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A COMPREHENSIVE SUPPORT PROGRAMME

**FOR CHILDREN AND ADULTS WITH AN INTELLECTUAL
DISABILITY**

The program of the Down Foundation

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The goal of the activity of the **Down Foundation** is to ensure that as many children with intellectual disability as possible are brought up within their own families, and to support their independent life when grown up. To assure this, the Foundation endeavour to provide a range of support services to the parents of these children, so that they are encouraged to bring the children up within the family and live an independent life as an adult, rather than send them away to institutions. All of the activities and projects during the past 20 years have been developed in pursuit of this goal. The Foundation's complex social service-system includes:

- providing an advisory service for parents;
- first aid from parents to parents from the birth of the child: 'Down Nanny service';
- clubs and trainings for families and intellectually disabled individuals;
- founding and organising civil initiatives, organisations
- organising conferences;
- supporting research, development and innovation;
- maintaining an out-patient-clinic: Down Ambulance;
- maintaining early development centre
- dental centre with anaesthesiology and intensive care;
- Respite-Care (crisis-) Homes;
- Day-Care Centres;
- establishing and maintaining different types of homes for independent living of intellectually disabled persons: independent life in flats with different scale of help;
- managing and supporting independent living of intellectually disabled individuals or couples in their own flats (SALSA Programme);
- practicing alternative education and vocational training;
- supporting and organising training and education for intellectually disabled persons: independents life skills, supported decision making, life-long learning;
- establishment of sheltered workplaces and support integrated employment;
- complex program for supported employment: ability-assessment, orientation, vocational training, employment with stepwise independence;

- organising courses, creative studio, theatre, orchestra, holidays and many other free-time programme for intellectually disabled children and adults, for their families, more and more in an integrated form;
- support for talented intellectually disabled persons;
- establishment of a music school for children with intellectual disabilities;
- sports and recreation programmes, organising sports programmes, sport-camps, sport-holidays in summer and during the winter-time, regular trainings, sports' education;
- training and education for professionals,
- advocacy and self-advocacy for intellectually disabled
- intellectual accessibility project: to turn the environment useful for all

These programs have considerably benefited children, adults and elderly persons with intellectual/developmental disabilities and their families by improving the quality of their lives.

DETAILED DESCRIPTION OF THE ACTIVITIES OF THE DOWN FOUNDATION

ADVICE AND INFORMATION for new parents: At the start, this activity developed spontaneously from parents' experience, since parents sooner or later turn to other parents for help and information in raising their child. Before the establishment of the Down Foundation I noticed that I had to repeat the same information many times weekly, and that my home had practically become an advisory office. To answer questions and to help solve other parents' problems, we collected volumes of information. We have found connections with experts such as special education teachers, and developed contacts with schools and hospitals. Our aim is to establish a database for information about Down's Syndrome and to publish useful information.

DOWN-NANNY SERVICE: In 1996 we started with a nation-wide service: first aid from parents to parents. Parents, on voluntary basis try to help both with practical and spiritual support for the „new” parents from the first minute. A network of local groups and clubs are doing this work, using a harmonised protocol and organizing workshops and case-discussions twice yearly. The benefit of this activity can be seen now. New parents are much more prepared for raising a child with intellectual disability. Their acceptance and problem-solving ability increased a lot. The aid-giving parents increased in self-organisation, self advocacy and self-supporting. Many new little groups, clubs and associations were established and are working in co-operation all over in

Hungary. Also co-operation with hospitals, clinics, governmental institutions and municipalities has been started.

INTERNATIONAL AND NATIONAL NETWORKING: Study tours abroad helped us in the beginning adapting some progressive programs. We contacted other Down's Syndrome Organisations and we started to work together and exchange information. This way we can disseminate up-to-date information for professionals and parents. During the 20 years activity Down Foundation was pioneer in several novel educational, health care and social services, such as early development, early reading, mathematics and drawing, music education, riding, organising sports, and sports philosophy for people with developmental disabilities. Down Foundation has established the first respite care home in Budapest and one of first 5 group homes for independent living.

RESEARCH and DEVELOPMENT: We are continuously following new scientific studies and social trends in education, social care, integration/inclusion of people with developmental disabilities. We write books and translate informational booklets which are targeted toward special education teachers, medical doctors and other professionals as well as students.

PUBLICATION of a series of *Down Booklets for Parents* (such as *Down's Syndrome, Briefly*; *A Down's Syndrome Baby is Born*; *A Handbook and Notes on the ULWILA Music Education Method*, *How to communicate Down syndrome? You have born, how to continue? Intellectual Accessibility: let's turn the environment accessible for everyone!*). We have also published brochures and leaflets with information about various programs and conferences both for parents and experts.

CONFERENCE, WORKSHOPS, DEVELOPMENTAL, THERAPEUTIC, SPORTS AND RECREATIONAL PROGRAMS for children and adults with intellectual disabilities, and their families.

VOCATIONAL TRAINING for teaching crafts and other trades to increase the chance to find a mainstream job. and make the life of intellectually disabled persons as full as possible. Craft workshops like pottery, basketry, felting, and weaving are very popular. Cooking courses are also very successful. Courses are organised in one of two forms: either weekends (two to three days over the weekend) or summer courses which are then combined with vacation.

The **SUMMER CAMPS, COURSES AND HOLIDAYS** are very well-liked. We generally have 300 to 350 children and adult participants in our camps each year in groups of maximum 20, along with 5–8 volunteer teachers and helpers, sports-trainers. The main camp is at the Lake Balaton, but we have a house in Dobogókő, where 8–10 persons may have holidays.

INTEGRATION & REVERSE INTEGRATION: Children who are non disabled, including sisters, brothers, friends, and the children of the volunteers are involved in the summer programs, and also in our other programs. In the beginning this kind of mixing disabled and non-disabled children was spontaneous and occasional, but today it is one of our most promising projects, which we call "Reverse Integration". In Hungary integration of people with disabilities (not only people with intellectual disabilities) is still limited.

FAMILY PSYCHOTHERAPY SERVICE: Many families break down after the birth of a child with a disability. To prevent the break-up of marriages, and to help families accept the child and the situation, we offer family therapy to families with children between one and three years of age. The form of this activity is a one week family holiday with a psychotherapist, who is responsible for the group-therapy, and with special education teachers who advise parents on the basics of early intervention.

SPORTS: The establishment of the Hungarian Sports Federation for Persons with an Intellectual Disability was undertaken to encourage sports activities and co-operation between smaller sports groups. Sports play a very important role in the life of a person with developmental disabilities. Sport not only promotes good physical health, but is also a popular leisure activity and a hobby during which people make friends, and feel proud of their accomplishment.

When we began to run sports programs in 1990, it soon became clear that in Hungary there is no official organisation of sporting events and championships. There was a need for a mechanism that would co-ordinate the work of small groups or clubs, and would regulate sports activities. Down Foundation and ten other actively working civil organization with sports activities established the Hungarian Sport Federation for Persons with an Intellectual Disability (HS-FID), in 1992. The Sports Federation soon become a member of the international sports organisation INAS-FID, and the Paralympic Committee (IPC). We participated in the first Paralympic Games for people with developmental disabilities in Madrid, 1992, in the First IPC World Athletic Championship in Berlin, 1995, in Atlanta Paralympics and finally won 5 gold medals in Sydney Paralympics.

RESPIRE CARE HOMES: Our Respite Care Homes are run 24 hours a day for families and ID individuals in crisis. Our was the first and until today the only two homes of its kind in Hungary. We consider this homes as our organisation's most important services. The home is open to people with all types of intellectual/developmental disabilities. Its purpose is to help families by improving their quality of life, and to prevent families from institutionalise their

child because of temporary stress. Besides catering to crisis-situations (such as those which arise due to illness in the family or an unplanned trip) we also serve parents so they can have leisure time without their child. Besides providing standard care and supervision, we also provide educational and developmental programs at these homes. The buildings also serve as the site for courses (including summer courses), and holidays. Last year, 22 000 days were spent by children and adults at our Respite Care Homes.

DAY CARE CENTRES: Day Care Centres play an important role: this is the place, where we can test the innovative services of education, training and social care, teaching independent life skills, such as cooking, housekeeping, travelling in the town and supported decision making. We have also begun to teach gardening. We have a program for using computers similar to anybody else. Our teaching materials are prepared in easy-to-read format.

SHELTERED AND SUPPORTED WORKPLACES

We maintain 3 sheltered workshops where disabled employees prepare crafts, such as jewellery, leather items, postcards, small ornaments and several types of gifts. 120 people are working in the handcraft workshops and another 30–40 in the “household”, meaning the teams working on house-cleaning, gardening, transportation, administration and maintenance & repair. Our most independent employees are directed to the open labour market.

DOWN OUT-PATIENT CLINIC: Together with the Bethesda Hospital in Budapest, we maintain a Down Out-Patient Clinic. This is a medical prevention and care facility with 16 specialists. There is a great need for such a service because children with Down's syndrome are often born with many other serious medical involvements requiring problems. Parents have to go from one specialist to another to get medical care for their child. Long waits in crowded waiting rooms at the cardiologist, endocrinologist, orthopaedist, eye-doctor, otologist, and neurologist. This out-patient clinic would bring all of the medical examinations under one roof. We have now completed the clinic including psychotherapy, family advice and social work in the clinic's program, which involves recruiting medical specialists and advertising the service to parents and doctors in maternity wards. The clinic has more than 500 clients, coming at least twice in a year for the complex preventive examination.

MUSIC EDUCATION WITH SPECIAL METHOD: The music education is based on the adapted German ULWILA method, using coloured notes and makes Intellectually disabled children and adults possible to play even in an orchestra. Our Foundation supports the education and the establishment of orchestras nation-wide and published the handbook for teachers.

The **GROUP HOME PROJECTS** include the establishment four type of integrated homes and the elaboration of the know-how and protocols. The four home-types work close together, accomplishing each other. These are:

- Respite care home
- Group homes in block-flats for 2–5 persons
- Independent flats in residential quarters in Budapest for 1–6 persons
- Homes in family houses for a bigger group of 8–12 persons
- Home for elder and for seriously handicapped people in family houses with large garden
- Support for intellectually disabled persons in their own homes.

A so called **Complex Program** was established in 1998 for 18–20 years old persons, trying to establish their independent life as soon as possible with the contribution of their parents. The programme is complex, because in addition to the housing there is organized education, vocational training, teaching self-support and spending of spare time, creating of workplaces, and designing and building the best fitting building for 12 young Down-syndrome persons. The realisation of the whole program supposes a high contribution of the parents, both with finances and with voluntary work. Two of the original residents, a couple have already moved into their own, completely independent home.

The **group homes in a block-house** is a different solution for independent living. Small flats in bigger panel-houses are relatively cheap, so the Foundation bought 3 flats close to each other for 5–5 intellectually disabled persons. These persons are mainly middle-aged people, with very old and ill parents or without any parents. Formerly they lived with their families, and we ensure now a group home for them, instead of sending them into a state-owned segregated institution. In this case the main goal is also a complex, comprehensive program: teaching them self service, independent life skills and ensuring the residents workplaces or day care, plus offering spare time programs, etc. We organised meetings and invited the other residents of the big panel house, to promote tolerance and integration.

We would like to prove, using these two models, that the main thing is the spirit and the good professional attitude, and that a good professional support can be achieved also in cheaper, less ideal buildings.

The **home for elderly people** is our last development. it is arranged in a bigger family house. In the basement of the house we started to establish a sports and rehabilitation centre.

SPONSORS, DONATIONS: Fund-raising is part of our every-day work. We apply direct marketing for the collection of donations and individual contracts with companies, which buy our products, prepared by the client-employees.

THE ORGANIZATION OF DOWN FOUNDATION is working today for more thousands of clients, 350 from these on a daily basis. The foundation has about 100 employees and 100 more intellectually disabled employees. The yearly budget is 2 million EUR. Main financial sources are the service charges, some governmental contribution, grant, sponsors, donation and own revenue generated by the products of the workshops.

The introduced programs and services are integrated into a service system, based on a holistic approach by providing person-centred services and support from the birth until elderly age.

In our work we consider most critical:

1. Establishing the models of services, such as respite care home, day care centre, group home, etc., which can support our main goal: to help parents and families in raising up their intellectually disabled child at home, within family. We have been pioneers in many innovative social services and their practical realisation.
2. Promotion through the media to make non-disabled people aware of both the existence and the problems of people with developmental disabilities, and that all people deserve and demand full life, with work, fun and friends, and that integrating people with disabilities into society is everybody's responsibility.
3. To encourage parents and also intellectually disabled people in self-advocacy and self-management. Trainings and courses are organised to reach this goal. Part of this work is the "Intellectual Accessibility" programme, which aims to teach intellectually disabled persons to take care their own management, to arrange documents and use public services, as well as educate service providers, including government offices to be able to accept and support intellectually disabled persons when using the services.