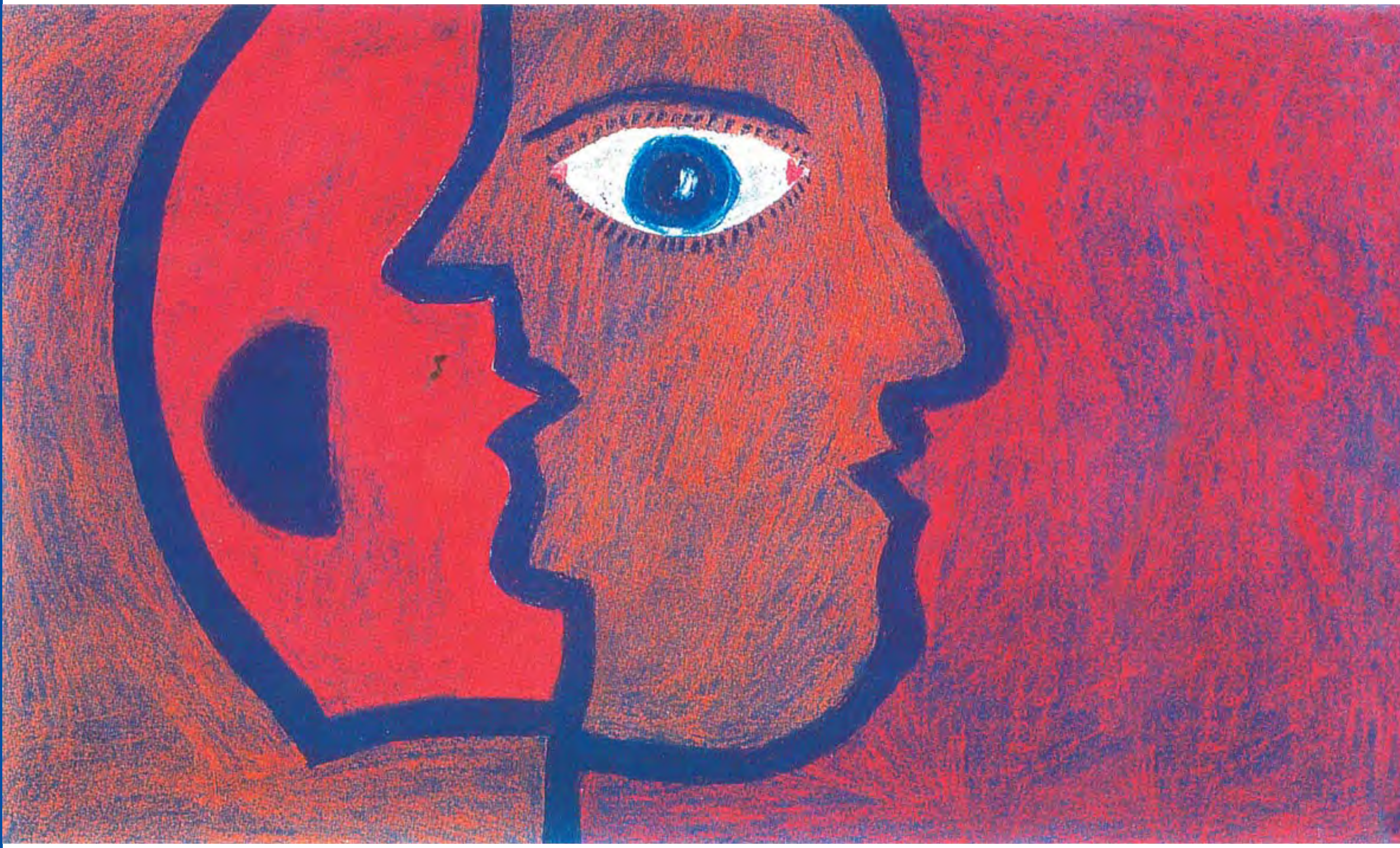
The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs



Report of a European Study

Volume 4: Examples of Good Practice

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The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs
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Picture on title page

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Summary

People with severe disabilities and/or with complex needs are dependent on the quality and reliability of support services. Some may need 24-hour care or a complex service arrangement involving different specialised professionals. Thus, service provision and service quality are a key concern in providing the necessary support for their inclusion in the life of society.

The Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs found that most of the concerned people with disabilities live either with their parents – often with insufficient support – or in specialised institutions that may tend to segregate people with complex support needs from society. Most often driven and organised by people with disabilities themselves or their families, some new and innovative service arrangements have been established in the twelve countries participating in the study. Volume 4 compiles a selected range of these examples of good service practice. The examples also show that services that are new and innovative in one country can be standard already in other EU Member States.

The examples were collated by the project's National Research Experts on the basis of qualitative interviews and site visits. They have been organised in six different groups:

1) Early Support
   An example from the United Kingdom demonstrates how early intervention can improve the life chances of a child with a severe disability.
2) Support for Families
   Family support is necessary to help families to cope with caring for their child with disabilities at home. From many examples, good practice from Belgium, Lithuania and the United Kingdom has been selected to demonstrate different approaches.
3) Day Activities and Work
   Examples of good practice from the Czech Republic, Sweden, the Netherlands and Spain show the importance of providing meaningful day structures and activities.
4) Housing and Personal Assistance
   Housing and personal assistance are two areas of special importance for adults. Examples from Sweden and Italy show how inclusive living can be organised.
5) The Use of Personal Budgets
   Personal budgets or direct payments give the user direct control of the necessary support arrangements. Examples from Germany, the Netherlands and the United Kingdom demonstrate that personal budgets are a flexible tool to organise support.
6) Specific Aspects of Service Provision
   This section highlights support arrangements for different specific groups of clients as well as the need for intersectorial cooperation. Examples from France, Germany, Italy, the Netherlands and Poland illustrate different aspects.

However, there is no doubt that good living conditions of people with severe disabilities are in many cases also a result of individual struggles and fortunate dispositions. In this context it becomes clear that good services try to be flexible, reliable and show respect for the person with disabilities by proactively supporting his/her individual empowerment processes. With their individual or organisation-based solutions for complex service needs these examples of good service practice are valuable as models for services in other countries.

Résumé

Les personnes ayant des besoins complexes sont dépendantes de la qualité et de la fiabilité des services de soutien. Certaines ont besoin de soins 24h/24 ou d'un montage complexe de services incluant différents professionnels. La fourniture de services et leur qualité sont donc cruciales pour inclure ces personnes dans la société.

L'étude sur les risques spécifiques de discrimination des personnes en situation de grande dépendance montre que la plupart d'entre-elles vivent avec leurs parents – souvent avec un soutien insuffisant – ou bien dans des institutions spécialisées, où il y a parfois une tendance à un isolement de la société. De nouveaux services innovants ont été mis en place dans les douze pays analysés dans cette étude. Le plus souvent ils sont gérés par des organisations de personnes handicapées et/ou leurs familles. Le volume 4 du rapport final de l'étude rassemble une sélection de ces exemples de bonnes pratiques. Nouveaux et innovants dans un pays, certains de ces exemples sont déjà la norme dans d'autres.

Ils ont été rassemblés par les experts nationaux à partir des entretiens et des visites. Les exemples sont classés en six groupes :

1) Soutien précoce et éducation
   Des exemples de Roumanie et du Royaume-Uni montrent combien les interventions précoces et l'accès à l'éducation améliorent les chances d'un enfant.
2) Soutien aux familles
   Pour que l'enfant handicapé puisse rester avec sa famille, il est nécessaire d'apporter de l'aide. Parmi d'autres, de bonnes pratiques en Belgique, en Lituanie et au Royaume-Uni ont été choisies pour illustrer ce groupe.
3) Activités de jour et travail
   Des exemples de Tchéquie, Suède, Pays-Bas et Espagne montrent l'importance d'offrir des structures d'accueil et des activités cohérentes.
4) Logement et aide à la personne
   Le logement et les aides à la personne sont cruciaux pour les adultes. Des exemples de Suède, Espagne et Italie illustrent le logement « inclusif ».
5) Usage de budget personnel
   Budgets personnels ou paiements directs donnent à l'usager un contrôle sur l'organisation des services dont il a besoin. Des exemples d'Allemagne, Pays-Bas et Royaume-Uni montrent que les budgets personnels sont un moyen flexible pour organiser le soutien.
6) Aspects spécifiques de la prestation de services
   Cette section met en évidence les modalités de soutien différentes selon le type d'usagers, et la nécessité de coopération entre les différents secteurs. Des exemples de France, Allemagne, Italie, Pays-Bas et Pologne en illustrent plusieurs aspects.

Cependant, il ne fait aucun doute que dans beaucoup de cas, la qualité de vie résulte aussi d'un combat personnel et de la chance. Sur ces bases, il apparaît qu'un bon service est un service flexible, fiable, respectueux de la personne, soutenant activement son processus d'autonomisation. Les exemples donnés, qu'ils soient individuels ou reposent sur une organisation, peuvent servir de modèles pour d'autres pays.

1. Early Support

Salford Early Support Team (United Kingdom)

Author: Alison Alborz. Interviewees: Lynne Moody and Jeanette Costello

The goal of the Early Support Team is to bring some ‘normality’ to the lives of families with a child between the ages of 0 and 5 years who have support needs. Their main task is to co-ordinate service delivery and support families, both emotionally and in their interactions with the different agencies they come into contact with. They do this through a key worker system and support materials devised to help co-ordinate information about the child and family, and the range of provider services.

The approach was founded about 5 years ago and developed from an original set of materials devised by the Royal National Institute for the Deaf and further developed with the needs of a wide range of children with disabilities in mind. A number of trial areas developed pilot services to test them with government funding. The Salford Service was a pathfinder authority in 2004 and when the trial was over in 2005 continued to operate with funding from the Salford ‘Sure Start’ programme. Salford Early Support has no direct funding at the moment. Local authority ‘Children’s Services’ budgets provide funding to local ‘Sure Start’ programmes, which are designed to provide education and support to children under the age of 5 and their families. The Salford Sure Start programme has committed part of its funding to maintain the three full-time staff posts in the Early Support service. Lynne comments that the service has no permanent funding of its own at the moment, however the service is highly valued by the families supported and so she is confident that in the longer term secure funding will be established. The materials used as part of the approach to family support are provided by the government.

The service provides support to families in a large metropolitan district in the North West of England of more than 2 million people and more than 12.5K children age 0-4 years (National census data, 2001). However there are only 2 full time designated key workers at present. They currently support about 80 families of children with disabilities, not all of these children have complex needs. The service has a ‘parents’ forum’ that contributes to the work of the service by providing feedback on its activities. The team plan that their designated key workers, that is those working for the service on a full time basis, will support children with complex needs and their families, while those with less complex needs will be supported by a lead professional using the same approach and methods. At the moment they have a waiting list for services and find it difficult to respond as quickly and flexibly as they would like. However, when more professionals are trained in the methods and can take on the dual professional/key working role, this should enable the full time key workers to be free to respond quickly to the needs of this group.

Case Study

Jenny (not her real name), is two and a half years old and lives with her parents and three older brothers in a large house. She was born with a syndrome called CHARGE which affects five parts of the body – including defects of the eyes, heart, nasal passage, genitals and ears, and a growth disorder. At the time of her birth there was no indication that Jenny would have disabilities. Both of her parents had been working full time and had a good lifestyle. When Jenny was born, she spent the first 9 months of her life in hospital. Her heart stopped every two weeks and she was not expected to live. As Jenny had been born and treated for her heart problems in another local authority area to where she lived, she was not known to any of the professionals in the Salford area until she came home. The Hearing Impaired Service in Salford work with children from birth and Jenny was seen at home by one of their team. This professional knew of the Early Support team and invited a key worker, Jeanette, to meet the family.

The Hearing Impairment Service worker arranged a meeting at the parent's home for the family to meet all the professionals they were likely to encounter due to Jenny's wide ranging needs, and invited the Early Support key worker. It was quite daunting for the parents to have 10 professionals in the home when their daughter had only just arrived home from hospital, but it alleviated the stress of 10 separate appointments and the time it would have taken to be introduced to each professional separately. At first, the mother was unsure about having another person to deal with in addition to the huge range of professionals, but Jeanette was honest about what she could help the family with, as well as what she could not do, in regard to all the family's needs. For example, no one else was taking into account the needs of the other three children in the family. Jeanette was therefore able to offer to assist with looking for sources of support for Jenny's brothers, such as holiday care and sources of funding to help with that.

Jeanette therefore became the family's key worker when Jenny was 10 months old and for the first year was a very regular visitor, visiting each week. The first 3 visits lasted about 3 hours each time and Jeanette spent this time listening closely to Jenny's parents. Jenny's mother had been through a trauma, but no one had said 'How are you coping?' She found out which professionals were involved with the family and approached them directly for the medical information required to ensure services could be co-ordinated. Jeanette then assisted the family with completing a profile on their daughter using the materials specially produced for the Early Support work. This profile then gave the professionals involved information they needed to properly support the family. Importantly, the information included details about the whole family and how they were feeling/coping. This is an aspect of families that professionals rarely have knowledge about, yet is very important if they are to support children with complex needs, and their families, well. The key worker also helped to create information book about dealing with feeding and the gastrostomy, in an emergency, and about how to communicate with the little girl because of the difficulties arising from her sight and hearing problems.

The visits established what the family wanted Jeanette to do, and much of the work involved enquiring about appointments with professionals and co-ordinating appointments so that hospital or home visit appointments could occur together. In addition, every three months Jeanette would arrange a family service meeting, where all the services involved would be represented at a meeting in the home and could plan, together with the family, the support they would be providing over the coming months. These meetings meant that each professional became aware of what every other professional was doing and could openly discuss with the family how their support would be provided.

The key worker is available to supported families at all times. Sometimes families only need to ask a simple question, at other times they act as a bridge to other professionals. For example, a child had started having severe epileptic seizures and her mother had been told that if a seizure lasted for more than 5 minutes, she should give her medication and rush her to hospital. The child had starting having clusters of seizures, however, each lasting about 2 minutes with a 2 minute gap in between. Overall this lasted more than 5 minutes. The mother asked the key worker to find out what she should she do – was this the same thing. The key worker was able to get in touch with the consultant immediately, because she had a 'mobile' number for him, and was able to reassure the parent within 10 minutes. This is one of the aims of the service, to be able to give parents easy access to help and a fast response to their concerns.

An early criticism of the service was that the key workers were doing too much for families making them unable to cope alone. However, Lynne points out that at the point their service is offered, the families are highly distressed and not in a state to cope on their own. The aim of the service is not to ‘take over’ but to support families until they are in a position to cope again. This means responding to what families need. It may include arranging a respite placement for a few days because the mother needs it, rather than the child. It may also mean that the key worker acts as a messenger to all the other professionals involved, for example, to say that the family want special ‘family time’ together and do not wish to be contacted or visited during a particular period.

Lynne and Jeanette comment that they have both worked in the disability field for many years, and this service ‘just feels right’, ‘It’s what families have been wanting and saying for a long, long time – and it’s happening’. At the moment the service is only offered until the child is 5, however they hope, and expect, that it will not stop then.

Innovation

This service is innovative in taking the family as its focus and including them in the ‘team’ aiming to support their child with complex needs. Multi-agency working is at its core with joint planning and joint goals. This contrasts with the traditional service delivery model in which professionals are seen separately, and plan and provide support in isolation from one another. The Salford Early Support team also gives parents confidence to challenge the advice they are given when it is unrealistic. The joint visits to families by groups of professionals, have also allowed the professionals to get to know each other and ask questions from one another about working together. The service, therefore, has many benefits for both families and those providing services to them, but especially for the child with complex needs who receives co-ordinated care within their family home.

2. Support for Families

Charnwood Nursery meets the needs of families with a young child with ‘special needs’ (United Kingdom)

Author: Alison Alborz. Interviewees: Anne Smith and Fliss Kyffen

Historically, the goal of Charnwood Nursery has been to meet the needs of families with a young child with ‘special needs’. They have done this irrespective of the family circumstances and have provided nursery education to children from a range of socio-economic backgrounds. They aim to help parents come to terms with their child’s disabilities and provide an accepting, safe place for families to get support. Charnwood uses a holistic approach to family support, believing that by supporting parents, the child with complex needs will be more effectively supported.

The nursery grew from a Mums and Toddlers Group set up by Grace Wyatt in the 1960s. Grace was approached by a parent with a child with disability and sought to include that child in her group. Charnwood with its ethos of providing care and nursery education for children with and without disabilities together grew into the current nursery and family centre.

The nursery provides care and education for children aged 0-5 years and is registered as ‘private and voluntary’ sector provision. It employs a full time Special Educational Needs Co-ordinator (SENCo), a part time special needs teacher, a Family Worker, the equivalent of 1.5 qualified nursery teachers and six nursery nurses with NVQ3 qualifications or above, as well as two special needs nursery nurses and one learning support assistant. Some of these nursery nurses have general nursing experience, which has proved invaluable in supporting children with complex health needs. The nursery also employs a physiotherapist to support children with complex needs and help them gain the most they can from their nursery experience. All staff have ongoing training from the Community Health Service on health issues such as epilepsy, stoma care and nasal/gastrostomy feeding.

As noted above, parents are an important focus for the nursery and their wishes and feedback guides nursery provision. For example, a group of parents asked the nursery Principal whether hydrotherapy could be provided or supported by the nursery. This therapy was organised in conjunction with a local special needs school and staff from nursery supported children needing this service to attend.

The nursery is partly funded by the Local Education Authority who purchase places for children with ‘special needs’ in the borough. Charnwood provides almost half of the resourced nursery places in the borough. Additional funds are raised through voluntary contributions and fund raising activities. The funding for ‘special needs’ places is a significant part of the nursery income, however the additional charitable donations allows the Nursery freedom to purchase extra services as required. Their charitable status allows them to redirect funds to follow the needs of the children. Nursery provides places for 75 children with a ratio of children with disabilities, to non-disabled children of approximately 1:3. The Nursery has 2 ‘nursery floors’, or areas. Both floors provide nursery provision in the morning whilst in the afternoon one floor functions as a nursery whilst the other functions as an Opportunity Group (a mums and toddlers group for both ‘mainstream’ and special needs children). The latter is supported by the Family Worker. The Opportunity group provides a place for parents to come and stay with their child and use nursery facilities, talk to other parents and get advice from nursery staff. Nursery also runs a coffee morning for parents six times a year offering the opportunity for parents to meet and chat, but also to ask questions of visiting professionals such as the physiotherapist or the local Primary Inclusion Officer, whose job it is to support inclusion of children with disabilities into mainstream education when they reach 5 years of age.

Children from Charnwood eventually move on to statutory school provision. Charnwood endeavours to support this process from a position of in depth knowledge of the child's capabilities in an educational setting. They work with the Primary Inclusion Officer to promote the best school placement possible for each child. Charnwood staff inform therapists of parental choice of school placement so that they can prepare for transfer to school and take parents and their child on school visits, prepare photobooks and social stories around going to school. This is tailored to individual need.

Case Study

Ella (not her real name), is two and a half years old and lives with her parents. She has profound and multiple learning disabilities, a gastrostomy fitted, visual impairment and severe epilepsy. Nappy changing and touch of certain textures can trigger tonic/clonic seizures, and between these seizures she experiences myclonic jerks. She has been known to have 200 seizures over a 2 week period. She is due to take up a nursery place shortly.

Prior to Ella's placement in Charnwood, Anne, the special educational needs coordinator, reads all the information available about her condition and organises training for all staff on her health needs. Anne emphasises that nursery staff have to be proactive in their preparation for providing nursery care and education for children with complex needs. The local authority purchasing the place for these children does not highlight the potential issues important in the care of children such as Ella. Nursery staff themselves must use their experience and foresight to equip themselves with the skills, supplies, or procedures, to safely and effectively care and provide education to the child.

Anne stresses that although the nursery receives documented information about Ella's needs, Charnwood actually places most emphasis on the information provided by parents. A meeting is arranged with the family, prior to Ella starting nursery, to build up a fuller picture of her needs and to begin to build a relationship with her parents. The nursery operates an 'open door' policy and can be contacted by parents at any time. The information forms the basis of an action plan for Ella's inclusion in Nursery. For example in relation to her epilepsy, it provides information for the Nursery Nurses on the pattern of her seizures and medication required. It describes the skills and interests that Ella has and ensures that all staff on the nursery floor are informed of her needs. All the staff will have had the training to deal with her ongoing needs in relation to epilepsy and a procedure and skill to deal with 'status eptilepticus' when a seizure lasts for more than 5 minutes. Importantly, the action plan also includes details of how Ella's parents wish staff to respond to Ella's needs. Anne comments that if there are differences in the way professionals' recommend a health task should be completed and how the parents perform the task, nursery staff follow parents' wishes, unless otherwise directed in writing by health professionals. Responsibility for a child's well being during nursery time is negotiated with the staff involved. Staff need to feel confident in their ability to perform care tasks. A lead adult is therefore identified and another person who will phone for an ambulance if required. Other nursery staff, in an emergency situation, will carry on dealing with the other children and maintaining the usual atmosphere in nursery.

Ella will attend nursery for short periods over 5 to 6 week introductory period. She will start with forty-five minute to one hour long sessions at nursery, gradually building up to the 5 half-day sessions she is entitled to, as funded by the local Education Authority. During the first sessions staff will observe the way that Ella's mother cares for her and will copy the way she performs care tasks. This allows a period of adjustment as Ella's mother becomes confident in the nursery nurse's ability to care for her child, and the staff member gains confidence in her own abilities. During her time at nursery, Ella's achievements will be celebrated and she will be enabled, through the use of aids and human assistance, to take part in the full range of nursery activities with her non-disabled friends. Anne comments that when they first meet families it is often clear that their interactions with professionals have focussed on the things their child cannot do. Parents are pleasantly surprised to find the nursery staff focus on ability.

When she attends nursery, Ella will have one to one support from an adult worker. This staff member provides a role model for the non-disabled children on how to interact with Ella. Fliss comments that the children are initially drawn to the adult but will soon begin to imitate their way of playing with Ella, and begin to include her in their play.

The local Primary Care Trust physiotherapist will visit Ella in nursery to advise on the equipment she will need to take part in Nursery activities. Funding can impact on the provision of equipment and sometimes means children must wait or alternatives found as an interim measure. The SENCo and special needs teacher will devise a 'Play Plan' for Ella to encourage her to develop her skills in the areas of skilful, pretend and social play. This plan will be revised continually and re-written every 6 months. It is implemented by a special needs nursery nurse.

Anne comments that one difficulty encountered in including children with profound and multiple learning disabilities, or complex health needs, in nursery is storing the large amount of equipment and supplies needed to support them. This can entail compromises and flexible thinking to ensure ease of access.

Charnwood nursery is free to follow its own framework for the care and education of the children it supports. This, Anne sees as an advantage, especially for children with complex needs. She comments that the statutory frameworks for nursery children – the 'foundation' curriculum, and that for those working below this levels, the 'p' levels – often fail to match the developmental pattern of these children. The nursery has sought to develop its own 'horizontal' framework based on the work of Roy McConkey. This means that, rather than being seen as 'stuck' at particular levels of development, the children are encouraged to achieve other skills at a similar level. In this way, a concept of 'achievement' is maintained. This scheme has been successful in nursery and has been adopted in a local primary school for a child who has moved on from Charnwood.

Innovation

In the traditional model of nursery provision, children like Ella would be deemed 'poorly' and unable to use 'mainstream' provision. Mainstream nurseries would consider themselves unable and unsuitable to provide nursery education to a child with such complex needs. Where a child with disabilities does attend a traditional nursery, the support needs of the family are often ignored. The Charnwood approach is family focused and child centred. All families are invited to use the support offered by Charnwood. Those families with a child with complex needs are supported to achieve a positive outlook on their child’s abilities and their place in society. The children are enabled to learn and play with their peers.

Charnwood has been so successful in this regard, staff need to be sensitive in alerting parents to the fact that this positive approach is not prevalent in the statutory school system. Anne comments that parents sometimes expect that the inclusive approach that has worked so successfully at Charnwood, will be continued through their child’s remaining school years. She has experienced situations were this meant supporting parents while they explored a school choice that she thought would not suit their child, and was then able to offer advice on alternatives when they eventually realised this for themselves.

The Charnwood approach to child achievement and development is also ‘empowering’ compared to the traditional hierarchical developmental model. Focus on broadening the range of skills of a child with complex needs, rather than their ability to progress to higher level skills, fosters a sense of achievement and, arguably, enhances self-esteem.

Tof-service provides respite to families (Belgium)

Author: Marie Jaspard. Interviewee: Christine Eeckman

The “Tof-service” is a home assistance service in the Brussels region providing families of people with multiple impairments and high support needs the opportunity to take a break.. Its mission is to offer break time to the families so they can have leisure time, a professional life, or simply rest. This assistance is also an occasion for people with disabilities to have a companion time while his/her parents have a break.

The principal activities of the service are:

1) Active home care: People taking care of people with disabilities at home are called ‘extra-sitters’ (extra because they are extraordinary). They are going to the home of a person with disabilities and taking over the parent’s duties during the night, the week or the week-end. The extra-sitter takes care of all usual care (meal assistance, bathing, clothing, bed time). He/she also offers activities like adapted games. The service has some adapted materials that extra-sitters can bring with them.
2) Taking people with disabilities outside the family house either to enjoy activities (e.g. going to the swimming pool) or for paramedical care (kinesitherapist).
3) Short stays like mini-camps with themes to allow families to have a real break of several days and people with disabilities to have adapted holidays.

Members of the team hope to have a close collaboration with the parents and professionals. Before any contact, a member of the team takes the time to meet the family and fill in a personal note book. This accurate document allows professionals to know the person and his/her needs better.

The Tof-service team comprises a psychologist coordinator (3/4 time), 3 extra-sitters (3/4 times each: one ergotherapist, one educator and a nurse) and one specialized educator (1/2 time). It is a creation of AP3 (Parents and professionals association for persons with multiple impairments). The service works with 40 different families per year. 75% of the people have more than one disability and 25% are autistic. The service is either for children or adults but in reality, 80% of the missions are for children aged from 5 to 15 years old. Families are from all social classes and all origins, thus being very representative of the Brussels population. More than half of the families are single parent and the mother is in charge of the person with complex needs.

Case Study 1

A mother living alone with her 22 year old son (C.) with autism associated with heavy comportment disorders cannot find any vacancies in institutions for adults. When she called Tof-service she was in distress. She was looking for an urgent solution for her son so that she would be able to keep her job. She also explained that she has difficulties dealing with her son’s comportment disorders. Tof-service came up with a three days per week care at home for C. so that she could work part time. This happened with one condition: she had to accept collaboration with a home service to deal with her son’s comportment disorders.

In this situation of a young autistic man living alone with his mum, the arrival of specialized professionals in the family home allowed the mother to bring some life rules for her son and the Tof-service’s team. Everyone applied the same rules to C. and his comportment disorders decreased. The mother was delighted to see her son’s evolution. The care continued on a very structured basis. Going out is now possible, the extra-sitter went to town by bus to eat out with C. and no problems occurred. The mother could not believe it, it had been so long since she had been out with her son.

It is important for the Tof-service team to consider each family as unique and expert in taking care of their child. The professional came into the family and listened. Parents and professionals shared their respective knowledge and went on, hand in hand. Professionals came up with short term, medium term and long term solutions.

Case Study 2

A young mother aged 20 years called Tof-service because her 2 year old child with a general late development was not accepted by any cribs. Everyone around her let her down because the child was too difficult to take care of: he cries all the time, he has difficulties eating and he cannot walk. Assistance services were full and refer the mother back to each other. She was out of resources. She heard about Tof-service as a specialized service for kids with multiple impairments. This mother’s needs are over the sole question of a “break” (global psychological assistance, adapted structures’ search assistance and a “break” too) but the team decided to do something so she could reorganise her life.

The service answers to a real need of the families and people in situation of high dependence by offering on the one hand a break time for the parents while on duty and on the other hand adapting activities supporting a social integration of the person with disabilities. A relationship of trust is established between the members of the team and the families. In this way the families feel less guilty for taking time off caring for their child by letting trusted professionals take care of their child.

The wish for the future is to find further means to offer more facilities to families (at the moment some “missions” have to be cancelled because extra-sitters are not available) and more camps. The team is always looking for volunteers for camp organization and administration work.

Family Support Centre helps people with complex needs (Lithuania)

Author: Egle Rimsaite, Interviewee: Gitana Kuzmaite, Head of Family Support Centre

Algis became a client of the Family Support Centre in 1998. Before this he attended a special school for two years but he failed as this school was not adjusted to his special and individualized needs. Classes were big and noisy; education was oriented towards the needs of children with higher intellectual ability. Teachers were not ready to give him enough attention: he was not able to eat, to go to the toilet himself, he was falling down while he had epilepsy attack. As Algis needed permanent care and attention his mother had to cancel her job and stay with him at home. She helped him to eat, to dress, to walk, to bath. Until Algis was 22 years old he received medical services and two years of totally unsuitable education.

When Algis' parents decided to let him visit Family support centre they met with workers, discussed Algis' capacities and composed a plan of what they want to achieve. Social worker, psychologist, doctor and his parents participated in the process. Day care groups in the family support centre were small, consisting of five to six persons. At the beginning he stayed in the centre for three hours in the morning, his mother used to come with him.

The start was quite difficult as Algis did not want to communicate; he had no social and domestic skills. Step by step he got used to the day structure of the centre, to the group, to the professionals working there. After several months he learned a lot: to eat, to wash dishes, to dress, to go to the toilet, to bathe, to talk in sentences, to recognize letters, and to draw. His social life also developed quite successfully: he got used to other people, he found friends, he learned how to go shopping, how to cross the street, etc. As Algis is very sensitive, every unusual sound scared him a lot. In the centre he was trained how to cope with it. Also his parents recognized his achievements as centre regularly meets family members and talks about the achievements of the clients.

The idea of the Family Support Centre was to train people with disabilities and to make them ready to visit a larger day care centre. Algis was ready to leave the centre and to go to some new place but there wasn't any suitable service for him in Vilnius city. In the beginning of 2006, he finally became client of a Day Care Centre for persons with intellectual disability. Here he benefits from a wide array of activities and more attention is paid to vocational training. He arrives in the morning by special bus and stays there for the whole day. His family is very happy because parents never expected that Algis would be able to spend all day somewhere other than at home.

At the weekends or when he has an epileptic fit Algis stays at home but he doesn't like it any more. He wants to be active, to go to the centre, to do something interesting. Algis has many friends in the centre, he also had several girlfriends. Occasionally he talks about his own family and having children. His parents have become accustomed to this and are not as shocked as they were before. Social workers of the centre taught them that it is normal to think of having a family and serious relations.

Algis will eventually be able to work in a social enterprise doing simple tasks and receive a salary. In Lithuania this is quite a new idea, but the network of social enterprises is spreading and so it is to be expected that Algis will join the labour market sooner or later.

3. Day Activities and Work

Day Centre Paprsek for children and youth with complex needs (Czech Republic)

Authors: Jan Šiška and Jana Vránová, Interviewee: Mrs Ivana Hejlová

This example of good practice will introduce Paprsek children's centre ('the Centre') that provides complex care for children and youth with complex needs in Prague. The Centre was established in 1994 as a model (example of good practice) facility under Prague's Municipality (Magistrate of City of Prague). In the social services area, the Centre was one of the first examples of a new type of service which did not follow the traditional segregational model of excluding children and adults with disability and their families from society, as was the only option for the parents before 1989. From an early stage the founders of the centre promoted the ideas of a modern humanistic perspective of services built on recognition of human rights of people with disabilities.

Four facilities in different parts of Prague have been opened. Together they provide a package of services: day-care centre, sheltered housing (for young adults), respite care, ambulatory counselling and early intervention (for children 0 - 7 and their families). These services have developed as a reaction to the requests and needs of users and their families. For example, sheltered housing was established for young adults who had gone through the day-care centre. The sheltered housing scheme supports the clients with complex needs in gaining independence from their families and fulfilling their right to be adults. There are also other programmes available, such as art therapy, music therapy, canistherapy and leisure time activities (ceramics, sports, trips).

The goal of the Centre is to provide interdisciplinary and comprehensive care for children and youth with severe disabilities/complex needs. Most often it is an intellectual disability combined with physical disability, visual impairment or disorders of socialization and communication. Comprehensive care also includes support for parents in their so called unfavourable social situation – a situation where they are at risk of social exclusion or at risk of placing the child in an institution, or at risk of excluding the child from compulsory education. In other words, the Centre supports families so that they can live an ordinary life as far as possible.

The service users are children from the ages of 3 to 18. The children have the opportunity to fulfil their compulsory school education in the Centre. There is also a second target group of users: youth from 18 till 30 who completed their school attendance in the Centre and continue with activities corresponding to their abilities and interests.

The users have opportunities to actively spend their day-time amongst their peers with happiness and fulfilment. They are offered a wide range of active and educative activities to develop the individual's potential as far as possible. The important goal is also to increase users´ abilities to become independent. The Centre also helps with contacting/mediating follow-up services and helps users with transition to supported employment/sheltered workshops, housing, etc.

Applicants or their family members make first contact via a phone call, e-mail or come to the service personally. The first meeting is arranged with the respective professional (a social worker, eventually a psychologist or another member of the team). The needs and interests of the applicant are examined. Then the applicant is offered the suitable and available service that is provided by the Centre, or he/she is referred to other organization if he/she is interested in a different type of service than the Centre offers. In the first meeting the extent and content of the service is explained as well as the cost. A suitable form of service provision is then discussed. The interested person can see the place and the facilities where the service is provided and also can take part in the programme if he/she is interested. During a second meeting, the needs of the user and his family are observed closely and then a team of experts coordinated by a psychologist together with the interested person and his representative develop proposals for the concrete form of rehabilitation and plan according to applicant's individual needs.

The goals to be reached by the service are determined by users themselves. The Centre supports the person in the process of formulating personal goals. The individual goals result from the possibilities and abilities of the user, the Centre tries with a great deal of effort to follow the individual needs of the users. At the end of the entrance period a contract between service user and the service is agreed and signed.

During the period of entering the centre a suitable key person from the team is appointed for the user. The key person gets to know the user, monitors the level of speech, motor and cognitive skills, socialization and self-sufficiency. These areas are taken into account in an "Individual Plan of Support and Development". The team of experts includes psychologist, speech-therapist, physiotherapist, paediatrician, nurse, Montessori-therapist, special pedagogue and social worker.

The main principles of activities in the Centre are the comprehensive, complex and interdisciplinary approach towards the users. Such an approach is parallel to the complex needs of the respective person. The idea is to provide such a type of care in one place, so it is accessible and available for the user when it is needed. The cooperation of health care, social care and educators is necessary. Despite the fact that the Centre is considered as a good example of complex care for people with severe disabilities, national policy and legislation does not offer enough support for providers of such schemes. The cooperation of the three concerned Ministries (Health; Labour and Social Affairs; Education, Sports and Youth) is far from satisfactory. The bill on comprehensive rehabilitation has been under preparation for more than ten years in the Czech Republic.

Families of a child with severe disabilities are often at a risk of burning out and breaking up. Therefore also psychotherapeutical support is provided to the parents. The idea is that the child's place is in his/her family. However, demands for supporting family services and respite care are much higher than the Centre can offer.

The child is naturally integrated into their family and community where he/she lives. The Centre therefore provides only day care in small groups of children. The buildings of the Centre are part of mainstream neighbourhood where informal networking of people with and without disability often takes place.

Gothenburg’s Stad Centrum provides day activities for people with complex needs (Sweden)

Author: Elaine Johansson. Interviewee: Mustapha Radi, Director of Daily Activities in the Centre of Gothenburg

This example of good practice is about good daily activities for persons with neuropsychiatric difficulties. Since February 2007 the city of Gothenburg has been providing daily activities to a small group of people who do not fit into the traditional day care centres. Six young adults are included in the activity, which is located in the centre of Gothenburg. Three of them are women and three are men. Two of the persons live in a group home according to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). The other four persons live in their own flats alone or together with a partner. One of them gets a home-help service. All of them need a lot of service and support from the society. They lack what we call social competence. They have difficulties in looking after their personal hygiene, to keeping appointments and eating regularly and healthily. They are often isolated and have no contact with other persons. Swedish legislation only allows drastic measures to be taken when a person is a danger for himself or for others.

The central urban district of Gothenburg gave priority, in 2006, to the opening of a day care centre for persons with neuropsychiatric disabilities. The handling officers had noticed that there was immediate need for such a centre. This target group did not fit in the ordinary daily activity centres. Very often the persons themselves did not want to go to those centres.

A working group was appointed consisting of representatives from the daily activity centres in the district. This group discussed the structure of such a centre. The difficulty was finding suitable premises. This process took quite a long time. Then the rebuilding of the premises took place during the end of 2006.

Three tutors were recruited for full time employment during the autumn of 2006 (one habilitation staff member and two habilitation assistants). In addition, two working advisors were to be working in cooperation with the permanent staff. These five persons met in January 2007 to make up an activity plan together with a consultant and the director in charge.

The target group is young people 16 – 35 years of age having neuropsychiatric diagnoses for instance autism with or without an intellectual disability, having the right to daily activities according to the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). The persons’ problems are difficulties in a social context and geting a job in the open market. They have difficulties cooperating with others and establishing social contacts. These difficulties can be caused by a lack of social abilities and lack of compassion. They also lack an ability to be flexible, an ability to generalize and to benefit from earlier experiences, difficulties to see the whole picture, contextualizing and difficulties interpreting the social codes in the society. They also have a different way of communicating and often motor disabilities. Some persons have special interests and can focus on details and be specific, careful, punctual with the point of obsession. The persons need acquire a structured every-day-life. They need to be seen and accepted to strengthen their self-esteem. Furthermore they need meaningful activities and a better awareness of their health to improve their quality of living.

The work started when the person with complex needs met the handling officer and working consultant. After this first meeting the working consultant made a survey together with the person with disability. It is important that the needs and interests of the person are clarified. The person with disability visited the new day care centre together with the working consultant. During that visit he or she met the staff. The person was then interviewed by the staff and a two-week introduction was established. The next step was that within four weeks a plan of action was made together with the person themselves.

The first person with disability started their day activities in February 2007. After that the remaining five persons came gradually. Today there are three young women and three young men.

The activity starts at 9:00 every weekday. The persons often have difficulties arriving on time so often staff have to phone and tell the person to come. Sometimes the staff even goes to the home of the person and brings him or her to the activity centre.

Every day starts with a common breakfast. It is not unusual that persons with neuropsychiatric difficulties do not eat nutritious food on a regular basis. One important purpose with the new activity centre is to teach the person to sleep enough hours every night, to eat good food regularly. The aim is to find working tasks to find out the individual abilities of the person.

The every-day tasks can be learning how to prepare food, learning about health and life style, food programs, getting regular exercise for example muscular training sessions. They are visiting different work places in the open market. They get information about different legal rights. They have been commissioned by a company to sort garbage. Staff are guiding them in every day situations and in work situations. They give support and encouragement at all times.

The objective of the day care centre is that every person shall have a practical vocational training place and finally a work in the open market. The first person in the group, a woman, has now received a practical vocational training place one day a week in a health service company.

This is one of the few examples of a daily activity for this group of people. Other persons in the same situation are in a traditional day care centre or are completely without anything to do during the day. The support is shaped individually according to the needs and interests of the person. The flexibility is big. This project is successful so far. There are reasons to believe that more activities like this will be established in the future. Even if there is no individual time table the purpose is that every person will stay in the activity for a period of time and then get a practical vocational training place and then a more regular job. However, Mr. Radi is convinced that the people with these difficulties always need some sort of personal support to be able to function fully in society.

VIC-Workhomes provide a normalised day structure (The Netherlands)

Author: Martin Schuurman, Sources: Hans van Wouwe, treatment coordinator ASVZ Group; publication *The strength of simplicity*; papers for IASSID-12th World Congress, June 14-19, 2004, Montpellier, France.

ASVZ South West is an organisation with about 4000 clients. In order to deal with people with very severe problematic behaviour over the past 14 years the organisation developed the method of Very Intensive Care Workhomes (VIC-Workhomes). In each home lives four clients supported by nine counsellors. At this moment, there are seven of these workhomes. Besides, ASVZ South West has homes with intensive support for about 200 – 250 clients.

The clients of the VIC-Workhomes

The clients who are treated have often led a life of isolation. They were regularly handled without respect. Their movement was drastically limited. They usually lived in a residential setting without any contacts to the outside world. The counselling was often focused on anxiety and other emotions. Counsellors have completely stagnated in their interaction and communication with these clients. A usual humane existence was a long way off.

Sebastiaan (1)

Sebastiaan hits, kicks, pinches, and bites his counsellors with exceptional intensity. He lives in an institution for people with intellectual disabilities.
We visited Sebastiaan in 2000, in the institution where he then lived. As part of the acquaintance, I would go with the two regular counsellors to see how Sebastiaan was taken out of bed, showered, and ate breakfast. The counsellors rejected my proposal to start. They wanted to wait until two people from security had arrived. In addition to the two regular counsellors, there were two guards present at all times in the background to keep Sebastiaan under control, if necessary.

At the beginning, I saw Sebastiaan lying in a closed room fixed in bed by different restraints. Sebastiaan had lay there for about 22 hours every day, constantly, for many months.
Despite his good health and young age, he was 23; he had various areas of decubitis on his hips and elbows.
Sebastian’s work consisted of placing certain tubes in a box, once or twice a day for 20 minutes. Upon completion, the counsellors would take them out, so that Sebastiaan can do the same work again, the next time.
Sebastian’s free time consisted of walking in the park, once a week. He went with a taxi to the park with two counsellors. Behind the taxi, the two guards followed in their car. In the park, the same path was always taken. Sebastiaan quickly walked the usual route and wanted to get back to the taxi as soon as possible. Within an hour, he was back in bed.
To influence his behaviour, Sebastiaan received daily medication, without any positive effect on his aggression.

(Hans van Wouwe, treatment coordinator)

The method of the VIC-Workhomes

The basic principle of the VIC-Workhomes is the recovery to a normal daily life as a perspective for clients with severe problematic behaviour. To achieve this, the method is geared to a recognizable and normal course of daily life based on creating a supportive climate. It is designed so that that the client experiences sufficient safety and trust, enabling him to stabilize himself in his world and to explore it further.

The core of the support lies in inviting, giving tasks, offering challenges, creating chances and giving room for personal contributions and initiatives, along with appealing to the competencies of the client, of course, within the parameters of his abilities. The development level of the client thereby informs the principle standard.

From the very beginning, the aim of the VIC-Workhomes has been ‘back to the basics’ and the recovery to a regular life. This is achievable by constantly giving form to the four main areas of daily life (self-care, taking care of the home, work and leisure time), regardless of the problems that occur. Back to the basics also means getting away from having insufficient respect, room, rationality, and sense of reality (the four R’s which have been a common thread from the beginning).

Meaningful activities, which offer sufficient challenge and a successful completion, are constantly being sought after for the living and working situations, and the leisure time. The activities must be tailored to bring the client into contact with the world around him. Because the client has difficulty with structuring his own time and can hardly deal with ‘empty’ moments, the daily schedule at the VIC-Workhomes’ day program is full.

Waking up, self-care, and caring for your home, working, shopping, cooking and a full leisure time, all sounds simple and logical. However, It is just doing the things everyone does. However, for a person with autism and intellectual disability, daily life is neither simple nor logical.. This is why everything is clearly and evidently presented. Moreover, what is always being dealt with is that the counsellor must constantly be aware of what he is doing. As soon as you diverge from your original purpose, you must ask yourself: What are we doing? What is the gist? With this, you give the client the footing, which s/he clearly needs.

A clear fundamental rhythm is the first step to offer the client that footing. Clearly separating the leisure time from the work, the morning from the afternoon, and the weekend from the weekday, is of essential importance. Everything that is unclear for the client can surely cause confusion, which can lead to escalation.

The daily support to the clients is given by the counsellors. The treatment coach is involved with the optimal coordination of the treatment programs of the individual clients, as well as the programs of the client groups, and those of the counsellors. This is all executed based upon the recommendations from the treatment coordinator.

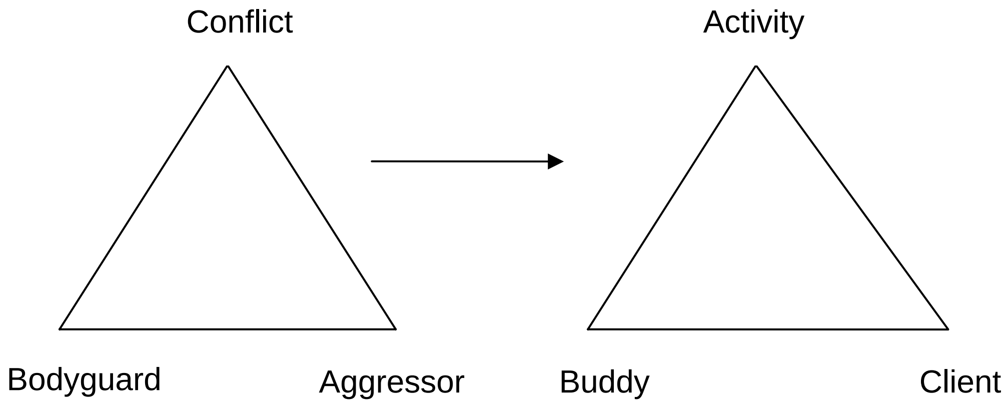
The counsellors are constantly occupied with giving order to the normal daily activities, so that the client can retain a grip on it. The client keeps a sense of belonging when the counsellors offer activities that the client is capable of, can be pleased with or are proud of. Whether it is putting out the trash or brushing their own teeth, it is about giving them momentum and certainty. Sometimes the counsellor keeps a distance and then gets closer again to offer support.

For the counsellors fine-tuning the proper development level of the client was a tedious learning process with ups and downs, persistence, and doubt. This is what led to the easy approach that the counsellors now apply. They understand the art of seeing through the clients' severely problematic behaviour and know how to work with them on creating meaningfulness by expanding their competencies. This is called 'co-creation in dialogue'.

The counsellor is supportive, but also assists. More or less, he guarantees that the client's activity succeeds. If the table must be set, it might be that the client merely places a few plates, while the counsellor places the remaining plates, utensils, food and drink on the table. The end result is that the table is set and that we have done it together. Through this, the client gains a positive and successful experience, which has a therapeutic effect.

The outcomes

Essential to the approach, is a simple ABC, in the form of a triangle. The outcomes can be shown in terms of this triangle. The problematic behaviour had been the overtone. The client was seen as the Aggressor, the counsellor seemed more like a Bodyguard and the Conflict took centre stage. In this type of competition-based triangle, the client, as well as the counsellor, could only achieve failure. In the method of the VIC-Workhomes you are turning away from the triangle Aggressor, Bodyguard, Conflict to Activity, Buddy and Client.



The outcomes of the method are:
- Intensive teamwork and dialogue between client and counsellor so that both create purpose by developing each other's competencies.
- The problematic behaviour sometimes disturbs the teamwork and dialogue, but the behaviour is merely a short interruption from being occupied with meaningful activities. They get back on track, as soon as possible. This gives the client a grip on the activity and on his counsellor.
- Client and counsellor feel more successful and competent, and that's what they are too.
- Self-care: eating together without self-mutilation.
- Caring for the environment and surroundings: a part of the day is filled in with shopping (for food), doing the wash, cleaning your room, etc.
- Doing meaningful work five days a week, together and by filling in your leisure time well.

Sebastian (2)

Now, getting back to Sebastian. By us, there are not two counsellors just for him, but for the group of four clients.
Sebastian lies in bed only at night and is not tied up. He makes his own bed, waters the plants, helps set the table, works in the garden, repairs rowboats and in his free time, regularly goes to the beach where he buys a cola at the vendor, all by himself.
Not long ago, I ran into him in the centre of Rotterdam, where, with three of his group members and two counsellors, he was shopping.

(Hans van Wouwe, treatment coordinator)

Conclusions

The experiences with the method of de VIC-Workhomes of ASVZ South West have learned that the method of working *together* with clients having very severe problematic behaviour is more beneficial than controlling and restraining their behaviour. It is a method that is quite uncommon in the Netherlands.

In this method, the starting point is that we must not be blinded by the client's difficult and aggressive behaviour. The apparent behaviour is merely the tip of the iceberg. Other symptoms arise in its place if we do not get a hold of the underlying cause. Often, we see that no answers are formulated other than protocols, medication, restraint, and isolation.

By being convinced that this must change and knowing that it can change, ASVZ South West utilizes the existent creativity of counsellors and professionals. In a continuous open dialogue with the clients, they help them discover or rediscover a feeling of competence. The client becomes engaged in his own life again.

Almost everything seems so natural: shopping together, gardening together, vacationing together, or going to the beach together. Differences are bridged over, because of the desire to work together with the goals of optimizing the co-creation, and keeping a dialogue with the client.

That is why, in their treatment of clients with extreme problematic behaviour, ASVZ South West formulates 'the recovery to a normal daily life' as its perspective.
By adopting this principle and also appealing to the client's competencies, together with them, they give purpose and meaning to their life.

Goyeneche Foundation and GUREAK provide social and work integration for people with disabilities (Spain)

Author: Maria José Goñi Garrido. Interviewees: Leyre Lasa, Eva Sánchez, Amaia Otaño (Day Care Centre Staff) and Antonio García (Juan's father)

Initially, the Goyeneche Foundation was designed to serve as a traditional day care service centre. However, it is currently undergoing an organisational transformation process intended to provide a service whose central focus is the individual and the communal environments. This new focus strives to enhance the personal development of people with disabilities and help them overcome their behavioural problems. The staff is composed of direct care personnel, middle management personnel and a service manager. The organisations provide services to people with intellectual disability and other related problems such as aging, mental disorders, behavioural problems, epilepsy, etc. Their mission is to become an advanced, leading programme that offers high-quality services, is socially responsible and supports people with intellectual disability to lead a satisfactory life in natural environments.

This example tells Juan's story, a 39-year-old man diagnosed with severe mental disability and epilepsy (disability percentage of 77%). Juan was the elder of three brothers; his parents had great difficulties in managing his behavioural problems (he tried to run away, attacked them verbally, and exhibited self-injurious behaviour). This situation and their later divorce forced them to commit Juan in a residence for people with disabilities in Pamplona, a city 100 km from his hometown.

At the age of 16, the social services gave him a place in a residential centre managed by the Public Administration, which accommodates 72 people with severe intellectual disabilities. The centre was opened recently and is only 4 km away from his mother's house. Simultaneously, he began to attend a new special education centre in the area. He visited his mother every weekend; he only saw his father in the summertime as the latter was working in France. His mother complained about her son's behaviour while visiting her. Finally, the city council found someone to assist her at home for two hours every Sunday.

Planning Support

At the age of 21, Juan joined an occupational workshop for people with intellectual disability from Gureak. During the first years his behaviour aggravated, he spent most of his working day (8 hours) doing nothing and when he felt uneasy he ran away. Thus, his working day was reduced to 4 hours as they considered 8 hours might be too much for him. Finally, he was referred to a day care centre that belonged to the same institution. The patients in this new centre were either old people or young people with severe intellectual disability and their activities were non-age appropriate and non-functional. His behavioural problems aggravated even more, which involved a more strict medication control and more restrictive strategies. His own safety and that of others ran a potential risk. The non-functional activities, the insufficient training and supervision of the personnel, as well as the lack of individual planning resulted in a worsening of his behaviour. Juan's repertoire of communication skills was small: he would only utter some words he used to express what he wanted; his messages, despite being short, tried to express the same as any other person his age. The usual answers to his demands were negative and his frustration grew progressively.

When he was 26 he began living in a group home with 6 other people with an intellectual disability in his hometown. This was managed by the Parents’ Association (Atzegi); there was always a caregiver and a housekeeper. Juan’s expenses for the residential service and the day care centre were financed by the Local Administration; he contributed 75% of his monthly income to the home group service, and 117.6 euros to his place at the day care centre.

In 2006, the day care centre facility moved to some new premises in the city centre, to a place he was well acquainted with. All community-based services were now within reach.

A functional assessment of Juan’s behaviour resulted in a new intervention support plan that involved an adaptation of his activity programme. The programme refocused on being more functional and including the training of independence skills, alternative skills (saying no, expressing emotions, achieving social skills) and skills that would help him use the resources of the community where he lived. Other interventions such as positive reinforcement programmes and reactive strategies for the management of problematic behaviour were added to the planning. Moreover, the direct support personnel were trained in positive behaviour support techniques and both the supervision system and the personnel support were also improved.

Current Support Arrangement and perspectives

At the beginning, the most difficult issues were to make everyone, who was involved in taking care of Juan, believe that his dreams could come true; stop seeing him as a child and empower him to do things. The risk of giving him more independency and autonomy with less regular support had to be assumed. An appropriate job placement, which gave him an opportunity and the support he needed while keeping the personnel ratio (1:6), had to be found. Besides, it was necessary to get his parents’ support, who had few expectations because of the many difficult moments they had experienced.

Juan’s current situation has improved significantly. He has a contract to work anhour a day in one of the supermarkets of the chain DIA as an ordinary employee, where he replaces the products on the shelves and also recycles cardboard boxes. This is a case of supported employment as it is the personnel of the day care centre who supports him in this job. He also participates in activities that he enjoys and that are meaningful to him such as going to the library (he cannot read but he enjoys looking at the pictures, doing adult puzzles, using the Internet or playing games on the computer). He moves freely in his neighbourhood running simple errands and talking to people who belong to his community. His run away attempts have disappeared and his aggressions and self-injurious behaviour are around zero. But most of all, he seems to be happy and enjoying life.

He receives regular support provided by the day care centre, the home group and by many people from his community (colleagues from the supermarket, the road sweeper, the librarian, etc). But most importantly, he needs less support than he previously did without his safety being affected, which is what he wanted. Everyone around Juan is involved in this planning: his parents, the home group personnel, the day care centre personnel and most of all, Juan himself.

Elements of good practice

This example of good practice shows how any person, regardless of his/her disability and behavioural problems, has the possibility to lead a normal life. When the intervention is conducted in natural environments, the support does not always need to be provided by hired personnel (it might come from volunteers or some acquainted person). Nor does a more individualised service need to be more expensive. This example of good practice also shows that by normalising the environments and the daily activities and adjusting them to the individual's needs, it is possible to achieve important behavioural improvements. His personal relationships with people without disabilities are very positive, based on mutual respect; the image people in his environment have about him is positive; he is satisfied with what he does and has the chance to be useful and productive.

The key to success has been a deep knowledge of the person (his characteristics, needs and wishes) and a long-term attention plan focused on the individual; the stability of the personnel that works with him and the precious collaboration of the Director of Human Resources of the Supermarket DIA and the cashiers. Had all of these positive actions not happened, Juan would have lived all his life in the residential care centre for people with severe intellectual disabilities where he once was committed and would have attended a day care centre far from his community, where his chances to participate in the community and integrate into society would have been very limited. It could have happened that as his behavioural problems aggravated, he might have been referred to more intensive support services, with more supervision and with higher medication doses.

The message this case conveys is how important it is to believe that people with intellectual disabilities also have dreams and are entitled to live a decent life within society.

4. Housing and Personal Assistance

Boendekooperativet Kikås Ekonomisk Förening provides individualised housing and support for people with severe disabilities (Sweden)

Author: Elaine Johansson. Interviewee: Ulla Olsson, Secretary of Boendekooperativet Kikås Ekonomisk Förening

This example will introduce Boendekooperativet Kikås Ekonomisk Förening in Mölndal, Sweden. Mölndal is a town situated south of Gothenburg and has about 60 000 inhabitants. The number of persons with complex needs is quite high in Mölndal because of the fact that two big institutions have been located there earlier – one for children and one for adults. Both have been closed for over ten years. When closing the institutions many residents wanted to stay in the neighbourhood.

The organisation Boendekooperativet Kikås Ekonomisk Förening is providing good housing and support to three persons with complex needs – two women aged 31 and 37 years and one man aged 31 years. All three get support from personal assistants. The parents of these three people run the organisation, which also owns the house. These three people have a flat of about 60 square metres of their own. In the house there also is about 150 square metres of common premises consisting of a kitchen, living room, an office, a bathroom with a bubble bathtub and a room for washing the clothes. Around the house there is also a garden with flowers, bushes and trees. The house is located close to nature and less than 10 minutes by car or bus to the town and shopping centres.

The support to the tenants is financially divided between the municipality and the Swedish Social Insurance Agency. The municipality is responsible for 20 hours per week and the remaining part lies on the Swedish Social Insurance Agency. Boendekooperativet Kikås is the employer of 15 personal assistants. Every person with complex needs is choosing his or her own assistants. All new assistants are employed on probation for a couple of months before they are employed on a regular basis. There is also a number of assistants working only a few hours when one of the permanent assistants is ill or having a day off. The parents are also working as personal assistants a few hours every months when their son or daughter is visiting. The decision making is done by a board of three parents – one from each family. Two of the board members have the main responsibility for the administration, which consists of bookkeeping, paying salaries, having contact with the trade union, the National Tax Board of Sweden etc.

Once during springtime and once during the autumn the parents meet and work for a few hours in the garden together with their adult children and the personal assistants. Every year there is also a Christmas party where the three tenants, their assistants, parents and siblings participate.

Case Study

This example of good practice is about a 31 year-old man with complex needs. The man, N., has a moderate intellectual disability, visual impairment and autism. He was born with deformed feet. An operation was necessary. He does not like body contact as many other persons with autism. He has the diagnosis Lawrence Moon Biedels Bardtes. N. can talk, hear and understand what people are saying but he cannot understand what people are thinking and feeling – the concept of mind. The world becomes unintelligible if you do not have the concept of mind.

N. lived with his family, mother, father and a younger brother, until the age of 18 when he moved to his flat. Most adult persons with complex needs in Sweden today move to a flat in a group home run by the municipalities, if they are not still living with their parents.

N. loves music and everything that makes noise. He is fond of sports of different kinds. He wants to experience things and to be together with people. He wants to be active. One day during the week he participates in a music activity in a day care centre. The rest of the week the personal assistants see to it that N. gets activities according to his wishes. He needs a structured life. He goes to the swimming hall, works on his computer, goes horse riding, paints, does gymnastics etc. The regular activities in the day care centre are not adapted to N. Unfortunately this is not an unusual situation for persons with complex needs. The municipalities are sometimes unable to meet the individual needs and wishes in day care centres.

In the beginning of 1993 the idea of starting a small parent-run residential home came up. Four couples of parents showed their interest and the planning began at the end of August 1993. During the autumn a study circle started supported by the municipality. The purpose was to find out the basic conditions for N. to move away from his parents. In the beginning of December 1993 the Boendekooperativet Kikås Ekonomisk Förening was founded. In January 1994, the new Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Assistance Benefit Act, came into force. All parents applied for personal assistance for their child with complex needs. An individual survey was established and the number of support hours was decided by the Swedish Social Insurance Agency.

The site where the house is located was owned by the municipality, who made a deal with a private constructing company. N could choose wall paper, colours and other materials in his own flat. Together with his parents furniture and all equipment for the flat was bought. Boendekooperatived Kikas Ekonomisk Förening entered into a contract with the municipality saying that the municipality would pay for all equipment in the common premises. The equipment would belong to the municipality for the coming five years. If the organisation would still exist after that period the organisation would be the owner of all equipment. N. got his own lease.

During the spring of 1994 N’ s personal assistants were employed and in June and N. moved out of his parents’ house and moved in with his three friends. There were four tenants from the beginning and the size of each flat was only 35 square metres. After a few years one of the tenants moved from the house. The flat in the house was empty for more than a year. The municipality paid for the rent in the meantime. Some other parents were interested to take over the flat but they thought it to be too small. In the beginning of 2000 the house was rebuilt and the remaining three persons got bigger flats. This increased the quality of living for all three both regarding the environment but also because there were less people in the house when one tenant had moved away.

From the beginning a director was employed to take care of all the administrative work. This situation lasted for around 9 years. After that the parents themselves took care of this task.

The mother of N. is talking about the good life her son now has. He can participate in society. He can do the things he is interested in. He needs support every hour and he has got very dedicated personal assistants doing everything to fulfil his wishes. When necessary N. can get support from the habilitation centre. The personal assistants have participated in different educational programmes but there are sometimes difficulties to find experts on autism. This is N’s main problem.

The structure of Boendekooperativet Kikås, with the big influence of parents, makes it possible to meet N’s individual needs all the time. At the same time it is important that the people with complex needs can live their own lives separately from the parents. This is an essential balance.

Regarding the qualifications of the personal assistants it is important the there are both men and women working and that they have different ages. The attitudes are the most important factor, not the basic education. They have to learn about N. and his personality. N. does not have the ability to participate directly in the decision making in the organization. But the cooperation between the personal assistants and the parents is solving this situation.

The Boendekooperativet Kikås Ekonomisk Förening has been working for more than 13 years. Some people said when N. moved from home that parents cannot cooperate. It is a normal situation that problems happen now and then but it shows that it is possible for parents to cooperate in a good way. All problems are solved inside the house. You do not need to call for some director from an office far away to act as judge. All persons with complex needs can influence their own lives according to their individual ability. This is not always the case in the group homes. The possibility to participate in the society has increased greatly. The risk of discrimination has decreased. According to N’s mother he has a much better life now compared to the situation when he lived with his parents. “We did not always have the energy to meet N’s wishes at home” was the final conclusion of the mother.

Boendekooperativet Solgläntan provides personal assistance to persons with complex needs (Sweden)

Author: Elaine Johansson. Interviewee: Marie Jarleng, President of Boendekooperativet Solgläntan and Bostadsrättsföreningen Skogsanden

This example of good practice will introduce Boendekooperativet Solgläntan and the housing co-operative called Bostadsrättsföreningen Skogsanden located in a small town on the island of Öland east of the Swedish mainland. Boendekooperativet Solgläntan is providing personal assistance to four grown-up persons with complex needs. Two of them are women and two are men in their thirties. The housing co-operative Skogsanden is only responsible for the house with the four flats. Each one of the tenants is the owner of their flat of 52 square meters. The common premises are 100 square meters and consist of kitchen, living room, lavatory, entrance hall, laundry room and a glazed-in terrace. From the beginning the municipality was paying a sum of money every year but this was stopped some years ago. The tenants are the owners of a mini-bus which can be used for transport.

The board of the Boendekooperativet Solgläntan consists of four persons and all of them are parents to the tenants, one from each family. Among the personal assistants there are two co-coordinators responsible for finding substitutes when necessary. They are also responsible for arranging meetings between assistants and parents.

Each one of the persons with complex needs can choose their own personal assistants. During the weekdays all of them are going to different day care centres. The support to the persons is paid partly by the municipality and partly by the Swedish Social Insurance Agency. The municipality is paying for 20 hours support per person and week.

Case Study

This example of good practice is also the story of Anette 33 years old. Her mother Marie is both president of the Boendekooperativet Solgläntan and the housing co-operative Skogsanden. Anette has a motor disability because of Spinal Bifida. She has Cerebral Pareses and is totally dependent on a wheel-chair. She has a moderate intellectual disability. She has deformed feet and also visual problems. She is wearing glasses. Anette was living with her parents from the birth until she moved from home in April 1994 to the current flat. She has a big sister and a little brother.

Anette has three personal assistants during daytime and three different assistants during the nights. The daytime assistants work until 21:15 in the evening, while the night assistant starts her work at 21:00. The night assistant brings Anette out of the bed in the morning before she has finished her job. Once a week Anette goes for a swim and then she needs two assistants at the same time.

Anette likes music and especially dance band music. She likes watching movies. Once a year she travels to Mallorca on vacation and then she gets support from two personal assistants. A friend in the same co-operative has also been a travelling companion a few times. Anette is very fond of people.

According to Marie, Anette has developed very much since she moved away from her parents. Marie does not think this would have happened if Anette would have stayed at home or would have moved to a traditional group home. The group homes are very often understaffed. Furthermore the legislation does not allow the support of personal assistants in a group home. Today Anette can participate in the society. She can decide about her own life according to her ability. Now and then she is questioning things in her every-day life. Marie as a parent also has influence over the co-operative and can follow the development of Anette.

The change of personal assistants is liable to change. Some assistants have children but otherwise the assistant group is very stable. Such a situation is quite unusual in Sweden today. Personal assistance is an occupation where the assistants change very often. This is a problem and does not make the person with disability feel safe and secure.

Regarding the cooperation between the co-operative and the municipality Marie expresses that they are not dependent on the municipality and therefore they do not need to have so much contact. Despite the fact that the municipality is paying for 20 hours support per week the whole administration goes through the Social Insurance Agency. On the other hand Anette has continuous contact with the habilitation clinic and at present it is the speech therapist who is giving computer training. The aim of this training is to make it possible for Anette to make her own choices on the computer.

Anette is registered in a day care centre run by the municipality. On Mondays Anette is not at the day care centre. At this time she is going to the dentist, hair dresser, shopping etc. On Mondays Anette and her assistant are also preparing food. On Tuesdays, Wednesdays and Fridays she is in the day care centre. On Thursdays she goes swimming, shopping and together with the assistant she eats lunch in a restaurant.

The needs of Anette are mainly linked to personal care. She needs food training, different kinds of activities, security and an environment that allows her to decide some things for herself. Marie describes how she was thinking for a long time about Anette’s future life. There were many phone calls before the picture was clear about the possibilities of building a parent-run-cooperative. From the beginning Marie was convinced that she did not want a traditional group home for her daughter.

During the planning time the new legislation came into force – the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Assistance Benefit Act. This made things easier for Marie and the other parents. The work to find a group of persons with complex needs and to persuade some parents to let go of their children took some time. During the first years the municipality made a financial contribution, but not anymore. In April 1994 the house was built and the tenants could move in.

The tenants are the owners of their flats. They can choose their own personal assistants. They can influence their every-day-life. They can participate in the society according to their individual needs and abilities. They can simply live like other persons in the same age in the Swedish society. The risk of discrimination is very small. The co-operative is working more like a family. Anette would probably have been more isolated and alone in an understaffed group home. She has learned to be considerate and has got a lot of social contacts. The parents have influence in the lives of their children but it is also important that the tenants are allowed to live their own lives without the control of the parents.

Self-Managed Personal Assistance for Independent Living (Italy)

Author: Christine Mary Cahill. Interviewee: Marco Piccoli, Central Coordination of SAVI Disability Services

The SAVI (Independent Living Support Service), part of the Disability Services, Social Care Sector of the Local Healthcare Unit (ULSS 22) of Bussolengo has the task of coordinating the Personal Assistance Programme for Independent Living for adults who apply for funding for this alternative. Applicants must be between 18 and 64 years of age, with a severe physical disability certified 100% invalid and receiving an accompanying allowance.

Marco Piccoli was responsible for Central Coordination of the SAVI when he met Antonella in 1999. Her father and only living relative had been recovering in a nursing home where he later died leaving Antonella completely alone and without support. Antonella was 36 and suffering from an advanced form of muscular dystrophy, she had speech difficulties and needed 24-hour care. Adequate services do not exist for persons with muscular dystrophy who do not have a familial support network and this aspect was critical in Antonella’s situation. Although she had a good social network, her friends could not guarantee the support she required. Her health and social care needs included physical therapy 1 hour 3 times a week, periodic medical check-ups in relation to her illness and respiratory problems (nocturnal oxygen therapy, spirometric lung monitoring, heart specialist, physiatrist, gastroenterology), the Local Healthcare Unit’s psychological support service and personal assistance. Domiciliary care was not adequate for a situation as complex as Antonella’s since there was always the risk of her being left without assistance owing to some inconvenience of the care worker.

She was referred to a community home where she stayed for 18 months. However, since she was intellectually very active, she felt segregated in this situation, She had a very active social life, an extensive network of friends, many interests, including painting in watercolours with her mouth. She was a member of AMFPA, Association of Mouth and Foot Painting Artists of the World and was involved in important artistic research for which she was engaged at least once a week. She had also accepted a public relations role for her group of artists which meant that she was finally able to count herself as an ‘employed person’. Because of her health problems she had suspended her studies but was planning to obtain her school-leaving certificate with a specialization in community home management.

She could not develop her interests and social relations in the community home as she was tied by the house rules and timetable, could not receive friends or go out when she liked. She therefore asked the Independent Living Support Service (SAVI) to find her a new arrangement according to her specific personal need to lead an independent life. It took 6 months to realise Antonella’s life project and a stroke of luck in finding an apartment over a community home that would be able to guarantee assistance if needed.

With this new arrangement, Antonella regained control of her life. Like everyone else, quality of life meant realizing her dreams and ambitions and not only basic necessities. Within her budgetary limits, Antonella was able to choose what she wanted to do. She managed her personal life project herself, in relation to everyday living and holiday periods, and paid the rent, petrol, household shopping, holidays and entertainment/hobbies out of her own resources (invalidity pension, accompanying allowance, her father’s reversionary pension). Since she could not afford qualified care workers (approx. 22000€/year), she hired non-qualified care workers (appox.14000€/year), whom she selected and trained personally. Her support needs included 3 daytime care workers, 3 night care workers and a care worker to substitute for illness and contractual holidays.

Antonella organised her project herself and the task of Marco Piccoli and the SAVI Service remained that of raising the necessary funds at the Conference of Lord Mayors. Antonella would also attend the Conferences as a self-advocate in order to state her case and request funding for her services. The Lord Mayors would listen to Antonella and, through her direct testimonial, could understand her situation. She was also actively involved in promoting self-managed care for independent living as a peer counsellor, participated in conferences and appeared on television.

Because of the particularly high costs, the Service and Antonella were considering finding another person with a disability to share her flat and thus reduce the night care costs. However, Antonella died in 2006 at the age of 43, before this could be arranged. Towards the end of her life, she could only communicate by using her eyes and lips and had already suffered deglutition problems for 4 years. She loved life but not a life prolonged artificially. She wanted to die a natural death without life-support aids and refused to be constrained by a respirator or fed via a PEG. She died surrounded by her friends and assistant after spending a pleasant evening at a country fête.

With her independent living project, Antonella became and remains a model for Marco Piccoli who knew her, and a point of reference for the Local Healthcare Unit responsible for Independent Living projects. At the moment, the ULSS 22 of Bussolengo coordinates 52 independent living projects. Negotiations are ongoing with the local Municipality’s housing department for special apartments composed of 5 individual rooms with facilities in common. The management costs are lower and this solution provides the opportunity to bring together people with different levels of autonomy. However, there always remains the problem of **cost**. Local Healthcare Unit resources are not infinite and a person’s income and social network are a determining factor for setting up an independent living project.

The difference between the traditional system and the Independent Living Programme is that funds are always available for the former whilst the latter exists in a precarious state, dependent on whether government budgets renew funding from year to year.

Although it is difficult to replicate at the same costs, Antonella’s experience remains a determining factor because it traced the future path for other persons with disabilities in the Bussolengo area. Antonella demonstrated that a person with a physical disability and good intellectual capacity is capable of self-representation and that it is important to make one’s situation of dependence visible to policy makers to make them understand diversity.

Her experience makes us understand that, even if they do not have the same strength of character as Antonella, persons with disabilities must be given the support necessary both to encourage their abilities, awareness, self-determination and self-management, and to persuade their families to step aside. The most precious lesson learnt from Antonella’s story is that it is necessary to organise services WITH persons with disabilities and not FOR them.

5. The Use of Personal Budgets

Jürgen Markus organizes his own services with a personal budget (Germany)

Author: Albrecht Rohrmann. Interviewee: Jürgen Markus

This Example of Good Practice introduces the story and the experiences of Jürgen Markus. It gives insight into the system of direct payment ("personal budget") in Germany.

Mr. Markus, who receives a direct payment, lives in his own house in Marburg, a middle-sized town in Hessia; he is married and active in different fields of voluntary work. He has had paraplegia ever since he suffered an accident 25 years ago and needs assistance in his daily activities. Direct payment in his case means that he gets a certain amount of money monthly and he himself is the employer of his assistants. His current arrangement as well as the means of obtaining is it important and cannot be overlooked when telling his story.

Jürgen Markus was born in 1957 as the third of 5 children in a rural area of Northrhine-Westfalia. He first visited a local school where he successfully finished in 1976 with an admission to study at a university. First finishing his alternative civilian service, he then went to Marburg to study Sociology and Political Science. From the age of six, he spent his free time in gymnastic clubs and continued to do so at the university which – as he says himself – was his doom. At the age of 25, he had an accident on the trampoline and broke two of his cervical vertebra in his neck, sustaining life-threatening injuries. He was rushed to a special hospital and spent 9 months there in rehabilitation. He describes the accident as a big change in his life. He had to say goodbye to his former ideas and dreams, which, next to the physical pain of his ordeal, also presented a mental challenge. During rehabilitation, he learned to use an electric wheelchair with his chin, so that he could slowly gain back mobility and autonomy. But he also remarks that in the hospital, everything was prepared for people with disabilities and that it was another challenge again when he finally left the rehabilitation centre. Since he absolutely wanted to go back to Marburg, he had to face the problem of being the only one there with such an impairment. The hospital itself recommended that he go to a nursing home, but this was not an option for him.

The challenge for Mr. Markus was to find a place to live with support outside a nursing home. Luck was on his side as Marburg had the only student accommodation in all of Germany with a connected nursing service. Mr. Markus started to use this service and is convinced that this decision had the biggest influence on his later life. He was one of the few who survived an injury like this in the beginning of the 1980s and got the chance to develop a new perspective on life. He honestly remarks that the nursing services' support was not sufficient at all and that it was mostly his fellow students who assisted him.

He finally succeeded in getting his own flat and started using a new model of support: Following the so-called "Heidelberger Modell", he had two young men doing their alternative civilian service ("Zivildienstleistende") at his side. But this again was not enough and together with his hospital, he petitioned for a special permit from the Ministry of Family Affairs and finally had 5 "Zivildienstleistende" assisting him. He says that, for the first time, he had an arrangement according to his needs and the opportunity to make decisions again for himself.

But in regard to his studies, Mr. Markus soon found that this was not his interest anymore. He stopped going to the university and was busy with other things: He had to face his new situation in life and joined a self-help group with a focus on political activism. Barrier-free environment was a big topic, but self-determination was also discussed. Jürgen Markus got in touch with local affairs. With the help of this group, he could gain back a new feeling of self-confidence and self-awareness; he thinks that otherwise he may have become addicted to medication and alcohol.

Mr. Markus stayed in the field of political work and joined the Green Party. He has been volunteering at the local parliament for 8 years. Using experiences and knowledge gained from his self-help group, he founded a nursing service assisting people in their homes ("ambulante Pflege"). He developed the founding concepts and is still one of the director's of this institution. He also remains in touch with the hospital and gives counselling help to those who have just been injured: he tells of his experiences and is a helpful guide for people in difficult times.

The system of assistance, in connection with technical aid, has not changed much in the last few years. After having "Zivildienstleistende" as personal assistants a couple of years, Mr. Markus finally decided to offer regular jobs to assistants and gain more continuity in care. Nowadays he can offer 3-5 full-time jobs; at the moment he has 6 assistants working for him mostly part-time.

One year ago, the agency bearing his financial responsibility suggested that he try the model of direct payment. An expert was sent to find out his possible support needs and evaluate the arrangement. Mr. Markus feared that granted costs may be cut, but the opposite was the case: The expert was impressed by his model and now recommends it to other people with disabilities. What impressed him the most was that all of the money paid to him was being put to good use. Surprisingly, there was no discussion about the fact that in general, support at home should be cheaper than a place in a residential home. The "personal budget" that he now receives is clearly oriented to his actual support needs and he gets along with it quite well.

Altogether, Mr. Markus cannot complain about the practice of granting technical aid. As the accident happened during a course at the university, it counts as an accident at work and so the employer's liability insurance association takes over the costs. Mr. Markus remarks that as soon as work or manpower is concerned, there are hardly any difficulties with payment. In brief he is quite satisfied with the direct payment – emphasizing that, especially at the beginning, he had very cheap arrangements with the young men doing their alternative civilian service.

Concerning his assistants, he has learned in the past years that it is more useful to offer part-time jobs because they keep motivation and job satisfaction high. All of his assistants have a second job – they then find it easier to identify with what they do. For Mr. Markus it is important that the colleagues can meet and exchange once a month when they talk about how they will be scheduled. They themselves can decide when they want to work – Mr. Markus is sure that giving this autonomy to his employees reflects back on him positively.

Mr. Markus has an assistant around him everyday from 8 a.m. to 12 p.m.; either one assistant comes the whole day or shifts change at 4 p.m. – Mr. Markus prefers the second arrangement as the employees seem more satisfied then. At night, he does not need assistance – something he trained himself hard for and which is very important to him. Being alone takes a lot of discipline, but also enables valuable privacy.

Next to his assistants, his own house is clearly important for his independence. Realizing his dream of independence a few years ago did not cause many financial problems: the house, in the heart of Marburg, is built in a way so that he can use every room on his own. He has several places where he can work and an elevator; everything works via infrared-technology. He can use the doors, windows, the elevator, the lights and even the stereo and television. With this personal autonomy, he found privacy and chances to be alone in his house.

He has his own car as well and emphasizes what it means for his personal mobility. He can go where he wants to whenever he wants to; he goes on vacations, visits friends or goes out.
Partnership, he thought, was not something he could have considered anymore after his accident, but having such a good support arrangement gave him the ability to participate in community life, where he had the chance to get to know new friends and meet his wife.

Examining the situations of people with severe disabilities in Germany, he argues that residential homes – although the quality of care might be very good – never really offer the chance to participate in the community. There are not enough assistants, he thinks, to really meet the needs and interests of people. Of course, he concludes, a lot of changes have happened in the last few years, especially concerning barrier-free environments. Laws are good and sufficient in general, but bringing them into practice will take decades.

Discrimination, he observes, mostly takes place in institutions. Mr. Markus criticizes the German model of special schools and sheltered workshops, which are still common practice and seem to be dead-end streets. More interaction between people with and without disabilities can help to abolish barriers in people’s heads, he thinks.

In the last few years he saw a change in granting technical aids: In the 1980s there was not much aid available, but what did exist was granted easily. Nowadays he sees that there is a lot of outstanding technical equipment, but the practice of granting is rather restrictive. Having ideal technical aid depends a lot on your own financial resources.

Mr. Markus is well aware of the fact that he is sort of privileged and still an exception. He himself thinks that coincidence and his courage to face life were the reason that he found his way to an independent and a self-determining life. He feels well integrated into his community, but also reflects that there are people with severe disabilities that do not have such a good situation in life.

Nevertheless, his example shows that it is possible to live in one’s own flat even when having a very high support need. Self-determination in this case has a clear and practical meaning because Mr. Markus himself decides whom he wants to employ and how he likes to have his assistance arranged. This well-functioning system of support shows that autonomy is also possible for people with complex needs.

Personal budget supports girl with complex needs (The Netherlands)

Author: Martin Schuurman; Sources: article in *BOSK Magazine*, 3(June), 2007; interview with Willie Tempelman, mother of Elsa

Elsa is a multiple complex and visually disabled girl of 13 years. She is completely dependent. Physically as well as mentally, she functions on the level of a four months old baby. The family consists of her father, her mother, her two brothers (16 and 11 years old) and sister (6 years), and herself. In spite of her limitations Elsa has the ability to hold on to people. She enjoys everything that happens around her. Music is a very important thing in her life; it makes her relaxed and aware. She enjoys it very much.She regularly attends concerts with her mother.

Elsa was born as a healthy girl. In the first week after the birth she probably was infected with the herpes virus, which severely damaged her cerebral cortex. She has many epileptic fits. In the first four years of her life, Elsa cried a lot. She had stomach ache and epileptic fits. By a special macrobiotic diet the stomach-aches disappeared when she was nearly two. By the age of four an EEG found that inside her brain epileptic fits occur continuously. Medication was adjusted to that, which made that Elsa became a very satisfied and cheerful child. Apparently, she had always suffered from epileptic fits which were not visible on the outside.

Ten weeks after her birth Elsa attended a regular child centre, but this did not suit her at all. She cried whole the day and didn’t want to drink. There were too many stimuli over there. Through an advertisement placed in the newspaper the family found the first babysitter, who enjoyed taking care of Elsa.

At the age of eight months Elsa went to a special day care centre for two half days a week. From this centre the family got one day a week homecare as well. When, because of cutbacks, these services had to be ended, her mother Willie applied for a personal budget (PGB). After much hassle with bureaucracy, she received it. At the beginning Elsa received 7.500 HFL a year. This amount was enlarged during the following years.

The higher the budget, the more creative Willie became in the way of spending. In 1996, Elsa went to the day care centre for two days a week. The intention was to let her, from age of four, attend the centre the whole week but with PGB it was possible to organise support at home, completely fit with Elsa’s needs and on a one to one basis.

So since 1996 Elsa has got a personal budget. She still attends two days a week the specialised day centre Anneriet in Doetinchem. Parts of her program at the centre are swimming, music therapy and physiotherapy. The costs are paid out of this budget.

The other days she stays at home and has her own day activities. A whole team of workers has been organised around her:

- Four people, in shift work, take care of Elsa.
- Three others during three days a week make music with and for her. Music is very important; it is used as means of communication. For instance, when Elsa is being lifted up, they always sing the same song. For years already, every day starts with one special compact disc of Marco Borsato.
- A physiotherapist, who already treats Elsa at home for more than 12 years.

- A Tibetan scale therapist. Once a month Elsa visits that woman; she lies on a table between big scales enjoying the vibrations and sounds. It makes her feeling relaxed and cheerful.
- A domestic help, which completely belongs to the team.
- One person who is available in case of emergency, when there is a sudden problem with the staffing.
- Elsa’s grandmother, who lends a helping hand, and a friend, who mainly takes care of the other three children.

With the exception of the physiotherapist - who is paid directly from the Exceptional Medical Expenses Act (AWBZ) - and the grandmother and friend, all these persons are paid out of the budget.

With regular care institutions they do not have much contact. With a PGB you can buy your help from them but the price is two or three times higher (because of the costs for overhead) compared with employing people by yourself. Besides, you do have more control and authority over personnel compared with buying them from an institution.

The organisation around Elsa in fact is a small company, which largely is self-steering. Willie, her mother, is the central contact person. Thirteen people may perhaps be a big group, but it always is the same people, there is not a greal deal of turnover.

Once every quarter, there is a team meeting with the four care givers. That is important because they each work on themselves, they don’t see each other during the work. In this meeting actual matters are being discussed and working schedules for the coming months are being filled in. The reports of these meetings are also given to all the other members of the team.
A couple of times a year a common activity is organised for the whole team; for instance going out of diner, a bicycle tour or a day trip. Also members of the team, or the team as a whole, attend training courses. The costs are paid out of the budget.

Because of the work the team is doing Willie is able to work 20 hours a week herself. By sharing care giving to Elsa with others she is able to pay attention sufficiently to the other children, who, for their part, are very satisfied with the helpers of Elsa. They also get attention from the workers and share with the music activities or the handicrafts.

The salary records have been kept by an external organisation, the service centre for personal budgets in Utrecht. Salaries are based on the CAO (collective labour agreements) of the homecare sector. Everyone fills in their lists with worked hours, which has been sent to the service centre which takes care for the salary records and the tax administration.

Elsa receives 5.500 euro a month. This budget is sufficient for running the whole company. However, in this system it is necessary that Willie also takes a great part of the care herself: from Monday to Friday from 16.30 and during the weekends. Elsa needs 24 hours care; she can not be left alone. It would be impossible anyway to pay real 24 hours care from a PGB.

Each six months Willie has to give accounts of the expenses from the budget to the health insurance office. On a special form she must write which expenses have been paid to whom. Incidentally, the financial administration is controlled by the health insurance.

The future is a difficult subject. The coming 10 to 15 years probably will be ressemble the situation as it is now. Then, the other three children sooner or later will leave the house. Maybe then it will be too silent at home for Elsa. Besides, Willie and her husband will be nearly sixty. Willie actually hopes a small miracle will happen then: that there will be a house like this one, where she can live with ‘normal’ young children, a nice house with a lot of music where Elsa can get much care and attention.

The company of Willie Tempelman is an example of a construction by which a multiple complex and visual disabled child can have a supported living in the society, far from the residential institutions. Elsa can stay at home and live with her own family. She can keep all the contact with her parents and her brothers and sister, which is of great importance for her as well as for the others. Because of the presence of a professional team the family members are able to combine their involvement and care giving to Elsa with their own school and working life. Obviously, the quality of life of all the family members is very high.

The company is also a good example of the opportunities and effects of the system of personal budgets. It shows that with a personal budget and an own company the possibilities for good services and support are in fact greater than by using services of regular service providers.

‘Individualised budgets’ maximise choice, control and flexibility (United Kingdom)

Author: Alison Alborz. Interviewee: Janet Cobb

The goal of an ‘individualised budget’ is to maximise choice, control and flexibility in the way services are provided to people with disabilities so that they can live a fulfilling life. Many people with disabilities and associated complex health needs, have unstable and fluctuating needs. Their health can change dramatically within a short space of time, but traditional health service delivery systems tend to be unable to respond to such changes because of the way NHS services are structured. This leaves families and professionals alike frustrated with currents options for support

Individualised budgets have been growing as an approach to service delivery over the last 3 to 4 years in England, though few people with complex health needs have been able to gain this type of service delivery to date. It is a radical departure from the traditional service delivery model, and funding, for the few individuals with complex health needs currently benefiting from an Individual Budget approach, is insecure. Many health professionals are still not aware of the approach, or its potential. Part of the difficulty arises because funds from the NHS budget cannot be used to purchase certain forms of care, or as an ‘individualised budget’, because of current NHS legislation. This is partly because the care needed to meet ongoing healthcare needs in the community, is often classified as ‘social’ care.

In addition, concerns from Health service managers range from perceiving people with disabilities and their supporters or family as unable to manage a budget, at best, to being likely to abuse such a budget at worst. However, accounting for budgets at a local level can be relatively straightforward, and an investment in families to provide them with enough information and support to manage their budgets effectively has been successful in a number of situations.

One way to move this agenda forward may be via organisations called Social Enterprises. Such organisations would provide management support to acquire budgets for their clients; provide key workers to liaise with the person with disabilities and their families about their needs; and provide access to care workers who would work directly with families. Social Enterprises would be controlled by the small number of families they supported, who would sit on the ‘board’ and influence the way they operate. Currently, however, because there are few people considering this as an option, individual professionals tend to take on this whole role, usually on an unpaid basis. Better organisation of the provision of individualised budgets would increase their availability. The funding for an individualised budget could be drawn from health, social care and education sources via a social enterprise, as necessary, to meet the needs of the person.

By its nature an individualised budget requires multi-agency co-operation and, although professionals may initially be unsure about working this way, it has the potential to make their role easier because they are fully aware of all the person’s needs, and the roles of other professionals in their life. Potentially, operation of an individualised budget means that there are no artificial ‘transition points’ at key life stages.

Case Study

Alison is now a young woman of 17 and has had an individualised budget for the last two years. However, for Alison to achieve a full life she needs a lot of support because she is cortically blind, has epileptic seizures, and is quadriplegic. Her physical difficulties mean that she is tube fed, needs suctioning on a regular basis and ventilation. She cannot communicate but indicates her approval through smiling or eye contact, and can reject an object or action she does not want/like. Alison needs constant monitoring to ensure she remains in optimal health.

Janet, a freelance professional who has worked in disability services for many years, was asked to meet with Alison's mother because the services she was receiving were due to change as she reached adulthood. A foster mother, who provided regular respite breaks for the family, was due to retire and the family knew that they could not cope without this support. Alison's mother was becoming increasingly worried and distressed with the thought of losing this service, and her own health was affected by the continuing nature of meeting Alison's health needs. Janet agreed to work as an advocate for the family.

Alison's mother described the family's situation through a series of informal 'chats'. For the first time this allowed the family to explore what they 'needed' in terms of support, rather than what they could 'get'. It became clear that Alison's mother thought that respite and foster care were the only options available to them, and she was grateful for whatever assistance the family could get. Janet commented that service providers, in their present forms, present an image to families that they know everything about disability, and have services within their 'gift'. However, underlying this is a fear of being sued, if attempts to depart from traditional approaches mean greater 'risk' for the client. This inhibits creative, lateral thinking about ways to meet families' needs. Discrimination is often an unintended consequence of providing 'traditional' services to people whose needs do not fit with what is on offer.

Janet approached Health and Social Care commissioning managers on the family's behalf. She found that over the 14 years of Alison's life, social workers had unintentionally misrepresented the complexity of Alison's needs due to a lack of health knowledge, which was important for understanding her complex needs. This meant that Alison's needs, and those of her family, were not communicated properly to a 'panel' who made decisions about support. There was little support from health services, other than from the paediatrician who helped to keep Alison healthy. The managers asked for a costed plan for services to provide Alison and her family with the support they needed.

Janet negotiated for a local 'Person Centred Plan' co-ordinator to write a plan and engage the relevant practitioners. This plan was costed at approximately £60,000 per year. The plan was presented to the commissioners to negotiate funding. However to set it in context, the family social worker also produced figures for the cost of supporting Alison in an 'out of district' residential college – the likely outcome if the family did not receive individualised support – this cost would have been approximately £175,000 per year. The commissioning managers were persuaded that the individualised budget was good for Alison and her family, because they would receive the support they needed and wanted, and was cost effective. The social care manager therefore committed funds of £27,000 to the budget, and the health care manager provided £30,000. This money is administered by the Social Services department, who pay monthly into Alison's trustee account. The local Disability Federation, an advocacy group, organise staff payments and provide assistance with hiring staff to work with Alison.

It took 18 months to research, negotiate, and organise help paid for by the Individualised Budget, but now Alison has a personal support team who support her each morning to get up, at the evening meal, at bedtime and during the night. They also support her to access traditional services, such as her family doctor, social worker and physiotherapist. Alison has received additional funding from the education authority for one to one support so that she can attend college, which would have been impossible otherwise as the college did not have the staff or expertise to care for Alison during her classes. Alison is now able to be included in everything her peers do. This has changed the perception of Alison’s future from one where she would go into a nursing care home, to one where she will continue to live in the family home after other family members have moved out.

Another benefit of the improved support made available through the Individualised Budget, is the improved lifestyle of the whole family. It means that Alison’s parents can spend more time together and give more attention to their other two children. Prior to having the individualised budget, much of Alison’s mother’s time was spent on everyday, necessary time-consuming tasks such as personal care and feeding. At this time Alison was included in activities, but if her mother had given her the social life she deserved, there would not have been time left to spend with anyone else in the family. However, through careful recruitment of appropriate personal assistants, Alison now has a fantastic social life. Her PAs are her ‘friends’ and enhance her life enormously. Now, Alison regularly goes to the theatre, cinema, restaurants, and for weekends away with her ‘friends’. In fact, she has a better social life than her mother – which, her mother feels, is exactly what should be expected for a 17 year old!

Innovation

Traditional service delivery provided many barriers for Alison to overcome. She would not have been included in society, but would have spent time in a series of segregated services. Such services tend not to be aspirational for the people who use them. Independent Living, as a concept, challenges the perceptions of traditional service providers as to how services should be organised to support the person’s place in society.

The traditional service delivery pattern, devised to meet a general level of need, is poorly matched to those with complex needs, such as Alison. It was not designed with such complexity in mind and therefore fails in relation to anti-discrimination policies. The implementation of an Individualised Budget for this teenager with complex needs has meant that she can be included in society. This approach has enabled service providers to live up to the rhetoric of ‘person-centred’ planning and services, and of anti-discrimination policy in terms of access to community facilities and equal outcomes from service use. The family is delighted with the outcome of this initiative, now they all have fulfilling lives and bright futures.

6. Specific Aspects of Service Provision

CICL Puteaux supports people with severe brain injuries (France)

Author: Jesus Sanchez. Interviewees: Mr Kohler, Director, and Mrs Brami, Coordinator, of the centre for the insertion of brain injured persons (Centre d'insertion pour cérébro-lésés, CICL)

The ADEP-CICL of Puteaux in the Department of the Hauts-de-Seine, close to Paris was created in 1993, thanks to the action of both the families and health professional workers in the field of brain injury. It is the first institution in which this kind of population may come just for the day. 21 brain-injured persons come to the service, they are between 20 and 60 years old.

The aims of the CICL are to favour the social, family, and if possible, professional reinsertion of brain injured persons, either this brain-injury comes from traumatism due to an accident, to vascular stroke and to an acquired tumour. It aims at reaching these objectives through the elaboration of individual projects for each person. These projects are adapted to each specific situation including rehabilitation and re-education activities, outside accompaniments and social mediations.

Brain-injured persons may either solicit the service by themselves or be directed there by professionals in the medical field (either working in hospitals or working as liberal) or medico-social field (institutions, services, associations, administrations). The coordinator, the director, and the psychiatrist see the brain-injured and approve the fact that their candidature is adequate. They make sure that they are partially self-dependant (can go to the toilet and eat by herself for example) and that they get assistance in their living environment. They also make sure that their place is close to the centre so that they could come regularly, without being too tired to participate in the activities that are proposed in the centre. In every case, there must be an administrative agreement from the Departmental House for Persons with Disabilities (MDPH). This agreement may be valid for three or five years.

Once in the centre, the brain-injured have a six weeks trial period during which they must participate in each activity and meet each member of the team. During the weekly institutional meeting, his case is discussed and next week program is fixed. At the end of this six weeks period, an individual project is elaborated, proposed to the person, then written to be signed by the person. This project may be set up for maximum one year but may be shorter, for example three months.

Group activities in which the user has to take part appear in his individual project; individual supports are also described in that document. The person must be present in the centre from 3 to 5 days per week, from 9:30 to 16:30. The length of the day and the number of days of attendance may be defined in a flexible and adapted way.

Group activities are chosen among a broad pallet :

- Rehabilitation groups: wooden work, artistic expression, painting, drawing, modelling, theatre, body expression, newspaper;
- rehabilitation groups: memory, logic, maths (to read a cheque or a tax form), communication, administrative questions, stability (balance);
- meal groups.

There are also outside groups which aim at helping persons to move outside, to locate themselves in the environment:

- solidarity groups: training for the voluntary help in associations, in the city (various partners such as the “Heart Restaurants”, or “Popular Help”… ;
- sportive groups with the help of a sporting organizer from “Handisport” (shooting, blowpipe, boccia, game of bowls, sport in a gymnasium in a nearby city…).

Individual treatments are possible in speech therapy, occupational therapy, psychomotricity, neuropsychology. A psychiatrist also follows the users. When a psychotherapeutic follow-up is needed, it can take place in the CICL or outside (in a medico-psychological centre or with a liberal professional).

Concerning brain-injured persons, the centre is the only one where people are not resident. It is a personal rehabilitation and transitional space towards the outside world.

Case Study

Jean, a 35 years old man had a very serious accident. He remained in coma and had serious lesions involving behavioural problems (he would undress himself in public), cognitive troubles, Hemiplegia, and visual troubles. Jean was also disathric which made his expression difficult to understand. He didn’t work anymore and lived alone in a studio-apartment which was one floor under his father’s apartment. He was very dependent on his father for his daily living and outside activities. His mother lived in the countryside.

At the beginning, work was done to help him to become self-dependent in daily and social living: taking his shower alone, warming his meal in the micro-wave, getting dressed, getting up with an alarm-clock and being on time at the meeting point for the centre’s car driver, travelling by himself to town. He also got rehabilitationto improve his capacities and important work was done to inhibit his propensity to get undressed in public or to make provocative verbal digressions.

Jean wanted to go back to work and his employer agreed with that plan but it was necessary to find him an adapted post. The CICL team studied with the firm (employer and colleagues) the possibility to define functions he would be able to assume, and with the National Fund for Work Insertion (AGEFIPH) the possibility to finance the required equipments. The CICL team also madecontact with many different services to find him an apartment close to his work, a life assistant, a cleaning assistant and transport service supports. So, Jean could go back to his former job and live in his own apartment not depending on his father. His vocational reinsertion was getting well during a few months but new difficulties occurred. Unfortunately the CICL could not solve these problems as Jean moved to the countryside. So the CICL guided him towards a similar centre.

The Foundation of People with Muscular Disorders (Poland)

Author: Ewa Wapiennik. Interviewee: Beata Karlińska

This example of good practice will introduce the personal assistance services provided by the Foundation of People with Muscular Disorders (latterly referred as the Foundation). The services of a personal assistant have been provided by the Foundation since the year 2000. Since 2004 this service constitutes a part of a larger project “Lift to Work”, which was accomplished within the framework of the EQUAL initiative. At its realization the Foundation cooperated with partners throughout the whole country (see: http://www.miesnie.szczecin.pl/equal/strgl.html). A pattern for the service of a personal assistant is provided by the solutions applied in the Scandinavian countries and the author of the concept to create these services in Poland was Fuga Mundi Foundation from Lublin. These services are meant for people with a severe movement disability (intellectually efficient), caused with muscular and nervous system disorders, which often require 24-hour care. They are helped in leading independent lives by their personal assistants. Persons who have succeeded in the recruitment process and have done well at personality tests can be employed as personal assistants. The Foundation does not require any special qualifications.

Case Study

Mr A., a young 23-year-old man, living in a village located near Gdańsk, has been the client of the Foundation for two years now. Mr A. suffers from a muscular and nervous system disorder and requires 24-hour care. He was able to move by himself before he was 10 years old. Due to the progress of his illness, when he was 10 he was able to move around only on a wheelchair. This caused major changes in his life as the school he attended was not adjusted to the needs of people with disabilities and he was offered individual teaching at home. Since then Mr A. stayed at home. Thanks to the individual teaching he graduated from the primary school, but he finished his education on this level at the age of 15. The most important problem was a lack of a secondary school adjusted to the needs of people with disabilities nearby and no possibility of transport. At home he was taken care of by his parents. When in 2004 the project “Lift to Work” was launched, the Foundation offered Mr A. and his 5-year-younger brother (also suffering from a muscular and nervous system disorder) to participate in the project. Mr A. began his participation in the project in 2005. He was 21 years old. The Foundation was aware of Mr A.’s situation as it was in the process of creating a database of persons suffering from muscular and nervous system disorders for some time.

The support of the service clients is determined on an individual basis. Each client completes a special questionnaire. Each of them is also interviewed. On this basis the client is offered a package of services provided by the Foundation. A decision on granting the services is taken by the Executive Board of the Foundation. The Executive Board also decides on the level of payment which is often of a symbolic nature. Persons benefiting from the services within the framework of the project “Lift to Work” receive the services for free. Both the services and payment for them are adjusted to the individual needs of the client and the possibilities of the Foundation. In case of Mr A. a specialist for assistants and transport was engaged in the planning process. Mr A. was offered 24-hour-long personal assistant’s services and education on the level of a secondary school in a special educational centre in a small town located near Szczecin, which is fully adjusted to the needs of persons with a substantial movement disability. The Foundation did not have the possibility to provide assistant’s services in Mr A.’s place of residence.

Mr A. requires his assistant’s support all day long. In the morning the assistant helps Mr A. with his morning washing activities, dresses him, helps him with having meals, takes him to school. The assistant is not present during the classes. Mr A. is then helped by his teachers and classmates. The assistant helps Mr A. during the breaks between classes. After classes he takes Mr A. from school, helps him in his leisure time, during meals, in the evening with his washing activities. Mr A. needs his assistant’s support even at night (he requires help when changing his position). In the daytime Mr A. is supported by several assistants, according to a determined timetable. The same assistant also helps Mr A.’s brother. Mr A. spends holidays and festivals at his family home. The transport is provided by the school. Mr A. is a very good student. After his graduation he would like to continue his education at university.

The story of Mr A. is very typical for young people with severe movement disabilities in Poland, especially for people living in the countryside. Very often these people stay at home after finishing their education on an elementary level. Thanks to personal assistant’s services Mr A.’s life ceased to consist of hours spent sitting at home. Mr A. used to be a very distrustful and closed person. Now he enjoys life, he has become more independent, he has learned to take his own decisions and make his own choices. He is very diligent when he studies and he sets new goals in his life.

For many people with movement disability, personal assistant’s services constitute the only chance to have an independent life. Unfortunately, they are not very frequent in Poland. One of the barriers for creating personal assistant’s services in Poland is the lack of knowledge. People with disabilities do not know that they can benefit from such services (or they are afraid of help provided by strangers), and civil servants do not know that such services can be provided. The Foundation conducts training concerning the abilities of using personal assistant’s services by people with disabilities and their guardians. EQUAL and its tools also create a possibility of dissemination, thanks to which the service is being popularized in counties local authorities all around Poland.

Personal assistant’s services provided by the Foundation are of a unique nature. In Poland there is a profession of an assistant to a person with disabilities, who supports and advises a person with disabilities in the rehabilitation process. To differentiate from this, the Foundation calls the service provided by it a personal assistant. A personal assistant in the Foundation is often called “an intelligent prosthesis”, and his work is often compared to the work of a translator. A personal assistant is not supposed to take decisions for a person with disability, but to help with the realization of a decision taken by this person; an assistant cannot become a substitute for social relations, but only make them possible. The Foundation has managed to create a model solution. Seven years of the project duration allowed them to learn about the threats and problems relating to the services of a personal assistant. The Foundation is also fighting the stereotype of a poor and helpless person with disabilities. Many very active persons with disabilities, making decent money, benefit from personal assistant’s services provided by the Foundation.

KoKoBe Oberhausen coordinates service provision for people with complex needs (Germany)

Author: Albrecht Rohrmann. Interviewees: Mrs F, KoKoBe, Mrs. F and N, Lebenshilfe

This example will introduce the ‘Kontakt- Koordinations- und Beratungsstelle für Menschen mit Behinderung’ (KoKoBe) in Oberhausen, Northrhine-Westphalia, Germany. This service has a coordinating function for local service providers and offers counselling for people with disabilities, especially for supported living and for managing care. The service is fully funded by the regional social administration board and runs in co-operation with three non-governmental service providers in Oberhausen. Provider cooperation was a pre-condition for funding. In the chosen example, the Service for Supported Living from the Lebenshilfe (AUW) is involved. Therefore the interviewees were one woman from the KoKoBe and two women working for the Supported Living Service. One is the client’s support worker, the other women work in the administrative area, but have been assisting the client for a long time.

This example of good practice is about a 33 year-old woman with complex needs and her transition from a residential home into her own apartment. The woman, called M., has an intellectual disability and severe mental health difficulties. She is also overweight. M. lived with her family until the age of 26 and then moved to a residential home. Typically in Germany, people with complex needs and their family members often see no alternatives other than residential homes for living outside of the family's home. Today M. shares a flat with another woman and both recieve assistance from the Supported Living Service (AUW). Both women have been using this service since its establishment two years ago. During the day, M. and her friend work in a sheltered workshop.

M. is partially independent in her physical care and can orientate herself well in a familiar environment. She needs support in preventive health care and various daily life activities in her household, with shopping, using public transport, managing her social benefits, etc. With her support arrangement, she gets along very well, but can also fall into a severe mental health crisis and must go to a psychiatric hospital for treatment.

Lebenshilfe has already been the service provider of M.’s residential home. As soon as M. learned that Lebenshilfe was about to offer a supported living scheme, M. clearly wanted to move out of the group home. She trusted Lebenshilfe and wanted to be involved in their supported living scheme. But it was difficult to get access to the program. At first, when M. said that she wanted to move out she faced a lot of scepticism. All the professionals around her and as well as her parents were afraid that M. might not be able to live on her own and feared that she would end up fully neglected and severely harmed. But M. persisted with her wish to move out and contacted the KoKoBe for counselling. An individual support planning process led to a way M. could live on her own: M. could live together with a good friend from the residential home *and* have a support arrangement provided by various services.

In various meetings, in which M. participated, the new supportive arrangement was planned, set up and achieved step by step: The sheltered workshop and the psychiatric hospital were involved in preparing for situations when M. falls into a mental health crisis. The residential home tried to prepare M. for her independent living as thoroughly as possible by teaching her skills in daily life activities. An individual training program was carried out by a support worker who got overtime for a few weeks. This support worker also helped M. and her friend find a suitable apartment. Impressed by this systematic planning process, M.'s parents gradually developed confidence that M. could live in her own flat.

M. was also helped with her application for the financing of the new service arrangement. It was obvious that M. would need extensive support, but also extremely flexible support because of her regular crisis periods. Through constant and personal contact to the social administration, a very individual arrangement was made possible and the neccessary number of 'professional support hours' was granted. A very important argument was that the increased costs at the beginning of M.'s new service arrangement could be regarded as an investment that could well end up as a 'return' of less cost later.

M. needed a lot of support with daily living activities after her move. Many small things were also very important to her and had to be arranged just the way they had been in the residential home. M. also had big problems using public transport but has gradually learned to use buses independently, even though sometimes she gets lost. The service has tried to give her training on what to do in this sort of situation and up to now nothing serious has occurred. M. feels rather happy in her flat; there are some problems in the relationship between the two women, but both do not regret having left the residential home. M. herself participates in a cooking-group and a women's group offered weekly by the KoKoBe. M.'s mental health problems are still a big and regular challenge. M. often has to go to the doctor and it is very important that she takes her medication strictly according to prescription.
The Supported Living Service (AUW) takes care of M. whenever she needs support or accompaniment. Sometimes they offer support beyond financing agreements because flexible help is needed in certain situations.

Other services are also actively involved in M.'s support arrangement: the sheltered workshop and her former residential home still wish to help her and try to support her wherever possible. The community mental health service will also offer help in an acute crisis situation if necessary. Cooperation with the psychiatric hospital itself is difficult sometimes, as AUW does not receive the necessary information. The family, volunteers and the family doctor help as much as possible. The KoKoBe, in close cooperation with the AUW-service, organizes regular meetings to reassess M.'s arrangement. M. is involved in the meetings as well. M. also seems to like having more activities in her free time. The financing arrangement of the support has become more difficult because the social administration has just granted less "professional service hours" than before.

In summarizing the experiences of M.'s transition from the residential home to her own flat, it was most important that she was backed by the KoKoBe, that she was actively involved in the planning process, and that it was possible to win over the residential home and other services for a coordinated planning approach despite initially having pessimistic outlooks.

All in all, the case of M. shows that a person with a high support need can live on their own and that it is possible to arrange supported living possibilities for people with difficult and complex needs in the face of a certain initial opposition. The Supported Living Service is always open to people who need support, no matter what their history or background. It was possible to solve cooperation problems between the different services, and the sufficient and flexible funding of support was successfully achieved.

Istituto Privata di Riabilitazione demonstrates the process of de-institutionalisation (Italy)

Author: Christine Mary Cahill. Interviewee: Dr. Giampiero Lapini, Health Director

N.T. is a man of 45 years of age with a intellectual disabilities complicated by a chronic psychotic disorder that involve deficits, chronic delirium and evident incoherence of thought, resulting in abnormal thinking and interpersonal communication. With this clinical picture, the support needs of N.T. are the following:

- institutional support for psycho-pharmacological therapy since there is no certainty that N.T. will take his medication if this is left solely to him;
- the support of a professional educator in problem solving because his interpretation of reality is not always effective and does not permit him to take adequate decisions;
- support in relation to his difficulty in undertaking and maintaining articulated tasks: in the use of public transport, for example, he is able to catch a bus if there is only one bus to choose from. The situation becomes too complex if there are several different buses to choose from;
- continuous supervision in complex situations owing to his difficulty in managing tension and requests of a psychological nature. Tension is a problem, also given the fact that he comes from a psychiatric prison hospital;
- prompts in relation to personal care, hygiene and dressing. He slides into a negative state if left to himself.

N.T. has completed the following steps in a process of deinstitutionalisation that lasted more than five years, in order to reach his present level of autonomy:

1) From the psychiatric prison hospital to a traditional residential care institution (RSD) - with the characteristics, very often noted in persons with concretized psychosis and experience of prison, which involve relational alterations with reality: for example, wearing an overcoat in summer and not dressing adequately in winter;
2) From the traditional residential care institution to an external group in a sheltered community home with 12 users. Here, N.T. improved his level of autonomy and was able to undertake a trial work placement;
3) From the sheltered community home to an apartment which he shared with another person in care. This apartment was opposite the community home that he could count on for support if necessary. In any event, he continued to be supported by specialised care workers. When his flat mate found a council flat and work placement in a regular company, N.T. lived alone for a period. This was not an optimal solution because he became sad and withdrew into a fantasy world;
4) He was therefore moved to another apartment, where he now lives with 2 other persons who have followed his same process.

N.T. is not economically self-sufficient. He works in a ‘sheltered’ restaurant (see description below). His wages supplement his civil invalidity pension but his income is not sufficient to maintain himself completely. In the restaurant, N.T. has the specific and restricted task of managing the bar and making the coffee, something which he can carry out with little support but which he would not be able to perform in an ordinary restaurant.

Since he has significant difficulties in managing money, he is closely supervised with constant checks on the way he uses and manages his money. At first, he spent all his money on soft drinks, which he loves.

He also needs to be supported in his social life. Things are easier in familiar situations with people who know him, where he is supported and there is some supervision. There are fewer problems than one might imagine. People will adapt and awkward situations will be straightened out. On the other hand, when he finds himself in a strange situation with people he does not know or who do not know him, aspects of bizarre behaviour prevail and relations can be complicated.

NT receives the following types of support:

- professional support: professional educators, a psychologist, personal assistants for independent living, household help and support at work;
- the support of workers from the Cooperative (not health/social care workers) such as the restaurant cook and waiter;
- informal support provided by his peers/flat mates/friends;
- some familial support: N.T. has a sister who visits him occasionally.

Care workers meet weekly to plan collaboration and programming. It is more dignified for the person concerned to be supported by professional care workers and the use of voluntary workers has not been developed. This form of support is more important for social inclusion and not in processes of autonomy.

Support is funded through the Local Healthcare Unit, 80% being charged to the Health Fund and 20% to the Social Fund. The Institution pays the rent of the apartments with the user paying a quota according to their possibilities.

The steps in the process of deinstitutionalization are illustrated in the story of N.T. This is a process that normally lasts 5 years and requires careful planning to cover all the steps. One can say that it is much less complicated to start from a full-time residential care situation because the costs decrease as the process evolves. It is also a mental process and the necessary conditions for its success are the possibility to work and to realize the consecutive steps in increasing autonomy.

Commercial activities have been created through collaboration with a social cooperative and the Institute. In the case of N.T., this is a restaurant-pizzeria, far from the Institute in an industrial-artisan district on the outskirts of Arezzo, and is open at lunch times and Friday and Saturday evenings. The most significant element of this organisation is that it represents a form of sheltered but real employment: sheltered because it is supported and real because it is in market competition with other restaurants, itself being to all effects a business enterprise. Persons following an independent living programme are integrated in this work environment. They are supported by the Institute's staff who work in the restaurant alongside the workers from the Cooperative and, in this case, a limited number of voluntary workers.

The process towards autonomy has also seen the constitution of couples: 2 couples have married and 2 cohabit. These are persons with a high level of functioning who are able to manage this kind of interpersonal relationship. They are supported through the weekly visits of a psychologist and special educator who check the familial situation and help with relationship problems.

There are plans to create similar procedures for persons with autism spectrum disorders. This will involve a strict cost analysis since, given their complex needs, persons with autism spectrum disorders require specialised care workers and continuous assistance.

The Institute Agazzi is a private accredited institution and therefore part of the national support system. As a Residential Care Service for persons with disabilities (RSD) it responds to regional legislation but its catchment area also comprises bordering regions. Within the national support system, codified systems are larger, with RSDs with 40 places and community homes with 12. They are subject to complex bureaucratic procedures and institutional rules and within this system it is therefore difficult for persons to reach the level of autonomy they are capable of. Traditional codified systems are not organised for processes of independent living. The person is referred to an institution and remains in an institution.

In relation to more traditional systems, the ‘innovative’ practice illustrated here lays emphasis on a progressive, flexible and, above all, graduated process and a particular way of understanding care and support, in that a process towards autonomy cannot be understood as a service provided with a beginning and an end. Work activities are a particularly important feature of this process. In an autonomy project, any form of participatory employment is essential and must be created even if a high level of support is necessary. It can take many forms, cook, waiter or bartender as in the case of N.T.

Substantially, this form of process towards autonomy is particular in that it is gradual and complete. It can be considered an example of good practice because it gives the person the possibility to recover and normalise their life, greater self-esteem and satisfaction, and a better quality of life with lower social costs for the community.

However, it is necessary to have the support of the community, rigorous programming, adequate support and maximum flexibility since the steps in the process are not necessarily the final point of arrival. A situation can change from one moment to the next and it is important to be able to adapt and not be frozen in one particular modus operandi. The limitations are inside our heads but, if one is adaptable, it is possible to see the emergence of surprising personal resources in people and the funny thing is that the steps in this process were originally the idea of some of the Institute’s interdicted users.

Organisation Omega promotes a culture of involvement (The Netherlands)

Author: Martin Schuurman. Interviewees: Marga Nieuwenhuijse (director), Paula Majoor (care assistant and coordinator participation project), Nienke Sondern and Quitty Pluimers (parents), Sophie de Beijl (orthopedagoge)

Omega (Amsterdam) is one of the eight day care centres for children with severe intellectual and multiple disabilities (MCG) in the Netherlands. It was founded in 1983 by a group of parents. The organisation has 60 clients split up into three categories of ages. Each category is split up into three groups of children. Omega offers the following services:

- Day care.
- Outpatient support at home and to regular playgroups.
- Specialised support to other service providers.
- Consultancies to the Centres for Consultation and Expertise (CCE's).

In 2009 Omega will move to a new building in IJburg, another part of Amsterdam. Then, the target group will be enlarged with new groups of 17-plus youngsters (four groups of six persons each). On this moment, a special study group is preparing the implementation of this enlargement (vision, plan, logistic consequences, etc.).

In the vision of Omega knowledge about the technical aspects of support is less important than the culture inside the organisation: the attitudes, the wish to treat somebody well, the involvement with the children, having the ability to look at them precisely. Specific parts of the vision are:

- Wanting to get everything out of the children. They want them to exert an influence on their environment as much as possible. Omega points at their development, their possibilities.
- Strong focus also on the parents and families: how can we achieve that child and family can together form a part of society? There is cooperation with parents, brothers and sisters in a natural way.
- Cooperation with the university (academic hospital of University of Amsterdam). The central focus of the research program is: what do you have to do in early stages of the life of MCG people to reach that they can participate in society as long as possible? What do persons with MCG need in their various life stages – from birth to death – of support and care?

The children usually arrive at the centre between 9.30 and 10.00. The program consists of: drinking, eating, changing nappies out of pure necessity. In the second half of the morning activities take place: music, swimming, playing with instruments, exercises. During the activity the children should have another posture than before. The assistants continuously speak to the children and explain what they are doing with them.

Areas in which children are stimulated to develop themselves are: to learn how to eat and/or drink, develop movement, develop communication, understand what is cause and effect. With respect to communication personal profiles have been made in which is recorded which stimuli and behaviour from the environment the child usually reacts to and what specific ways of communication the child itself generally uses (facial expression, muscular tensions, physical reactions, etc.).

Participation project

In various ways, Omega is involved with participation of MCG children in society. Frequently, visits occur to places like the zoo, fair or performances of the ‘cliniclowns’. Besides this, Omega supports the families in leading life as normal as possible and gives support to regular day care centres in taking care of MCG children. Some of the children of Omega still attend a regular centre for one day a week.

An important activity is the participation project of the organisation. The workers of Omega noticed that many children reacted happily and alert to visits of their brothers and sisters. They tried to get in touch with regular services like schools and child care centres in order to broaden the contacts of the children with non-disabled peers. Eventually, Omega set up a project by which children attend once a week over the course of a year a class group of a basic school. A professional care assistant is always with them (one to one). In fact, the assistant acts as an intermediary between child and group. This year four children got to participate in this way. For example one child attends a weekly music lesson at a basic school. Another one plays in a kindergarten class. And one of the boys joins the gymnastic lesson in the highest group of the basic school.

The project is financed by sponsors. There is a waiting list with 19 children on it. There also are contacts with secondary schools. There is the intention that a boy of 16 will attend a carpentry lesson at a technical school.

The purpose of the project is not only to give the MCG children the opportunity to participate but also to let children from the regular schools know that peers with MCG exist. Part of the project is that the whole basic school class visits Omega during the year. Sometimes this is combined with a common activity, like a treasure hunt. Usually, the school classes enjoy it very much. One of the boys of the regular school wrote after a visit to Omega in his personal report: ‘These children are different, but far from creepy’.

It is very important that the need for participation and social contact comes from the child itself, that he or she will give signs for it. Only when these signs are given participatory activities should come up. The question is: what are the needs, how can we locate them? To uncover the needs you have to observe them very well and be conscious of specific details (like movements of the eyes).

Before the child is able to express its needs, the following conditions have to be achieved:

- The child has to have some awareness of the outer world, knowing that life doesn’t end with its own body.
- The child must have the ability and openness to have an active connection with someone else. There has to be eagerness to meet someone.
- Participation must have a goal. Like: ‘I can become alert and consequently have more influence to my environment.’ Or: ‘Let me enjoy the voices and sounds around me.’ Or: ‘I want to make contact.’ The boy of 16 who will attend a carpentry lesson at a technical school enjoys the music they play as well as the tough way his peers talk to him. And the boy who attends the gymnastic lesson at the regular basic school is happy being able to drive fast with his wheel chair through the sport hall.

However, the basic needs of physical and mental comfort these children do not realise in the regular circuit. Their needs change fast during the day due to the epilepsy and alert problems they have. So the day care centre and their home are the basis, where they can have rest after whatever kind of activity they had.

Omega wants to enlarge the participation for their children and has the intention to have available a standard package of activities. The move to IJburg is a stimulator to work this out. The organisation wants to think about the possibilities of participation creatively. But they want to do it carefully: you always have to be aware of the variety of the needs and demands of the children. The question always arises: whose interest is it to go outside and do something in society? Omega tries and evaluates.

Omega also wants to develop the other direction of participation, namely bringing society inside the organisation. It is quite an effort to connect with regular basic schools; they want them to visit Omega more often. For example, they will start a reading project by which the children can enjoy the sphere and voices of the readers, who for their part can see the reactions of the children and feel this experience themselves. Generally, the sector as a whole can still make a big progression in these kinds of activities, Omega finds.

Another issue for the future is the support Omega gives to regular day care centres. In this the organisation also has to make a trick. They have the feeling that they can offer and transmit their specialised expertise to regular organisations much more than at present.

The parents

Parents of the children of Omega experience the organisation as the very specialist one for children with MCG. Moreover, by the care and support Omega gives, they can live as a family as normal as possible and participate in society. And that is what they want, at least as long as possible. ‘As long as possible’, because parents experience that the older the child is, the more complicated family life is. ‘The other children in the family pass their MCG brother or sister intellectually and increasingly get their own life. So it is impossible to make the normal growth and development as a family.

Parents say there is great interest of Omega for the other children in the family. Brothers and sisters feel very welcome to visit the organisation. They have grown up with Omega. ‘Omega takes care of the family as a whole; they see you as a family. Omega knows how to say that things at home can be better, that’s their approach. They never reprimand.’

At the regular schools which the brothers and sisters attend there often is not much concern with the disabled brother or sister. In group discussions there not much attention is paid to him or her. ‘Sometimes it seems as if the disabled brother or sister does not exist at all for the school teacher.’

With respect to the participation activities of Omega parents are positive. They like the prudent approach of Omega and that the organisation always makes the needs of the children the starting point. ‘No one benefits from forced participation.’

Conclusions

Omega is a day care centre for children with severe intellectual and multiple disabilities which combines solid care with an open view of society. The aim of participation is achieved through an attitude of judiciousness and staying very close to the needs and wishes of the children. So the activities of participation are tuned to the individual needs and abilities. Omega has acquired a lot of specialised expertise. Regular organisations in the field of education and care should take advantage of it.

Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs

People with severe disabilities and/or with complex needs and their families are at risk of discrimination in almost all areas of life. They are mostly not considered in policy development and implementation at local, regional, national and European level. It is high time for all stakeholders to undertake positive action against the high risk of discrimination of this group of European citizens.

These are some of the conclusions drawn by the participants of the "Study on the Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs" that was financed by the European Commission. The study was managed by the Commission's Unit for the Integration of People with Disabilities (Unit G3) in the Directorate General for Employment, Social Affairs and Equal Opportunities.

Inclusion Europe, the European Association of People with Intellectual Disabilities and their Families, was responsible for the coordination and implementation of the study. The research work has been lead by Dr. Johannes Schädler of the Zentrum für Planung und Evaluation Sozialer Dienste (ZPE) of the University of Siegen. Twelve National Research Experts from Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom were responsible for collecting and analysing national data and representatives of nine European NGOs contributed to the development of the policy recommendations.

The results and recommendations of the study are presented in four Volumes:

- **Volume I: Policy Recommendations**
- **Volume II: Research and Analysis**
- **Volume III: Country Reports and Stakeholder Interviews**
- **Volume IV: Examples of Good Practice**

They are available on the website of the European Commission at **ec.europa.eu/employment_social/disability** or on Inclusion Europe's website at **www.inclusion-europe.org.**

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