

PERJÉSINÉ GAZDAG ÉVA

The Corner House Residential Home

What does a disabled young person need? Is it a difficult question? The answer is definitely not one. A young person who lives with a disability needs exactly the same things like his peers: a home, a job, income, well-spent leisure time, friends, a partner, a family, and health care. What actually makes this listing different is that in order to achieve all these things these young people also need support from others.

Parents raising a child with a disability dream about offering assisted living to their children in adulthood. This sort of assisted living has no tradition in Hungary. The best example in the country would be the network of institutes, "Down Foundation Helping the Development of the Intellectually Disabled". This organization embraces the whole life span of disabled people from birth to old age.

1. The way to the residential home

Until the '80s social services were operated solely by the state in Hungary. A number of intellectually disabled people lived with their families. Those who were not lucky enough to grow up in a family were hospitalized in public institutes. Some changes occurred in the social-political processes that had an impact on this national monopoly. The following major important changes strengthened one another (Galambos, Papp, Verdes 2003:14).

- a. The number of social problems increased dramatically, often leading to health and mental issues.
- b. The national social-political and health care systems that were supposed to prevent and solve the above mentioned problems, were unable to fulfill their duties.
- c. New organizations and movements were founded.

Although more and more civil organizations (associations, foundations, etc.) were founded, their status was insecure due to lack of national and public support.

At the end of the 1950s Benkt Nirje formed his experiences with the disabled into a principle, which is called the normalization principle. The aim of normalization is to offer the intellectually disabled life ,models and conditions for living

that are approximately similar to the usual norms that of the nation (Nirje, Perrin, 1989). Essentially, normalization is a developmental process.

As this principle was becoming increasingly popular in Hungary and the intention for integration has become dominating civil organizations dealing with disabled people have been gaining influence. Due to their pressure and the consequence of the special educational paradigm change, the giant institutes started to divide into smaller institutes which resulted in the formation of properly sized homes. But these institutes were still quite different from those that parents who raised their disabled children would have preferred. They wanted their children to live the same quality life they had had while living with their parents. The national solution has not arrived yet. Initiatives by strong-willed, innovative parents have contributed a lot. These parents have realized that this is the only chance for their children to receive the help he or she needs by keeping their human dignity, their sense of being an adult and their ability to act. Other parents had to face the difficulties of getting old or sick and not being able to take care of their disabled sons and daughters who had spent their whole lives living with their parents. These parents wanted to secure the future for their children at all costs, but at the same time – just like young and dynamic parents – they were not satisfied with the old existentially and professionally poor institutes (Gruiz, 2000).

The 1993 Act III. provides a legal background for the existing social administration and social services but it does not mention residential homes that, however, had already started to operate based on foreign example.

The first foundational residential home built with French support was opened in 1991 as part of the Bark Community in Dunaharaszti. The residential homes of the civil sphere were developed through parental initiatives, mainly with foreign support.

Legislation legally acknowledges 'the institute of the residential home' but the it has been long overdue for them to achieve the status of 'assisted residence'. The 17th § of the 1998 Act XXVI regarding the rights and equality of disabled people mentions the residential home as an alternative way of living that can be chosen by the intellectually disabled. The financial background has not been cleared yet, though. Although institutes maintained by civil organizations have taken over governmental duties, they only get normative financial support if they function as a care providing institute or home for disabled people. The situation was solved in 1999 by the Act LXXIII, §31. The legal expression 'residential home' has been in existence since then.

2.The short history of the Down Foundation [1]

The Down Foundation has been functioning in this form since 1992. Dr. Katalin Gruiz declared its principles. The Foundation is supervised by a board of trustees who are parents. As the professional role of the organization was increasing professionals became members of the board of trustees. This meant physicians, SEN teachers, social care professionals and economists became trustees of the Foundation. Later on they produced pamphlets, they brought in new early intervention and teaching methods from abroad and – most importantly – they brought new perspectives that they popularized in parents’ meetings and conferences. ”New perspective” referred to the way that was in matching the wishes that of the parents. This change of perspectives would never have been successful without adopting rules and practices from western countries.

The Foundation started to move towards its present profile when they had opened their first crisis home. The purpose of this home was to make the life of parents of children with Down syndrome easier. This institute offered the potential of a home environment with professional assistance in case parents fell sick, had to leave for whatever reason or just simply needed some spare time. Völgyi Katalin had a leading role in opening this home. First she had worked voluntarily and then she became the leader of the home as a full time employee. Later on, the original purpose of the institute changed. Families contacted them in extreme crisis situations. Severely disabled people arrived who could not be taken care of at home, severely autistic children and young adults were brought here by their parents who had had no spare time for years and more and more young or elder disabled persons who had lost their parents asked for shelter. Instead of smiling children with Down syndrome, severely disabled people moved into the home which put a huge strain on the nurses and on the Foundation.

In 1993, as soon as the social law had been passed, the Foundation launched its Transition Home project. This was a governmental project: they were supposed to receive financial help from the government which they did not receive for years. After the situation had been fixed the Board of trustees came up with new plans. Along with the Transition Home project they also launched the Daycare Centre project. This home became full very fast requiring a second home and soon afterwards a third one. They searched for foreign contacts to learn about the most recent services. As parents they had an idea in their minds concerning the ideal solution but they would not have been able to fight the perspective obstacles if

they could not refer to the already operating foreign models. Later, this became their working method: using parents' feelings, ideas and using the international practice and establishing it in Hungary the Foundation draughted the optimal solution and they compared it with the actual Hungarian practice. The difference was shocking but it also gave inspiration for the next steps which were lobbying, fundraising, and realization. Since the parents were the practical leaders of the Foundation, they knew that a service such as a home would not solve all the problems. A complex service network was needed which would be utterly different from old, traditional national institutes. They recognized that the residential home was only part of a complex solution, which would be assisted living. To acquire the sense of independent living, one should actually live independently: that needs to be taught to one and one needs to learn it. In order to accomplish this independence, self-esteem, a job and an income of one's own are crucial, and so are knowledge, partners, friends and family. They acknowledged how far their clients were from this point, but they also realized what they needed to learn: cooking, shopping, using money, behavior, etc, the list was never-ending. They had to learn a lot about the practice and ethics of providing help. Because of the lack of textbooks on the issue they could only rely on their own experience. They wanted to learn how to help a disabled person so that they serve his or her growth to independence. They wanted to form a helping attitude that was different from traditional Hungarian mentality full of regret and condescension.

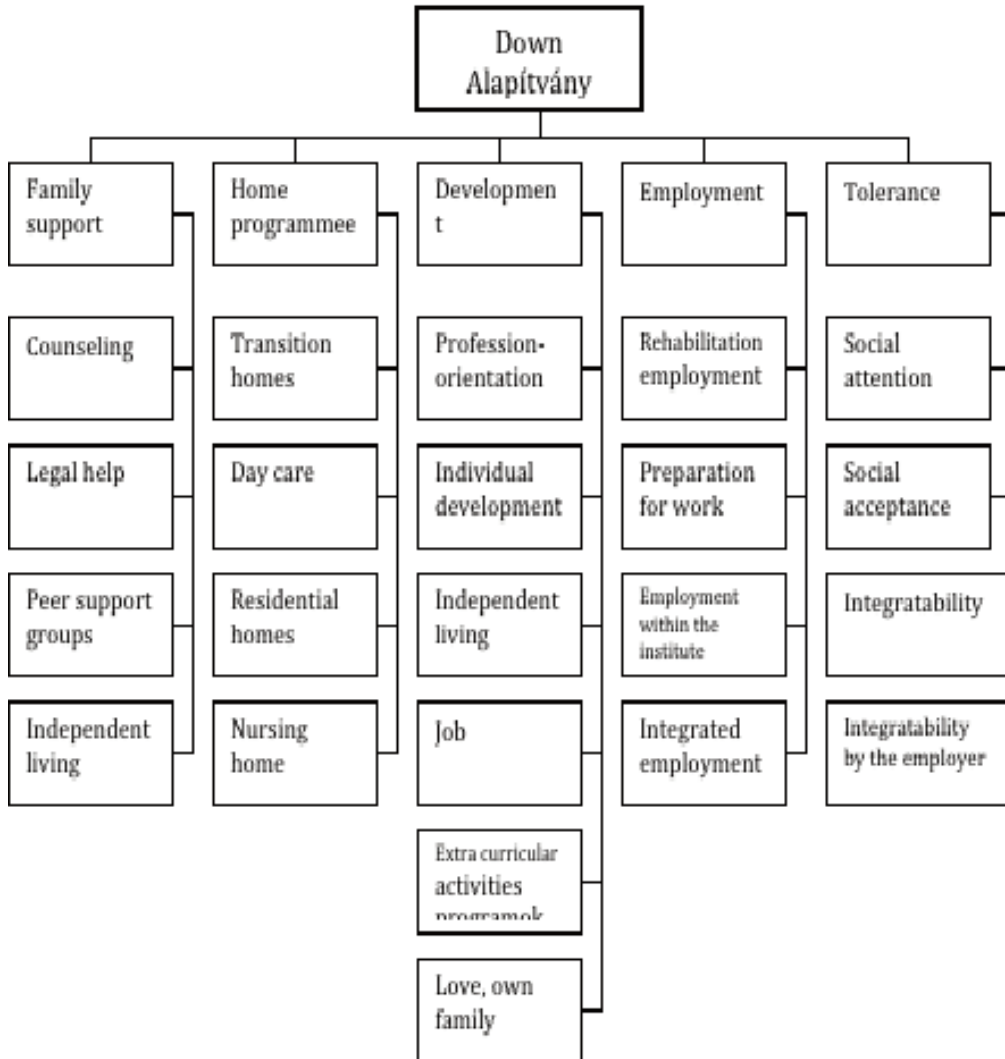
The next important event was when the organization joined residential home developing program in 1996-97 operated by the "Kézenfogva Alapítvány". It was easy for them to join a program that was based on educating disabled people to live an independent life while they are young and not when they are getting older and it is difficult for them to learn new things. This was the Corner House project that they considered to be as close to an optimal solution as they could get at the time. The tenants, who are now 27-29 years old, were 16 years old when they were taught the idea and the requirements of the residential home. The parents participated in several prospective and life strategy trainings and the plan of the residential home was made with their help.

3. Orchestrating the network

When the disabled young adult who grew up in a family finishes school the family starts panicking. What shall we do now? The Down Foundation offers help for

this new life situation. The parents' trainings prepare the family for the changes and at the same time they display the available services. The complex service that the Foundation offers fulfills the idea of assisted living for disabled young adults.

1st image: The Foundation's adult service



Source: Gruiz, 2009:75

In order for a disabled young adult to be capable of assisted independent living many conditions have to be provided. The best practice is when preparation starts early in childhood by the family. The goal is to teach the child to be able to take care of themselves, to cope with society's requirements on their own. Maybe the first few sentences of this article come to our minds: just like their peers. According to Dr. Gruiz Katalin this is why it is important to see that the preparation for assisted living is crucial for the disabled young adult's quality of life: independence in school and in a job has to precede living in a residential home (Gruiz, 2000:246-259). Preparing the parents to "let their children go" is just as important – this is the key for both parties to have a positive attitude towards life after the disabled person has left home.

Disabled young adults need help to be able to live an assisted life. The professionals of the Down Foundation prepare the young adults for independent life. The parents' and the Foundation's 6 year program helped the tenants to gain their maximum independence.

The tenants plan their own future with professionals' assistance and they learn to use their own homes as part of their training. The conductors teach them household chores, financial management, and, later on, they help them find jobs and even help them with their daily problems if necessary. Besides the professionals, the help provided by the family, relatives and friends is very important. The amount of the help depends on the condition of the disabled person. Some of them need day and night care while others only need help with major decisions. Every one of them gets the amount of help s/he needs, no more, no less.

4. The Corner House residential home [2]

The program and the home itself was created with the alliance of professionals, parents and sponsors and with the support of the "Kézenfogva Foundation", the Mayor's Office in Budapest, the Ministry of Public Welfare, Bankaritas and Uniqua Insurance.

Corner House Home has been operating since 2000. The tenants of the home are 23-28 years old mentally challenged young adults with Down syndrome who are partially self-supportive.

The home operates in a suburban environment in a two-storey family house built in 1990. The Foundation had bought it in 1998. It has been remodeled several times to satisfy the needs of its tenants.

Most of the 12 young adults (5 boys, 7 girls) attended the same kindergarden group and, then, attended to the same class in school. 11 of them are skilled workers, for 2 years they learnt fancy-leather design, and for 3 years carpet weaving. Five of them have received their certificates, the others received license. They now work in their respective fields. Only one of the young adults is under guardianship, the others are full right citizens. Their mental skills are more or less at the same level. According to the leading supervisor this is an important aspect because it is easier to organize the daily life and the different programs for them.

Right now there are no vacancies in the home. The tenants are young, the Foundation offers them a life-long place in the home with full amenities (food, medical and mental care, financial assistance). This means that because of the large demand, new residential homes need to be built. In this one there will be vacancy only in case one of the tenants is leaving.

The particulars of the homes: on each storey there are 6 bedrooms and 2 bathrooms. Each tenant has a room of his or her own which they have furnished themselves. The kitchen and the dining room are on the first floor. They clean the communal areas together and everyone does his own room.

Altogether five employees work in the home. They are social workers and SEN conductors. At night one helper stays in house to attend the needs of the tenants, during the day 2 or 3 of them help the young adults.

On weekdays the young adults go to work with one of the helpers. One of the 12 tenants works as a cleaning assistant in offices; the others make leather gifts, ear rings in the Sight Workshop 6 hours a day. In the afternoon they go to different programs and/or trainings. Once a week they go to ride horses and/or to row. They often go to cinema, to theater, to bowling and to ulwila classes. The girls like to do belly dancing and they all participate in different music-dance performances. They all receive logopedia and individual development training once a week. Wednesday is free – they call it ‘recovery day’. On Wednesday they clean the house, do the gardening, it is time for some hairstyling, and they also do the laundry this time of the week.

They organize daily routine in the home with the spirit of integration. They invited the neighborhood to the opening. They went and bought cakes, flowers, and books. They have been on good terms with their neighbors ever since.

At the weekends tenants spend some of their time with their families. Oddly enough, while parents visit their children in the home regularly, siblings never come to the residential home. The supervisor of the home, Timea Magyari thinks

that the problem might be due to the fact that at the beginning of the program siblings were not participating in the preparation process. Parents are old now and it is time their siblings adopted some of the tasks. If they exclude themselves from the program, they will never learn about the life of their disabled brothers and sisters and, then, this change cannot take place smoothly, without conflicts.

The parents, professionals and the tenants discuss problems at regular work meetings. These group meetings are rare now because the professionals of the home consult parents individually. This is more personal, and each meeting is more productive this way. Parents, tenants and helpers can each call for a meeting.

Just like their peers, these young adults wish to have love relationships, they fall in love and they break up. The tenants have a rule they have shaped together. If they are together for 3 years, they can get engaged. After this point they can move in together, one room becomes their bedroom and the other one turns into a living room. If the relationship still works out well the 2 rooms can be jointed.

Practice shows that if 2 disabled persons live together they need less help than when they live separately on their own. Their knowledge, their cognition merge in synergy (Gruiz, 2009: 84). In case of living together, the question of having a child inevitably crops up. This possibility might be scary for outsiders and helpers as well. The Hungarian system is not prepared for this yet. Foreign examples show that assisted living also works well in case of whole families. It should be noted, that there is no general truth, or general solution, the question depends on the person and on the situation (Gruiz, 2009:84).

The young adults participated in sexual educational classes a few times. The supervisor of the institute with the help of professionals from “Kézenfogva Foundation” tried to prepare the parents and the tenants for this part of social life, too. According to the supervisor, the training went without any problems for the „guys” but it was difficult for parents and helpers.

People with Down Syndrome have difficulty understanding the idea of the value of money. Helpers pay extra attention to teaching the handling of money to the young adults. The supervisor receives the money and divides it for the tenants. This way they understand that they get their money for their work. Helpers function as mentors as well, each tenant has a personal tutor who pays more attention to them if needed. They talk to him or her about what they would like to buy, what they save money for, for how long they have to save for it. These amounts go to the safe of the house. After tuition fee has been collected the rest of the money is

transferred to the tenant's account.

The residential home is supported by national normative support, sponsors, from tenders and via tenants' tuition fee.

Institutional tuition fee: 56.000 HUF, individual tuition fee: 22.000 HUF/person.

In the lives of these young adults different problems appear. At the beginning parents had the problem of not being able to let their children go. Because of this the Foundation organized different trainings for parents. The problem could not be solved permanently. Some parents still emotionally blackmail, they try to ban things for their children. The young adults have proved many times that they are able to live independently and some of the parents simply cannot accept this.

What is to be done next?

Yes, even now the road yet to be taken is infinitely long. The other home program of the foundation is SALSA: young adults live in their own homes without on-line assistance. Right now 3 couples and 4 single individuals live in independent flats. The helper, when needed, visits them 1-5 times a week and is always available on the phone. These mentally challenged people lead a household of their own, they take care of their social responsibilities. They go to work, go out, just like everyone else.

5.Summary

Every acting society ought to design how to fulfill the requirements of the normalization principle. The state and the society speak via how they treat their disabled citizens. The (far) future can be nothing other than treating disabled and non-disabled people equally. This means that everybody has the same right for self-realization, for human dignity, for freedom, and acceptable living conditions. If they need help they should get the right amount in the right way. A stage of this process is that homing for disabled persons is solved and is secured even when their families cannot take care of them. The Down Foundation shows an example with its different residential homes to the governmental and civil sector.

NOTES

[1] Based on the interview with Dr. Katalin Gruiz (President of the Down Foundation Serving the Development of Disabled People)

[2] Based on the interview with Tímea Magyari (Supervisor of the Corner House Residential Home)

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Perjésiné Gazdag Éva: A Sarokház Lakóotthon

Mire van szüksége egy fogyatékkal élő fiatalnak? Nehéz a kérdés? A válasz nem az. Egy fogyatékkal élő fiatalnak ugyanarra van szüksége, mint ép kortársainak: lakásra, munkára, keresetre, értelmesen eltöltött szabadidőre, barátokra, társra, családra, egészségügyi ellátásra. Amitől mégis más lesz ez a felsorolás: mindehhez szükségük van segítségre is. Minden olyan szülő, aki fogyatékos gyermeket nevel, arról álmodik, hogy gyermeke segített önálló életet élhet. Magyarországon ennek nincsenek hagyományai. Hazai viszonylatban példaértékű az Értelmi Fogyatékosok Fejlődését Szolgáló Magyar Down Alapítvány intézményrendszere, melynek segítségével átfogják a fogyatékos ember egész életívét: a baba születésétől az időskorú személyek ellátásáig.