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APPENDIX A

THE INTERVIEW SCHEDULE/PROTOCOL

NAME

AGE

SEX/GENDER

PREGNANCY

BIRTH HISTORY

NEONATAL HISTORY

MILESTONE - SITTING

WALKING

FIRST WORDS

SENTENCES

FEEDING

POTTY TRAINING

METHODS OF DIAGNOSIS

MEDICAL PROBLEMS

FAMILY HISTORY

PARENTAL MARITAL STATUS

MATERNAL AGE OF CONCEPTION

MARTENAL HIGHEST EDUCATION

MARTENAL OCCUPATION

PARTENAL AGE OF CONCEPTION

PARTENAL HIGHEST EDUCATION

PARTENAL OCCUPATION

NUMBER OF SIBLINGS

TOTAL NO. OF ROOMS

TOTAL NO. OF OCCUPANTS

CAREGIVER AGE

CAREGIVER HIGHEST EDUCATION

CAREGIVER OCCUPATION

MEDICAL PROBLEMS

STATE GRANT

OTHER SUPPORT GROUPS

SCHOOL

START PROGRAMME

TOTAL DURATION

NO. OF SESSIONS

DUPATION OF SESSION

OTHER INFORMATION

MENTAL AGE (MONTHS)

FAMILY POSITION

CAREGIVER

SICKNESS IN INFANCY

MOTHERS ILLNESS IN PREGNANCY

FUTURE PREGNANCY

FAMILY SUPPORT

ATTITUDE TO START PROGRAMME

FAMILY HISTORY OF DOWN SYNDROME

DOCTORS EXPLANATION

THERAPIST EXPLANATION

PRESENT MEDICAL COMPLAINTS

APPENDIX B

THE S.T.A.R.T.

In its present form, the programme identifies six areas seen as the basis for the development of the child. These are briefly discussed below:

1. Social and emotional development

Play is an integral part of social and emotional development. Two types of play are recognized:

1.1 **Group play** which embodies the following:

a) The development of an awareness of the environment including other individuals.

b) The development of awareness of oneself.

c) The development of awareness of one's ability to manipulate the environment as in:

i) Distinctive play

ii) Incidental play

iii) Explorative and experimental play

iv) Constructive play

v) Fantasy play

1.2 **Group interaction,** encompassing

i) Solitary - child prefers to play all alone

ii) Observer - child has no part in playing

iii) Parallel - child will play alongside a group

iv) Co-operation

v) Interaction

2. Activities of Daily Living

The area is seen as vital in promoting the greatest degree of independant function.

The areas of focus are:

a) Feeding and drinking

b) Manners - Table manners and consideration of others.

c) Toiletting - Including handwashing.

d) Dressing - Body and shoes.

3. Gross Motor Development

Development in this area is influenced by individual handicap.

Training is done on the following:

a) Positioning

b) Balance and locomotion

c) Co-ordination: Eye - foot

Eye - hand

Hand - foot

d) Spatial awareness

4. Fine motor Development

The aim here is to encourage the child to develop as high a level of co-ordinative function as possible. Attention is given to:

a) Free movements

b) Reaching

c) Grasp and release

d) Manipulation skills

e) Precision placement

f) Bilateral co-ordination

5. Cognitive Development

In this area the focus is on:

a) **Sensory Stimulation**, namely: Auditory, visual, olfactory, kinaesthetic and tactile.

b) **Body concept**, body image and body awareness.

c) **Spatial Awareness**: position in space and spatial relations.

d) **Colour Concept**: Matching, identifying and naming.

e) **Shape Concept**: Matching, and naming.

f) **Size Concept**

g) **Number Concept**

6. Communication

Attention is given to verbal and non-verbal methods of communication such as:

a) **Receptive Language**: responding appropriately to communication and people.

b) **Expressive Language,**

i) Initiation

ii) Expressing

c) **Using Language**

d) **Verbal interaction**

Information extract from Sunshine Centre document - Profile of the Sunshine Association - Sunshine Centre Procedure

4.4.1.4 The Training Programme

Teacher councillors are training to take S.T.A.R.T. to homes of families having handicapped children. The present approach is that of community involvement.

4.4.1.5 The Service Structure

The service operates both as centre base and home base. It adopts a comprehensive medical and multi disciplinary approach by making are of other services available in the community. The service structure comprises:

Management Control

Directors

Supervisors **Consultants**

Teacher Consultant

Home-based sessions were also given to parents. Parents were given instructions and demonstration to apply to their children on a daily basis. The staff consisted of a trained speech therapist and a speech therapist.

APPENDIX C

DEVELOPMENTAL MILESTONES OF CHILDREN WITH DOWN SYNDROME

1 *GROSS MOTOR ACTIVITIES*

ACTIVITY	Children with Down's syndrome		'Normal' children	
	Average Age	Range	Average Age	Range
Holds head steady and balanced	5m	3m to 9m	3m	1m to 4m
Rolls over	8m	4m to 12m	5m	2m to 10m
Sits without support for one minute or more	9m	6m to 16m	7m	5m to 9m
Pulls to stand using furniture	15m	8m to 26m	8m	7m to 12m
Walks with support	16m	6m to 30m	10m	7m to 12m
Stands alone	18m	12m to 38m	11m	9m to 16m
Walks alone	23m	13m to 48m	12m	9m to 17m
Walks up stairs with help	30m	20m to 48m	17m	12m to 24m
Walks down stairs with help	36m	24m to 60m+	17m	13m to 24m
Runs	around 4 years		—	
Jumps on the spot	4 to 5 years		—	

2 *PERSONAL/SOCIAL/SELF HELP ACTIVITIES*

Smiles when touched and talked to	2m	1½m to 4m	1m	1m to 2m
Smiles spontaneously	3m	2m to 6m	2m	1½m to 5m
Recognises mother/father	3½m	3m to 6m	2m	1m to 5m
Takes solids well	8m	5m to 18m	7m	4m to 12m
Feeds self with biscuit	10m	6m to 14m	5m	4m to 10m
Plays pat-a-cake, peep-bo games	11m	9m to 16m	8m	5m to 13m
Drinks from cup	20m	12m to 30m	12m	9m to 17m
Uses spoon or fork	20m	12m to 36m	13m	8m to 20m
Undresses	38m	24m to 60m+	30m	20m to 40m
Feeds self fully	30m	20m to 48m	24m	18m to 36m
Urine control during day	36m	18m to 50m+	24m	14m to 36m
Plays social/interacting games	3½ to 4½ years		—	—
Bowel control	36m	20m to 60m+	24m	16m to 48m
Dresses self partially (not buttons/laces)	4 to 5 years			
Uses toilet or potty without help (often too small to get up onto a toilet, unless a special step is available)	4 to 5 years			

3 FINE MOTOR AND ADAPTIVE ACTIVITIES

ACTIVITY	Children with Down's syndrome		'Normal' children	
	Average Age	Range	Average Age	Range
Follows objects with eyes, in circle	3m	1½m to 6m	1½m	1m to 3m
Grasps dangling ring	6m	4m to 11m	4m	2m to 6m
Passes objects from hand to hand	8m	6m to 12m	5½m	4m to 8m
Pulls string to attain toy	11½m	7m to 17m	7m	5m to 10m
Finds objects hidden under cloth	13m	9m to 21m	8m	6m to 12m
Puts 3 or more objects into cup or box	19m	12m to 34m	12m	9m to 18m
Builds a tower of two 1" cubes	20m	14m to 32m	14m	10m to 19m
Completes a simple three shape jigsaw	33m	20m to 48m	22m	16m to 30m+
Copies a circle	48m	36m to 60m+	30m	24m to 40m
Matching shapes/colours	4 to 5 years			
Plays games with simple rules	4 to 5 years			

4 COMMUNICATION ACTIVITIES

Reacts to sounds	1m	½m to 1½m		0 to 1m
Turns to sound of voice	7m	4m to 8m	4m	2m to 6m
Say da-da, ma-ma	11m	7m to 18m	8m	5m to 14m
Responds to familiar words	13m	10m to 18m	8m	5m to 14m
Responds to simple verbal instructions	16m	12m to 24m	10m	6m to 14m
Jabbers expressively	18m	12m to 30m	12m	9m to 18m
Says first word(s)	18m	13m to 36m	14m	10m to 23m
Shows needs by gestures	22m	14m to 30m	14½m	11m to 19m
A few two word sentences	30m	18m to 60m+		
Uses words spontaneously and to communicate	1½ to 6 years			

(Adapted from Cunningham C. **Down Syndrome: An Introduction to Parents.** Page 205- 206)

APPENDIX D

GRIFFITHS DEVELOPMENT SCALES

The tests examine the developmental profiles of each individual child tested as shown in the following figure:

160	A	B	C	D	E	F	G
150							
130							
120							
110							
100							
90							
80							
70							
60							
50							
40							
30							
20							
10							

The Griffiths tests allow for assessment in fives (0 - 2 yrs) and six (3 - 8 yrs) areas namely:

Locomotor Development (Subscale A)

This subscale offers opportunity to observe physical development in young children. It includes ability to run, trot, kick and throw the ball.

Personal - Social (Subscale B)

This scale allows for the assessment of personal and social development by making use of such item as the ability to use spoon, cup, dress and activity body parts.

Hearing and Speech (Subscale C)

This is the most intellectual of the scales and allows for the opportunity to study growth and development of language. Its items include ability to use words, appropriately, identify and name toys, to tell and listen to stories, and show in story books.

Eye-hand Co-ordination (Subscale D)

This subscale relates to handwork and visual ability of the child. The relevant items here include building tower with blocks, drawing and manipulation of toys, drawing (sketching) and threading beads.

Performance (Subscale - E)

This subscale is largely a scale of performance, enabling the examiners to observe and measure the skill of manipulation, speed of working and precession. The items include formboards, removal and placements of lids.

Practical Reasoning (Subscale - F)

This subscale concentrates on recording the earliest indication of arithmetic, comprehension and the realization of the simplest practical problems. It indicates the child's ability to benefit from formal schooling.

APPENDIX E

1. LETTER TO PARENTS/CAREGIVERS

Dear .....

You are kindly requested to bring your child .... to Speech Therapy Department at Baragwanath Hospital on the ...., as there will be a discussion regarding assessment of your chi' l's progress.

Your co-operation in this regard will be highly appreciated.

Yours sincerely

DR I Skenjana

MBChB DCH

Please note: 1. All bus, train and taxi fares will be refunded.

2. Please do not take out your hospital records.

3. Kindly bring this letter with you and show it at the gate on demand.

Thanks.

APPENDIX F

2. CONSENT FORM FOR PARENTS/CAREGIVERS

EVALUATION OF THE BENEFITS OF THE START PROGRAMME ON CHILDREN WITH DOWN'S SYNDROME BETWEEN AGES OF 6 MONTHS TO SIX YEARS

Investigator: I.N.B. Skenjana MBChB DCH

Parent's Name:.. ....

Parents of: .....

I agree to allow my child to participate in study involving Down Syndrome children at Baragwanath Hospital, Sunshine Centre and Transvaal Memorial Institute. I understand that the study is intended to evaluate whether the START home programme is of benefit in the development of Children with Down Syndrome between the age of 6 months and 6 years. I further understand that there are no foreseeable risks or discomforts involved in this study.

I also understand that my participation in the study will require that a series of ability tests will be administered to my child. These tests will be performed in a single visit of approximately 2 hours. It is agreed that all information concerning participation in this research will be kept confidential. I understand that I may withdraw from the study at any time without penalty, by contacting Dr I Skenjana (Tel: 725-4130 Ext 672). I understand that my signature means I have read this form, understand the procedure to be followed and voluntarily agree to participate in the project entitled:-

The Benefits of a Home Program for children with Down's Syndrome as measured by Griffiths Development Scale.

SIGNATURE:.....

DATE:.....

PARENT OR GUARDIAN

INVESTIGATOR (WITNESS):.....

APPENDIX G

CODING SYSTEM

CODE : Experiment (101 - 121) Controls (201 - 221)

Diagnosis

AGE : Months

SEX :
- Unknown - 0
- Male - 1
- Female - 2

PREGNANCY
- Unknown - 0
- Normal - 1
- Abnormal- 2

BIRTH HISTORY:
- Unkown - 0
- Normal - 1
- Abnormal- 2

NEONATAL HISTORY:
- Unknown - 0
- Normal - 1
- Abnormal- 2

MILESTONES:
- Age at in months - sitting -
- walking -
- first words -
- sentence -
- feeding -
- potty training -

MEDICAL PROBLEMS: - Unknown - 0

- Yes - 1

- No - 2

METHOD OF DIAGNOSIS: - Unknown - 0

- Clinical - 1

- Clinical & Biochemical - 2

FAMILY HISTORY:

1. PARENTS MARRIED - Unknown - 0

- Yes - 1

- No - 2

(a) Mothers age at conception - in years

Mothers highest education - Unknown - 0

- Std 1 - Std 5 - 1

- Std 6 - Std 8 - 2

- Std 9 - Std 10 - 3

- Tertiary - 4

- College/University - 5

Mothers Occupation - Student - 0

- Never Worked - 1

- Not Working - 2

- Unskilled Labourer - 3

- Skilled Labour - 4

- Semi Professional - 5

- Professional - 6

(b) Fathers Age - in years

Fathers Highest education
- Unknown - 0
- Std 1 - 5 - 1
- Std 6 - 8 - 2
- Std 9 - 10 - 3
- Tertiary - 4
- College/University - 5

Fathers Occupation
- Student - 0
- Never Worked - 1
- Not Working - 2
- Unskilled Labourer - 3
- Skilled Labourer - 4
- Semi-professional - 5
- Professional - 6

Siblings = No. of siblings

Medical Problems - None - 0
- Yes - 2

Size of House - no of rooms -

Total number of people in the house -

(2) CAREGIVER (OTHER THAN PARENTS)

Caregivers age in years

Caregivers highest education

Nil - 0
Std 1 - 5 - 1
Std 6 - 8 - 2
Std 9 -10 - 3
Tertiary - 4
College/University - 5

Caregiver (Other than Parent)

Caregivers Occupation	Student/child - 0 Never Worked - 1 Not Working - 2 Unskilled Labour - 3 Skilled Labour - 4 Semi professional - 5 Professional - 6
Medical Problems	Nil - 0 Yes - 1 No - 2
State Grant or other Financial Assistance	Not Known - 0 Yes - 1 No - 2
Other Support: - Advisory - Physical - Financial	Not Known - 0 Yes - 1 No - 2
School	Unknown - 0 Yes - 1 No - 2
S.T.A.R.T. Home Programme	Unknown - 0 Yes - 1 No - 2
S.T.A.R.T. for how long in months	
Time per session	15 mins - 0 15 -30 mins - 1 30 - 60 mins - 2
No. of sessions in a week	- 0 - 1 - 2 - 3 - 4 - 5
Griffiths Developmental Scales	A = 0 B = 1 C = 2 D = 3 E = 4 F = 5 D = Q = 6
Medical examination - illnesses	Unknown - 0 Yes - 1 No - 2