

# Early identification and screening

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# Golu's Story



- Golu is a 7 year old from a small village called Konou near Allahabad
- At 2 1/2 yrs she had fever with seizures which could not be treated at the village
- She was then taken to Allahabad where after 5 days in a hospital she returned unable to speak or comprehend
- When her parents realized that her regression was not temporary, they went back to Allahabad and remained in the hospital for a month.
- The hospital room cost Rs 1000 a day depleting the resources of the poor farming family

- She was given injections and several bottles of saline by the doctors
- Finally a relative suggested they come to Mumbai where they had friends
- At Ummeed she was diagnosed with autism and behavior therapy begun
- She now has learnt a few signs and to feed and dress herself
- The family lives with some friends in a small room in the slums. Golu's father drives an autorickshaw. They can't wait to go back to the village.....

# Diagnosis In India

- Singhi & Malhi, PGIMER Chandigarh (2001) - Total no of children diagnosed with autism below age 5, Nov 97 to Jun 99 was 16
- Kalra et al, All India Institute of Medical Sciences(2005) 62 patients with autism in 1 year
- Juneja et al, Maulana Azad Medical College, Delhi (2005). 51 patients with autism in 2 years

*There are an estimated 4 million children with autism in India*

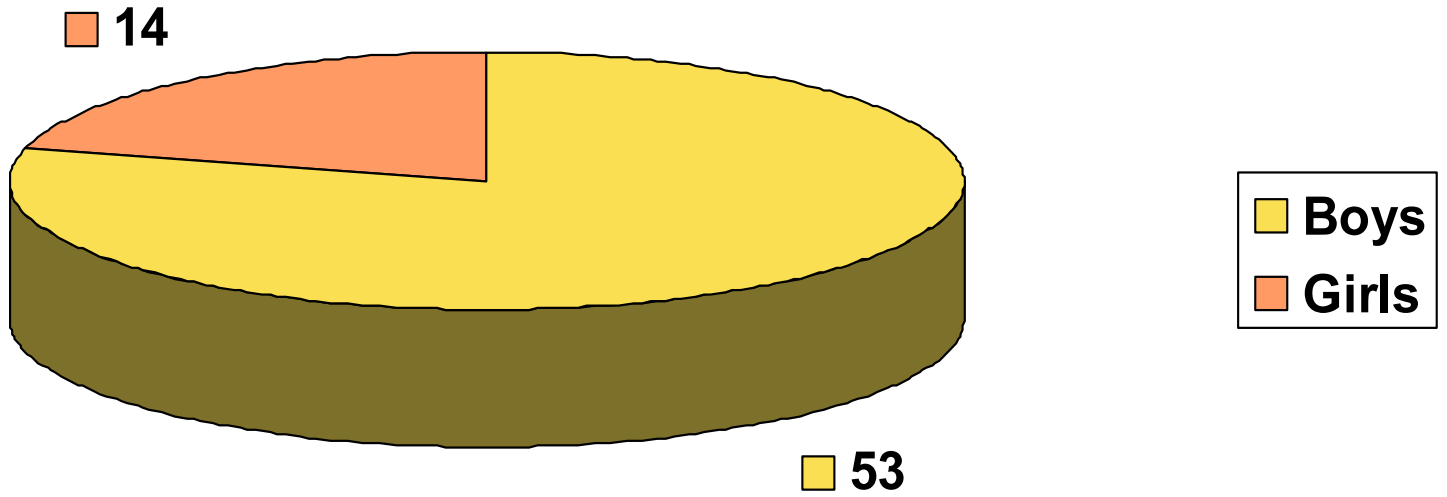
# The Journey to Diagnosis

- Mean age at which parents first develop concerns – 25.7 months
- Mean lag before parents sought help - 7.1 months
- Mean age at first diagnosis of Autistic Spectrum Disorder – 4 years and 11 months

( Daley 1999, Study of 95 families from 4 metros)

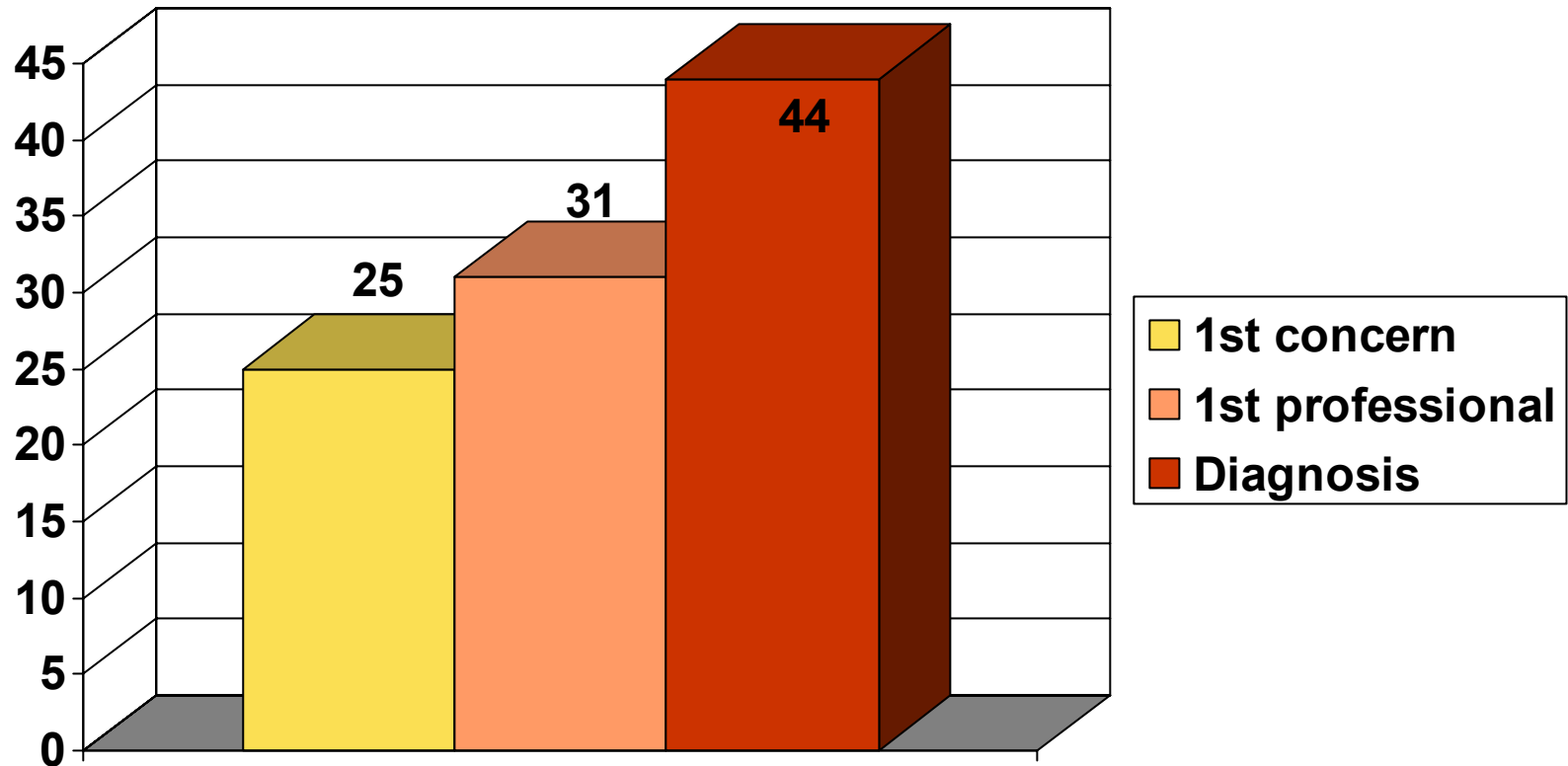
# Services for Children with Autism in Mumbai

## Ummeed Child Development Center

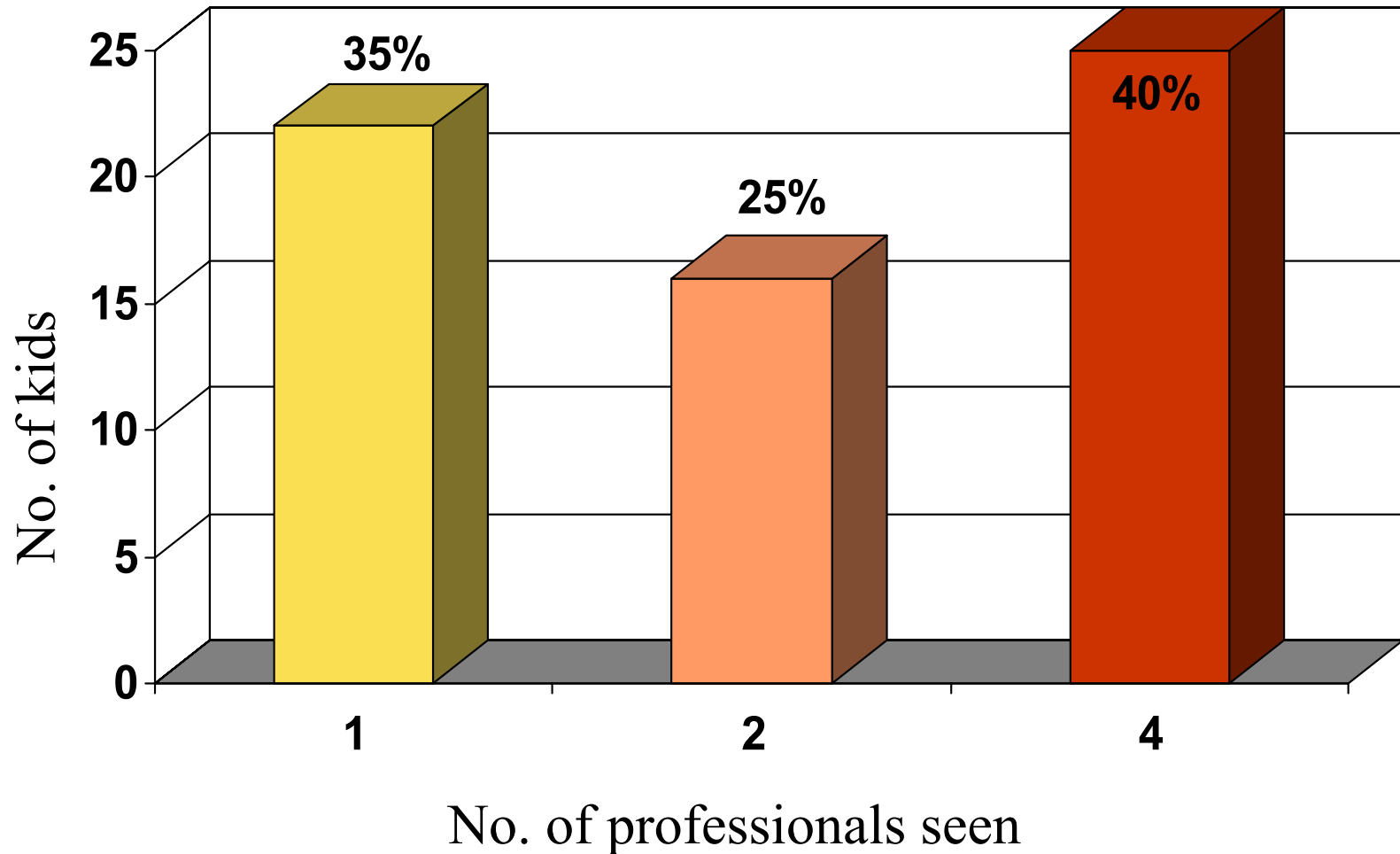


Boys: Girls:: 3.79:1

# Mean Age ( months) at diagnosis



# No. of Professionals Seen Before Diagnosis



# Possible Contributors to Late Diagnosis - *The Eye Does Not See..*

Daley ( 2002) - study of psychologists, psychiatrists and pediatricians

- 2/3rd believed autism is a 'rare disorder'
- Language delay often not perceived as essential to diagnosis
- Belief that the 'male Indian child speaks late' — parents and professionals
- Criteria for 'language delay' vary (Daley & Sigman)

# Screening - Q & A

What does it do?

- Developmental screening – Aims to identify children who need a comprehensive assessment

# Why

- Early identification implies early intervention
- Data supporting early intervention particularly strong for ‘at risk’ populations and some disabilities – e.g. autism
- Early intervention improves outcomes in the ‘social model’ – significant benefits wrt family acceptance, inclusion in schools

# Where

Wherever we can find parents of young children

- Anganwadis,
- maternal and child health clinics
- preschools, primary schools( EI for Learning disabilities and ADHD)
- workplaces
- places of worship

# With What

- The Ten Question Questionnaire with or without probes
- Documented to be an effective, sensitive screening tool in many developing countries
- Does not require extensive training or expertise in disability
- Even developed countries have recognized the superior sensitivity of parent reported questionnaires (e.g. PEDS, ASQ)

# Who

- Anganwadi workers
- Village Health Workers
- Teachers
- Parents of children with disabilities accessing services – often effective advocates, sensitive to needs of parents, can be a nidus for SHGs
- Field workers from NGOs working with other health/education related issues in these populations

# What Next

- Diagnostics – the real challenge
- Urgent need to train professionals to administer Phase 2
- Need to include disability in the curricula of medical schools, nursing schools, degrees in psychology, education, social work
- Involve NGOs and private practitioners with expertise
- Offer CMEs and Bridge courses for those in practice

THANK YOU!

