

## U-Link

U-Link is a non-governmental organisation (NGO) duly registered in Mauritius. Our mission is to be a helping hand to disabled children in the Mauritian society.

We strongly believe that all children with disabilities must benefit from facilities and services available in Mauritius to promote and enhance their standard of living and quality of life.

In line with our medium term aims, we have compiled this booklet to:

1. Disseminate information about the availability of day care centres, resource centres and other facilities.
2. Promote the lifestyle of the disabled adults of tomorrow through nourishing a sustained childcare culture.
3. Enable disabled children to indulge in appropriate educational, healthy leisure and recreational activities.

We trust that this guide will serve its purposes and will create greater awareness in Mauritius.

*The U-Link's Team*

## Table of Contents

Message from Chairman of U-Link	2
Foreword by Dr David Lingiah, Psychologist	3
Cover Story	6

### **Part 1: Service Providers**

#### **Section 1**

List of registered NGOs for disabled children	9
---	---

#### **Section 2**

Government services	37
---------------------	----

### **Part 2: General Information**

#### **Section 1**

The disabled and the non-disabled child	46
---	----

Disability or call it what you may!	49
-------------------------------------	----

#### **Section 2**

A summary of common long term disorders	53
---	----

#### **Section 3**

Some useful websites	79
----------------------	----

## Message from Chairman

As a parent of twins with severe handicap, I have learned to value information. It took us time and patience to try and have sufficient information to assist us as parents to care for our children - be it information on the variety of conditions that produces incapacity in our children, the various support groups, their locations and their facilities offered, or be it information about our disabled children's rights.

Lack of information makes us care in a haphazard fashion, by trial and error, especially for those of us who experienced disability first hand for the first time. Very often we do not know where to turn, and often make assumptions that later proved wrong.

We, at U-Link, have felt the need to partially fill this gap; provide some basic information on the various centres operating in Mauritius, their locations and contact persons, their aims and objectives and the client group they support.

We have also felt the need to inform the readers about some of the conditions that are prevalent in Mauritius, some useful websites for further information, and various government departments involved in providing support to the disabled.

We are grateful to all the NGOs who have kindly given us information on their activities for publication and the NGO Trust Fund for their generous financial support that have enabled us to realise this project.

*M. Ali Jookhun*

## Foreword

Dr David Lingiah

I am aware of U-link's work among the disabled on the island. It gives me great pleasure to write this foreword to their comprehensive Guide to Disability resource that will prove to be a useful tool for all those concerned.

Currently in my homeland of Mauritius I read of the brave steps being taken by the Hon. Mrs Sheilabai BAPPOO, Minister of Social Security, National Solidarity and Senior Citizen Welfare and Reform Institutions, in getting the rights of disabled people in or out of employment to be respected. It is time someone at this level champion the cause of this group of people. The case of the disabled should be given top priority whenever it is debated and supported in order to improve their situation. A country that does not respect its disabled section of its citizens and empower them is a sign of poor leadership. Everyone must play his/her part in helping the disabled to live and experience life to the full here and everywhere!

Taboos and stigmas are the shackles of a society. There are specially trained professionals in Mauritius already to provide this support and enable our disabled compatriots to maximise their potentials and feel part of the broad community of citizens with equal rights and obligations. With proper counselling and the involvement of the Ministry of Social Security I am convinced that the vulnerable groups will feel empowered to play a more active role in our society. Transformation can occur within a supportive framework.

Wherever and whenever this supportive healing work takes place there is always a positive outcome.

I well remember reading about Girish Hurloll, the blind singer who won the first prize at the recent song competition at the MGI. “Ce soir-là, il a fait vibrer l'auditorium du Mahatma Gandhi Institute (MGI).” He was invited at the Ministry of Social Security “à une réception en son honneur.” Praising the blind artist/singer, the Minister said: Girish Hurloll est un exemple à suivre et une preuve, s'il en fallait, qu'un handicap n'empêche pas l'épanouissement d'un talent. So saying, Mrs Bappoo has recognised and paid tribute to the talents of the disabled in general. She hoped all those with such talents could be supported by the various groups. “We can create a place for them in society: “ *nous capave faire enn place pour zot dans la société* ”, she had said.

On the 3rd December 1992, the United Nations General Assembly decided on the World Programme of Action for Disabled People. The United Nations committed itself and its members to promote the full participation of disabled people in social life and development as well as prevention and rehabilitation measures. This day has become recognised as a major vehicle for the annual celebration by disabled people of their lives, their culture and their worth. Yet many problems are still unresolved. Disabled people are not yet fully considered within international development issues. They are still excluded from society in many countries of the world. Even where effective disability legislation is in place, the implementation lacks ideas and is hindered by negative attitudes towards disabled people.

Now I see a concrete example of the disabled participating

fully in life and going on to win the respects and support of the Minister. Every day hundreds if not thousands of people worldwide suffer from some form of disability in their daily life. Some cope better; some poorly. While some feel stigmatised others face their conditions bravely and plough on regardless. Some enjoy feeling pitied by their friends and neighbours; while others are determined to act as examples of courage to make of life the best despite their visible scars, deformities and other handicaps. It is all to do with an attitude of mind and strength of character of the individuals concerned. While many fall victims to their fears and taboos; others are putting up a brave struggle to fight all manner of stigmas in society. They are an inspiration to us all and to themselves. NGOs like U-Link deserve all the support they need to continue to enable the disabled persons realize their potentials as equal members of our society.

The U-Link's Guide to Disability is a timely document. It is hoped that with this publication resource the disabled within our Mauritian society will obtain a fair deal from us all. In this way there will be no difference in them being seen other than within the "Guette nous pareil" philosophy.

*david.lingiah@ntlworld.com*

## Cover story

We are grateful to Ali and Banu for their kind permission to print the picture of their son and late daughter which summarise our caption of “guette nous pareil”.

Their late daughter Umraanah, one of a set of twins, who were both totally dependent in all aspects of daily living. Her sister, Irfaanah, passed away when she was 5 years old and Umraanah passed away last year – God rests both their souls.

Their brother, Irfaan, was born 5 years ago and is enjoying a normal childhood, full of life and used to enjoy his sister’s company very much.

Irfaan would participate in the care of his sister and she would respond in turn with a beautiful smile and loving touches.

To Irfaan, Umraanah was his sister and he saw her as such. In his eyes, there was no incapacity, no handicap, no inabilities..... just plain affection, beautifully expressed without fear, taboo or hypocrisy or jealousy. He accepted his sister as she was and was never in search of any explanation about her condition..... To him she was as human and as alive as he is.

The two of them, in their innocent behaviour and bonding inspire people to “guette nous pareil”

**Part 1:**

**Service Providers**

*We tend to forget that happiness doesn't come as a result of getting something we don't have, but rather of recognizing and appreciating what we do have.*

*Frederick Keonig*

*Experience suggests it doesn't matter so much how you got here, as what you do after you arrive.*

*Lois McMaster Bujold*

## **Section 1:**

# **List of registered NGOs for disabled children**

## **Association de Parents D'Enfants Inadaptés de L'Ile Maurice (APEIM)**

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**Address:** 39, Route St Paul, Phoenix

**Tel:** 696 4400 / 696 5365

**Email:** [apeim@intnet.mu](mailto:apeim@intnet.mu)      **Website:** n/a

**Contact person(s):** Ms Irene Alessandri

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**Aims:** To cater for the development of persons with intellectual disabilities and other related problems.

**Age group catered for:** Children & Adults

**Types of disability catered for:** Physical & Mental

**Types of activities:**

1. Health - medical & paramedical
2. Early intervention
3. Education & inclusion
4. Training programmes
5. Home visits

## **Association Des Parents D'Enfants Aux Besoins Spéciaux (APEBS)**

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**Address:** 9, Rue Remono, Curepipe

**Tel:** 674 6916

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs Virginie Hardy

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**Aims:** “Un accompagnement adapté aux besoins de l'enfant en tenant compte de son handicap, à travers les formes traditionnelles de la scolarisation”.

**Age group catered for:** 8 to 18 years

**Types of disability catered for:** Mental

**Types of activities:** 1. School for children with special needs  
2. Reading, writing, numeracy, sports, cookery, drawing, dance, theatre and basic IT skills

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## Association des Parents de Déficients Auditifs (APDA)

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**Address:** 8, Dupin Street, Curepipe

**Tel:** 676 4681

**Email:** hearapda@intnet.mu

**Website:** n/a

**Contact person(s):** Ms Mariam Sumun / Ms Kamini Tulwa

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**Aims:**

1. To see that deaf persons are fully integrated in society.
2. To protect deaf persons against exploitation, humiliation and other derogatory treatment.
3. To help them to have access to all educational facilities.

**Age group catered for:** more than 9 months old

**Types of disability catered for:** Deafness as major handicap

**Types of activities:**

1. Pre-primary and primary school
2. Parent Education Unit
3. Seeking training and employment for deaf people
4. Organisation of sign language course
5. Produce audio and video educational programmes

## Association Anou Grandi

**Address:** Royal Road, Mon Loisir, Rivière du Rempart

**Tel:** 412 6778

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs Gina Poonoosamy

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- Aims:**
1. To work towards the development of children to run institutions to cater for children with special needs.
  2. To work for the defence of the rights of the children.
  3. To organise, develop and contribute in leisure activities.
  4. To organise training for parents.

**Age group catered for:** 6 to 15 years old

**Types of disability catered for:** Special needs

**Types of activities:** Running of a primary school and provision of various educational facilities for children special needs.

## **Association Dominique Savio**

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**Address:** 5, Shakespeare Lane, Beau-Bassin

**Tel:** 467 7019

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs R.Uppiah

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**Aims:** To operate a day care centre for the welfare of the handicapped.

**Types of disability catered for:** Physical & Mental

**Types of activities:** Day care centre facilities

## **Association des Malades et Handicapés de L'Est**

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**Address:** Opposite RCA School, Poste de Flacq

**Tel:** 413 9346 / 413 4507

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs Sakir / Mrs T. Beedassy

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**Aims:** To promote the welfare of the disabled persons.

**Types of disability catered for:** Mental

**Types of activities:** Initiation to daily living skills & basic writing skills.

## Amour Sans Frontières

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**Address:** Beau-Sejour, Piton

**Tel:** 283 0138

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs K. Minerve / Mrs J. Rousset

**Aims:** Rehabilitation & Social Integration of the  
handicapped.

**Types of disability catered for:** Physical & Mental

**Types of activities:** Running of a day care centre

## CEDEM

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**Address:** Beetun Lane, Floréal

**Tel:** 697 7640

**Email:** [cedem7@intnet.mu](mailto:cedem7@intnet.mu)      **Website:** n/a

**Contact person(s):** Mrs Sehenaz Hossain Saeb

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- Aims:**
1. To implement projects set out to improve the lives of both disabled and normal children in Mauritius.
  2. To provide every child with a better future.
  3. To assist in the creation of a society where all children are loved and have access to quality education.

**Age group catered for:** Children

**Types of disability catered for:** Physical & Mental

- Types of activities:**
1. Early childhood development centre
  2. Family Counselling Unit
  3. Special school for slow learners and handicapped children
  4. Training programmes for social workers, teachers & parents
  5. Shelters for children in distress
  6. Community development programmes

## Century Day Care Centre

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**Address:** 4, Kleber Street, Cité Martial, Port Louis

**Tel:** 216 8080

**Email:** century.welfareass@intnet.mu      **Website:** n/a

**Contact person(s):** Moomeesa Hossen Mamode  
Ahmud Fouad Uteene

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**Aims:** To cater for the educational and other needs of physically and mentally handicapped children.

**Age group catered for:** Children

**Types of disability catered for:** Physical & Mental

**Types of activities:** Special school for handicapped children

## **Craft Aid (Mauritius) Co Ltd**

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**Address:** Sir Edgar Laurent Street, Rose-Hill

**Tel:** 464 2922

**Email:** [craftaid@intnet.mu](mailto:craftaid@intnet.mu)      **Website:** [www.catgin.com/artist](http://www.catgin.com/artist)

**Contact person(s):** Mr Soodesh Mockoobam

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**Aims:** Providing paid employment for disabled persons.

**Age group catered for:** 18 - 60 years old

**Types of disability catered for:** Physical & Mental  
including Deaf and Dumb

**Types of activities:** 1. Manufacturing of textile products  
2. Paper made products  
3. Packaging of sugar

## **EDYCS Epilepsy Group**

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**Address:** 8, Impasse Labourdonnais, Port-Louis

**Tel:** 508 0904 / 213 1733

**Email:** n/a

**Website:** <http://edycsepilepsy.intnet.mu>

**Contact person(s):** Ms Roubinah Isseljee  
Ms Artee Chamroo

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**Aims:** To promote lifelong access and opportunities for persons suffering of epilepsy and their families, to be fully included participating members of their communities through advocacy, public awareness and education.

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**Age group catered for:** All age groups

**Types of disability catered for:** Neurological and Mental

**Types of activities:** 1. Patients' diagnosis, medical checkups  
2. Home visits  
3. Organising fund raising activities  
4. Advocacy, Epilepsy campaign

## Flacq Disabled Centre

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**Address:** Near August Volaire Stadium, Flacq

**Tel:** 413 3089 / 413 0897 / 494 0986

**Email:** n/a

**Website:** n/a

**Contact person(s):** Ms Vishwanee Aukhey

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**Aims:** To promote the welfare of disabled adolescents and help them for their integration in the mainstream of society.

**Age group catered for:** 4 to 27 years

**Types of disability catered for:** Physical & Mental

**Types of activities:** 1. Painting, sewing, learning  
2. Outings & camping  
3. Basic academic learning

## Fondation George Charles

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**Address:** Royal Road, Terasson, Pointe aux Sables

**Tel:** 234 5415

**Email:** n/a

**Website:** n/a

**Contact person(s):** Miss Gisele Ithier

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**Aims:** Rehabilitation and Reinsertion of mentally handicapped children.

**Age group catered for:** Children

**Types of disability catered for:** Mental

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**Types of activities:** 1. Basic writing, reading and numeracy  
2. Basic woodwork  
3. Sports activities

## Friends In Hope

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**Address:** Sookdeo Bissoondoyal Avenue, Bonne Terre,  
Vacoas

**Tel:** 526 0840

**Email:** [fihope@intnet.mu](mailto:fihope@intnet.mu)    **Website:** [www.friendsinhope.com](http://www.friendsinhope.com)

**Contact person(s):** Mrs Jocy St-Mart  
Mrs Martine Neveu

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**Aims:** To provide care and support to persons suffering from severe psychiatric disorders such as Schizophrenia and bipolar disorder.

**Age group catered for:** 16 - 60 years old

**Types of disability catered for:** Mental

**Types of activities:** 1. Development of social skills  
2. Development of life skills  
3. Arts and crafts

## Groupe Lizié dan la Main

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**Address:** Louis Pasteur St, Forest Side

**Tel:** 675 1777

**Email:** mejjoa@intnet.mu

**Website:** n/a

**Contact person(s):** Mr Reynolds Pernal

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**Aims:** To cater for the welfare of visually impaired and blind persons.

**Age group catered for:** All age groups

**Types of disability catered for:** Physical

**Types of activities:** 1. Preprimary, primary and adult education  
2. Braille transcription  
3. Workshop of rattan

## Handicapes Sans Frontières

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**Address:** 48, Dr Guy Ithier Street, Mare Gravier,  
Beau-Bassin

**Tel:** 465 7770

**Email:** pgumani@hotmail.com    **Website:** n/a

**Contact person(s):** Mr Prakash Gumani

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**Aims:** 1. To cater for sports and leisure.  
2. Exchange of friendship.  
3. Promote better integration in society.

**Age group catered for:** 18 years and over

**Types of disability catered for:** Physical & Mental

**Types of activities:** Sports - Petanque, wheelchair tennis,  
indoor games & outings

Affiliated to Physically Handicapped Persons Sports Fed (PHYSFED) & Disabled People International (DPI).

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## Islamic Centre for disabled children

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**Address:** Military Road, Cite Martial, Port-Louis

**Tel:** 240 9815

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs Salima Alleemudder, MSK

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**Aims:** To provide assistance to disabled children living in the vicinity of Port-Louis.

**Age group catered for:** Children

**Types of disability catered for:** Physical & Mental

**Types of activities:** 1. Basic academic knowledge & literacy courses  
2. Outdoor activities

## Lois Lagesse Trust Fund

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**Address:** 101, Rue Colonel Maingard, Beau Bassin

**Tel:** 454 9806 / 465 5119

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mr Daboo

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**Aims:** To aid, train and educate all Blind Persons and to assist them in obtaining medical treatment and suitable employment.

**Age group catered for:** All age groups

**Types of disability catered for:** Physical

**Types of activities:**

1. Pre-Primary & Primary School
2. Braille
3. Orientation & Mobility
4. Daily Living Skills

## Mauritius Mental Health Association

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**Address:** Avenue Berthaud, Stanley, Rose-Hill

**Tel:** 465 9508

**Email:** mmhain@intnet.mu

**Website:** n/a

**Contact person(s):** Helene de Casanove

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- Aims:**
1. To promote education for children with intellectual disabilities.
  2. To assess and develop their capacity in academic and technical work.
  3. To further integration.

**Age group catered for:** Children & adults

**Types of disability catered for:** Mental, Mild and Moderate Impairment

- Types of activities:**
1. Day Care
  2. School for children with special needs
  3. Sheltered workshop
  4. Occupational therapy

## Physically Handicapped Welfare Association

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**Address:** Joseph D'Argent Street, Rose-Hill

**Tel:** 464 4845

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mr. S. Poinen  
Mrs O. D. Mathuvirin

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**Aims:** To promote the welfare of the disabled and help them to become more self sufficient.

**Age group catered for:** 16 to 60 yrs

**Types of disability catered for:** Physical & Mental - Mild  
Hearing impairment

**Types of activities:**

1. Daily work
2. Sewing, Embroidery, Craftwork
3. Gardening
4. Home visits to disabled persons
5. Provide wheelchairs on loan
6. Outings for persons attending the centre

## Rêve et Espoir

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**Address:** Royal Road, Black River

**Tel:** 483 6492

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs Miguy Gourrege

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**Aims:** To provide a school for handicapped children.

**Age group catered for:** Children

**Types of disability catered for:** Physical & Mental

**Types of activities:**

1. Basic Literacy & Numeracy Skills
2. Basic Reading
3. Craftwork

## **Society for Aid to Children Inoperable in Mauritius (SACIM)**

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**Address:** 2, Britannia Park, Vacoas

**Tel:** 6961842 / 6861821

**Email:** [sacim@intnet.mu](mailto:sacim@intnet.mu)

**Website:** n/a

**Contact person(s):** Dr. Amrit Rajkomar  
Mrs. Chantal Hurlall

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**Aims:** To provide an aid to poor Mauritian children suffering from conditions which cannot be operated locally but which can be operated abroad and to obtain such treatment abroad.

**Age group catered for:** 0 to 18 yrs

**Types of disability catered for:** Physical

**Types of activities:** 1. Processing new cases & Arranging for their treatment abroad  
2. Ensuring follow-up of such cases upon return to Mauritius

## **Society for the Welfare of the Deaf**

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**Address:** Pope Hennessy St, Beau-Bassin

**Tel:** 464-3834

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mrs A. Bissoonauthsing

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- Aims:**
1. To aid, train and educate all deaf persons in Mauritius.
  2. To assist them in obtaining medical treatment and employment.
  3. To grant material relief which they may need.

**Age group catered for:** All age groups

**Types of disability catered for:** Physical

- Types of activities:**
1. Special Education
  2. Parent Counselling
  3. Prevocational Training
  4. Speech Therapy & Diagnostic Facilities

## **Southern Handicapped Association**

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**Address:** Coastal Road, Riambel, Surinam

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**Tel:** 625 4055

**Email:** n/a

**Website:** n/a

**Contact person(s):** Mr R.Bondy

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**Aims:** To cater for the welfare of the mentally retarded and to provide educational facilities to children who are not accepted in the mainstream.

**Types of disability catered for:** Mental

**Types of activities:** 1. Basic reading, Writing and Numeracy  
2. Woodwork and Handicraft

## **Special Educational Needs Society (SENS) - Ruth School**

**Address:** Charles Lee Street, Rose-Hill

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**Tel:** 467 6741

**Email:** sensmu@intnet.mu      **Website:** n/a

**Contact person(s):** Mrs Khalpey

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**Aims:** To help children with dyslexic problems.

**Age group catered for:** 6 to 12 years

**Types of disability catered for:** Learning disabilities

**Types of activities:** 1. Educational programmes  
2. Therapeutics  
3. Workshops for parents

## **The Way to Light Association**

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**Address:** 18, Yves Forget Street, Roches Brunes,  
Beau-Bassin

**Tel:** 464 6491

**Email:** thewaytolight@servihoo.com    **Website:** n/a

**Contact person(s):** Mrs Ameena Abdoolah

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**Aims:** To promote widespread numeracy & literacy to children and young adults with multiple disabilities and visual impairment.

**Age group catered for:** Children & young adults

**Types of disability catered for:** Physical & Mental

**Types of activities:**

1. Physiotherapy
2. Occupational Therapy
3. Pedagogical education and Braille

*Disability is a matter of perception. If you can do just one thing well, you're needed by someone.*

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*Navratilova, Martina*

*In every exertion of the body when pain begins to be  
experienced, it is immediately relieved by rest.*

*Hippocrates*

## **Section 2:**

# Government Services

## **Ministry of Social Security and National Solidarity & Senior Citizen Welfare and Reform Institutions**

The policy of this Ministry is to empower people with disabilities. The following departments / institutions listed below are in place to assist:

### **(i) Disability Unit**

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The Disability Unit of the Ministry serves as a "focal point" for issues relating to disability: advocacy, education, training, employment, accessibility, sports and leisure.

The Unit liaises with the various governmental and non-governmental organisations, which provide a wide range of services to children and adults with disabilities in Mauritius and Rodrigues.

This Unit also works in close collaboration with the Welfare Unit of the ministries to provide wheelchairs, spectacles, and hearing aids to disabled children.

Parking coupons (for free parking facilities where there is the sign "disabled") and bus passes (for free bus transportation) are also delivered by this unit provided an application is duly made.

The disability unit also provides a service of drafting report on any matter in relation to a disabled person, so that he can have the required assistance.

Contact Person: Mr A. Bankur  
Tel. 208 9913 Fax No.210 3216  
E-mail: [abankur@mail.gov.mu](mailto:abankur@mail.gov.mu)

**(ii) National Council for the Rehabilitation of the Disabled Persons (NCRD)**

The NCRD is the National Co-ordinating Committee for disability issues in Mauritius. It advises on policy matters, makes proposals for improving the quality of life of persons with disabilities, plays a "brokerage role" in favour of NGOs, co-ordinates the activities of voluntary associations and liaises with national and international organisations.

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The Secretariat of the NCRD is based at the Disability Unit of the Ministry.

Contact Person: Mr A. Bankur  
Tel. 208 9913 Fax No.210 3216  
E-mail: [abankur@mail.gov.mu](mailto:abankur@mail.gov.mu)  
Website: <http://ncb.intnet.mu/ncrd/index.htm>

### **(iii) The Training and Employment of Disabled Persons Board**

The Training and Employment of Disabled Persons Board has been set up under the Training and Employment of Disabled Persons Act, 1996.

Its main objective is to promote training and employment opportunities for persons with disabilities in accordance with the provisions of the Training and Employment of Disabled Persons Act, which, inter alia, stipulates that the labour force of all employers having 35 employees or more should include 3% of disabled persons.

Contact Person: Mr C. K Bundhoo, General Manager  
Tel. No.: 248 8987 / 248 8986  
Address: Calebasses

## **Social benefits granted to disabled persons**

### **1. Basic Invalidity Pension**

(a) A person aged 15 to 60 who has a permanent incapacity of 60% or more, is eligible for a monthly allowance of Rs 2025.

(b) The beneficiaries of Basic Invalidity Pension are also eligible for Child Allowance to a maximum of 3 children:

- (i) child under the age of 10 - Rs 655
- (ii) child aged 10 and over - Rs 705

An employee of the private sector who has a permanent incapacity of 60%, receives in addition to his non-contributory invalidity pension of Rs 2 025, a contributory invalidity pension, the amount depending on his contribution to the National Pensions Fund.

## 2. Social Aid

The Social Aid Act provides for the payment of an allowance to disabled persons who do not benefit from the above-mentioned allowances, for example;

- (i) an adult who cannot work following a handicap;
- (ii) an adolescent aged 15 to 20 who cannot work following a handicap;
- (iii) a disabled person who has the responsibility of an orphan aged 15 to 20;
- (iv) a disabled person who has the responsibility of an abandoned child aged 15 to 20.

## 3. Carer's Allowance

A disabled person aged 15 to 60 who requires constant care, receives, in addition, to his Basic Invalidity Pension, a carer's allowance of Rs 1 225.

Children below the age of 15, who are disabled, receive a carer's allowance subject to the parents' annual income not exceeding Rs 130 000.

#### **4. Unemployment Hardship Relief (UHR)**

A disabled person who can work, but has not been able to find a job receives an UHR in addition to his Basic Invalidity Pension.

#### **5. Assistive Devices**

The Ministry provides wheelchairs free of charge on universal basis and hearing aids to persons with hearing impairment, free of charge, subject to their annual income not exceeding Rs 130,000.

Applications are registered at the Social Security Office of the locality on presentation of a medical certificate, birth certificate and pension card.

#### **6. Special Pads**

Special pads for disabled persons suffering from incontinence are exempted from customs duty.

#### **7. Exemption from Customs Duty**

Wheelchairs, hearing aids and prostheses which are provided for disabled persons, are exempted from Customs Duty, Sales Tax and Import Levy.

#### **8. Adapted Cars**

Disabled persons benefit from exemption of Customs Duty on specially adapted cars. A request must be made at the Ministry, which will submit appropriate recommendations to the Ministry of Finance.

*Source: [www.gov.mu](http://www.gov.mu)*



## **Part 2:**

# **General Information**

*Adversity does teach who your real friends are.*  
*Lois McMaster Bujold*

*What lies behind us and what lies before us are tiny matters  
compared to what lies within us.*  
*Ralph Waldo Emerson*

## **Section 1:**

# **The disabled and the non-disabled child.**

## **Disability or call it what you may!**

### **The disabled and the non-disabled child.**

In order to understand disability in children and where their needs differ significantly from those of non disabled children, it is good to have an understanding of the normal development process. The stages of development are normally the same for all children, e.g. they sit before they

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can walk etc, but the rate of development varies. For example, some do not crawl before they walk while others just stand and walk.

Disability or disease in a child has a great impact on parents and the immediate family. Chronic illness or disability in the infant or young child may produce considerable additional care needs - usually provided by the parents themselves. Increasing numbers of children receive high dependency care provided at home over long periods.

The attention which is given, particularly to infants and very young children with disabilities, may differ in kind from that given to non-disabled children of the same age; but this does not mean that the amount of attention given is more than that required by a non-disabled child of the same age. Many non-disabled children wake at night and require attention. Similarly young children who are not disabled require care in relation to bodily functions such as eating, washing, dressing, undressing, and using the toilet. Some children, however, may not be receiving the attention they need as a result of their disabilities. The particular circumstances and needs in each case must be individually assessed.

Assessment of care needs has to consider the fact that children develop both physically and mentally. This may

result in decreased care needs in some areas and an increase in other areas. Increasing maturity may lead some children with chronic illness or disabilities (e.g. the child with diabetes mellitus) to assume responsibility for the care of his condition and so require less supervision. Training received may also have its effect, notably with hearing and visual impairment children.

On the other hand, physical development may increase the burden of disablement: a child with learning disability may require more rather than less supervision as he gets older and becomes more mobile. Adolescents with disabilities will also have to cope with care needs against a background of changing patterns in body functions and social attitudes. Sometimes anti-social behaviour is commonly encountered at this time.

### **The Non Disabled Infant**

Non-disabled infants require a great deal of attention in connection with their bodily functions. They must be fed, winded, changed and bathed frequently. In addition, if emotional development is to proceed normally, an infant must be handled, cuddled, talked to and played with regularly. Even when the infant is asleep, periodic checks are made on him.

### **The Infant with Disabilities**

Considering the amount of care and supervision which is required by a non-disabled infant, that required by an infant with disabilities may not be much greater than that needed by a non-disabled child. The kind of attention given may differ: for example, instead of being handled in an ordinary manner, the infant with disabilities may need more specific stimulation or formal passive movements of the limbs in the

form of exercise, but the amount of care or supervision may not be greater than that given to a healthy infant.

### **The infant with severe disabilities**

Infants with certain disabilities will require considerable amounts of stimulation, care or supervision, in addition to the normal care routine.

**These disabilities include:**

- (i) Infants with frequent loss of consciousness usually associated with severe fits.
- (ii) Infants with severe impairment of vision and/or hearing (although it is unlikely that hearing loss will be picked up until the child is several months old).
- (iii) Infants with multiple disabilities.
- (iv) Other categories of infants with disabilities may well require extra care: infants with renal failure, with cystic fibrosis, with asthma, with cerebral palsy.
- (v) Some infants with developmental delay/learning disabilities who require prolonged periods to take adequate amounts of each feed. Some children with Down's syndrome may fall into this category.
- (vi) Care Involving Technical Procedures. The care of some infants with disabilities involves the use of technical procedures.

## Disability or call it what you may!

Disability knows no nationality, ethnic origin or caste. It affects one and all without discrimination. It does not matter if a child is born in a rich family or in the slums. What is

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different is the quality of life that disabled children can have, dependent on their parents' financial means and the country they live in.

The attitude of parents to their child's disability is of crucial importance. We know of parents who feel ashamed of their child's disability to the point of hiding them in the house, even tying their legs to the table to stop them venturing outside – neighbours may not even be aware of the child's existence; on the other hand we have parents who will try and make the child lead as normal a life as possible: normal schooling, shopping trips, games and sports.

It is not easy at first for any parent to welcome disability in their family. Some will perceive it as a failure on their reproductive prowess – defective seedlings, to be crude; others view it as a punishment from God and will be forever asking the question: 'What did we do to deserve this?'; while others see it as a challenge: 'I have a disabled child, so what? I will search for all available literatures on the illness and I do not care what specialists may say, somewhere someone has the answers to help my child lead a fairly normal life'. Some people may not want to be parents of a disabled child. Nowadays it is a routine in Obstetric Clinic to check for potential disability in the foetus. Depending on the level of disability or deformity, the Obstetrician may offer facilities for abortion following counselling. Other people may opt for

abortion regardless of the level of disability. This choice is not available in every country as in some countries abortion is illegal. They will never know the pain and pleasure of raising such a child.

The label of disability itself differentiates the child from others. But it does not matter what word we use, very quickly

the new word will have the same connotation in the child's mind as well as in the attitude of others. So, often to be politically correct, one has to refer to disability or even certain medical terminologies using different phrases. No sooner we get used to the new terminology that it becomes politically incorrect and a new term is introduced – Why? Does that make the child suddenly as by magic, recover skills that he did not have previously?

In Mauritius, in recent years, we have made great strides in recognising the rights of the individual, disabled or not. There is for example legislation regarding access for disabled people to public buildings, the right to a financial allowance, the emergence of various organisations to provide support, including special schooling, for disabled people. We all know for decades now the existence of the Lois Lagesse School for the blind. We have a similar organisation for the deaf. Now we have a variety of Non Governmental Organisations, ONGs, with Government backing, which provide additional support to the disabled. We have visiting specialists from abroad who give advice and practical assistance and help raise awareness.

Our attitude has changed over the years. I still remember calling my next door neighbour's kid as '*cassepatte*' because he walked in a funny way – he suffered from childhood Polio and never had any support in terms of physical rehabilitation.

People forgot or never knew that his name was Henri. Now luckily, today's Henri will have quite a different lifestyle, where his physical disabilities would not hamper to a great extent his position in society.

But there is still a lot to be done in order to assist people with disability as well as their families. There is a need for all Mauritians to learn about the value of every person, disabled or not, provide support as may be required but above all, adjust our thinking and behaviour so that we no longer treat the Henri of this world as '*Cassepatte*'.

*If you can't do what you want, do what you can.*  
*Lois McMaster Bujold*

*There is no try. Do or do not.*  
*Yoda*

The greatest achievements are those that benefit others.  
Denis Waitley

## **Section 2:**

# **A summary of common long term disorders**

### **Learning Disability**

The day-to-day lives of people with a learning disability and their families have always been much affected by the way

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they are perceived and treated by the communities they live in. The history of public and private attitudes over the last three centuries is one of intolerance and lack of understanding. (*Mencap, UK*)

### **A definition of the language of learning disability:**

There is confusion regarding the use of terminology when describing disability. This varies from country to country and also whether the perspective is medical, social or educational.

- "*Learning disability* and *learning difficulties* are used in the US and sometimes elsewhere to denote educational problems of a specific nature, such as dyslexia. In Great Britain, the Department of Health adopted *learning disability* as the preferred alternative to *mental handicap*. However it has been argued that *intellectual disability* is a more accurate term. This is used by the World Health Organization (WHO). However in the United Kingdom, *moderate / severe learning difficulties* is used as a legal term in the field of education." *Prof. Roy Mc Conkey, (Chair of Learning Disability, University of Ulster)*

### **Learning disabilities - what are they?**

- Learning disabilities refers to a variety of disorders that affect the acquisition, retention, understanding, organisation or use of verbal and / or non-verbal information.
- Learning disabilities range in severity and invariably interfere with the acquisition and use of one or more of the following important skills:

1. *oral language* (e.g., listening, speaking,

- understanding)
2. *reading* (e.g., decoding, comprehension)
  3. *written language* (e.g., spelling, written expression)
  4. *mathematics* (e.g., computation, problem solving)

### **Learning Disability - a working definition**

- Learning disability can affect the way in which a person takes in, remembers, understands and expresses information. People with learning disability are intelligent and have abilities to learn despite difficulties in processing information. Living with a learning disability can have an ongoing impact on friendship, school, work, self-esteem and daily life. People with learning disability can succeed when individualised self-management skills and strategies are developed and suitable accommodation is provided. ([Australian Learning Disability Association](#))
- Persons with learning disabilities require specialised interventions in home, school, community and workplace settings which are appropriate to their individual strengths and needs, including specific skills instruction; the development of compensatory strategies; the development of self-advocacy skills and appropriate [accommodation](#).

People with learning disabilities may also have difficulties with organisational skills, social perception and social interaction.

## Down's syndrome?

Down's syndrome is a genetic condition i.e. something you are born with, which is present in the baby from the moment of conception. It is caused by the presence of an extra chromosome. Chromosomes are tiny particles, which are present in every cell in every tissue in the body. They carry the 'blueprint' for all the characteristics we inherit. This blueprint is carried in the form of a coded message in a chemical substance called DNA. There are 23 pairs of chromosomes in each cell, 46 in total. One of each pair comes from the father, one from the mother. In 1959, a French geneticist, Professor Jerome Lejeune, discovered that Down's syndrome was caused by the presence of an extra copy of chromosome 21, making 47 chromosomes in all.

The name 'Down' comes from the English doctor, John Langdon Down, who first described the syndrome in 1866, nearly 100 years before the extra chromosome was discovered. People with Down's syndrome all have a certain degree of learning disability. The degree of disability varies from person to person and it is impossible to tell at birth to what extent the handicap will be.

### **What causes Down's syndrome?**

As yet, we do not know what causes the presence of the extra number 21 chromosomes. It can come from either the mother or the father. The most common type of Down's Syndrome, Standard Trisomy 21 (also known as Primary Trisomy 21 or Regular Trisomy 21), occurs because of an unusual cell division which has produced either an egg or a sperm with 24 chromosomes instead of 23. When this egg or

sperm fuses with an ordinary egg or sperm, the first cell of the developing baby has 47 chromosomes instead of 46, and all that baby's cells will have 47 chromosomes. There is no way of predicting whether a person is more or less likely to make eggs or sperms with 24 chromosomes.

### **Could it be prevented?**

Nobody can be blamed for a baby having Down's syndrome. Nothing that was done before or during pregnancy has caused it. It occurs in all races, in all social classes and in all countries throughout the world. It can happen to anyone.

Standard Trisomy 21 is not hereditary. However, once a person has one baby with Down's syndrome, the chances of having another child with the condition are increased. It would be helpful to talk to a genetic counsellor prior to considering future pregnancies.

### **What does the extra chromosome mean for our baby?**

All people with Down's syndrome share certain physical characteristics, though not every child with the condition has every characteristic. A baby will have inherited physical characteristics from both parents, just like any other child, as well as sharing some of the common signs of Down's Syndrome.

The extra chromosome means that a baby will be slower in his development and will have a certain degree of learning difficulty, but most children with Down's Syndrome do learn to do most of the things other children do. It's just that their development is usually delayed.

### **Common signs of Down's syndrome**

The baby may have looser muscles and joints than other

babies. This will improve as he gets older.

- He may have lower than average birth weight and put on weight at a slower pace than other babies.
- Babies with Down's Syndrome often have eyes that slant upward and outward. Their eyelids often have an extra fold of skin. This does not mean that there is anything wrong with the eyes. They just look different. Hence the previous terminology of 'Mongolism'.
- The back of the baby's head may be flatter than average.
- Many babies with Down's Syndrome have a single crease which runs right across the palm of the hand. Doctors often look for this characteristic crease, as a sign that a baby may have Down's Syndrome. However, some babies who do not have Down's syndrome also have a crease like this.

All babies are different from each other and the same is true for babies with Down's syndrome. This means that in some babies the characteristic signs of Down's Syndrome are fairly easy to recognise soon after birth, whilst others may look and behave little differently from other babies. However, experienced doctors and midwives are usually very good at picking up subtle differences, which suggest that a blood test should be done to check the chromosomes.

Children with Down's Syndrome can grow up to live long and fulfilled lives provided they are allowed the opportunities to develop self-help skills and independence. People with Down's Syndrome can thrive well into their fifties, facing many of the challenges we all encounter: school, further education, work and a home of their own.

## Cerebral Palsy

**Cerebral Palsy (CP)** is a group of disorders whose major feature is brain damage. Most of the time this damage is done before / during or shortly after birth and can be due to a variety of causes. It can be caused by a brain injury that would occur due to a fall down stairs or car accident, however when this is the cause it is more commonly called Traumatic Brain Injury.

### Other Terms for Cerebral Palsy

- Traumatic Brain Injury
- Stroke or Cerebral Vascular Accident (CVA)
- Little's Disease
- Infantile Cerebral Paralysis
- Dyskinetic cerebral palsy or Dystonia (Athetoid CP)

There are four types of CP: **Spastic, Athetoid, Ataxic, and Mixed**. Spastic (hypertonic) CP is characterised by tight muscles. In Athetoid (dyskinetic, hypotonic, dystonia) CP involuntary movements are present. Ataxic CP occurs when the Cerebellum has been damaged, thus causing lack of coordination and jerky movements. **Spastic CP** is the most common type of Cerebral Palsy and is present in about 50% (depending on who's statistics you use) of people with CP. Spastic CP may also be called Hypertonic Cerebral palsy because there is in essence an over abundance of muscle tone. It can be subdivided into 5 types, two of which are extremely rare and will only be mentioned here casually so that you may have a complete understanding of Cerebral Palsy.

## Autism

Although it was first identified in 1943, Autism is still a relatively unknown disability. Yet autistic spectrum disorders are estimated to touch the lives of over 500,000 families throughout the UK alone.

People with Autism are not physically disabled in the same way that a person with cerebral palsy may be; they do not require wheelchairs and they 'look' just like anybody without the disability. Due to this invisible nature, it can be much harder to create awareness and understanding of the condition.

Because an autistic child looks 'normal', others assume they are naughty or the parents are not controlling the child. Strangers frequently comment on this 'failing'.

### **What is Autism?**

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Children and adults with Autism have difficulties with everyday social interaction. Their ability to develop friendship is generally limited as is their capacity to understand other people's emotional expression.

People with Autism can often have accompanying learning disabilities but everyone with the condition shares a difficulty in making sense of the world.

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There is also a condition called Asperger Syndrome, which is a form of Autism used to describe people who are usually at the higher functioning end of the autistic spectrum.

### **What are the characteristics of Autism?**

People with Autism generally experience three main areas of difficulty; these are known as the triad of impairments.

- **Social Interaction** (difficulty with social relationships, for example appearing aloof and indifferent to other people)
- **Social Communication** (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice)
- **Imagination** (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively).

In addition to this triad, repetitive behaviour patterns and resistance to change in routine are often characteristic.

### **What causes Autism?**

The exact cause or causes of Autism is / are still not known but research shows that genetic factors are important. It is also evident from research that Autism may be associated with a variety of conditions affecting brain development which occur before, during, or very soon after birth.

### **Diagnosis**

The earlier a diagnosis of Autism is made, the better the chances are of a person receiving appropriate help and support.

### **Can people with Autism be helped?**

Special education and structured support can really make a difference to the life of a person with Autism, helping to maximise skills and achieve full potential in adulthood.

### **What is Asperger Syndrome?**

Asperger Syndrome is a form of Autism, a condition that affects the way a person communicates and relates to others.

A number of traits of Autism are common to Asperger Syndrome including:

- difficulty in communicating
- difficulty in social relationships
- a lack of imagination and creative play

However, people with Asperger Syndrome usually have fewer problems with language than those with Autism, often speaking fluently, though their words can sometimes sound formal. They do not usually have the accompanying learning disabilities associated with Autism; in fact, they are often of average or above average intelligence.

Because of this, many children with Asperger Syndrome enter mainstream school and, with the right support and encouragement, can make good progress and go on to further education and employment.

### **Key characteristics of Asperger Syndrome**

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Asperger Syndrome shares many of the same characteristics as Autism. The key characteristics are:

### **Difficulty with communication**

People with Asperger Syndrome may speak fluently but they

may not take much notice of the reaction of the people listening to them; they may talk on and on regardless of the listener's interest or they may appear insensitive to their feelings. Despite having good language skills, they may sound over-precise or over-literal. In order to help a person with Asperger Syndrome to understand you, keep your sentences short - be clear and concise.

### **Difficulty with social relationships**

Unlike the person with 'classic' Autism, who often appears withdrawn and uninterested in the world around them, many people with Asperger Syndrome want to be sociable and enjoy human contact. They do still find it hard to understand non-verbal signals, including facial expressions, which make it more difficult for them to form and maintain social relationships with people unaware of their needs.

### **Lack of imagination**

While they often excel at learning facts and figures, people with Asperger Syndrome find it hard to think in abstract ways. This can cause problems for children in school where they may have difficulty with certain subjects such as literature.

### **Special interests**

People with Asperger Syndrome often develop an almost obsessive interest in a hobby. Usually their interest involves arranging or memorising facts about a special subject, such as train timetables. With encouragement interests can be

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developed so that people with Asperger Syndrome go on to study or work in their favourite fields.

### **Love of routines**

People with Asperger Syndrome often find change upsetting.

Young children may impose their routines, such as insisting on always walking the same route to school. At school, they may get upset by sudden changes, such as an alteration to the timetable. They often prefer to order their day according to a set pattern. If they work set hours then any unexpected delay, such as a traffic hold-up, or a late train, can make them anxious or upset.

These are the main features of the condition, but because every person is an individual, these characteristics will vary greatly and some may be demonstrated more strongly than others.

### **What causes Asperger syndrome?**

The causes of Autism and Asperger Syndrome are still being investigated. Many experts believe that the pattern of behaviour from which Asperger Syndrome is diagnosed may not result from a single cause. There is strong evidence to suggest that Asperger Syndrome can be caused by a variety of physical factors, all of which affect brain development - it is not due to emotional deprivation or the way a person has been brought up.

### **Is there a cure?**

Asperger Syndrome is a developmental condition affecting the way the brain processes information and there is no 'cure'; children with Asperger Syndrome become adults with Asperger Syndrome. Much can be achieved to make life less challenging with appropriate education and support.

With time and patience, people with Asperger Syndrome can be taught to develop the basic skills needed for everyday life, such as how to communicate appropriately with people.

### **The importance of early diagnosis**

Because the condition of people with Asperger Syndrome is not as marked as those with Autism, they may not be diagnosed for a long time. This can mean that their particular needs may go unrecognised and parents may blame themselves, or worse blame their child for their unusual behaviour.

### **What does the future hold?**

Some children are in mainstream schools where their progress depends on the support and encouragement of parents, carers and teachers. Some children with Asperger Syndrome go to special schools for children with Autism or learning disabilities. Because their disability is often less obvious than that of someone with Autism, they are, in a sense, more vulnerable. They can, sadly, be an easy target for teasing or bullying at school.

As they get older, they may realise that they are different from other people and feel isolated and depressed. They often want to be sociable and are upset by the fact that they find it hard to make friends.

But the future for people with Asperger Syndrome does not have to be bleak. Adults with Asperger Syndrome can and do go on to live fulfilling lives, can pursue further education and look for employment and can develop friendship - though informed and understanding employers and colleagues are essential.

## **Definitions of terms often used**

### **Assessment**

A systematic and thorough evaluation of the strengths, weaknesses and problems of a person.

*Dictionary of mental handicap, M Lindsey*

### **Attention**

The ability to concentrate or attend.

*Handbook of Autism and pervasive developmental disorders,*

*DJ Cohen and FR Volkmar eds; 2nd ed*

### **Attention deficit disorder**

Deficit in the ability to sustain attention

*Thesaurus of psychological index terms*

### **Attention deficit hyperactivity disorder**

A developmental disorder of early childhood causing problems with attention, activity levels and impulsivity.

### **Autoimmune diseases**

A collection of conditions in which the body's immune system attacks its own tissues, identifying them as foreign

substances. Genetic factors may play a part in this abnormal function, but the causes are not clear.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Behaviour disorders**

Disorders characterised by persistent and repetitive patterns of behaviour that violate societal norms or rules or that seriously impair a person's function.

*Thesaurus of psychological index terms*

### **Behaviour therapy**

Scientifically based approach to modifying and shaping behaviour by identifying and manipulating the triggers and reinforcements of specific behaviours.

*Autism: the facts, S Baron Cohen and P Bolton*

### **Behavioural techniques**

Psychotherapeutic approaches which use classical conditioning and operant learning techniques in an attempt to eliminate or modify problem behaviour, addressing the client's overt behaviour rather than their thoughts, feelings, or other cognitive processes.

### **Challenging behaviour**

Behaviour of such intensity, frequency or duration that the

physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to or use of ordinary community facilities, or impair a child's personal growth, development and family life.

*CB Foundation*

### **Childhood disintegrative disorder**

This refers to a rare occurrence of normal early development until at least aged 24 months, followed by a rapid neurodevelopmental regression that results most often in autistic symptomatology. CDD usually occurs between 36 and 48 months of age but may occur up to 10 years of age.

*Screening and diagnosis of autistic spectrum disorders, PA Filipek et al, Journal of Autism and developmental disorders 1999, 29(6)*

### **Cognitive behavioural therapy**

A technique for the treatment of mental disorder that is based on the concept that how people perceive the world and themselves influences their behaviour and emotions.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Communication disorders**

Impaired ability to communicate usually due to speech, language or hearing disorders.

*Thesaurus of psychological index terms*

### **Compulsions**

Stereotyped behaviours that are repeated again and again. They are not inherently enjoyable, nor do they result in the completion of inherently useful tasks.

*ICD10*

### **Developmental disabilities**

Generic terms relating to all children and adults with a substantial continuing disability originating in childhood.

*Encyclopedia of special education; 2nd ed*

### **Dyslexia**

A significant difficulty with or impairment in reading ability, when reading is compared with other aspects of psychological functioning. Dyslexia can be of various types and have a variety of causes.

*Children with Autism, Trevarthen et al*

### **Dyspraxia**

Impairment or immaturity of the organisation of movement with associated problems of language, perception and thought.

*CaF directory of specific conditions and rare syndromes*

### **Elective mutism**

Condition in which children talk in one situation, for

example, at home, but remain silent elsewhere, e.g., at school.

*The autistic spectrum: a guide for parents and professionals,*  
*L Wing*

### **Genetics**

Branch of biology concerned with heredity and individual characteristics.

*CaF directory of specific conditions and rare syndromes*

### **Hyperactivity**

A pattern of behaviour in children who have problems concentrating and who are always overreactive.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Hyperkinesia**

Excessive motor activity, voluntary or otherwise.

*Oxford companion to medicine, J Walton, PB Beeson, R  
Bodley Scott eds*

### **Immunology**

The study of immune responses to the environment.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Language skills**

The use of language for communicative competence. The ability to use language as a tool to aid interaction within society, via communication with individuals and groups.

*DP*

### **Lesch Nyhan syndrome**

Hyperuricaemia (high serum levels of uric acid) due to a defective gene. Patients with this syndrome are prone to have uric acid kidney stones and mental retardation.

*Online medical dictionary*

### **Microcephaly**

Defect in the growth of the brain which causes it to be smaller than a normal brain.

*CaF directory of specific conditions and rare syndromes*

### **Multiple disabilities**

Simply the presence of more than one disability in the same individual. There are too many possible combinations to list, e.g., Autism and deafness, physical disability and Down's Syndrome.

*DP*

### **Neurological disorders**

Disorders of the brain and nervous system.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Nonverbal communication**

Communication through use of facial expression, posture, gesture and body movement.

*CARS*

### **Obsessions**

Ideas, images or impulses which enter a person's mind again and again in stereotyped form. They are almost invariably distressing.

*ICD10*

### **Obsessive compulsive disorder**

Anxiety disorder where an individual has to perform specific actions such as washing. These activities may reach such proportions that the individual's entire life is centred upon them.

*CaF directory of specific conditions and rare syndromes*

### **Occupational therapy**

Method of treatment by means of purposeful occupation. The goals are to arouse interest and confidence and exercise mind

and body.

*Oxford companion to medicine, J Walton, PB Beeson, R  
Bodley Scott eds*

### **Pathology**

Science which deals with the causes of, and changes produced in the body, by disease.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **Phenylketonuria**

Genetic disorder that results from lack of a single gene that normally codes for the enzyme required for the body to process phenylalanine, an amino-acid present in most foodstuffs. Affected individuals, unless given a special diet with low levels of phenylalanine, present with developmental delay and often with Autism.

*Children with Autism, Trevarthen et al*

### **Prognosis**

A forecast as to the probable result of an illness, particularly with regard to the prospect of recovery.

*Black's medical dictionary, G Macpherson ed; 38th ed*

## **Psychotherapy**

Psychological rather than physical method for the treatment

of psychological and psychiatric disorders.

*Black's medical dictionary, G Macpherson ed; 38th ed*

## **Regression**

To go backwards. This usually refers to the loss of skills previously acquired, especially those basic skills related to early childhood.

*Dictionary of mental handicap, M Lindsey*

## **Repetitive behaviour**

Abnormally intense preoccupation with one subject or activity; distress over change; insistence on routines or rituals with no purpose; repetitive movements, such as hand flapping.

*The early origins of Autism, P M Rodier  
Scientific american, 2000, 282 (2) pp 38-45*

## **Respite care**

Provision of care, relief or support to carers of physically or mentally disabled persons.

*Thesaurus of psychological index terms*

### **Rett syndrome**

A profoundly disabling neurological disorder which only affects girls. The girls appear normal at birth and acquire infant skills to the 9 to 12 month level. A slowing of

development then occurs and regression, with loss of skills in speech and hand use and social withdrawal, begins at around one to three years. Motor development is severely impaired, with difficulty in planning and co-ordinating movement.

*CaF directory of specific conditions and rare syndromes*

### **Rubinstein Taybi syndrome**

A genetic disorder where children usually have normal birthweights, but subsequent growth is poor and developmental delay is usual. The most striking feature is broad, sometimes angulated thumbs and first toes.

*CaF directory of specific conditions and rare syndromes*

### **Savants**

Individuals with moderate or profound learning disabilities, who possess special talents, usually in the areas of music, mathematics, drawing or calendrical calculations.

*Autism: The facts, S Baron Cohen and P Bolton*

### **Self injurious behaviour**

Self-directed violence including hitting the head with a clenched fist, banging the head against hard objects, skin picking and eye gouging.

*Physical interventions: A policy framework, J Harris et al*

### **Self stimulation**

Behaviours which are thought to be used to provide stimulation to the individual. These occur more commonly in people who have severe learning disabilities, especially if they have autistic traits or are under stimulated.

*Dictionary of mental handicap, M Lindsey*

### **Serotonin**

A major neurotransmitter involved in depression and anxiety. A quarter to a third of people with Autism show abnormally high levels of serotonin in the blood.

*NAAR Glossary*

### **Smith Magenis Syndrome**

A genetic disorder where common characteristics include some degree of self-injury, sleep disturbance, developmental delay, short stature, decreased sensitivity to pain, hyperactivity and destructive or aggressive behaviour.

*CaF directory of specific conditions and rare syndromes*

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### **Speech therapy**

Professional assistance in diagnosing and treating a whole spectrum of acquired and developmental communication disorders.

*Black's medical dictionary, G Macpherson ed; 38th ed*

### **SPELL**

An educational approach to overcome or reduce the disabling effects of Autism, creating an atmosphere which has structure, positive approaches and expectations, is empathetic, low arousal and maintains vital links. It emphasises consistency of approach and the importance of mainstream opportunities and settings.

*NAS*

### **TEACCH**

Treatment and Education of Autistic and related Communication handicapped Children is a whole-life approach to helping children and adults with autistic spectrum disorders, developed by Eric Schopler in North Carolina. The principles and concepts of the TEACCH system are improved adaptation; parent collaboration; assessment for individualised treatment; structured teaching; skills enhancement; cognitive and behaviour therapy and generalist training.

*NAS*

### **Tourette syndrome**

A condition characterised by multiple tics characteristically involving the facial area (twitches, blinking, nodding) as well as phonic (vocal) tics. The onset of symptoms usually occurs between the ages of 2 and 21.

*CaF directory of specific conditions and rare syndromes*

### **Turner's syndrome**

A chromosomal condition affecting 1 in 2,500 girls where the second X chromosome is absent or abnormal. Turner's syndrome is generally characterised by short stature and non-functioning ovaries, usually leading to absence of pubertal development and infertility.

*CaF directory of specific conditions and rare syndromes*

### **West's syndrome**

Condition usually commencing between 3 and 8 months of age characterised by infantile spasms and often associated with a change in behaviour and a slowing of development of the child.

*CaF directory of specific conditions and rare syndromes*

## **Section 3:**

# **Useful websites for more information on disability**

## Useful websites for more information on disability

In this section, we have listed some of the international organisations in the field of disability. While visiting these websites, you can have an international picture of how people around the world are tackling the issue of disability, information that could be of help and what new equipments are being available for disability. Below is a list of these websites:

### **Disability World** - [www.disabilityworld.org](http://www.disabilityworld.org)

Disability World is a new web-zine dedicated to advancing an exchange of information and research about the international independent living movement of people with disabilities.

### **Disability Resources** - [www.disabilityresources.org](http://www.disabilityresources.org)

Disability Resources is an organisation established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently.

### **Disability Now** – [www.disabilitynow.org.uk](http://www.disabilitynow.org.uk)

Disability Now publishes a fortnightly publication which cover the latest news stories, bring you comments from the UK's most influential disabled campaigners, guide you through the latest developments in motoring and equipment and offer a selection of lifestyle and arts features.

**HFriends.com** - [www.hfriends.com](http://www.hfriends.com)

HFriends.com hosts a chat room where you can chat with

other disabled persons from all over the world.

**Independent Living Research Utilisation** - [www.ilru.org](http://www.ilru.org)

Independent Living Research Utilisation creates opportunities for independence for people with disabilities through research, education, and consultation. Its goal is to expand the body of knowledge in independent living and to improve utilisation of results of research programmes and demonstration projects in this field.

**Rehabilitation International** –

[www.rehab-international.org](http://www.rehab-international.org)

Rehabilitation International is a global network of people with disabilities, service providers, researchers and government agencies. It advocates the promotion and implementation of the rights and inclusion of people with disabilities.

**The World Institute on Disability** - <http://www.wid.org>

The World Institute on Disability is a non-profit research, public policy and advocacy centre dedicated to promoting the civil rights and full societal inclusion of people with disabilities. They focus on four areas: employment and economic development; accessible health care and Personal

Assistance Services; inclusive technology design; and international disability and development.

**Contact a Family** - [www.cafamily.org.uk](http://www.cafamily.org.uk)

Contact a Family is for families who have a disabled child and those who work with them or are interested to find out more about their needs. It provides useful information and there is a helpline by e-mail, where people can explain their difficulties and ask for advice.

**Adders.org** - [www.adders.org](http://www.adders.org)

Adders.org aims to promote awareness to Attention Deficit/Hyperactivity Disorder and to provide information and as much free practical help as they can to sufferers, both adults and children, and their families in the UK and around the world via their website.

**Down's Syndrome Association** - [www.dsa-uk.com](http://www.dsa-uk.com)

Down Syndrome Association provides information and support for people with Down's Syndrome, their families and carers, as well as being a resource for interested professionals. Their aim is to help people with Down's Syndrome to live fully their lives.

**Disability Alliance** - [www.disabilityalliance.org](http://www.disabilityalliance.org)

Disability Alliance's principal aim is to improve the living standard of disabled people by breaking the link between poverty and disability. Their services include the provision of advice, information, campaign work, research and training.

**Employment Opportunities** - [www.opportunities.org.uk](http://www.opportunities.org.uk)

Employment Opportunities is a charity, helping people with disabilities to find and to retain work. It also provides a wide

range of support and advice to employers on disability and employment issues.



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***Disclaimer***

*This booklet does not aim to produce an exhaustive list of NGOs in the disability sector nor a complete list of long term disorders. It is intended to be used for general information only and may not be considered as any specific advice.*