

**EUCERD JOINT ACTION
GUIDING PRINCIPLES
ON TRAINING FOR SOCIAL SERVICES
PROVIDERS
EXAMPLES OF TRAINING
PROGRAMMES**

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INTRODUCTION

This document was elaborated in the scope of the [EUCERD Joint Action](#) Work Package 6 ‘[Specialised Social Services and Integration of Rare Diseases into Social Policies and Services](#)’.

The following examples of training programmes for social services providers are an outcome of the multi-stakeholder EUCERD Joint-Action workshop on ‘[Training for Social Services Providers](#)’ (Copenhagen, October 2013) and are complementary to the policy document ‘[EUCERD Joint Action Guiding Principles on Training for Social Services Providers to the European Commission, Member States and all Stakeholders](#)’.

This document contains examples of training programmes organised by [Frambu Resource Centre](#) for rare diseases (Norway), [Edubolirare training platform](#) for rare diseases (Romania) and [Diakonische Stiftung Wittekindshof](#) Adapted Housing Service for Prader-Willi Syndrome (Germany).

These examples of training programmes’ curricula intend to inform Member States, social services, patient groups and all other stakeholders on existing training programmes which can serve of inspiration when developing and implementing training programmes for social services providers.

Why do social services providers need training to handle cases of people living with a RD?

Rare diseases (RDs) are rare, complex and often chronic. Additionally, there is currently no treatment available for most RDs. The combination of these factors makes people living with RDs a particularly vulnerable group with very complex needs that require multidisciplinary care within a holistic approach. Care provided by qualified social services and policies throughout life has then an instrumental role to play in empowering people with RDs and improving their health and well-being.

On the other hand, rarity leads to an enormous scarcity of knowledge and experts, to lack of resources and good practices, therefore creating huge obstacles to the comprehensive and integrated care that patients with RDs need. This lack of knowledge and resources have made it difficult to spread information on RDs to medical professionals and even more to professionals working outside the medical field.

Social services providers need to be made aware of RDs specificities in order to guarantee the quality of the services they provide. Training of social services providers is a needed and efficient way to empower professionals, families and patients to face the challenges caused by RDs.

Who are the social services providers?

The training programmes for social services providers currently available and future programmes to be developed based on the ‘[EUCERD Joint Action Guiding Principles](#)’ are intended for all social service professionals working at private or public, in-patient or out-patient, European, national or regional facilities e.g. social services and structures, Centres of Expertise, hospitals, schools, local council, etc.

These professionals are in direct contact with people with RDs or are involved in the planning and logistics of the services provided. Such professionals include, among others: social workers, personal assistants and carers, psychologists, teachers, nurses, therapists, as well as administrative and reception staff. Other professionals might benefit from this type of training, depending on the organisation of services and care in each Member State.

TRAINING PROGRAMMES AT FRAMBU RESOURCE CENTRE FOR RDs, NORWAY

Introduction and background information

Frambu Resource Centre for Rare Disorders is a private foundation funded by the Norwegian state, which provides services for over 120 rare diagnoses.

Services provided are supplementary to the normal treatment and care that every citizen is entitled to in Norway and include Respite Care Services, Therapeutic Recreation Programmes, residential courses, seminars, communication and documentation services, counselling, consultations, research projects, outreach activities in users' local community, etc. Programmes run are for both families and professionals, covering patients' life cycle, from childhood to old age.

Frambu's team is composed of about 85 professionals: half involved in the logistics and administrative processes and the other half involved more directly in care provision, including doctors, social workers, psychologists, physiotherapists and occupational therapists, amongst others. Frambu provides services to 2300 beneficiaries every year.

Target public

Frambu's courses target health professionals at local health services, professionals in the education system and other professionals who provide services to individuals with one of Frambu's rare diagnosis (e.g. social workers at local level).

Trainers

The training providers are usually part of Frambu's staff and have knowledge on the concerned RD, and on patients followed by the resource centre. These trainers can be, for example: special teachers, doctors, physiotherapists. When needed, Frambu sub-hires external experts, such as geneticists, usually as invited lecturers.

Mission, Vision and Scope

Frambu believes that training programmes are essential to ensure that Norway's social services providers are better prepared to care for people living with a RD, leading to an increase of quality in the services offered at local level. Therefore, Frambu aims at training all professionals who provide services to Frambu's clients within social services at regional and local level.

Frambu makes an effort to ensure that the training programmes are appropriate and proportionate, adapted to the level of knowledge and the needs of the professionals trained and of the patients cared for.

Trainings and the National Plan/Strategy for RDs

In Norway, there is an Act (law) concerning municipal health care services, the Health and Care Services Act. According to this Act, the municipal authorities shall ensure that all people residing in the municipality are provided with necessary health services. The municipality's responsibilities include then all patient and consumer groups.

People living with a RD in Norway are entitled to an 'Individual Plan' containing an outline of objectives, resources and services required by the patient. It is up to the municipal authorities to follow up the daily routines of this Individual Plan in patients' homes, as long as possible.

Frambu is part of Norway's network of National Competence Centres for RDs, which has been given the responsibility to ensure the provision of guidance and dissemination of knowledge and competence to the health services and other service providers at municipal level as well as to clients/patients. Therefore Frambu has a role in supporting municipal services in getting more prepared to handle cases of people living with a RD helping these services to fulfil the mission that has been given to them under the Health and Services Act.

Funding, Costs and Evaluation

Frambu has its own budget, sustained by public funds. The training programmes are included in this budget. The costs of Frambu's trainings are mostly covered by Frambu's funding, coming from the state. Participants might be asked for a small fee to participate in courses and training seminars arranged at Frambu. Visits from Frambu to the local communities to provide training are usually free of charge. Training by video-conference is free of charge.

Frambu reports to the South-Eastern Norway Regional Health Authority who is responsible for evaluating the services provided at this recourse centre.

Some of Frambu's courses are recognised by professional societies, such as the medical association, the physiotherapists association and the association of psychologists. These organisations accredit the participants that successfully conclude the training programmes.

Collaborative Multi Stakeholder Holistic Approach

Frambu works closely with patient organisations, local communities and expert professionals to develop the training programmes. A big part of the training preparation is around the follow up of literature and information on the best treatment and care practices for each disease. This is partly done by Frambu's own staff, but also in connection to University Hospitals in the areas of paediatrics, genetics, and in specific areas relevant to each RD.

Patients/families and patient organisations are often consulted during the process of conception of the training contents and can also be involved directly in the training programmes by giving their testimonial.

Content and Organisation

Training at Frambu is provided during courses, seminars and consultations. Training can be performed in the format of group training, organised by diagnoses, or as individual training, when referring to handling a particular patient/family.

Most of the current training is provided to carers in the local communities: by having Frambu's staff travelling all over Norway and by using video-conference and distance learning methods, whenever suitable.

A big part of Frambu's training is theoretical, covering subjects concerning the specific disease, handling the patient, etc. Frambu's physiotherapists and occupational therapists always provide practical advices and explore the concepts in practice with the professionals trained. The training of special education teachers usually also includes a practical component.

Training modules contain diverse information considered relevant in each specific [group of] diagnosis: information on the disease, home environment and accommodation, special education, adaptation to work place, facilitation of access to services. Common modules to all trainings, regardless of the diagnoses, are the information on the disease and information on legal rights of patients and their families.

Training Programme: 'Neurofibromatosis Type 1 – more than spots on the skin? Visible and hidden challenges'

Target public: service providers working with children and adolescents with the diagnosis, employees in kindergarten, school, service providers and leaders at the municipality.

Trainers' background: Medical doctors, educators in special education, nurses.

Partners: National Centre for Attention deficit Hyperactivity Disorder, Tourette Syndrome and Narcolepsy; specialists in clinical education.

Mission and objectives: Frambu's staff experiences that the professionals/social services providers who meet people with Neurofibromatosis Type 1 often have difficulties in understanding the

challenge and the seriousness of the diagnosis. These patients often need regular medical care and help to manage their daily routine. Frambu expects that this course will generate more knowledge and understanding of this diagnosis. The professionals/social services providers should be able to provide proper care and support patients to achieve a quality of life suitable to their needs.

Content of the training programme:

Medical information; cognitive aspects; ADHD in childhood, in youth and in adults; facilitation of everyday life; friendship and leisure; experience; group discussion to share experiences; [Video: Young with NF1¹](#) - three young adults share their experiences and reflections about life with the diagnose NF 1; professionals from Frambu commenting on selected topics and the use of film/video as a training instrument.

Training methods: live training and use of videos for patient experiences.

Training Programme on Angelman Syndrome

Target public: families; health and social care professionals.

Trainer's background: [Mary-Louise Bertram](#), Special Educator, working in Australia, Canada and USA and Specialist in Angelman syndrome.

Partners: Frambu invites experts in RDs from all over the world to cooperate in this training: e.g. England, Netherlands, Germany, USA and Australia.

Content of the training programme²:

- Practical communication strategies;
- Use of tablets as working tool;
- Experience from communication strategies;
- Medical information,
- Behaviour challenges;
- Legal rights.

Training methods: live training, broadcasted by via video-conference; video from interview with Mary-Louise Bertram [available online](#).

¹ <http://vimeopro.com/frambu/nf1>

² Report of the course and all presentations (in Norwegian) can be downloaded at <http://www.frambu.no/hovedmeny/nyheter/rapport-fra-fagkurs-om-angelmans-syndrom/7af4d5b8-f402-4f7e-8272-eead3aecc518>

TRAINING PROGRAMMES AT EDUBOLIRARE PLATFORM, ROMANIA

Introduction and background information

[Edubolirare](http://www.edubolirare.ro/)³ University is the first E-learning platform for RDs in Romania. The platform is managed by the Romanian Prader Willi Association (RPWA) who holds the presidency of the National Alliance for RDs in Romania.

Edubolirare is a website designed, created and developed under the project 'Norwegian-Romanian Partnership for Progress in RDs' funded by the program Innovation Norway. RPWA training team provides training services (authorised/accredited) to adults using three formats: courses "face to face", online courses, and combined courses (face to face + online). These courses aim at preparing professionals to manage people with RDs and to support their integration in the community. Each course includes an optional module for the management of RDs.

Through Edubolirare platform, RPWA provides information and socio-medical training, a difficult and challenging sector, and at the same time, an area where there is a need for a professional approach to information and training. The information is publicly accessible.

Target public

Trainings from Edubolirare target adult patients diagnosed with RDs, young persons with disabilities generated by RDs, parents and care takers, health professionals (family doctor, geneticists, haematologist, neurologist, nutritionist) and other specialists (psychologist, special education teacher, kinesiotherapist, speech therapist).

Trainers

The training providers are usually part of RPWA staff and have knowledge about patients diagnosed with RDs. These trainers can be special education teachers, doctors, physiotherapists, psychologist, psychiatrists, neurologists, nutritionists, medical assistant etc. Whenever needed, RPWA invites external experts to support the training courses, such as geneticists, haematologists, and oncologists.

Mission, Vision and Scope

The Edubolirare platform aims at training specialists in the detection, diagnosis and treatment of RDs and is created in partnership between Romania and Norway.

Trainings and the National Plan/Strategy for RDs

Trainings for the professionals involved in the management of RDs and for parents, personal assistants and patients are mentioned in the Romanian National Plan for RDs, without budget allocation.

Funding and Evaluation

The medium cost per person trained is of approximately 100 €.

Six of Edubolirare's training courses for professionals are evaluated and accredited by the Ministry of Education and the Ministry of Work. The main funding sources for the training courses are projects, participants' fees and funds from local authorities (e.g. training for personal assistants).

Collaborative Multi Stakeholder Holistic Approach

The training programs are developed in partnership with the Romanian Society for Medical Genetics, the Romanian Doctors' Collegium and the Medical University Timisoara. The Orphanet Romania team has been also involved in the development of training curricula and training for medical professionals.

³ <http://www.edubolirare.ro/>

Content and Organisation

The Edubolirare portal is an innovative initiative that highlights the unexploited potential of web resources for training and information on RDs. Visitors of the webpage can access for free information about more than 100 RDs, tips for prevention and early diagnosis of a RD, electronic journals for patients and specialists, training programs in the field of RDs. Training is provided through the portal and also through courses, seminars, consultations, conferences, meetings and videoconferences.

Training is provided using courses, seminars, consultations, conferences, meetings, videoconferences, mostly in the format of group training, organised by diagnoses. Individual training is also used on handling a particular patient/family is also provided when needed. Part of the training courses is organised at the NoRo Centre.

These training courses are completed through an online platform. This platform establishes the duration of each course depending on the level of difficulty, type of program and other criteria for quality maintenance and makes sure to inform the trainee about the course length at the time of his/her registration. Each course has an attached study plan that student can always access and must respect. The student is obliged to prepare documentation, to perform partial exams, to attend face to face meetings planned to carry out practical activities, to perform the final exam and a practical test (when applicable).

A considerable part of the training is theoretical, covering subjects on the RD and on how to handle the patient. Practical advices are also provided and explored.

Training modules contain diverse information considered relevant in each specific group of diagnosis: information on the disease, home environment and accommodation, special education, adaptation to work place, facilitation of access to services. Common modules to all trainings, regardless of the diagnosis, are the information on the disease and information on legal rights of patients and their families.

Training Programme: Socio-cultural educator

Target public:

- Specialists from rehabilitation centres for people with disabilities, community services, day-care centres for children and adults, e.g. psychologists, special education teachers, social workers, teachers;
- Teachers from special and regular education that have contact with children with special needs (e.g. various deficiencies, learning disabilities, behaviour disorders, ADHD, autistic spectrum disorders);
- Staff from hospitals and clinics, e.g. nurses, occupational therapists;
- Parents and patients, members of patient organisations;
- Members of non-governmental organisations working in the field;
- Students who wish to acquire skills in the field;
- Any person wishing to obtain skills in the field.

Content of the course:

1. Interactive communication;
2. Team work;
3. Professional development;
4. Developing projects for educational entertainer;
5. Ensuring participants' security during the activities;
6. Promoting activities and the organisation image;
7. Coordination the multidisciplinary team of educational entertainers;
8. Implementation of needed activities;
9. Implementation of complex projects;
10. Development of pro-social behaviour;

Training methods: blended learning, with face-to-face and online self-study.

Completion of the course: writing and sustaining a graduation project.

Certificate Type: graduation certificate with letterhead of the Ministry of Education and the Ministry of Labour, Family and Social Protection. The course is accredited by the National Council for Adult Professionals Training.

Training Programme: Personal Assistant for Severely Disabled People

Target public:

The course is addressed to the personal assistants employed through individual employment contract to take care of the disabled persons who are not autonomous in their daily activities. Personal assistants can also be one of the relatives of the disabled person.

Content of the course:

1. Planning the activities;
2. Permanent training;
3. Working in a multidisciplinary team;
4. Providing primary care;
5. Ensuring the beneficiary's nutrition and feeding;
6. Adapting the environment to the needs of the beneficiary;
7. Monitoring the beneficiary's health;
8. Communication between the personal assistant and the person with disabilities;
9. Assisting the disabled people's activities and their participation in the family and the community;
10. Supporting school integration and continuing education;
11. Supporting the professional integration of the person with disability;
12. Supervision of the rights people with disabilities.

Training methods: blended learning, with face-to-face and online self-study.

Completion of the course: writing and sustaining a graduation project.

Training Programme: Art Therapist

Target public:

- Specialists from rehabilitation centres for people with disabilities, community services, day-care centres for children and adults, e.g. psychologists, special education teachers, social workers, teachers;
- Teachers from special and regular education that have contact with children with special needs (e.g. various deficiencies, learning disabilities, behaviour disorders, ADHD, autistic spectrum disorders);
- Staff from hospitals and clinics, e.g. nurses, occupational therapists;
- Parents and patients, members of patient organisations;
- Students who wish to acquire skills in the field;
- Any people who wish to acquire skills and to learn to express themselves through art.

Content of the course:

1. Interpersonal communication;
2. Team work;
3. Professional development;
4. Planning specific activities;
5. Defending the beneficiaries' rights and interests;
6. Monitoring the evolution of the beneficiaries;

7. Preparing the work sessions;
8. Stimulation/development through movement;
9. Stimulation/development through visual art;
10. Stimulation/development through music;
11. Stimulation/development through theatre and games.

Training methods: blended learning, with face-to-face and online self-study.

Completion of the course: writing and sustaining a graduation project.

Certificate Type: graduation certificate with letterhead of the Ministry of Education and of the Ministry of Labour, Family and Social Protection. The course is accredited by the National Council for Adult Professionals Training.

Duration of training: 108 hours divided in 36 hours of theoretical instruction and 72 hours of practical instruction.

Training Programme: Methods and Techniques of Integration for People with Disabilities

Target public:

- Personal assistants from public institutions;
- Caregivers of people with disabilities;
- Social workers from public institutions.

Content of the course:

- Integration of people with disabilities: definitions and benefits;
- Methods and techniques to integrate people with disabilities in the community;
- Organising support groups and/or social networking;
- Practical examples of activities for the integration of people with disabilities in the community.

Training methods: online at the Edubolirare platform. The main methods of training are: text, video presentations, examples and case studies.

Completion of the course: is achieved after applying an online assessment.

Certificate Type: certificate emitted by the Romanian Prader-Willi Association.

Training Programme: Rehabilitation Educator

Target public:

- Specialists from rehabilitation centres for people with disabilities, community services, day-care centres for children and adults, e.g. psychologists, special education teachers, social workers, teachers;
- Teachers from special and regular education that have contact with children with special needs (e.g. various deficiencies, learning disabilities, behaviour disorders, ADHD, autistic spectrum disorders);
- Staff from hospitals and clinics, e.g. nurses, occupational therapists;
- Parents and patients, members of patient organisations;
- Members of non-governmental organisations working in the field;
- Anyone wishing to obtain competences in the domain of rehabilitation education.

Content of the course:

1. Interpersonal Communication;

2. Multidisciplinary team work;
3. Personal development and continuous professional training;
4. Establishing the plan of specific activities for stimulating and recovery of the assisted person;
5. Organising activities;
6. Taking care of the assisted person;
7. Following the rights and interests of the beneficiary;
8. Participation at the evaluation of the beneficiary;
9. Participation in the implementation of the personalised intervention plan;
10. Development of the assisted person's personal skills and social autonomy;
11. Overseeing the integration/reintegration of beneficiary in the family and in the community;
12. Supporting beneficiaries in developing positive attitudes towards themselves and others.

Training methods: blended learning, with face-to-face and online self-study.

Completion of the course: through written examination and a graduation project.

Certificate type: graduation certificate with from the Ministry of Education and the Ministry of Labour, Family and Social Protection. The course is accredited by the National Council for Adult Professionals Training.

Duration of training: 108 hours divided into 36 hours of theory and 72 hours of practice.

Training Module: Model on Rare Diseases, included in all training courses (partly)

Content of the module:

1. Introduction to RDs;
2. RDs characteristics and their importance for the health system and the general population
3. The diagnosis of RDs;
4. Clinical diagnosis;
5. Para-clinical diagnosis;
6. Clinical manifestations of RDs.

TRAINING PROGRAMME AT DIAKONISCHE STIFTUNG WITTEKINDSHOF ADAPTED HOUSING SERVICES FOR PRADER-WILLI SYNDROME, GERMANY

Introduction and background information

Diakonische Stiftung Wittekindshof (DSW) is a non-profit organisation, founded 1887, working in a Lutheran tradition.

The institution is traditionally mainly taking care of people with mental disabilities. Since 20 years ago, DSW also works with people with other kinds of disability, including people with Prader-Willi Syndrome (PWS).

DSW takes care of more than 3500 people with different disabilities – 68 of them with PWS – and has nearly 3500 employees, in more than 60 locations in North Rhine-Westphalia.

The offer of accommodation covers all ranges of ages. DSW has more than 1200 places for adults in sheltered workshops and over 250 places in specialised schools.

20 years ago many people with different kinds of disabilities lived together in group homes. In the last 10 to 15 years, there was a big change in the approach to adapted housing and today DSW takes care of more people in small groups and in their own apartment.

DSW started a group home for adults with PWS in 1998 in a rural countryside place. Today DSW has 68 places for adults with PWS at 4 different units. One unit of 12 places is housing children and youth. In all these places, residents are divided in small groups of 2, 4 or 6 people.

The offers for people with PWS were implemented in partnership with the St. Bernward Clinic Hildesheim (Nutrition, Endocrinology), the Heart and Diabetes Centre Bad Oeynhausen (Diabetes, Endocrinology), with the University of Duisburg-Essen (Genetics), the Regens Wagner Stiftung Absberg and with the PWS Association in Germany. These are partners in the whole adapted housing programme and are involved in the training programme as invited speakers.

Target public

The participants in DSW training programme are full-time or part-time employees of the organisation and participate in the modules during their working time.

All trainees have over 3 years of higher qualification and they are usually pedagogues/educators, special educators, ergo-therapists, nurses, carers, social workers or psychologists.

All the staff elements who are working in direct day-to-day contact with the residents with PWS receive training concerning the housing environment (group home, apartment-living) and the working field (sheltered workshops). Every time DSW starts a new group home, the whole team is trained within the same curriculum.

Trainers

All trainers have more than 15 years of experience working with people living with PWS. They are endocrinologists, nutritionists, psychologists and social workers.

Mission, Vision and Scope

The main principle of DSW is to build up an inclusive society where people with and without disabilities live together sharing different competences and experiences, in a supportive environment. DSW considers that one basic factor to reach this goal is to have carers which are informed, competent and empathic.

The training programme aims at preparing new staff (but also older employees) for the task of taking care of people with PWS. For DSW it is absolutely necessary that all staff members are very well informed about the needs and the specificities of the people living with PWS. They will then be able to provide the safety and reliability that people with PWS need in their environment, so that they have the chance to develop in a positive way.

Trainings and the National Plan/Strategy for RDs

There is no direct connection between DSW's training programme and the German national strategy for RDs. Currently, there is no centre of expertise officially designated for PWS in Germany. DSW is presently investing in establishing contact with policy makers involved in the development and implementation of the National Plan for RDs.

DSW is not aware of any specific national regulation concerning training of social services providers on the job, nonetheless, services are obliged to hire 50% of their staff amongst professionals with at least three years of formal superior education.

Funding and Evaluation

The programme is financed by DSW's own budget.

There are no fees to be paid by DSW's staff. When DSW trains social services providers from other institutions, these have to cover the costs of approximately 2100€ per trainee.

Up to now, there is no formal evaluation or accreditation of this training programme. The course entitles trainees to receive a certificate, which is the only education certificate for PWS in Germany.

Collaborative Multi Stakeholder Holistic Approach

Most of the modules are performed by Dr. Norbert Hödebeck-Stuntebeck from DSW. Some modules are led by external partners, such as Dr. Constanze Lämmer (St. Bernward Clinic Hildesheim) and Dr. Hubert Soyer (Regens Wagner Absberg).

As the training is performed "on the job", patients are intrinsically directly involved.

Content and Organisation

The training programme is composed of 10 modules. Staff members need to perform all these modules in the first two years of work with people with PWS. The basic modules are ideally made during the first three months of work with PWS.

The number of participants in each module varies from 4 to 20, more frequently from 10 to 15.

The modules have both theoretical and practical components, in different proportions, adequate to the modules' contents. All in all, the programme has 50% of practical training.

Most modules are performed in the format of group training and some modules can be done one-on-one, when relevant.

Training is performed at DSW for internal staff trainees and at the employer institutions of the external trainees.

Education course for caregivers of people with Prader-Willi Syndrome

Time frame: 150 hours training, 14 days

Content of the course:

I. Basic Modules – to be concluded within the first three months after starting to work with PWS:

Module 1 - Introduction to Prader-Willi Syndrome

Module 2 - Behaviour analyses

Module 3 - Behaviour modifications

II. Deepening Modules - to be concluded within the first two years after starting to work with PWS:

Module 4 - Communication

Module 5 - Nutrition Management for Prader-Willi Syndrome

Module 6 - Neuropsychology of Prader-Willi Syndrome

Module 7 - Case supervision

Module 8 - Supervised Internship

Module 9 - Team Supervision

Module 10 – De-escalation Management

Module 1 - Introduction of the Prader-Willi Syndrome

The module starts with the presentation of the genetic causes of PSW as well as the clarification of its prevalence and incidence.

Additionally, the different physiological symptoms which have to be considered for individuals with PWS are described. Following those initial explanations, the module focuses on the actions that need to be taken in order to avoid or compensate the negative effects of these symptoms' features.

The cognitive features and particular variations are also presented as well as the possible actions to be taken in these matters.

The psychological and emotional features which are described in detail in this module represent the biggest challenges for people with PSW when engaging into social interactions.

The module demonstrates as well the theoretical understanding of the 'challenging behaviours' as the main issue affecting the social interactions from people living with PSW with other people. Finally, the module includes a description of the treatment model and care model which is adopted at DSW when supporting children, adolescents and adults affected by PWS.

<i>Duration</i>	½ Day, 4 hours
<i>Trainer</i>	Psychologist
<i>Training methods</i>	Presentation, work in small groups, exercises
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

Module 2 - Behaviour analyses

<i>Duration</i>	1 Day, 7 hours
<i>Trainer</i>	Psychologist
<i>Training methods</i>	Presentation, work in small groups, exercises
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

This module takes as starting point the 'challenging behaviour' which can be observed constantly when taking care of individuals with PWS.

As introduction, there is a discussion about the necessity and significance of behaviour analyses and about the field of application and the efforts needed when taking care of people with PWS.

The analysis of behaviour in a concrete situation is used to clearly illustrate an example of a challenging

behaviour ('search questions').

The following step is the analyses of the 'social conditions' (environmental factors) at that time the challenging behaviour occurs.

After that, the trainees do an analyses of the 'previous conditions' and of the effects of the general 'consequences'.

The inclusion of the biographical data (life history) as well as the development of the challenging behaviour gives further helpful and essential information in order to create an 'understanding process' of particular behaviours and initiate a behaviour modification.

Module 3 - Behaviour modifications

The module on behaviour analyses lays the grounds to the instruction on the process of understanding the basis for behaviour modification.

The prevention process, the most important process of the behaviour modification, is introduced at the beginning of this module.

Structural as well as personnel possibilities of prevention of critical situations and behaviours are also discussed.

<i>Duration</i>	1 Day, 7 hours
<i>Trainer</i>	Psychologist
<i>Training methods</i>	Presentation, work in small groups, exercises, role playing
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

The concrete handling of a situation with a challenging behaviour (i.e. what to do when confronted with a problematic situation) is another important part of the behaviour modification process. Concrete methods to deal with this situation are demonstrated and trained. The reflection on the critical situations with the shown massive challenging behaviours gives people with PWS the possibility to work on a change of the socially not acceptable behaviour, and to engage on a self-determined solution or to work on alternative behaviours.

Module 4 – Communication

<i>Duration</i>	1 Day, 7 hours
<i>Trainer</i>	Psychologist
<i>Training methods</i>	Presentation, work in small groups, exercises, role playing with video feedback
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

The groundwork for communication is presented based on the theoretical understanding of the psychologist Schulz von Thun. Possible ways of communicating and the level of a message with the possible stages of perception will also be presented and practiced. The method of role playing gives the participants, trainees in progress, the chance to widen or compensate their own strong and weak points, by being in direct contact with people with disabilities and by discovering and practicing

exercises and instructions.

Module 5 – Nutrition Management for Prader-Willi Syndrome

Supporting people with PWS in different every-day-situations requires the knowledge of their relationship with food and their non-adequate perception of the feeling of satiation. The mutual analysis with the concerned people provides an introduction into the problematic nature in which their individuality has to be considered. This analysis is needed and is done in cooperation with the team. The seminar negotiates a basic knowledge of nutrition of optimised mixed food for the everyday offer of care. The participants learn about the suitable/unsuitable beverages and food as well as about the characteristics of single groups of food. They learn how to reduce the caloric concentration of meals and that hear about the great significance of carbohydrates' metabolism with insulin involved.

<i>Duration</i>	1 Day, 7 hours
<i>Trainers</i>	MD, Nutritionist
<i>Training methods</i>	Presentation, work in small groups, exercises
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

The work in small groups supports the transfer of knowledge into praxis. Different meals will be weight and combined, based on calorie amounts.

Besides discussions on nutrition's physiological knowledge, the psychological aspects of eating security and of the creation of every day and 'Sunday-situations' (exceptions) will also be discussed. The concrete plans and their possibility of their concretisation will be discussed in plenary.

Module 6 – Neuropsychology of Prader-Willi Syndrome

<i>Duration</i>	1 Day, 7 hours
<i>Trainers</i>	Psychologist, Pedagogue
<i>Training methods</i>	Presentation, work in small groups, exercises, role play with video feedback
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

The background of this module is the genetic and epigenetic development of human beings.

A special focus is placed on the process of learning, at the neuronal level.

In relation to PWS, the hypothalamic area and the mirror neurons are the most interesting parts of the brain which help to

understand more about the behaviour of people with PWS. Known defects of the hypothalamic area are the typical deficits in PWS.

The application of this knowledge in every-day care with people with PWS follows the goal of increasing the number of synaptic connections in these special brain areas.

Exercises to train this development are coming from of: kinaesthetic, change of perspective and communication. Participants will use role playing to be trained in these themes.

Module 7 - Case supervision

In this module, participants get a chance to present the main biographical information of the person with PWS of which they are taking care of.

The case presentation is focused on a challenging behaviour orientated approach and on the behaviour analyses methodology used in module 2.

The developed hypothesis for this challenging behaviour based on the behaviour analyses, will be discussed further by the other participants. The main goal of this exercise is to find new perspectives of understanding and new or other ideas of handling this behaviour.

At the end of their presentations, trainees who introduced the case present suggestions of how to involve the new ideas in the future of their every-day care of people with PWS.

<i>Duration</i>	½ Day, 4 hours
<i>Trainer</i>	Psychologist
<i>Training methods</i>	Working in plenary, working in small groups
<i>Hand-out materials</i>	None
<i>Location</i>	Class/seminar room

Module 8 - ‘Supervised Internship’

<i>Duration</i>	2 Days, 14 hours
<i>Trainer</i>	Educator
<i>Training methods</i>	Working together with the professional carers in the field
<i>Hand-out materials</i>	None
<i>Location</i>	School or sheltered workshops

The main goal of the two day internship is to get an insight view into the other fields of life of the clients, which are areas where the staff does not normally support them (working, school). The knowledge of these experiences makes communication between the various groups of different sector caregivers easier by decreasing misunderstandings.

This process supports a more structured, clearer

and easier to understand environment for people with PWS and in this way it helps to decrease the frequency of the challenging behaviours.

Module 9 - Team Supervision

An external supervisor (i.e. someone who is not part of the institution) supports structural and process orientated reflections within the team. The focus of the reflections is on the clients and concerns all aspects of the support. There can also be reflections about all processes and the interpersonal matters of the staff in order to develop a positive culture in the team and to increase supportive processes and decrease inhibitions.

One of the main goals is to support the communication in the team so that most of the resources can be used for taking care to the people with disabilities.

There is a fixed rhythm for the team supervisions: every 2 years, there need to be 6 sessions of team supervision.

<i>Duration</i>	3 Days, 21 hours
<i>Trainer</i>	Supervisor (external)
<i>Training methods</i>	Supervision
<i>Hand-out materials</i>	None
<i>Location</i>	Seminar room

Module 10 - De-escalation Management

<i>Duration</i>	3 Days, 21 hours
<i>Trainers</i>	Psychologist and Educator
<i>Training methods</i>	Presentation, working in small groups, exercises, role play with video feedback
<i>Hand-out materials</i>	PowerPoint slides of presentations
<i>Location</i>	Class/seminar room for presentation and exercises; small rooms for groups

An approved and certificated de-escalation program ([ProDeMa®](#)) is used in this module. This Program has 7 steps of de-escalation.

The first step is searching for prevention aspects in the environment to decrease or stop challenging behaviour.

In step two, the focus lies on the self-perception of the staff and the aspects of the interaction of the staff with the people with the challenging behaviour. Step three is a dedicated to checking the possible

reasons for the challenging behaviour, which lie in the person who shows this behaviour.

Step four is the centre (heart) of the training programme, the method of the verbal de-escalation, which will be trained in phases and by video feedback role play.

In step five and six techniques to protect against aggressive behaviour are shown and trained.

The last is focused on taking care of staff members, after physical or psychological injury.