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# Can We Improve the Care of Children With Disabilities?

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# Objectives

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- ❑ What are the problems facing children with disabilities?
  - ❑ What do we need to do?
  - ❑ How can we improve care in low resource settings?
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# Problems for Children with Disabilities

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## Physical handicaps

### ■ Motor skills

Locomotion

Upper body

### ■ Communication

Developmental delay

Hearing

Speech

Autism

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# Special Problems for Children with Disabilities

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- Hidden by the family
  - Ignored by professionals
    - Needs aren't understood
    - The patient may be difficult to take care of and/or communicate with
  - Cost of care and education
  - Lack of access to professionals who have experience or interest in taking care of these problems
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# Special Needs for Children with Disabilities in Low Resource Countries

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- ❑ Lack of trained personnel
  - ❑ Cost of care for children with special needs
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# Audiological Needs for Children with Disabilities

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- ❑ Hearing is vital for speech development
  - ❑ Need for good audiological evaluation with expertise in pediatric audiology and working with children with special needs
  - ❑ Need for early detection
  - ❑ Need for rehabilitation
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# What are the Consequences of No Hearing?

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- No communication
  - No language (speech)
  - Without language how do you describe something or even think?
  - Safety issues
    - Can't localize sounds
    - Can't hear warnings from individuals or horns
    - Can't hear vehicles coming
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# Early Diagnosis

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- The most important thing is for a child with any hearing loss, but especially severe to profound hearing loss to be identified and treated as early as possible.
  - The primary goal of aural rehabilitation is enhanced communication skills
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# Effect of Hearing Loss on Speech and Language Outcome

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- Several recent prospective trials, found no correlation between OME and language development
- Almost all developmental research in OME has excluded high-risk children
- Prospective trials collect otherwise healthy kids with intermittent, short-term or unilateral OME that was identified by intense screening

*Paradise NEJM 2001;344:1179-87*

*Paradise J Pediatrics 2003;112:265-277*

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# High-Risk Kids with OME

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- Kids with co-morbidities will need intervention sooner and more often:
    - Cleft palate (overt, submucous)
    - ADD,ADHD
    - Speech/Language delay
    - Autism spectrum, PDD
    - Syndromic/craniofacial disorder
    - Psychomotor retardation, sensory deficits, intellectual or cognitive impairment or school problems
    - Sensori-neural hearing loss
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# Reasons For Delayed Diagnosis

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- Parental reluctance to investigate
  - Primary physician
    - “Overanxious parent”
    - Natural slow development
    - Reliance on crude tests
    - Reluctance to refer
  - Lack of adequate
    - Tests
    - Testers
    - Facilities
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# One Attempt to Improve Care for Children with Disabilities in Kenya

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- Recognition of a lack of trained personnel, especially in the district hospitals and rural areas by a Kenyan neurodevelopmental pediatrician in 2008
  - Her vision/goal was to provide training and improvement of skills for professionals working with children with disabilities
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# Vision/Goals

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- ❑ A conference to upgrade skills of professionals working with children with disabilities
  - ❑ Improve recognition of problems and earlier treatment for best results
  - ❑ Cross train professionals in speech therapy, occupational therapy, physical therapy and audiological assessment in district hospitals
  - ❑ Train a cadre of professionals to give the course and then train colleagues in provincial and district hospitals
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# Approach

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- One week seminar stressing care of children with cerebral palsy, developmental delay and autism
  - Team from Medical Education International
    - Developmental pediatrician
    - Speech therapist
    - Physical therapist
    - Occupational therapist
    - Teacher of special needs children/social worker
    - Pediatric otolaryngologist
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# Seminar

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- Location – Children’s hospital in Nairobi with a dedicated clinic for children with disabilities
  - Content
    - Normal development
    - Lectures on recognition, differential diagnosis and treatment of CP, DD and autism
    - In depth workshops with patient presentations and hands on practice of techniques
      - Sessions for specific specialists
      - Sessions for other specialties to learn basic skills
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# Attendees

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- 2010 – 60 attendees from 4 different countries and several Kenyan provinces
    - Physical therapists
    - Occupational therapists
    - Physicians
    - Speech therapists
    - Teachers of the deaf
    - Special needs teachers in the schools
    - Audiologists
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# Results

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- Attendees were very enthusiastic and felt they had gained much from the seminar
  - One year later
    - Average age of referral for children with disabilities to the Children's hospital dropped from 8 years of age to 3 years of age
    - One PT from a provincial hospital reported using basic skills in ST which he had learned at the seminar to treat the patients with disabilities he was seeing for PT needs
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# Future Plans

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- Yearly visits, but next year at least half of the lectures will be given by Kenyan professionals
  - By 2014 have the Kenyans give the entire seminar and then take the seminars to the Provincial hospital level
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# Summary

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- ❑ For visiting teams from high resource countries to be successful there has to be training and transfer of skills consistent with the countries needs and resources available, plus repeat trips
  - ❑ Encourage national professionals to train others and share their skills with others throughout the country
  - ❑ This does not require a lot of expensive equipment
  - ❑ Can improve diagnosis, early referral and improved outcomes for children with disabilities
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