



Audit of Health Supervision Services for Children with Down Syndrome

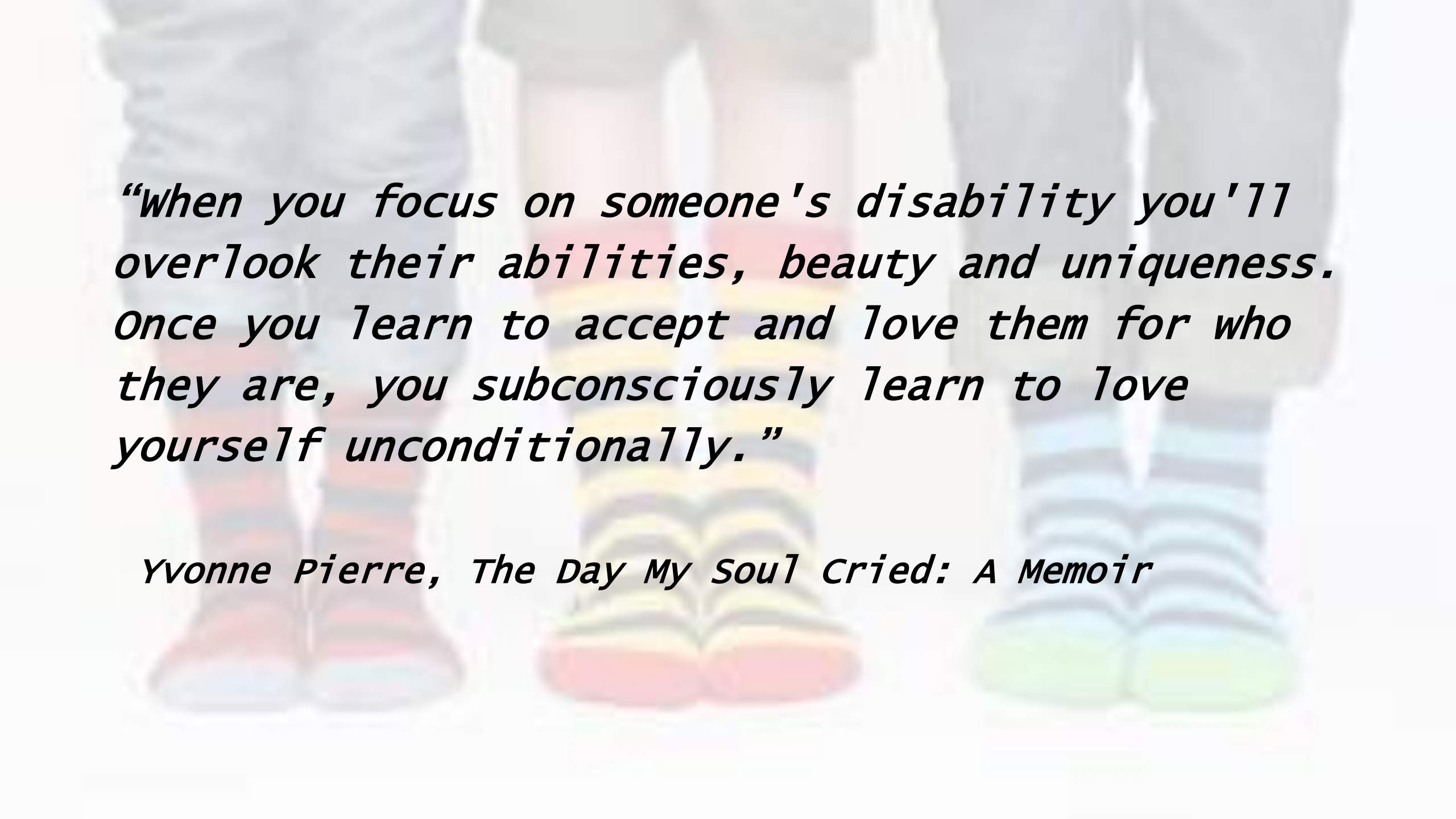
Community Paediatrics SWRHA

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“When you focus on someone's disability you'll overlook their abilities, beauty and uniqueness. Once you learn to accept and love them for who they are, you subconsciously learn to love yourself unconditionally.”

Yvonne Pierre, The Day My Soul Cried: A Memoir



AIM of Audit

To appraise health supervision services available
within SWRHA for the long term
management of children with Down Syndrome (DS)

AAP GUIDELINES FOR DS

- The following outline is designed to help the paediatrician provide care for children with Down syndrome & their families
- It is organized by the issues that need to be addressed in various age groups & throughout childhood

AAP GUIDELINES FOR DS

Several areas require ongoing assessment throughout childhood and should be reviewed periodically at developmentally appropriate ages

AAP GUIDELINES 2011: Health Supervision

- Birth - 1 Month
- 1 Month - 1 Year
- 1 Year - 5 Years
- 5 Years - 13 Years
- 13 Years - 21 Years or Older

Assessment through childhood

The background of the slide features a blurred image of three children's legs and feet. The child on the left is wearing grey pants and brown shoes with red and blue striped socks. The child in the middle is wearing red pants and yellow and black striped shoes with yellow and black striped socks. The child on the right is wearing grey pants and blue and white striped shoes with blue and white striped socks.

- Personal support available to family
- Financial & medical support programs
- Supplemental Income benefits
- Injury & abuse prevention with special consideration of developmental skills
- Diet & exercise to maintain appropriate weight

BIRTH - 1 MONTH

- Confirm diagnosis with a karyotype
- Discuss & review : hypotonia, facial features

BIRTH - 1 MONTH

Feeding

Squint &
cataracts

Hearing loss

Heart defects

Duodenal
atresia

Leukemia

Constipation

Respiratory
Tract infection

Hypothyroidism

BIRTH - 1 MONTH



Heart defects - Perform ECHO
Feeding issues -Radiographic assessment
Eyes – check for red reflex & squint
Hearing loss – perform hearing tests (OAE, BAE)
Duodenal atresia/ anorectal atresia- history & clinical exam

Heart defects - Perform ECHO

Feeding issues -Radiographic assessment

Eyes – check for red reflex & squint

Hearing loss – perform hearing tests (OAE, BAE)

Duodenal atresia/ anorectal atresia- history & clinical exam

AAP GUIDELINES FOR DS: BIRTH - 1 MONTH

- Constipation – evaluate for restricted diet, limited fluid intake or GI malformations & Hirschsprung disease
- Gastroesophageal reflux- diagnosed & managed clinically
- Congenital hypothyroidism- Obtain TSH & T4

AAP GUIDELINES FOR DS: 1 month – 1year

- Physical exam & lab studies
- Review risk of otitis media
- Administer pneumococcal vaccine
- TFTs screen : rpt at 6 , 12 months then annually

AAP GUIDELINES FOR DS: 1 month – 1year

- Within the 1st 6 mths – discuss symptoms of obstructive sleep apnoea
- At each visit- discuss the importance of maintaining the C-spine during certain procedures
- Monitor weight & follow weight- for- height trends

AAP GUIDELINES FOR DS: 1 month – 1year

- Within the first 6 mths of life evaluate for squint & cataracts
- Monitor infants with cardiac defects
- Monitor CBC for signs of iron deficiency anemia
- Monitor for signs of neurologic dysfunction- seizures

AAP GUIDELINES FOR DS: 1 - 5 years

- Obtain History & Physical exam
- Monitor risk of OM & hearing Loss
- Check audiogram every 6 months until 3 years if tympanic membranes are not visible

AAP GUIDELINES FOR DS: 1-5 years

- Obtain x-rays between 3-5 years of age to evaluate atlanto-axial instability if symptomatic
- Annual Thyroid & ophthalmological screening
- Discuss symptoms of sleep apnea

AAP GUIDELINES FOR DS: 1- 5 years

- Review early intervention : OT , ST, PT, Preschool, school placement & performance
- Discuss : behavioural issues, discipline ,sibling adjustment, socialization, recreation, diet & physical activity

AAP GUIDELINES FOR DS: 5 -13 years

- History & physical exam
- Annual audiology and ophthalmology screening
- Annual TFTs

AAP GUIDELINES FOR DS: 5-13 years

- Discuss dermatologic complications- especially dry skin
- Discuss sleep apnea
- Monitor growth patterns

AAP GUIDELINES FOR DS: 5-13 years

- For children on a diet that contains gluten, review for symptoms potentially related to celiac disease
- Counsel parents that some sports place children at increased risk of spinal cord injury
- Discuss the need for gynaecologic care in the pubescent girl

AAP GUIDELINES FOR DS: 5-13 years

- Discuss school placement & developmental intervention
- Discuss socialization, family status, financial & guardian relationships
- Discuss sense of responsibility
- Counsel families regarding the transition from elementary to middle school

AAP GUIDELINES FOR DS: 13 to 21 years

- History & physical exam
- Annual audiology screening
- Annual TFTs & CBC
- Annual cardiac evaluation for mitral & aortic valvular disease

AAP GUIDELINES FOR DS: 13 to 21 years

- Discuss dermatologic complications
- Discuss sleep apnea
- Obtain ophthalmologic evaluation every 3 years

AAP GUIDELINES FOR DS: 13 to 21 yrs :

- Transition of Care
- Vocational Training
- Sexuality & Socialization

AAP GUIDELINES FOR DS: 13 to 21 yrs

The background of the slide features a blurred image of three children's legs from the waist down to the feet. The child on the left is wearing grey pants and red and blue striped socks. The child in the middle is wearing grey pants and yellow, blue, and red striped socks. The child on the right is wearing grey pants and blue and white striped socks. The overall image is out of focus, serving as a decorative background for the text.

- Contraception
- Group Homes & Independent Living
- Financial & Guardian Relationships

AAP GUIDELINES FOR DS: 13 to 21 yrs

- Psychosexual Development
- Menstrual Hygiene
- Recurrence risk of DS in female pts

AUDIT



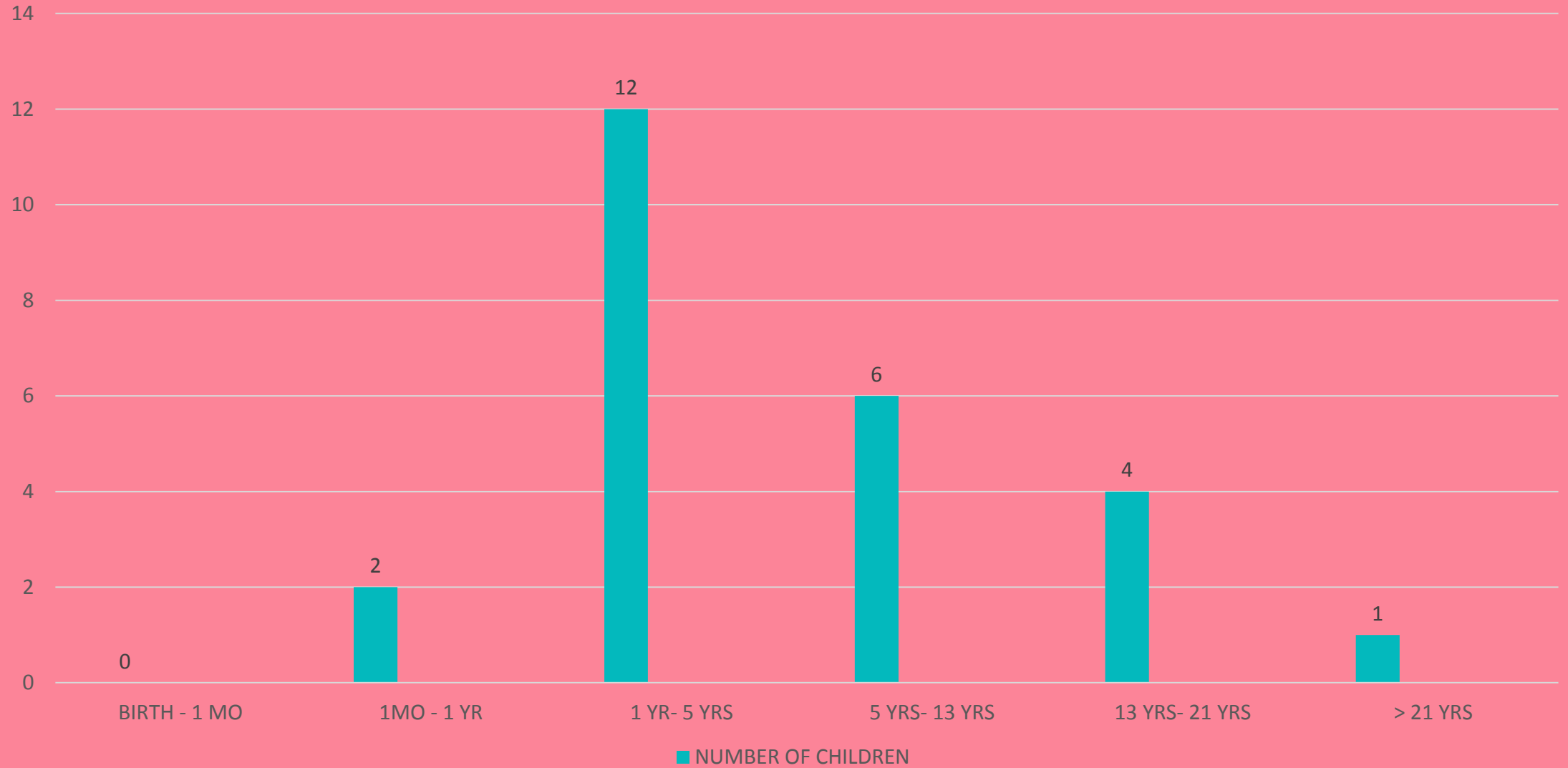
Methodology of audit

- Children diagnosed with DS were selected from the SFGH cardiac clinic database & telephone contact information was obtained
- A Performa was designed to obtain specific information through telephone interviews with parents based on AAP 2011 guidelines highlighting health supervision services for children with DS

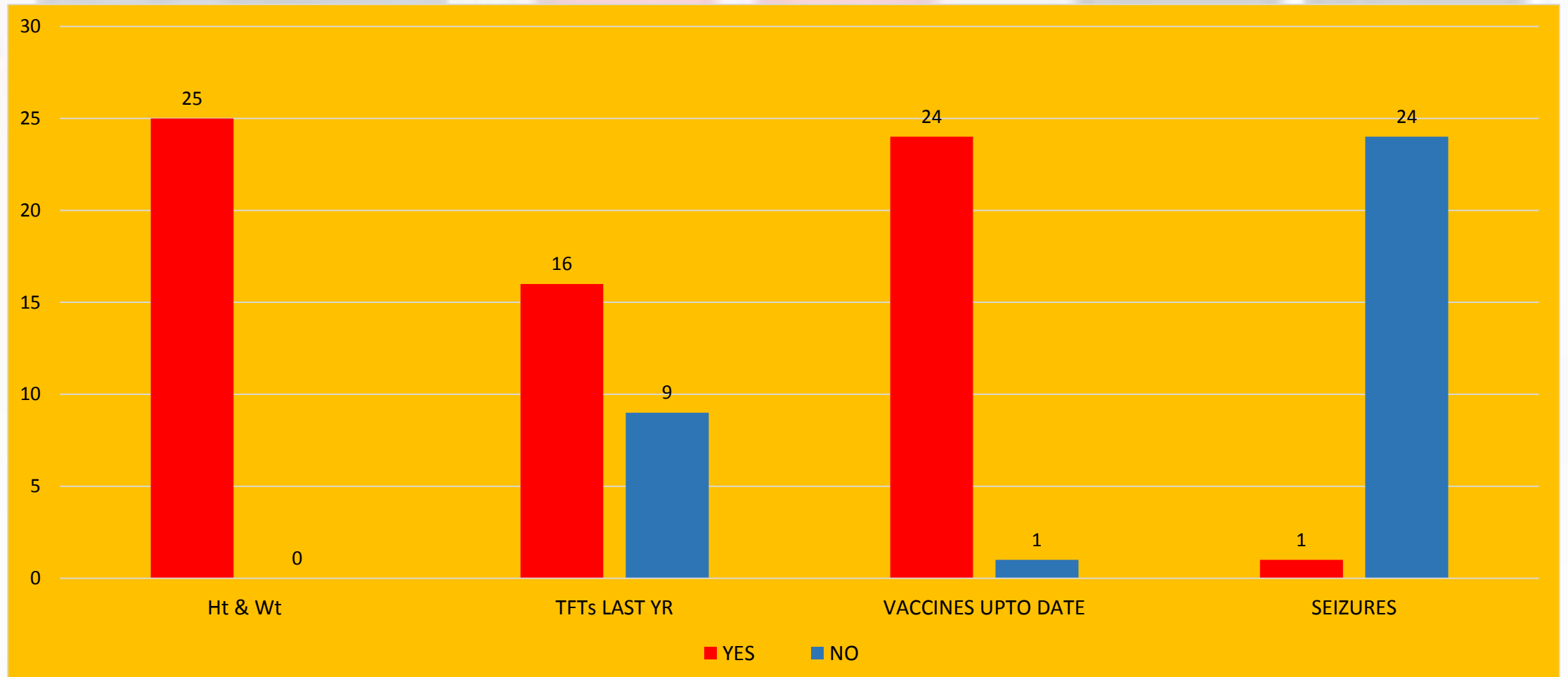
Data Collection

- 37 patient names & numbers were obtained
- From those, 2 were deceased
- 10 patients were unreachable
- 25 parents agreed to participate in the survey

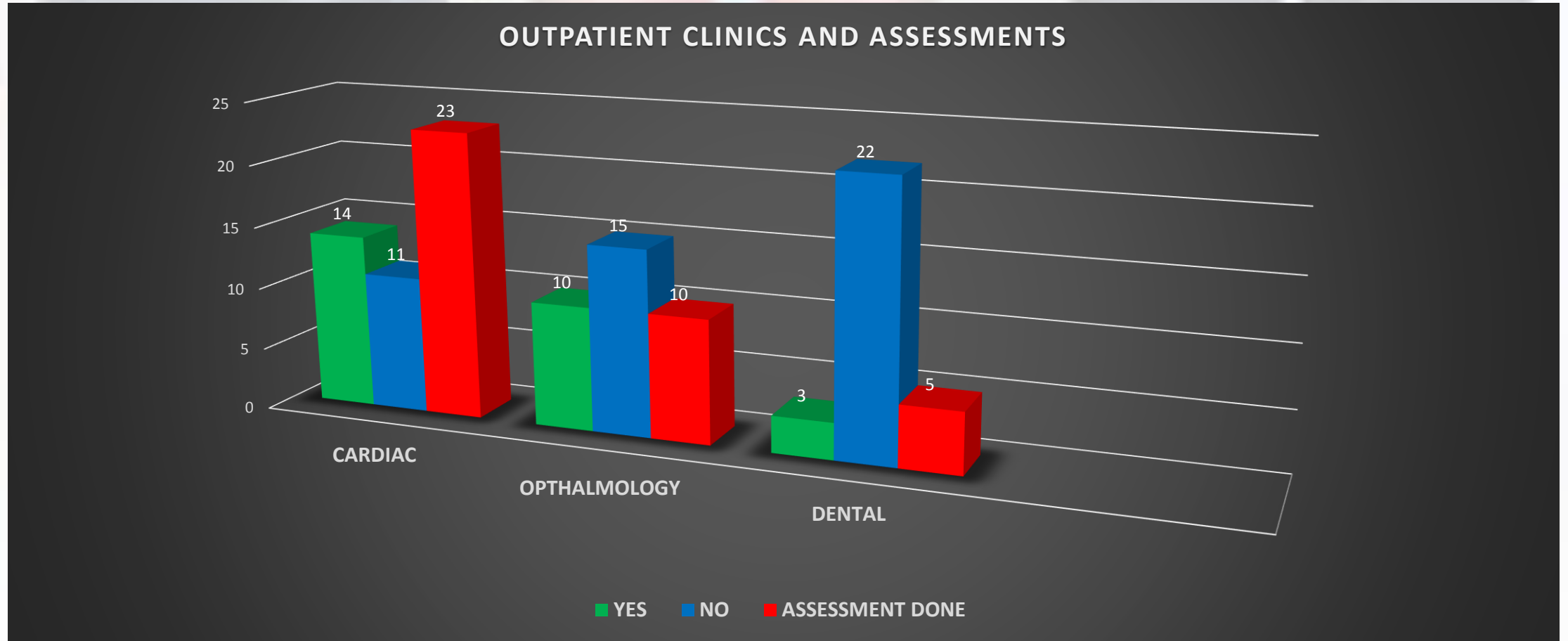
AGES OF CHILDREN INCLUDED IN THE AUDIT



Evaluation of data

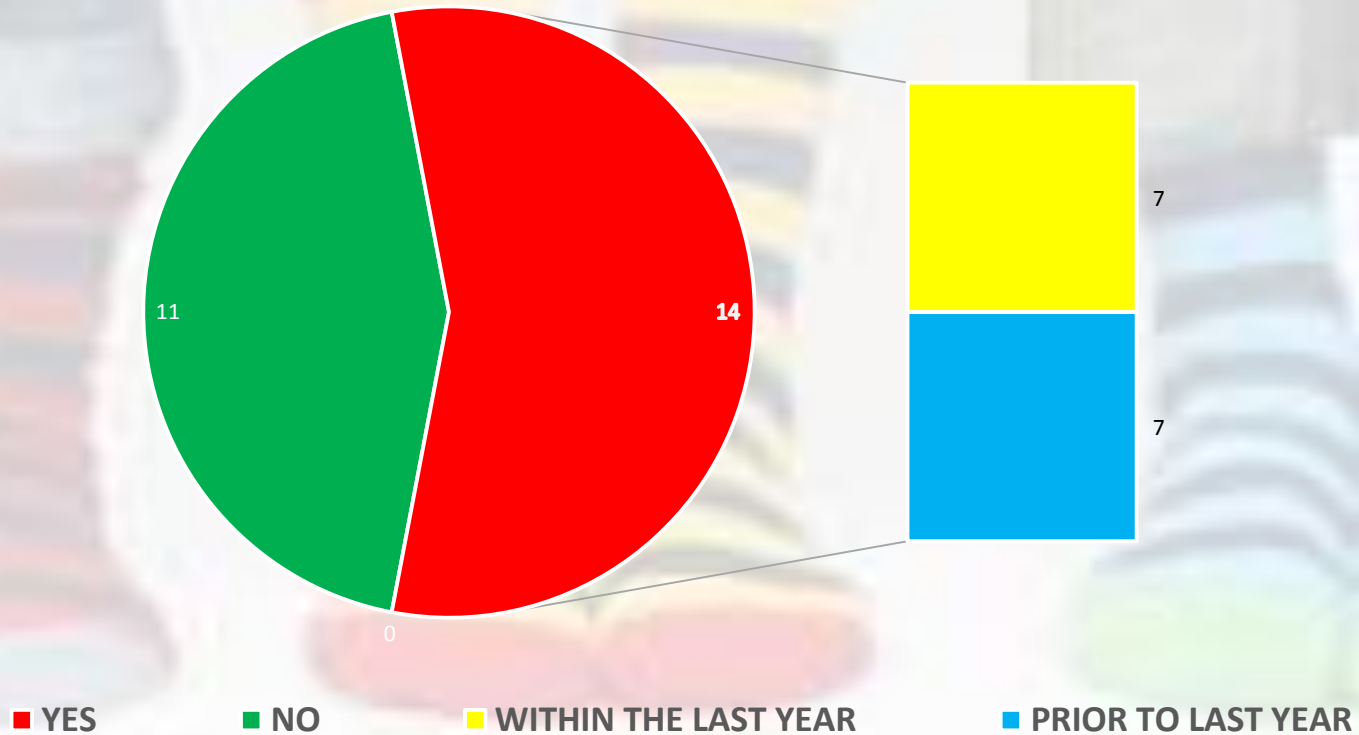


Outpatient Clinics & Assessments

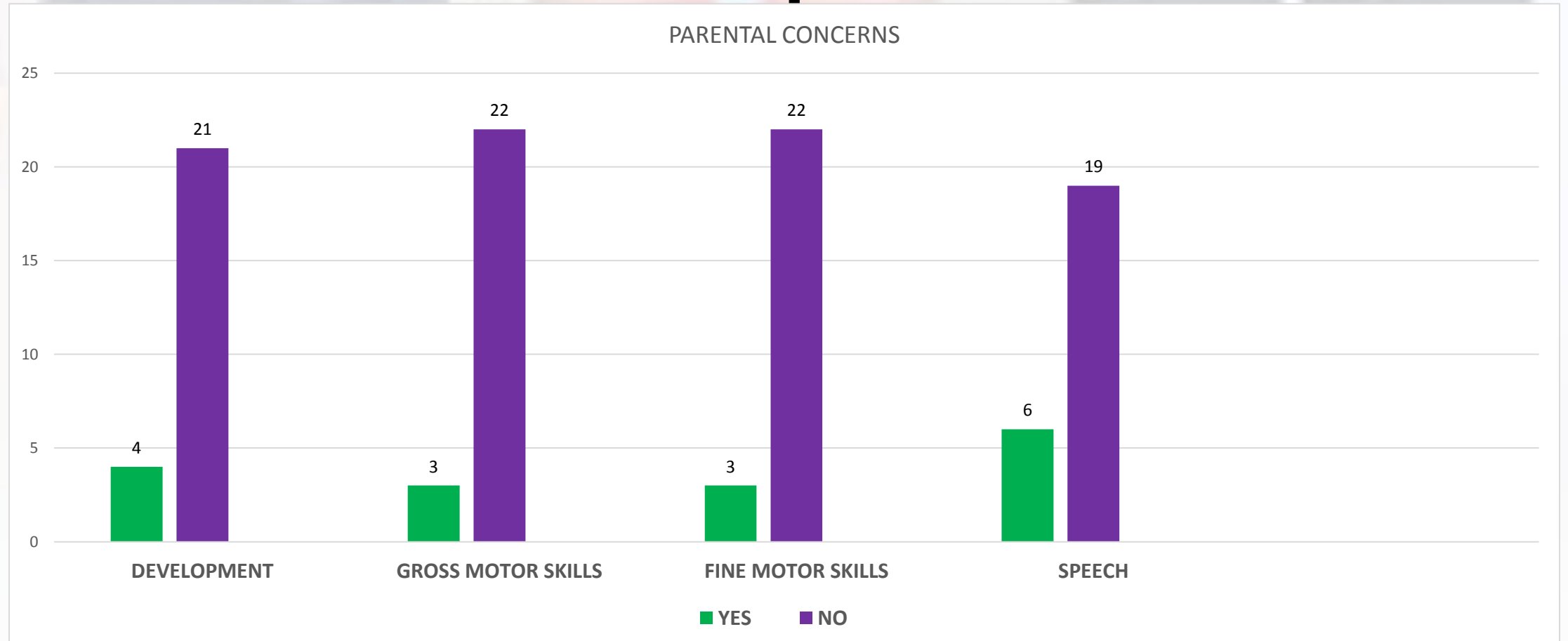


Hearing Assessment

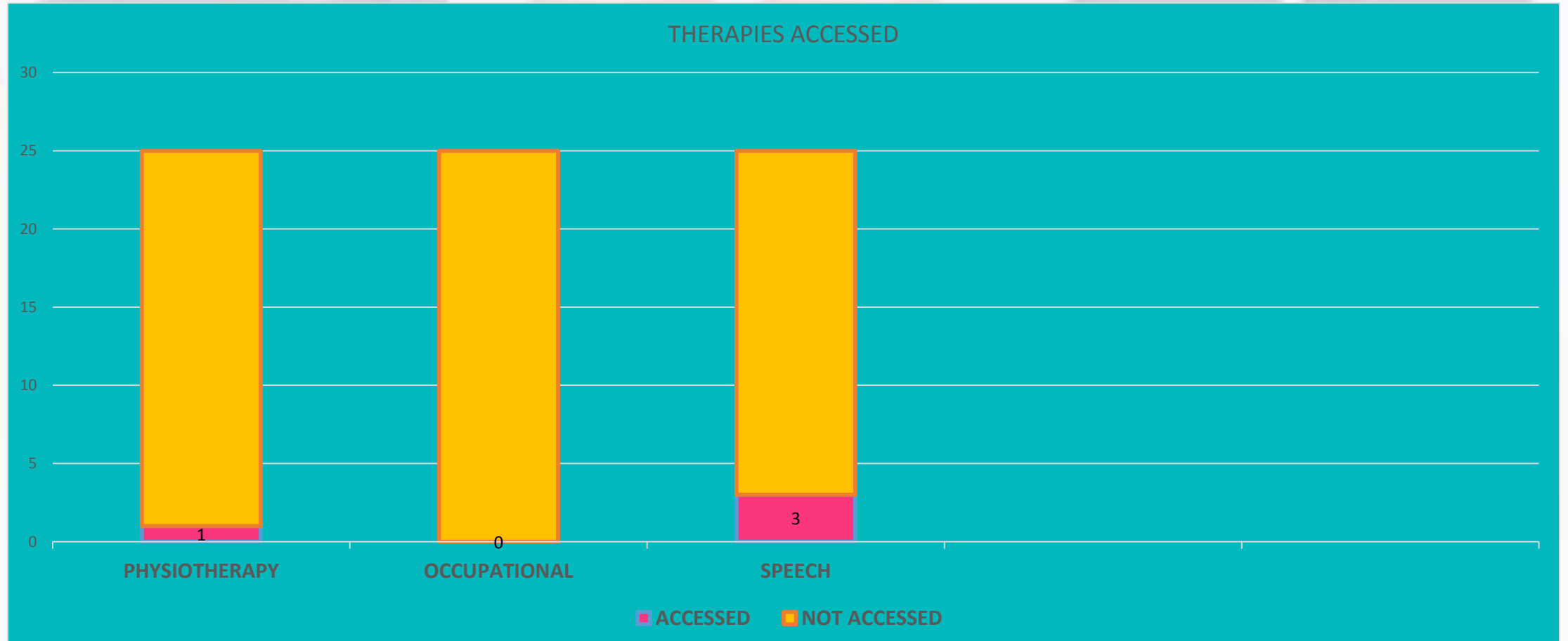
HEARING TEST EVER DONE



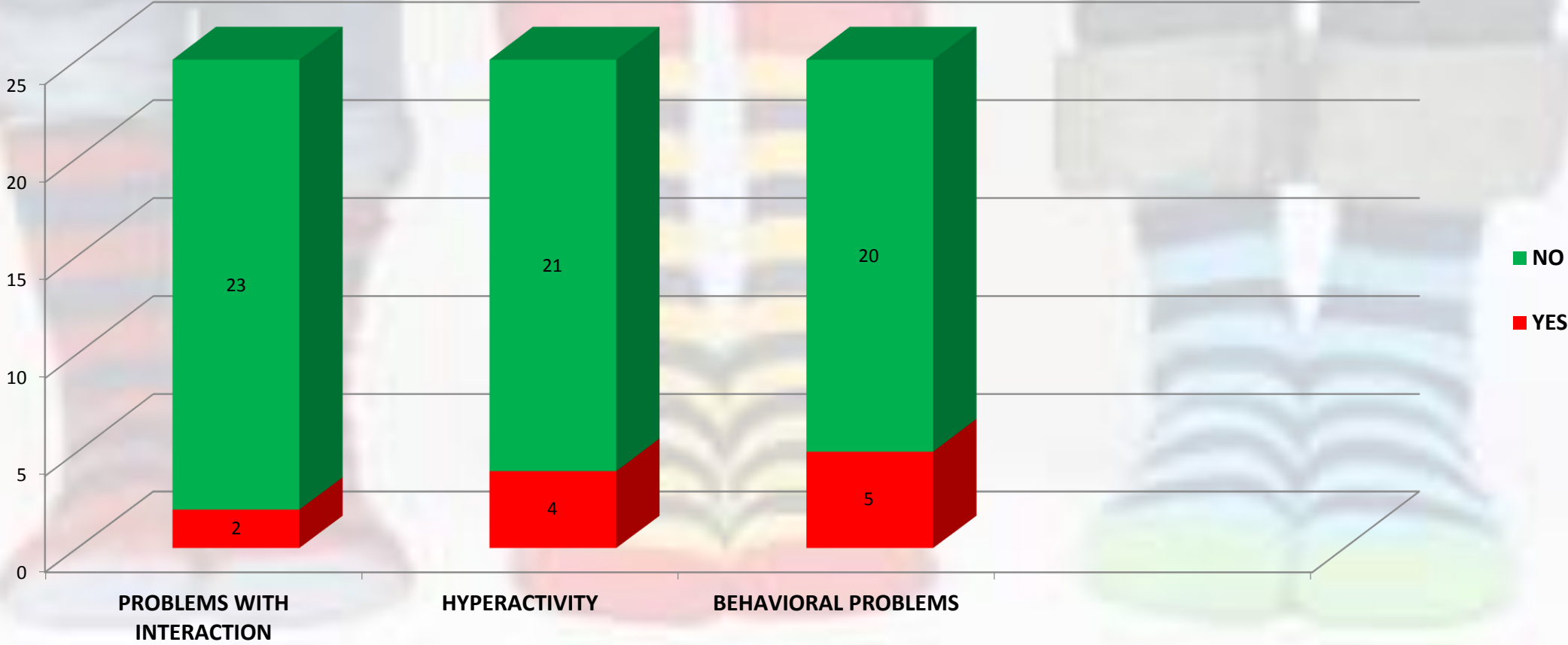
Parental Concern regarding Development



Therapies Accessed

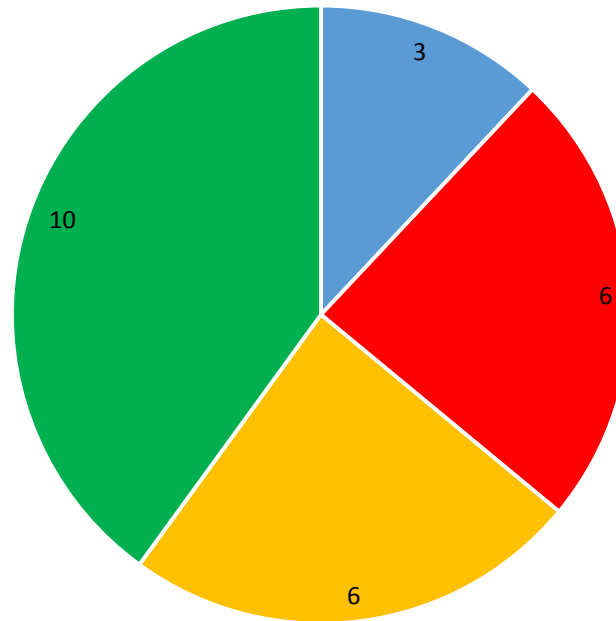


Behavioural & Social Problems



Type of Education

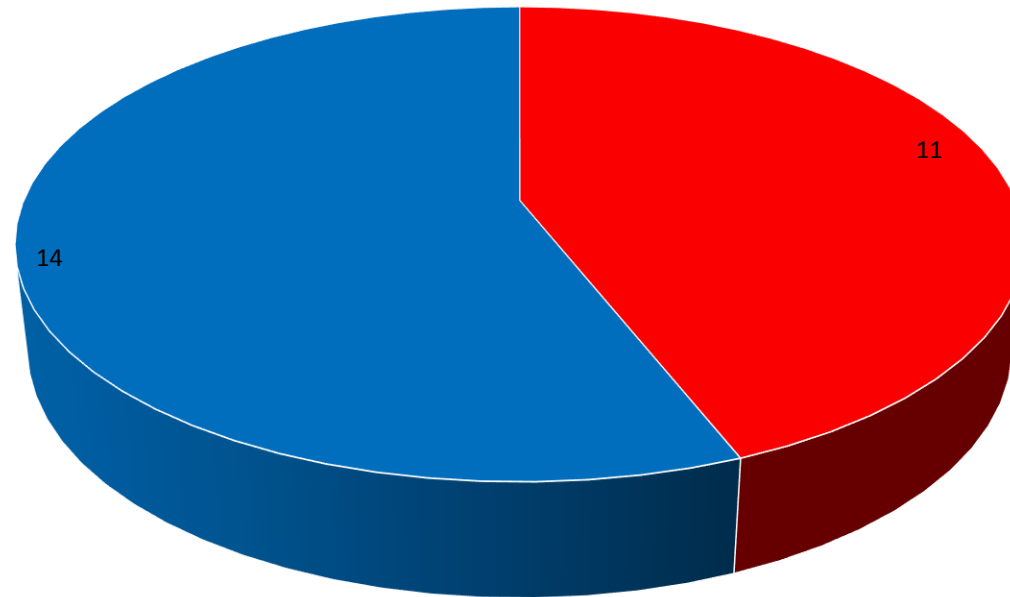
TYPE OF EDUCATION



■ PRESCHOOL ■ SPECIAL SCHOOL ■ HOMESCHOOLED ■ NOT IN SCHOOL

Access to Grants

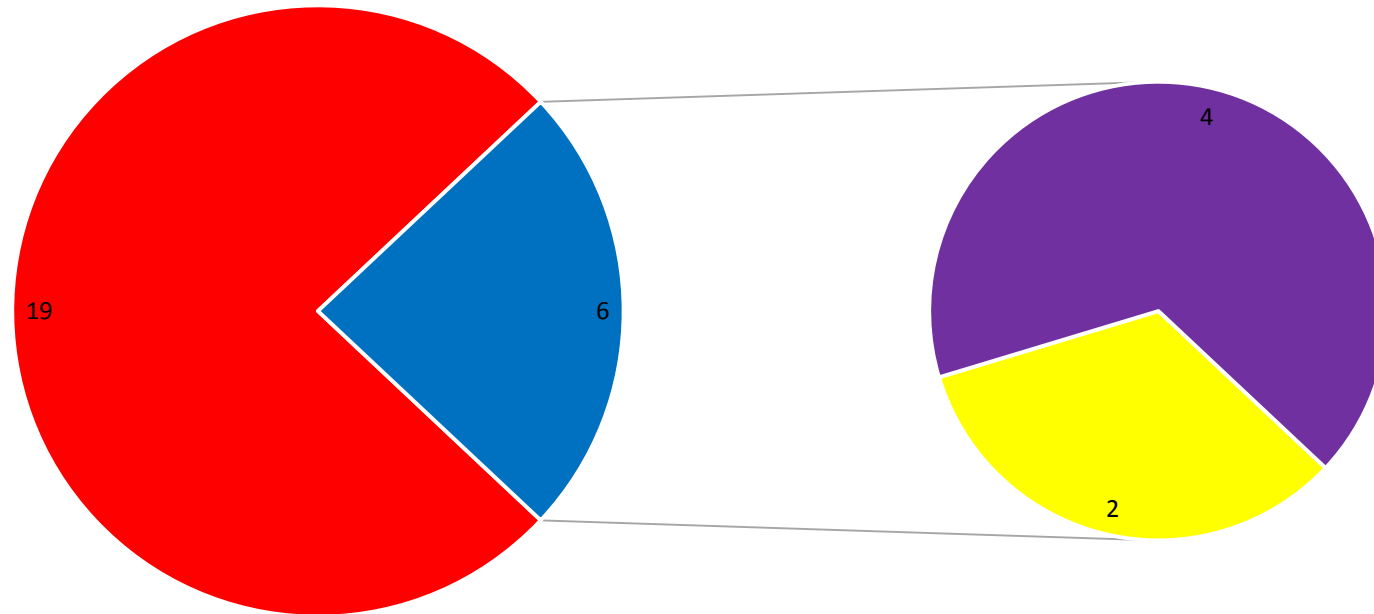
ACCESS TO SPECIAL CHILD/WELFARE GRANT



■ YES ■ NO

Access to Support Groups

ACCESS TO DOWN SYNDROME SUPPORT GROUPS



■ YES ■ NO ■ SOUTH GROUP ■ FAMILY NETWORK

Discussion Points

- Availability of Laboratory Investigations
- Consistency regarding long term follow up for Ophthalmology, ENT, Dental.
- Availability of range of developmentally appropriate hearing tests

Discussion Points

- Parental perception of their child's developmental skills
- Access to basic therapies like Speech and OT
- Availability of specialised training and counselling with respect to transitional care, sexuality, choice of vocation and behavioural issues

Discussion Points

The background of the slide features a blurred image of three people's lower legs and feet. The person on the left is wearing grey trousers and brown shoes with red and blue striped socks. The person in the middle is wearing grey trousers and red shoes with yellow and blue striped socks. The person on the right is wearing grey trousers and green shoes with blue and white striped socks.

- Access to Inclusive Main Stream Education
- Access to Psych-Educational assessments
- Access to Social Welfare supports
- Access to Family Support Groups

Recommendations

- Implement revised standardised checklist in Clinics for long term and holistic health supervision for children with DS.
- Advocate that priority be given for TFTs & other investigations.
- Liaise with other specialties such as ENT, Ophthalmology and Dental regarding guidelines for long term follow up

Recommendations

- Continue Advocacy for developmentally appropriate hearing tests within the public service
- Further studies should be done to assess parents' perception of DS and Quality of Life achievable.
- Continue Advocacy for support services such as Speech, Occupational & Early Intervention Therapy in the public system

Recommendations

- Explore options for further training on counselling as pertains to transitional care, sexuality, choice of vocation & behavioural issues
- Continue to Liaise with Student Support Services regarding Mainstream Inclusion with appropriate supports.
- Continue to advocate for improved accessibility for Psychological Education Assessments

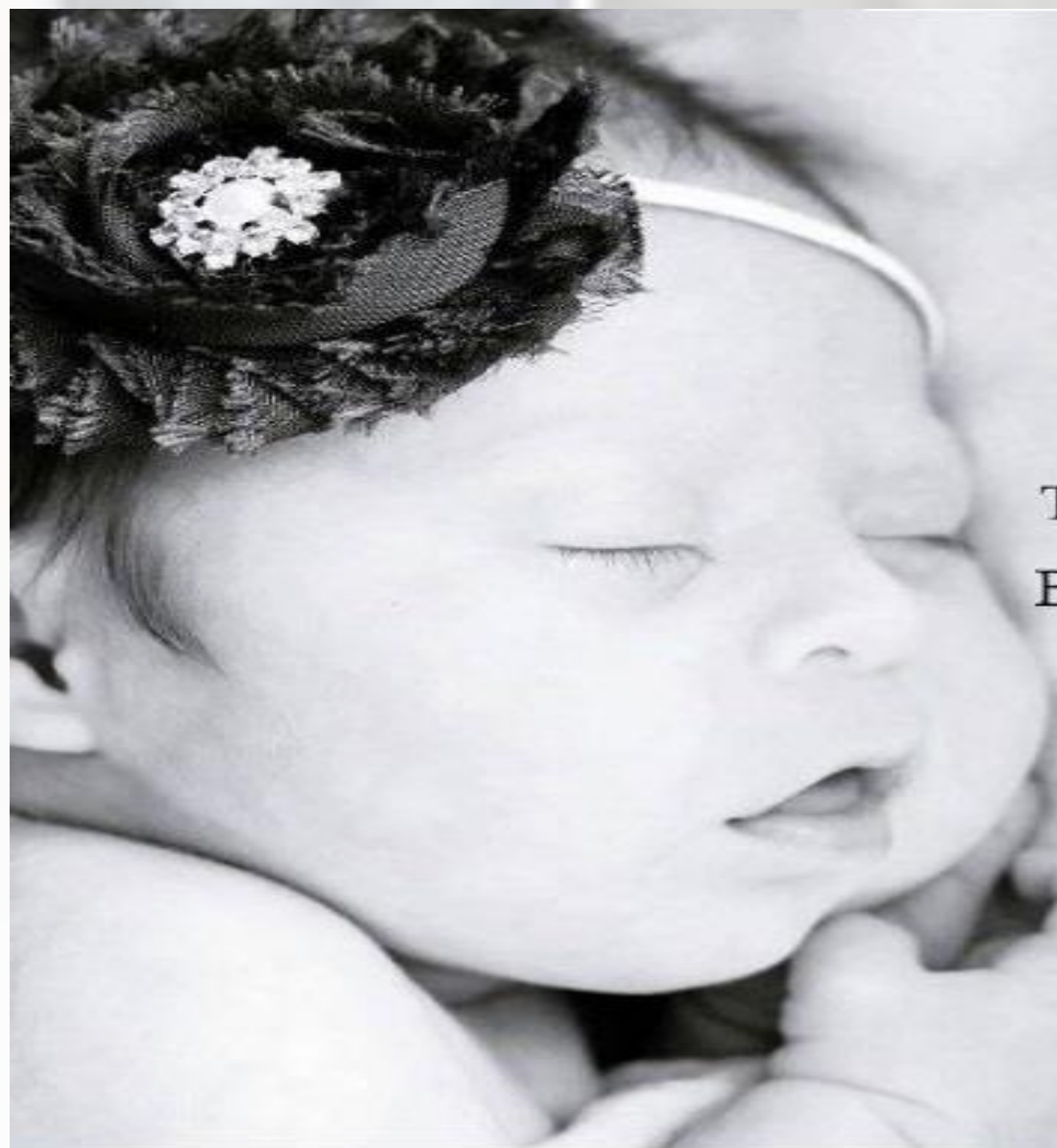
Recommendations

- Continuing advocacy regarding access to social welfare provisions
- Advocate for a revised Special Child Grant assessment form.
- Continue to encourage families to join family support groups.

References

- <http://pediatrics.aappublications.org/content/107/2/442>





My face may be different
But my feelings the same
I laugh and I cry
And I take pride in my gains
I was sent here among you
To teach you to love
As God in heaven
Looks down from above
To him I'm no different
His love knows no bounds
It's those here among you
In cities and towns
That judge me by my standards
That man has imparted
But this family I have chosen
Will help me get started
For I am one of the children
So special and few
That came here to learn
The same lessons as you
That love is acceptance
It must come from the heart
We all have the same purpose
Though not the same start
The Lord gave me life
To live and embrace
And I'll do as you do
But at my own pace

An illustration of three pairs of legs from the waist down, each wearing a different style of striped sock. The left pair wears grey cargo pants and socks with horizontal stripes in red, blue, and brown. The middle pair wears brown shorts and socks with horizontal stripes in yellow, grey, and red. The right pair wears dark grey pants and socks with horizontal stripes in light blue, dark blue, and green. The text "THANK YOU" is centered over the middle pair of legs.

THANK YOU