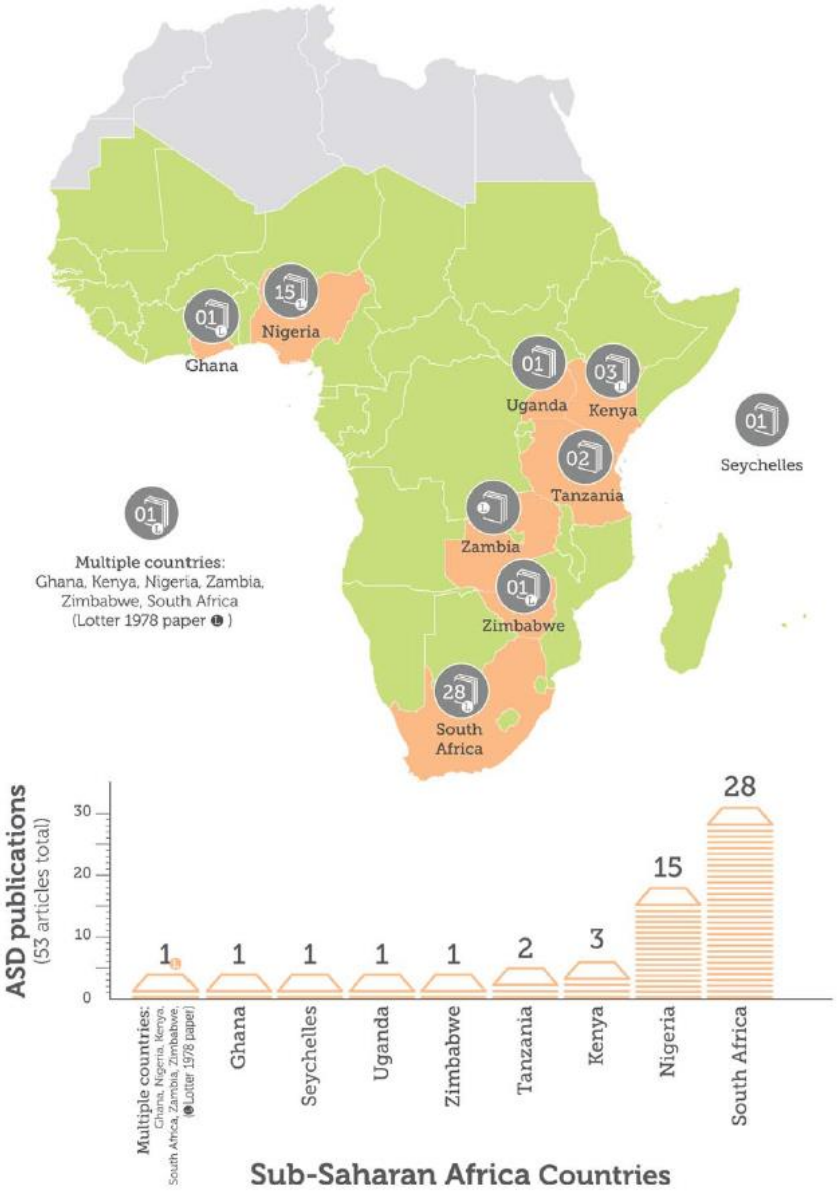
Marcus et al, 2009; Hollander at, 2012; Weinssman & Bridgemohan, 2012; Owen et al, 2009 ; McDougle et al, 2005 ; Mallow et al, 2011; Kaplan and McCracken 2012

Publications on ASD:



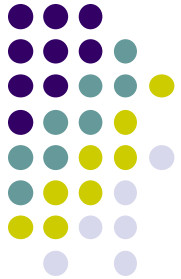
Franz et al, 2017

Which countries in Africa?



Franz et al, 2017

Some gaps in ASD research in SSA



- No large-scale or population-based studies.
- Hardly any studies on clinical features using standardized diagnostic instruments.
- Findings biased to tertiary settings and high socioeconomic families.
- Minimal data on the the genetics and genomics of ASD.
- Lack of longitudinal or early intervention studies of children with ASD.

Closing the knowledge gap of ASD in SSA:

- Enhance awareness about ASD in all communities and to all stakeholders.
- Implementing education and training about ASD across all levels of health, education, and the social care sector.
- Develop research- funding infrastructure and capacity in ASD across the life span.

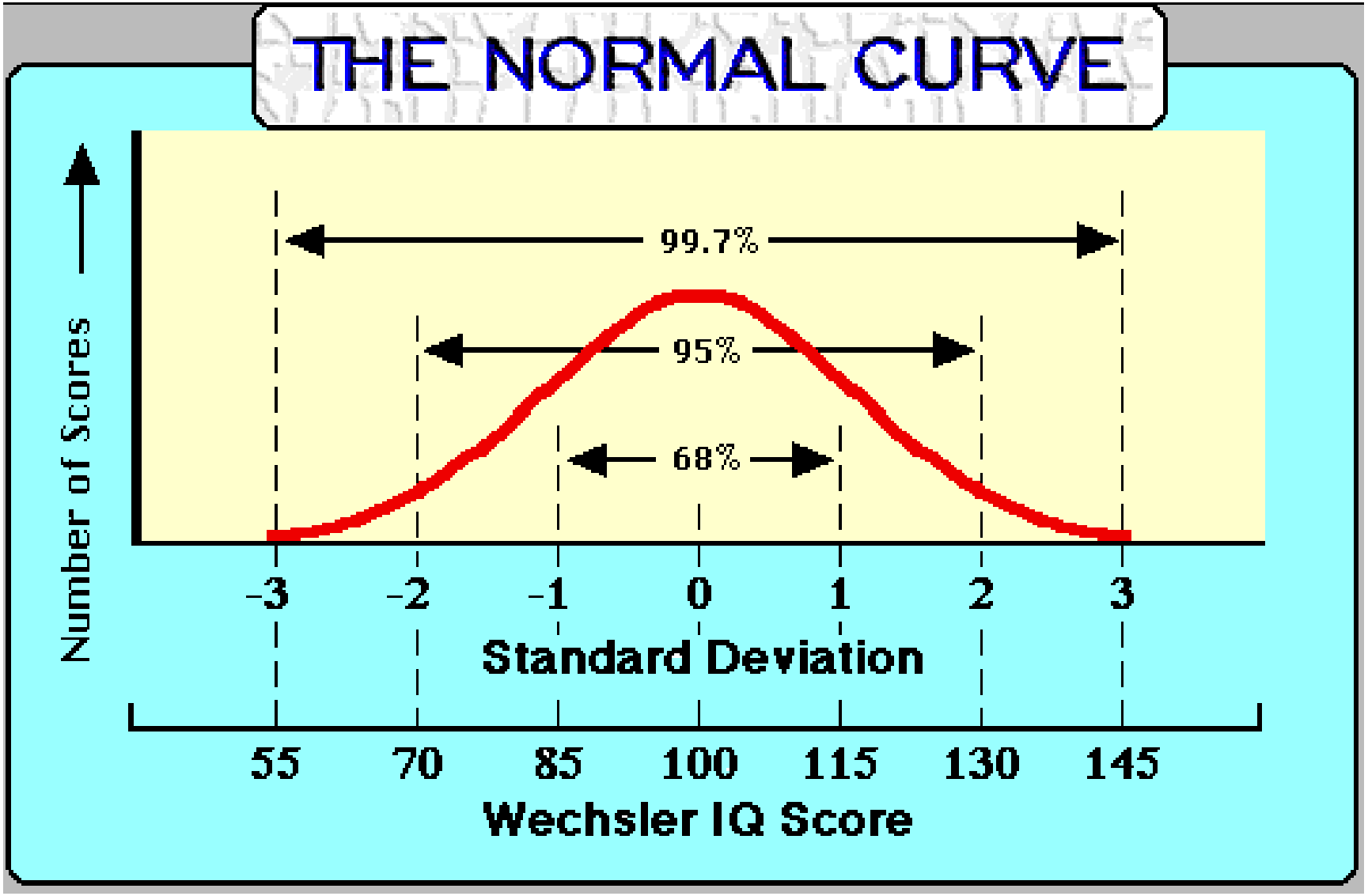
2. The case of Intellectual disability (ID)

DSM-5 definition of I.D

- In DSM-5, intellectual disability is present when Intelligent Quotient (IQ) is approximately two standard deviations or more below the population.

- Equivalent to an IQ score of about 70 or below.

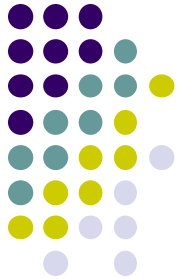
IQ Score distribution



Classifications of ID severity

	DSM-IV Severity levels based on IQ categories	DSM-V Severity levels classified on the basis of daily skills
Mild	Approximate IQ range 50–69	Can live independently with minimum levels of support.
Moderate	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.
Severe	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.
Profound	IQ < 20	Requires 24-hour care

What is Intellectual disability (I.D)?



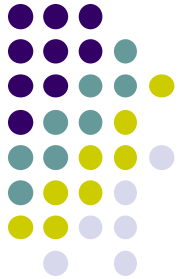
- Clinical description - considerable range of abilities and interpersonal qualities
  - DSM-5 diagnostic criteria:
    - Deficits in intellectual functioning
    - Concurrent deficits or impairments in adaptive functioning
    - Below-average intellectual and adaptive abilities must be evident prior to age 18

Specific Examples of Adaptive Behavior Skills

Conceptual Skills
Receptive and expressive language Reading and writing Money concepts Self-directions
Social Skills
Interpersonal Responsibility Self-esteem Gullibility (likelihood of being tricked or manipulated) Naiveté Follows rules Obeys laws Avoids victimization
Practical Skills
Personal activities of daily living such as eating, dressing, mobility, and toileting Instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation and doing housekeeping activities
Occupational Skills
Maintaining a safe environment

Cengage learning 2016

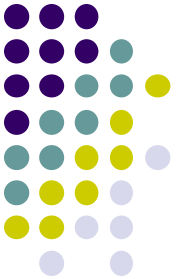
Burden of Intellectual Disabilities (1)



- Highest prevalence of people with ID seen in low- and middle-income countries (LMICs).
- People with intellectual disability (ID) amongst the most marginalized groups globally.
- They experience social exclusion on a much greater scale than their able-bodied counterparts.
- This experience is intensified within contexts of poverty such as those on the African continent.

McKenzie JA et al, 2013; Maulik, P.K. et al, 2011

Burden of Intellectual Disabilities (2)



- Approximately 1% of the global population has an intellectual disability.
- Overall prevalence estimated at **10.37/1000** population (95%CI 9.55–11.18 per 1000 population).
- Highest prevalence seen in **low-income countries** at **16.41 /1000** population (95%CI 11.14–21.68).
- **High income countries** at **9.21 /1000** population (95%CI 8.46–9.96).

Maulik P.K. et al, 2011.

Prevalence of I.D's in Africa

Country of study	Author	Study design	Age	Conditions assessed	Prevalence and Spectrum
Ghana[20]	Biritwum et al (2001)	Cross-sectional survey, (N=2556)	1–15 yrs	Various cognitive, physical, sensory disabilities	***Overall 18.0/1,000***; prevalence increased with age
South Africa[23]	Christianson et al (2002)	Two-phase design, interview and pediatric, developmental assessment (N=6692)	2–9 year olds	Intellectual disability (ID) and associated disability	***35.6/1,000 in population with ID*** (64/1,000 severe and 29.1/1,000 mild)

Prevalence of I.D's in Africa

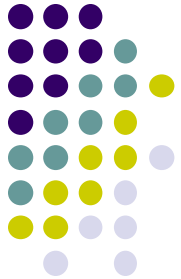
Country of study	Author	Study design	Age	Conditions assessed	Prevalence and Spectrum
South Africa (Kwazulu Natal)[24]	Couper (2002)	Descriptive 2 stage study (N=2036)	Children under the age of 10 years	Childhood disability	***Overall confirmed prevalence rate 60/1,000;*** mild perceptual or learning disability17 /1,000;
Kenya	Mung'ala Odera V et al (2006)	Descriptive 2 stage study (N=955)	Children 6-9 years	Childhood disability	***Moderate/severe NI was*** (41/1000), Cognition

Risk factors for ID:

Timing	Biomedical	Social	Behavioral	Educational
Prenatal	1. Chromosomal disorders 2. Single-gene disorders 3. Syndromes 4. Metabolic disorders 5. Cerebral dysgenesis 6. Maternal illness 7. Parental age	1. Poverty 2. Maternal malnutrition 3. Domestic violence 4. Lack of access to prenatal care	1. Parental drug use 2. Parental alcohol use 3. Parental smoking 4. Parental immaturity	1. Parental cognitive disability without supports 2. Lack of preparation for parenthood
Perinatal	1. Prematurity 2. Birth injury 3. Neonatal disorders	1. Lack of access to prenatal care	1. Parental rejection of caretaking 2. Parental abandonment of child	1. Lack of medical referral for intervention services at discharge
Postnatal	1. Traumatic brain injury 2. Malnutrition 3. Meningoencephalitis 4. Seizure disorders 5. Degenerative disorders	1. Impaired child–caregiver interaction 2. Lack of adequate stimulation 3. Family poverty 4. Chronic illness in the family 5. Institutionalization	1. Child abuse and neglect 2. Domestic violence 3. Inadequate safety measures 4. Social deprivation 5. Difficult child behaviors	1. Impaired parenting 2. Delayed diagnosis 3. Inadequate early intervention services 4. Inadequate special education services 5. Inadequate family support

Cengage learning 2016

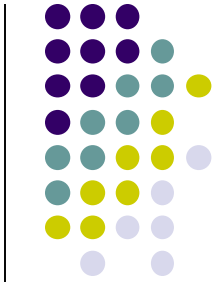
What is required for the diagnosis of I.D's?



Due to the varied causes and consequences of ID an initial evaluation should address:

- intellectual and life skills,
- the identification of genetic and non-genetic aetiologies,
- the diagnosis of conditions that need treatment (e.g., epilepsy and phenylketonuria).

Other procedures to aid in ID diagnosis



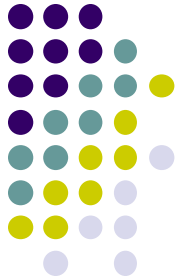
- **Prenatal** and **perinatal** medical histories.
- **A physical examination-** congenital malformations, dysmorphic features.
- **Genetic evaluations**- in the case of Fragile X syndrome, an FMR1 gene mutation analysis
- **Metabolic screening-** urinary tests for oligosaccharides, mucopolysaccarides, amino acids.
- **Neuroimaging assessment-** in cases of microcephaly or macrocephaly or when a specific neuroanatomical effect exists (tuberous sclerosis).

Comorbidities in ID

- Communication disorders
- Learning disabilities
- Cerebral palsy
- Epilepsy
- Various genetically transmitted conditions.
- ADHD
- Other psychiatric conditions- schizophrenia, depression.

Fletcher et al, 2007; APA, 2013

How should we manage a child with ID?



- Treatment involves a multi-component, integrated strategy
  - Considers children's needs within the context of their individual development, their family and institutional setting, and their community

Treatments for ID (1)

Focuses on treatments:

1. That address any underlying cause of ID, such as restricting phenylalanine in the diet of patients who have phenylketonuria.

2. On early behavioral and cognitive interventions, special education, habilitation, and psychosocial supports.

Szymanski and Kaplan, 2006

Treatments for ID (2)

3. Of comorbidities with the aim of improving the patient's functioning and life skills, such as targeted pharmacologic treatments of behavioral disorders among children with fragile X syndrome **OR** pharmacological treatment of the epilepsy with Lamotrigine, Oxcarbamazepine, Zonisamide and Levetiracetam.

Hagerman and Polussa, 2015

Closing the knowledge gap of ID in SSA:

- More rigorous research to understand ID in the African context.
- Develop pathways to prioritize ID in non-disability related and across impairment programmes.
- Draw on informal and traditional forms of care and participation to inform future education & health care.

3. The Case of Cerebral Palsy.

DMCN Developmental Medicine & Child Neurology

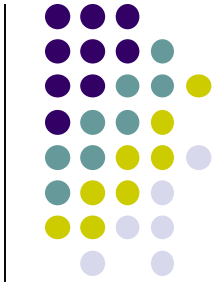
A report: the definition and classification of cerebral palsy April 2006

Report Executive Committee:
Peter Rosenbaum (Definition Panel Chair) MD, *CanChild* Centre for Childhood Disability Research, Hamilton, Ontario, Canada.
Nigel Paneth (Classification Panel Chair) MD, Department of Epidemiology, Michigan State University, East Lansing, MI, USA.
Alan Leviton MD, Neuroepidemiology Unit, Children's Hospital, Boston, MA, USA.
Murray Goldstein* (Co-Chair) DO, MPH, United Cerebral Palsy Research & Educational Foundation, Washington DC, USA.
Martin Bax (Co-Chair) DM, FRCP, Division of Paediatrics, Obstetrics and Gynaecology, Imperial College, London, UK.

Panel Consultants:
Diane Damiano PhD PT, Washington University Department of Neurology, St. Louis, MO, USA.
Bernard Dan MD, PhD, Hôpital Universitaire des Enfants, Reine Fabiola, Université Libre de Bruxelles, Brussels, Belgium.
Bo Jacobsson MD, PhD, Perinatal Center, Sahlgrenska University Hospital East, Goteborg, Sweden.

Surveillance of Cerebral Palsy in Europe

Cerebral Palsy (CP) definition :



Five key elements

- - a **group** (several different disorders)
- - of **permanent** but not unchanging
- - disorders of **movement** and/or of **posture** and of motor function
- - due to a **non progressive**
- - interference/**lesion**/abnormality of the **immature brain**

- **Accompanying disturbances of other functions**
  Sensation, perception, cognition, communication, and behaviour

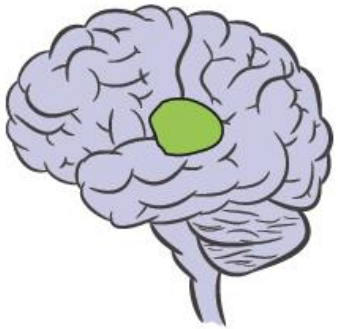
- **Associated with medical problems**
  Epilepsy, secondary musculoskeletal problems

(SCPE DMCN 2000, Rosenbaum DMCN 2007)

Type of CP: depends on the part of the brain that is affected

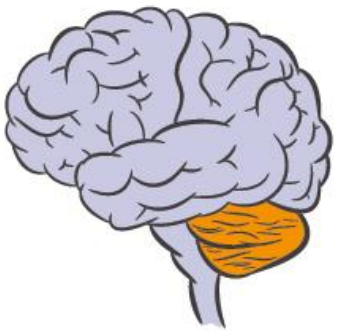
Stiff muscles (spasticity), associated with damage to or developmental differences in the

cerebral cortex



Uncontrollable movements (dyskinesia), associated with damage to the

basal ganglia



Poor balance and coordination (ataxia), associated with damage to the

cerebellum

Mixed, a combination of two or more types, associated with damage to

multiple areas of the brain

Gillette Children's
Specialty Healthcare

CP subtypes according to SCPE Classification

Unilateral Spastic

Dyskinetic

Bilateral Spastic

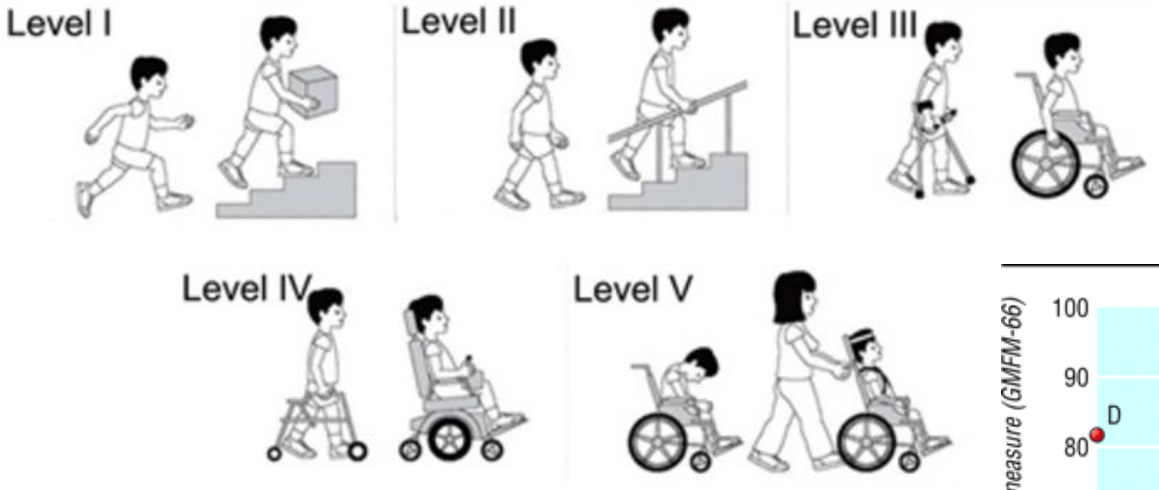
Ataxic

Unclassifiable

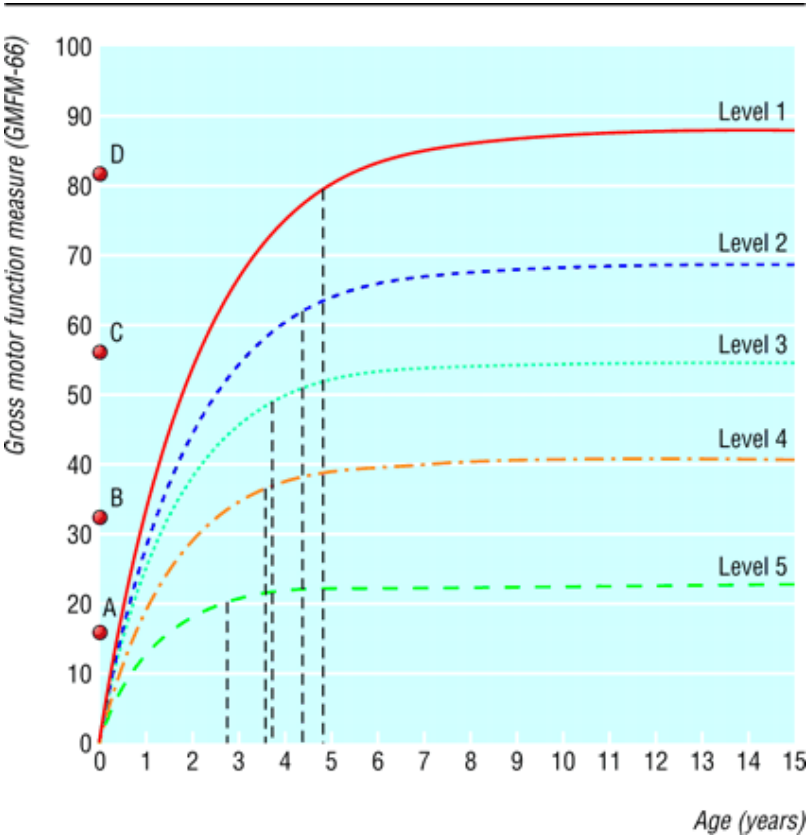
Classification levels for describing abilities of child with CP

- **Functional level of abilities**
  - **GMFCS** - Gross Motor Function Classification System
  - **MACS** - Manual Assessment Classification System
  - **CFCS –** Communication Function Classification System
  - **EDACS**- Eating & Drinking Ability Classification System

Gross Motor Function Classification

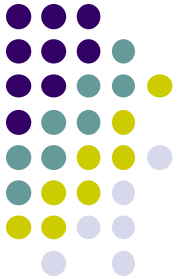


- 5 levels
- Self-initiated movement



Hans Forssberg

What is the clinical profile of children with Cerebral palsy in Uganda?



CURIE Study Consortium

UGANDA

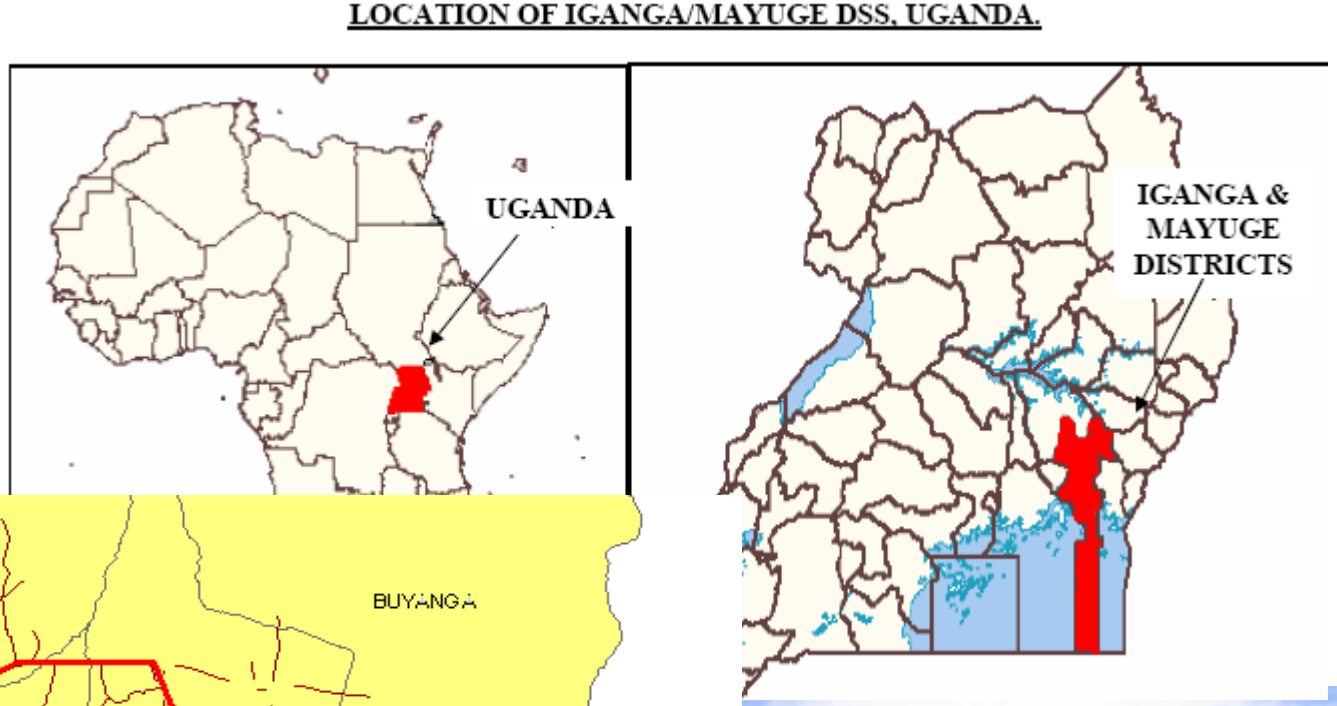
SWEDEN

SOUTH AFRICA

UNITED STATES
OF AMERICA

Study Methods:

Study site & Location



Methodology

- **Study design**
  - Population-based, cross-sectional.
- **Population**
  - At time of study **65 villages: 15,964 households** and **85,562 individuals**
  - Children aged 2–17 years were **41,319.**
- **Data source**
  - Data used for this study were from the March 1, 2015, to June 30, 2015, surveillance round.

Estimating prevalence, & determining clinical features of cerebral palsy

Stage I

Census team

2 screening questions

Based on Movement and Posture

Stage II

CP field team

More questions plus assessment of mobility and motor control

Possible CP identified

Stage III

CP specialist team

Confirmation of CP diagnosis

Classification

Possible aetiology determined

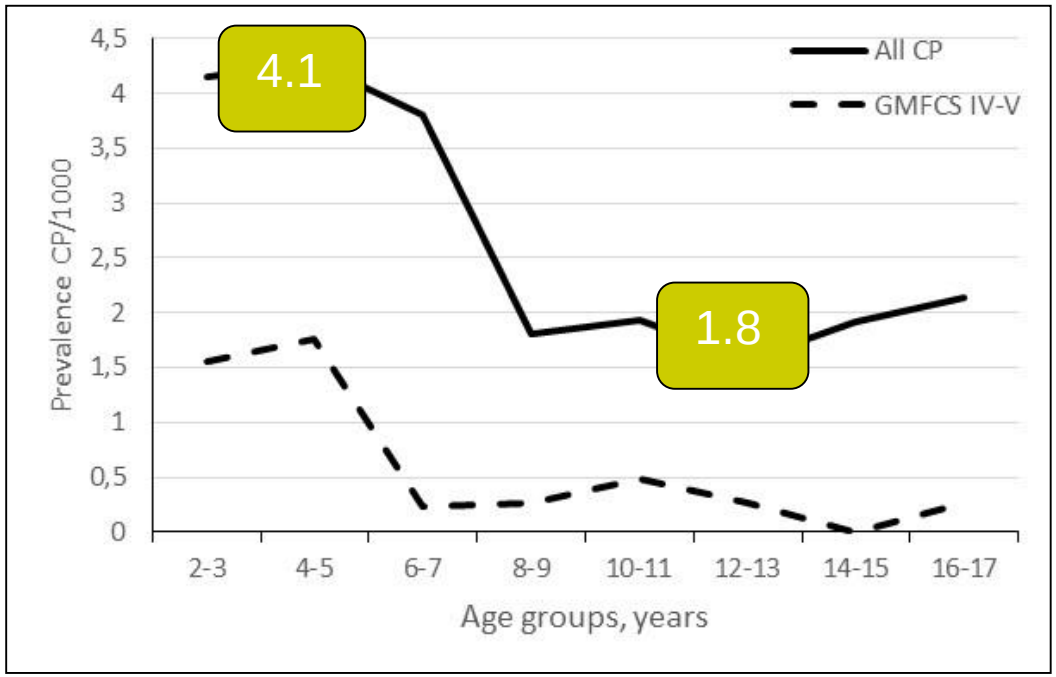
Expert team of physiotherapists and occupational therapists.
Determine CP severity.

Triangulation using Key Informants
Additional children identified

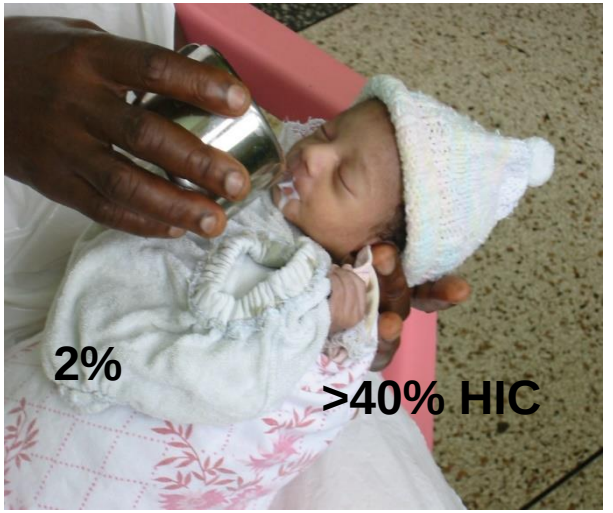
Study Results:
CURIE-I & 2

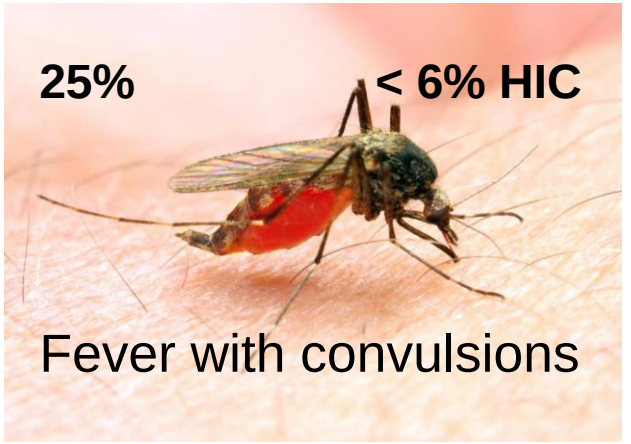
Prevalence of Cerebral palsy

Prevalence 3.1 per 1000 children (HIC 1.8-2.3)



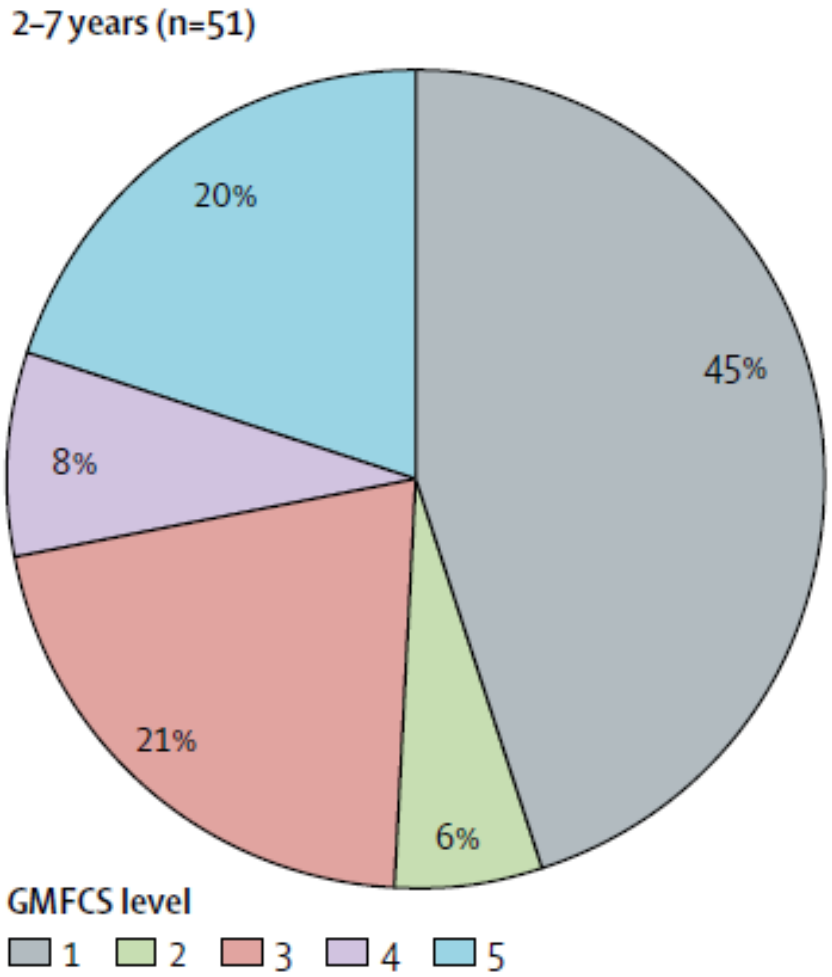
Prevalence decrease driven by less older children with severe motor impairment

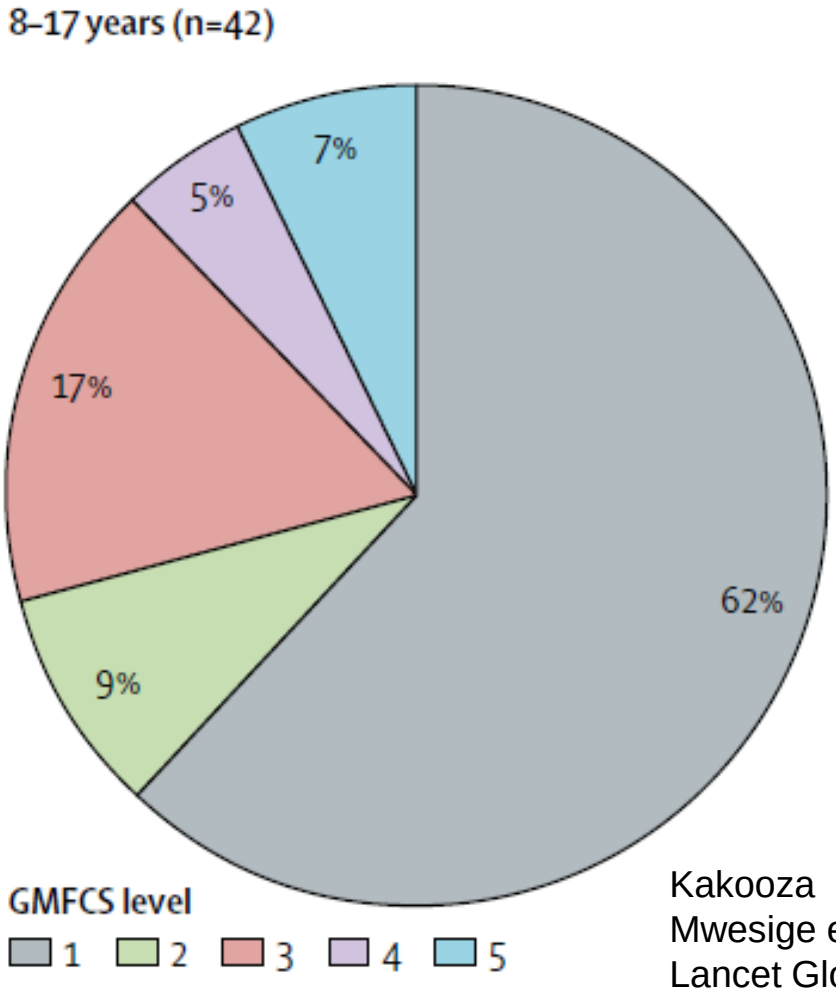




Kakooza-Mwesige et al, 2017

Severity of CP per sub cohort





Kakooza Mwesige et al Lancet Global Health 2017

Most common subtype- Unilateral Spastic.

CP subtype according to SCPE Classification

Unilateral Spastic
46%

Dyskinetic 9%

Bilateral Spastic
40%

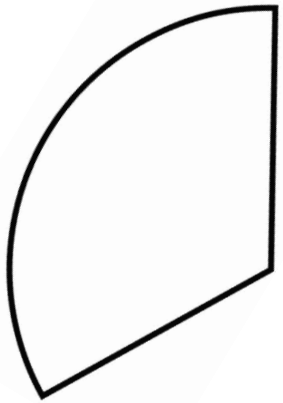
Ataxic 2%

Unclassifiable 2%

Kakooza Mwesige et al Lancet Global Health 2017

Mobility & communication of the children:

Children aged 2-5 years could not walk



Children aged 6-17 years could not walk

One third of children could not talk

Common comorbidities in CP cohort

	Associated impairment	2–5 years (*N*=33)	6–17 years (*N*=60)
1.	Intellectual disability	15 (45)	35 (58)
2.	Behavior impairment	4 (12)	12 (20)
3.	Seizures	10 (30)	23 (38)
4.	Vision impairment	5 (15)	6 (10)
5.	Hearing impairment	1 (3)	6 (10)

Andrews C et al, 2019

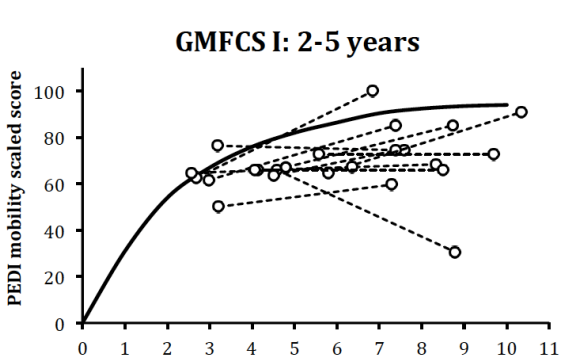
Wheel Chair usage:

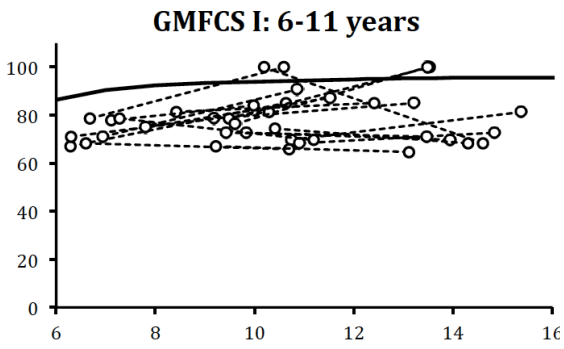
Only three of the non-walking children had wheelchairs (8%)

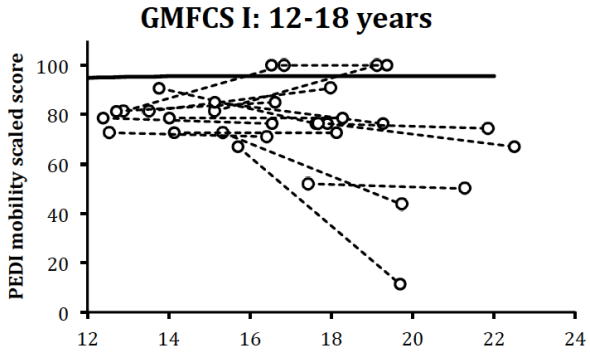
Education & other services:

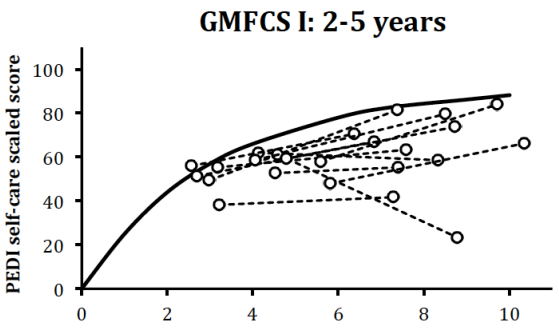
- Only <u>ONE THIRD</u> of the children aged 6-17 years were in school (18/60).
- LACK of assistive devices for communication, seeing or hearing

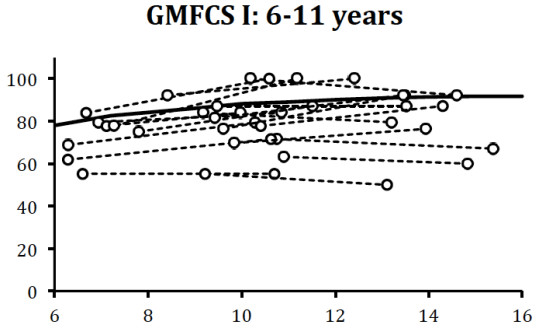
Mobility and self-care development compared to HIC

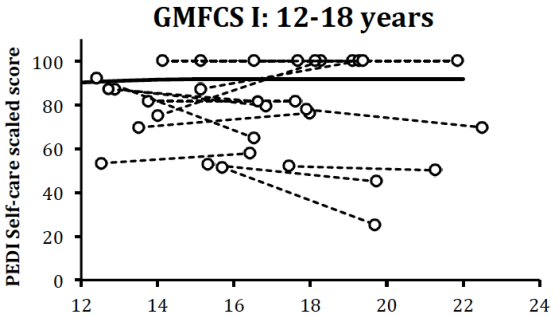








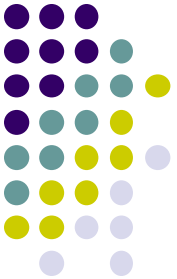




Children with CP in Uganda score below HIC trajectories
Young and mildly impaired children have less improvement over age compared to peers in HIC
Probably due to lack of services and assistive devices

Carin.andrews@ki.se

Cerebral Palsy in Uganda Main findings



- Higher prevalence than in HIC
- Fewer preterm born children
- More post-neonatal cerebral palsy (x5)
- Excessive premature mortality 25xhigher
- No/little rehabilitation services
- No/little assistive devices
- Poor school attendance
- Poor development of mobility and self-care skills

Children with disabilities die prematurely and do not reach their developmental potential

What are the implications of these findings?

How do we close the knowledge gap of CP in SSA ?

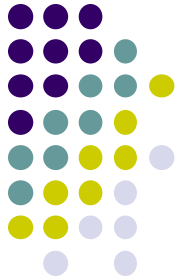
Clinical Implications :

- There is need to set up rehabilitative /counselling services for these caregivers to provide emotional and social support.
- The development of a facilitated, participatory, community-based approach to rehabilitation training- to maximise participation and improve the quality of life of affected caregivers and infants.

Advocacy implications

- Need to raise awareness regarding Cerebral palsy in both community and among the health care workers.
- Stigma reduction of Cerebral palsy through use of testimonies of success stories or support of “champion caregivers” to act as examples.
- Use of the local media such radio talk shows, drama groups, television or billboard adverts to educate the public on CPs to help reduce stigma and support community acceptance and expanded medical services for disabled children.

Stakeholders implications



- The Ministry of Health and concerned Stakeholders to cultivate collaborative networks with local companies to develop low cost, user friendly assistive devices, where possible, so as to reduce financial cost and maintenance rehabilitation challenges.

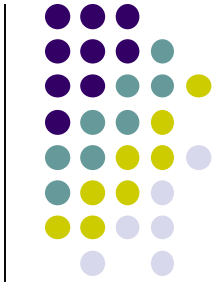
- There is need to strengthen links between government, researchers, clinicians, therapists, and those providing specialist training and care in Africa.

4. The case of ADHD

What is ADHD?

- A complex neurodevelopmental disorder of the brain's self-management system and executive functions.
- Exhibited as persistent age-inappropriate symptoms of inattention, hyperactivity, and impulsivity that are sufficient to cause impairment in major life activities
  - Characteristic behaviors vary considerably from child to child
  - Different behavior patterns may have different causes

Three distinct types of ADHD

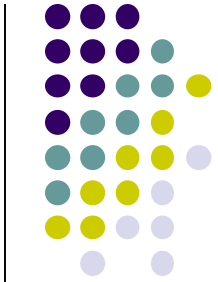


- ADHD is one of the most common *neurodevelopmental* disorders of childhood and adolescence.

TYPES OF ADHD

- Predominantly hyperactive-Impulsive ADHD
- Predominantly inattentive ADHD (formerly called ADD)
- Combined presentation-ADHD

Risk factors for ADHD



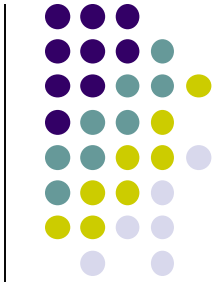
- Genetic influences-ADHD runs in families
- Factors that compromise development of the nervous system before and after birth may be related to ADHD
- Mother's use of cigarettes, alcohol, or other drugs during pregnancy are associated with ADHD
- Decreased blood flow to prefrontal regions and pathways connecting them to limbic system.
- Brain abnormalities- ADHD children have smaller total and right cerebral volumes (by 3-4%), smaller cerebellum, and delayed brain maturation.

Prevalence of ADHD in Africa:

- Limited published data on ADHD from Africa.
- Pooled prevalence rates-7.47% (95% CI 60-9.26).
- In DRC, a prevalence of 6% among primary school children aged 7-9 years.
- In Nigeria, a prevalence of 8.7% among school children aged 6-12 years
- In Kenya, prevalence of 6.3% among children aged 6-12 years.

Kashala et al, 2007; Adewuya et al, 2007; Wamithi S, 2012; Ayano et al, 2020

Meta-analysis study on the prevalence of ADHD in children and adolescents in Africa

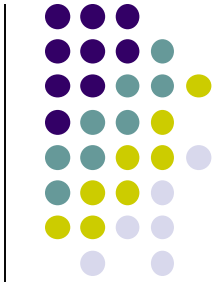


- Prevalence of ADHD was greater in boys (10.60%) than in girls (5.28%) with a male : female ratio of 2.01:1.

- Inattentive type (ADHD-I) most common subtype, followed by hyperactive–impulsive type (ADHD-HI) and the combined type (ADHD-C) with the prevalence of 2.95%, 2.77%, and 2.44% respectively.

Ayano et al, 2020

Some common ADHD symptoms:

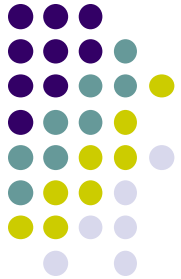


- Inattention,
- Lack of focus,
- Poor time management,
- Weak impulse control,
- Exaggerated emotions,
- Hyperfocus,
- Hyperactivity,
- Executive dysfunction

Diagnosis of ADHD using DSM V

- Lists nine symptoms that suggest Inattentive ADHD.
- Lists other nine that suggest Hyperactive-Impulsive ADHD.
- A child may be diagnosed with ADHD only if he or she exhibits at least six of nine symptoms from these ADHD symptom check lists.

Diagnosis of ADHD using DSM V

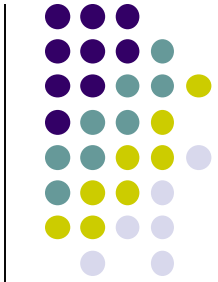


- If the symptoms have been noticeable for at least six months in two or more settings — for example, at home and at school.
- The symptoms must interfere with the child's functioning or development.
- At least some of the symptoms must have been apparent before age 12

Associated Characteristics

- Children with ADHD often display other problems in addition to their primary difficulties
  - Cognitive deficits
  - Speech and language impairments
  - Developmental coordination and tic disorders
  - Medical and physical concerns
  - Social problems

Accompanying Psychological Disorders and Symptoms



- Up to 80% of children with ADHD have a co-occurring psychological disorder
- Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD)- role of COMT gene.
- Anxiety disorders- worsens symptoms or severity of ADHD
- Mood disorders-
  - ADHD at 4-6 years is a risk factor for future depression and suicidal behavior
  - 20-30% of children with ADHD experience depression.

Treatment for ADHD:

- The primary treatment approach combines:
  - Stimulant medication
  - Parent management training
  - Educational intervention

Medication

- Stimulants have been used to treat ADHD since the 1930s
  - Among the most effective stimulants are dextroamphetamine and methylphenidate
    - May help normalize frontostriatal structural abnormalities and functional connections
  - Effects are temporary and occur only while medication is taken; beneficial in short-term
    - Questions surround long-term benefits and later adjustment

Parent Management Training (PMT)

- Provides parents with a variety of skills
  - Managing the child's oppositional and noncompliant behaviors
  - Coping with emotional demands of raising a child with ADHD
  - Containing the problem so it does not worsen
  - Keeping the problem from adversely affecting other family members

Parent Management Training (PMT) (cont'd.)

- Parents are:
  - Taught to understand biological basis of ADHD
  - Given set of guiding principles
  - Taught behavior management principles and techniques
  - Encouraged to spend time each day sharing enjoyable activity with their child
  - Taught how to reduce their own levels of arousal

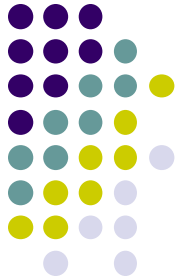
Educational Intervention

- Teacher and child must set realistic goals and objectives
- Response-cost procedures are used to reduce disruptive or off-task behaviors
- Many strategies are basic good teaching methods
- School-based interventions for ADHD have received considerable support

Intensive Interventions

- Holiday treatment programs
  - Maximize opportunities to build effective peer relations in normal settings and provides continuity with academic work so gains from school year aren't lost
  - Are coordinated with stimulant medication trials, PMT, social skills training, and educational interventions

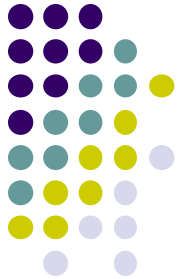
Additional Interventions



- Family counseling and support groups
  - Help family members develop new skills, attitudes, and ability to relate more effectively
- Individual counseling
  - Helps children with ADHD deal with their problems and feelings of isolation and abnormality
  - Helps build their sense of self-competence

How do we close the knowledge gap of ADHD in SSA ?

Future ADHD studies should:



- Assess the possible reasons for gender difference in epidemiology of ADHD in Africa.
- Investigate the low male : female ratio in Africa as compared to global findings.
- Explore context specific ways to prevent and treat ADHD among children and adolescents in Africa.

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