# Developmental delay

## *Executive summary*

## Introduction

Developmental delay (DD) is defined as significant delay (>2 standard deviations below the mean) affecting children < 5 years of age in one or more of the following developmental domains:

* Gross motor
* Vision & Fine motor
* Hearing, Speech & Language
* Social, Emotional & Behavioural

Global developmental delay is defined as significant delay in two or more developmental domains. The degree of developmental delay is further subclassified as:

* mild (functional age < 33% below chronological age)
* moderate (functional age 34%–66% of chronological age)
* severe (functional age < 66% of chronological age).

While DD may not be permanent, it can provide a basis for identifying children who may experience a disability. Early recognition of DD is crucial to commencing timely interventions, prevention of complications, developing family understanding and support networks and creating a more stimulating and protective environment for the child.

## Target users

* Nurses
* Doctors

## Target area of use

* Gate clinic
* Outpatient department
* Ward

## Key areas of focus / New additions / Changes

This guideline provides an approach for doctors and nurses to follow in assessing children for developmental delay as well as some guidance in how to manage them.

## Limitations

We have limited access to tests and management options for these children.

## Causes of developmental delay

DD can result from antenatal or postnatal damage to brain development although in 50% of cases the cause is unknown:

**Antenatal:**

* Genetic/syndromes (20-50%)
* Cerebral malformations (7%)
* Early maternal infections e.g. rubella, toxoplasma, CMV
* Late maternal infections, such as varicella, malaria, HIV
* Toxins—for example, alcohol, pesticides, radiation, smoking
* Drugs—for example, cytotoxics, antiepileptics

##### **Postnatal**

##### Cerebral palsy/complications of prematurity (2-10%)

##### Postnatal infections e.g. meningitis, encephalitis, CMV

##### Metabolic or endocrine disorders, such as hypoglycaemia, hyponatraemia or hypernatraemia, dehydration (1-5%)

##### Toxins e.g. lead, mercury, arsenic, chlorinated organic compounds, solvents

##### Trauma, especially head injury

##### Severe understimulation, maltreatment, or domestic violence

##### Malnutrition, especially deficiency of iron, folate, and vitamin D

##### Maternal mental health disorders, most commonly depression

## Red flags to suggest developmental delay

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| **Age** | **Signs** |
| *6 weeks* | Unresponsive to sound or visual stimuli |
| *6 months* | Poor head control, floppiness, not reaching |
| *9 months* | Can’t sit unsupported; no babble |
| *12 months* | Not communicating by gestures, such as pointing; not weight bearing through legs |
| *18 months* | Not walking; no symbolic play; no speech |
| *2 years* | Not joining two words; cannot run; not pointing at objects to share interest with others |
| *3 years* | Not communicating with words; cannot climb stairs |
| *All ages* | Loss of developmental skills at any age (regression)  Parental or professional concerns about vision, fixing/following at any age  Hearing loss at any age  Persistent low or high muscle tone, floppiness or asymmetry of movements  Complex disabilities  Persistently toe walking  Head circumference > 99th centile or < 0.4th centile |

## History

A comprehensive clinical assessment, including history and examination, is crucial when planning investigations:

* Studies have demonstrated that we can identify the cause of DD in 1/3rd of cases by history and examination alone.
* With clinical evaluation prompting investigations, we can identify another 1/3rd.

Suggested screening questions:

* Do you have any concerns about the way your child is behaving, learning, or developing?
* Do you have any concerns about the way he or she moves or uses his or her arms or legs?
* Do you have any concerns about how your child talks and understands what you say?
* Has your child ever stopped doing something he or she could previously do?
* Do you have any concerns about how your child is learning to do things for himself or herself?

Clarify if this is a child who has never met their developmental milestones vs. a child who has regressed developmentally, having previously been well. Regression suggests either a change in social/environmental factors, recent illness or neurological/neurodegenerative causes.

A thorough and systematic pre-, peri- and postnatal history is crucial and will help guide investigations (aetiology) and management. Important factors to cover:

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| **Prenatal** | **Perinatal** | **Postnatal** |
| Previous miscarriages or birth defects  Unexplained sibling death  Use of teratogens including drug and alcohol misuse  Prenatal history of Intrauterine infections or severe maternal infection/life threatening event  Maternal conditions e.g. HELLP syndrome, HTN, GDM, pre-eclampsia  Fetal movements ↓  Significant antepartum haemorrhage | Birth weight and head circumference  Birth asphyxia  Poor Apgars and requiring prolonged resuscitation  Development of hypoxic ischaemic encephalopathy  Birth trauma | Trauma  Current or previous Infection including meningitis/sepsis  Seizures  Episodes of hypoglycaemia |

Other past medical history: co-existing infections (acute or chronic), co-existing chronic conditions (particularly neurological), severe malnutrition

Social history: parental consanguinity, familial relationships, environmental stress, neglect, health and development of siblings

Family history: DD, neurological conditions, learning difficulties, genetic disease

## Examination findings

### Growth parameters:

* Measure and plot head circumference on appropriate standardised WHO growth chart.
* Measure weight and height/length. Calculate weight-for-height Z score (WHZ score < -3 = severe acute malnutrition).

### Thorough developmental assessment:

* Examine all domains (gross motor, fine motor, language, socioemotional and cognitive skills).
* If equivocal then follow up every 3-6 months with repeat clinical/dysmorphology and developmental assessments over time

### Detailed top-to-toe examination:

* Dysmorphism and congenital abnormalities
* Head shape (including fontanelle) and facial features
* Skin and cutaneous stigmata
* Spine
* Abdomen – check for organomegaly
* Limb abnormalities
* Genital abnormalities
* Abnormal neurological (especially tone) or cardiovascular examination

### Hearing and vision assessment:

Identification and correction of sensory deficits are essential and may provide pointers to the underlying aetiology.

The following features are suggestive of:

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| **Genetic cause/unifying syndrome** | **Metabolic condition** |
| * Any child with moderate/severe developmental delay of unknown cause. * Family history of DD or learning disability. * Parental consanguinity Congenital anomalies, unusual facial features or multisystem problems in addition to DD * Unusual growth parameters e.g. microcephaly or macrocephaly, short or tall stature, failure to thrive or severe obesity. * Sensory problems or odd behaviour | * Family history of DD or learning disability * Previous history of sudden infant death * Parental consanguinity * Regression * Abnormal head size * Organomegaly * Coarse features * Seizures * Abnormal neurology including hypotonia or movement disorder |

## Key principles of management

* Exclude reversible causes:
  + Infection (acute or chronic e.g. TB)
  + Undernutrition/failure to thrive
  + Social difficulties e.g. neglect, family isolation, maternal depression
  + Iron deficiency anaemia,
  + Hypothyroidism
* Prevention/amelioration of comorbidities, particularly nutritional.
* Anticipate child needs and initiate multidisciplinary networks early.
* Parental counselling and pychosocial support is very important.
* Regular follow up and continue monitoring developmental progress/regression.

Where tests and treatments are not available at CSD or in Gambia, consider referral to Dakar if the parents are able to afford this (but remember to make it clear when making a diagnosis will not change outcome, as parents may spend their last money on this if they are not properly counselled).

## Investigations

Indications for further investigations are:

* Severe delay: Development <50% of expected milestones at that chronological age
* Global delay: Significant delay affecting 2 or more domains of development
* Any plateauing or regression of development

### First line investigations:

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| *Bloods* | FBC, Urea and creatinine, Electrolytes including HCO3   * Calculate anion gap (Na + K – Cl – HCO3) 🡪 normal anion gap is 8-16 mEq/L * If the anion gap is high then consider metabolic acidosis (+/- underlying metabolic disorders)   Fasting blood glucose, AST, ALT, bone profile, uric acid, lipid profile, creatine kinase (CK)  Thyroid function tests: TSH, free T4  Other tests not available at CSD: Vitamin B12, lead level, lactate, iron studies |
| *Serology for congenital infections* | Syphilis (RPR/TPHA) and HIV1+2  Other tests not available at CSD: Toxoplasma, cytomegalovirus, rubella |

### Second line investigations:

These depend on clinical assessment and availability. Tests in bold are currently available in CSD.

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| *Special blood tests (if*  *available)* | Genetic tests: Karyotype and microarray  Metabolic tests (in addition to 1st line above):   1. Blood: ammonia, serum amino acids, VLCFA, white cell enzymes 2. Urine: organic acids, glycosaminoclycans (MPS screen)   **Infection screen:** ESR, microbiology if suspect chronic infection, TB investigations (if +ve history) |
| *Plain imaging (X Rays)* | **Chest XR:** if chronic infection or malignancy suspected  **Limb XR**: useful if the child has limb abnormalities  **Skull XR:** Useful if abnormal sutures and cranial shape suspected (e.g. craniosynostosis) |
| *Neuro-imaging* | Neuroimaging should be done if abnormal head circumference (microcephaly, non-familial macrocephaly, rapid change in head circumference), focal neurological signs, seizures   1. MRI brain: gold standard 2. **Cranial ultrasound:** may be useful to assess intracranial pathology in an infant (if anterior fontanelles not closed) 3. CT head: only request if intracranial calcifications suspected (Toxoplasmosis, CMV) 4. EEG: If seizures, speech regression, neurodegeneration/regression |
| *Ultrasound* | **Abdominal ultrasound** is useful if multiple congenital abnormalities or hepatosplenomegaly on examination to exclude intraabdominal organ abnormality |
| *ECHO* | **ECHO** if multiple congenital abnormalities or dysmorphic features to exclude cardiac lesion |

## Management of co-morbidities

**Congenital abnormalities:** see details of cleft surgical and orthopaedic teams below.

**Sensory abnormalities (hearing and vision):** see contact details below

**Contractures/hypotonia:** consider diazepam usually before bedtime (will help with discomfort), refer for physiotherapy support at Banjul, EFSTH.

**Seizures:** consider starting anti-epileptic medications e.g. carbamezapine or sodium valproate (avoid in women of child bearing age), refer to epilepsy guideline MeG-CLS-056.

**Malnutrition** (including obesity) or failure to thrive:

* Dietary advice should be given to parents
* If severe acute malnutrition (WHZ score < -3): refer to WHO malnutrition guidelines including supplementation and antibiotics; may need admission
* If undernourished but not SAM, give dietary advice and refer to local clinics for nutritional support

Ensure **vaccinations** up to date and regular anti-worming treatment.

**Gastro-oesophageal reflux:**

* High index of suspicion if poor swallow evident (e.g. ++ mouth secretions), neurological abnormalities, recurrent vomiting especially post feeds, recurrent chest infections.
* Consider Omeprazole +/- Ranitidine PO (refer to BNF for children for doses).
* Consider aspiration pneumonia as a differential for children with DD and poor swallow presenting with infective LRI symptoms.

**Neurodevelopmental support:**

There is little medical support available in the Gambia, but if parents can afford referral to Dakar, then the following criteria should be used to guide this:

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| **Features in the history** | * Regression or possible regression including significant change in behaviour * Possible or definite seizures * Movement disorder: continuous or paroxysmal * Muscle pain/fatigue * New onset sensory impairment e.g. significant decline in visual acuity * Cognitive decline/behavioural change in a child with epilepsy or ASD |
| **Examination findings** | * Neurological signs: dystonia, ataxia, movement disorder, for example, chorea, focal signs, cranial nerve signs, muscle weakness/signs of a peripheral neuropathy, arthrogryposis/joint contractures, CP picture without a clear cause/history * Other signs: sensorineural deafness * Neurocutaneous features * Organomegaly/cardiomegaly * Course or dysmorphic facial features * Cerebral palsy |

## Multi-disciplinary care and services

All referrals should be made on headed MRC paper (or from an MRC email):

* Epilepsy support: Support for children with epilepsy: The Gambia Epilepsy Association, [gambiaepilepsy@yahoo.co.uk](mailto:gambiaepilepsy@yahoo.co.uk), +220 994 9034/ 995 5418
* Cleft team: Smile Train charity offers free cleft surgery annually at the polyclinic EFSTH, Banjul, contact Dr Okafor +220 999 6487, Papis Sanneh +220 993 1506, Perannans +220 715 1055
* Dental team: polyclinic EFSTH, Banjul
* Orthopaedic team: Outpatient department EFSTH, Banjul. Clinic is usually held on Wednesday mornings.
* Physiotherapy: EFSTH paediatric daily outpatient clinics (they will liaise with Department of Social welfare who provide support from occupational therapy e.g. provision of mobility aids, wheelchairs)
* Schools: encourage parents to enroll children into educational system (either mainstream or special needs depending on level of disability)
  + Respite care home/school for children with learning difficulties (Eastern Gambia): Hart Foundation, Serrekunda, [geoffharthouse@yahoo.com](mailto:geoffharthouse@yahoo.com), +220 9926258
  + Rural support organization for the disabled, Basse, +220 566 8101, [rsodgambian@gmail.com](mailto:rsodgambian@gmail.com)
* Support for children with physical disabilities: Gambia Association of the Physically disabled; also organizes sports activities and support groups – contact [gambiadisabledsports@yahoo.co.uk](mailto:gambiadisabledsports@yahoo.co.uk), +220 992 3377/ 7790158/ 9983480
* Hearing difficulties:
  + Audiology at the polyclinic at EFSTH, Banjul
  + St John’s School For the Deaf, Kanifing [stjohnsdeafgambia@hotmail.com](mailto:stjohnsdeafgambia@hotmail.com), Daniel Mendy on +220 779 0286
* Visual difficulties:
  + Sheikh Zayed Eye care centre, Kanifing +220 996 7049/ 208 8707 (includes 2 visits per year by ophthalmology NGO Eye Care Gambia [www.eyecaregambia.com](http://www.eyecaregambia.com))
  + Fresh Start Foundation, Brikama, [info@fsfgambia.org](mailto:info@fsfgambia.org)
  + Sightsavers, Kairaba Avenue
  + Gambia Organisation For The Visual Impaired (GOVI) and School For the Blind, Kanifing

## Psychosocial support

Prepare, educate and support parents. It is important to tackle concerns around stigma and misunderstanding of aetiology of disease (e.g. supernatural causes).

Counselling:

* Discuss parental concerns and expectations (refer to support organisations above).
* If suspected genetic or metabolic disease – discuss likely recurrence risk for future pregnancy (+/- family planning options).
* Children with disabilities and DD often cannot communicate their pain or problems in the same ways as children without DD, therefore, advise parents to have a low threshold for seeking medical review (especially if unsettled/discomfort/pain/infective symptoms)

Support for literate parents:

* <https://www.parentcenterhub.org/dd/>
* <https://parent2parent.org.nz/developmental-delay-dd-diagnosis-and-prognosis/>
* <https://specialneedsjungle.com/help-parents-worried-childs-development/>

## Follow up

Every 3-6 months depending on clinical need.

* Aim to repeat developmental assessment at every visit to monitor progress/regression
* Detailed history and examination including head circumference and other growth parameters (ensure plotted on WHO growth charts)
* Assess for other comorbidities (may need medications e.g. for seizures or hypertonia)
* Clarify baseline at each appointment to check progress/deterioration
* Explore parental ideas, concerns and expectations

## Key Issues for Nursing care

* Be sensitive to looking after a child with disability or developmental delay and aware of potential limitations to movement and communication.
* Clarify baseline at the start of admission so that any change or deterioration can be easily recognised (note that children with DD may not be verbal and may convey any pain or discomfort in an unusual way).

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| **Written by:** | Name: Anja Saso | Date: 30 November 2018 |
| **Reviewed by:** | Name: Baderinwa Abatan | Date: 29 April 2019 |
| **Version:** | **Change history:** | **Review due date:** |
| 1.0 | New document | 31 May 2021 |
| Review Comments (*if applicable)* |  |  |