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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

MATERNAL HIGHEST EDUCATION

MATERNAL OCCUPATION

PARENTAL AGE OF CONCEPTION

PARENTAL HIGHEST EDUCATION

PARENTAL 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
DURATION 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
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 independent 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:
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.
## DEVELOPMENTAL MILESTONES OF CHILDREN WITH DOWN SYNDROME

### 1 GROSS MOTOR ACTIVITIES

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

### 2 PERSONAL/SOCIAL/SELF HELP ACTIVITIES

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th><strong>Average Age</strong></th>
<th><strong>Range</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Smiles when touched and talked to 2m</td>
<td>1 1/2m</td>
<td>1m to 4m</td>
</tr>
<tr>
<td>Smiles spontaneously</td>
<td>3m</td>
<td>2m to 6m</td>
</tr>
<tr>
<td>Recognises mother/father</td>
<td>3 1/2m</td>
<td>3m to 6m</td>
</tr>
<tr>
<td>Takes solids well</td>
<td>8m</td>
<td>5m to 18m</td>
</tr>
<tr>
<td>Feeds self with biscuit</td>
<td>10m</td>
<td>6m to 14m</td>
</tr>
<tr>
<td>Plays pat-a-cake, peep-bo games</td>
<td>11m</td>
<td>9m to 16m</td>
</tr>
<tr>
<td>Drinks from cup</td>
<td>20m</td>
<td>12m to 30m</td>
</tr>
<tr>
<td>Uses spoon or fork</td>
<td>20m</td>
<td>12m to 36m</td>
</tr>
<tr>
<td>Undresses</td>
<td>30m</td>
<td>20m to 48m</td>
</tr>
<tr>
<td>Feeds self fully</td>
<td>36m</td>
<td>18m to 50m+</td>
</tr>
<tr>
<td>Urine control during day</td>
<td>1 1/2 to 4 1/2 years</td>
<td></td>
</tr>
<tr>
<td>Plays social/interacting games</td>
<td>36m</td>
<td>20m to 60m+</td>
</tr>
<tr>
<td>Bowel control</td>
<td>4 to 5 years</td>
<td></td>
</tr>
<tr>
<td>Dresses self partially (not buttons/ laces)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses toilet or potty without help</td>
<td>4 to 5 years</td>
<td></td>
</tr>
<tr>
<td>(often too small to get up onto a toilet, unless a special step is available)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 3 FINE MOTOR AND ADAPTIVE ACTIVITIES

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

### 4 COMMUNICATION ACTIVITIES

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>1m to 1½m to 1½m</th>
<th>0 to 1m</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reacts to sounds</td>
<td>1m to 1½m to 1½m</td>
<td>0 to 1m</td>
</tr>
<tr>
<td>Turns to sound of voice</td>
<td>7m to 8m</td>
<td>4m to 6m</td>
</tr>
<tr>
<td>Say da-da, ma-ma</td>
<td>11m to 15m</td>
<td>7m to 14m</td>
</tr>
<tr>
<td>Responds to familiar words</td>
<td>13m to 18m</td>
<td>10m to 14m</td>
</tr>
<tr>
<td>Responds to simple verbal</td>
<td>16m to 24m</td>
<td>10m to 14m</td>
</tr>
<tr>
<td>instructions</td>
<td>18m to 30m</td>
<td>12m to 18m</td>
</tr>
<tr>
<td>Jabbers expressively</td>
<td>18m to 36m</td>
<td>14m to 23m</td>
</tr>
<tr>
<td>Says first word(s)</td>
<td>22m to 30m</td>
<td>14½m to 19m</td>
</tr>
<tr>
<td>Shows needs by gestures</td>
<td>30m to 60m+</td>
<td></td>
</tr>
<tr>
<td>A few two word sentences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses words spontaneously and to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>communicate</td>
<td>1½m to 6 years</td>
<td></td>
</tr>
</tbody>
</table>

(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:

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
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<tbody>
<tr>
<td>160</td>
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<td>130</td>
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<td>120</td>
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<td>90</td>
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<td>60</td>
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<td>50</td>
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<td>10</td>
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</tr>
</tbody>
</table>
The Griffiths tests allow for assessment in five (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 child’s progress.

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

Yours sincerely

DR I Skenhana
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):..................................................
## CODING SYSTEM

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

### Diagnosis

### AGH: Months

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

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

### BIRTH HISTORY:
- Unknown - 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**

<table>
<thead>
<tr>
<th>Mothers highest education</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td>Std 1 - Std 5</td>
<td>1</td>
</tr>
<tr>
<td>Std 6 - Std 8</td>
<td>2</td>
</tr>
<tr>
<td>Std 9 - Std 10</td>
<td>3</td>
</tr>
<tr>
<td>Tertiary</td>
<td>4</td>
</tr>
<tr>
<td>College/University</td>
<td>5</td>
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</tbody>
</table>

(b) **Mothers Occupation**

<table>
<thead>
<tr>
<th>Mothers Occupation</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Student</td>
</tr>
<tr>
<td></td>
<td>Never Worked</td>
</tr>
<tr>
<td></td>
<td>Not Working</td>
</tr>
<tr>
<td></td>
<td>Unskilled Labourer</td>
</tr>
<tr>
<td></td>
<td>Skilled Labour</td>
</tr>
<tr>
<td></td>
<td>Semi-Professional</td>
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<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>6</td>
</tr>
</tbody>
</table>
### (b) Fathers Age - in years

Father’s Highest education

- Unknown: 0
- Std 1 - 5: 1
- Std 6 - 8: 2
- Std 9 - 10: 3
- Tertiary: 4
- College/University: 5
- Student: 0
- Never Worked: 1
- Not Working: 2
- Unskilled Labourer: 3
- Skilled Labourer: 4
- Semi-professional: 5
- Professional: 6

### Siblings = No. of siblings

- None: 0
- Yes: 2

### 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)

<table>
<thead>
<tr>
<th>Caregivers Occupation</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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Medical Problems

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State Grant or other Financial Assistance

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Other Support:

- Advisory
- Physical
- Financial

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School

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S.T.A.R.T. Home Programme

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S.T.A.R.T. for how long in months

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No. of sessions in a week

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Griffiths Developmental Scales

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Medical examination - illnesses

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Author  Skenjana N

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