PsyCoVIA

Psychological and psychiatric comorbidity in persons with a visual impairment

Book of Good Practices

Colophon

PsyCoVIA – Book of Good Practice

Psychological and psychiatric comorbidity in visually impaired adults

March 2023

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Berufsförderungswerk (BFW) Halle - www.bfw-halle.org
Regional Institute Rittmeyer for the Blind - www.istitutorittmeyer.it
Budapest School for the Blind - www.vakisk.hu
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Preface

The content in this book is the result of the PsyCoVIA-project. In this international project, that was funded by the Erasmus+ Programme of the European Union, organizations from five different European countries were involved. Each of these organizations organized a three-day meeting in which knowledge and experience about the care and treatment to adults with a visual impairment and comorbid mental health problems were exchanged.

The information that was shared during these meetings was collected and brought together in this digital book of good practices. This book can therefore be seen as a resource book, in which the rich information shared during these meetings is documented. This book can be used by care professionals who provide care and treatment to this client group and/or related stakeholders that search for more information or consultation about the care and treatment of adults with a visual impairment and comorbid mental health problems.

Reader's guide

The book contains a rich source of information, consisting of a summary of the presentations that were held during the meetings, a description of the cases that were discussed and other relevant information. The reader can use the navigation panel to scroll through the information and select the part of the book that is relevant for the reader. Furthermore, within the different descriptions cross-references are made to related PowerPoint Presentations for more in-depth information. When finished reading the PowerPoint Presentation, the navigation panel can be used to navigate back to the main text or another part of the book.

After an introductory chapter, each following chapter represents the content of a specific meeting with a theme (specific psychiatric disorder) and has the following structure:

- Background information
    - Definition of the psychiatric disorder
    - Expert's talk
    - Other presentations
    - Quotes
- Case discussions
    - Case description
    - Advices on support and/or treatment mentioned in the group discussion
- Good practice for persons with VI and the specific psychiatric disorder

The content of each meeting was collected and documented by the organization that was the host of the meeting. In each chapter the 'own writing style' of the specific organization can be recognized.

During the project we have done great effort to document as much as possible of the activities that were conducted in the meetings. However, due to different factors some documentation was not fully restored. Therefore, not all PowerPoint presentations could be included in the appendix and some advice/conclusions of the case discussions could not be described in the book. In this case, only the case description is presented as this can also be seen as useful information.

We hope that this book provides the reader a rich overview of the important aspects in the care and treatment for adults with a visual impairment and comorbid mental health problems and helps the reader to gain knowledge and expertise in their own work.

Content

Introduction

In this chapter background information is given about the goal of the project, its structure and information about the organizations that participated in the project and the participants that contributed to the project.

Goal of the PsyCoVIA project

The complexity of visual impairment with multiple additional disabilities is the reason that care providers have to choose for a very individualistic approach. There is hardly any literature available on how to work with this target-group. Especially literature about the combination of mental health (psychological and psychiatric) problems combined with visual impairment (VI) is lacking. Within the total population of VI people, this group is relatively small. Therefore, it is necessary and unavoidable to cooperate with partners abroad to develop more expertise in supporting that target group in their societal participation, mainly by collecting good practices.

All partner organisations in this project are member of the European network ENVITER (European Network for Vision Impairment Training and Research). Within the field of VI they (also) offer support to an extremely problematic group of multiply impaired people (1) who are not able to compensate for their vision loss because of the comorbid psychiatric (and other) disabilities, (2) who are not able to compensate for their psychiatric challenges because of the visual impairment and (3) who suffer from an increased psychological vulnerability. During six Transnational Project Meetings (TPM's) professionals and sometimes also members of the target group have shared their knowledge and experience. All collected good practices from the six meetings are brought together in this digital 'Good Practices Book' that will be used for further training of professionals (educators and trainers) in the field of VI adults

Each of the partners organised a TPM (the main applicant organised two) on one of the themes that were selected beforehand by the project partners. The focus of this project is on adults, however since many psychiatric problems find their origin in younger years the project range starts from age 14 and up.

A good practice is not only a practice that is good, but a practice that has been proven to work well and produce good results. It is a successful experience, which has been tested and validated, in the broad sense, and deserves to be shared so that a greater number of people can adopt it. In this PsyCoVIA project we have been sharing experiences among the project partners. With this Book of Good Practices we also want to share them with the rest of the world.

Structure of the project

The main applicant (RCS) has structured the overall project approach (in addition to their responsibility for financial and administrative arrangements in general) but each TPM has been organized by one of the project partners. A guideline was developed for these TPM's with support of the project partners. After selection of the most important topics (all concerning visually impaired adults with additional mental health problems), six joint TPM's were organized in the same structure:

Day 1 - meeting of the project contact persons (one of each partner organization) regarding the coordination of the overall project; - feedback on experiences resulting from the former TPM (except for the first TPM of course); - presentation on the national (and/or regional) situation of the target

group (prevalence, participation, service provision, financial matters); - if applicable a guided tour through the organizing institute, with a focus on the theme of the TPM;

Day 2 - presentations of good practices (and if possible, research) concerning the theme of the TPM by oral and/or poster presentations and/or workshops and/or case studies and discussion;

Day 3 - continuation programme like day 2 (first half-day); - meeting of contact persons with the external evaluator; - closing session with contact persons with a focus on progress agreements.

In the evening a social programme was organized consisting of having dinner together and a city tour by night.

There have been six three-day TPM's of which two online as a result of the COVID pandemic:

Organization	Country	Theme	Date
Robert Coppes Foundation	The Netherlands	Personality Disorders & Psychoses	January 2020
Center for education and rehabilitation 'Vinko Bek'	Croatia	Eating disorders & addiction	June 2021 (online)
Budapest school for the blind	Hungary	Behavioral disorders	October 2021 (online)
Rittmeyer Institute for the blind	Italy	Autism spectrum disorders	May 2022
Berufsförderungswerk Halle	Germany	Depression & anxiety	September 2022
Robert Coppes Foundation	The Netherlands	Post-traumatic stress disorder	October 2022

During these meetings a protocol has also been developed for discussing the case studies consisting that have been presented. Since it turned out to be an unexpected by-product but also a very useful protocol, it is considered as one of the outcomes of this project that will be shared too (see appendix 1: Standardized formats for case discussion).

Participating organizations

In this project five organizations were involved and from these organizations a variety of care professionals participated. The following provides an overview and short description of the participating organizations and the names and profession that participated in the project.

Budapest School for the Blind, Hungary

The school was founded in 1825 and has been operating in its current building since 1901.

From early development to vocational school education, the institution provides education for children with special educational needs: mainly visually impaired students and children with multiple disabilities.

The authority of the institution is nationwide. Visually impaired children from the countryside can use the college's services starting from kindergarten.

The educational work is supplemented by the activities of many supporting employees, such as school psychologist, child and youth protection employee, special education assistants, dormitory child supervisors, ophthalmologist, pediatrician, orthopedic specialist, psychiatrist, nurses, etc.

The institution has many significant external relationships due to its very complex task system. Some examples: Professional-pedagogical relationship with the university, cooperation with interest protection and civil organizations. We have foreign professional contacts, as well as cooperation with institutions participating in integration.

The aim of the institution is to ensure that the children in care receive the education and training that best suits them. They should have the widest possible opportunity to spend their free time usefully. The overall goal is that visually impaired people can learn the highest level of independent living according to their abilities and feel like full members of society. That is why the Budapest School for the Blind strives for cooperation with each other, with the parents, the environment, and the institutions and organisations that support their work.

Participants

Budapest School for the Blind:

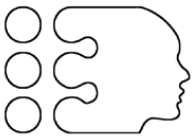
- Janka Braun - Special education teacher
- Orsolya Büki - Special education teacher
- Ildikó Gálné Németh - Consultant psychologist, special education teacher
- Borbála Jáki – Conductor, teacher
- Emese Tóth - Special education teacher
- Eszter Varjú - Special education teacher, mental health professional
- Anna Váró – Physiotherapist

Other Organizations:

- Dr. Judit Balazs - psychiatrist

Center for education and rehabilitation 'Vinko Bek', Zagreb, Croatia

Work with blind people in Croatia began when the National Institute for the Education of Blind Children was founded in Zagreb in 1895. The Institute was founded on the initiative of the first typhologist/teacher of blind children- Vinko Bek. At that time, it was the only institution for the education of the blind people in this part of Europe. Today, the Center for education and rehabilitation in Zagreb is named in honor of Vinko Bek.



Throughout history, the structure of work with blind people has changed. The work first began by working with blind children in elementary school. Over the next decades, the work program expanded to include young people and adults with visual impairment through specific rehabilitation programs, as well as in the work of psychologists, occupational therapists, speech therapists, social workers, medical services, physiotherapy, kinesitherapy, sensory integration therapy, music therapy and art therapy. Also, at the end of the 1970s within the Center a braille printing press, as well as a printing press for enlarged printing, was opened. The specific programs that are implemented as part of psychosocial rehabilitation in Center are: orientation and mobility, braille literacy program, everyday living and social skills training, functional vision training and assistive technology. The Center has educational programs with the possibility of elementary, high school and music education. Also, the Center provides a program of early intervention for children up to the age of three years (and exceptionally, when needed to the age of seven years), as well as a kindergarten for preschool children with visual impairments.

In 1992, blind disabled people from the Homeland War were included in the rehabilitation programs, and in 1996, the Department for Adults was opened, which was financed by the former Ministry of Veterans Affairs. Today, the department works at that address by full name Department for Psychosocial Rehabilitation of Adults. The department includes persons with severe visual impairment in adulthood, adults who have severe visual impairment since birth, childhood or early youth, and who have not been trained for independent living through a rehabilitation program or who have undergone changes; personal, family, spatial or social. Also, the department includes adults who have visual impairments and multiple disabilities. The goal of the program offered at the department for adults is a more independent and good quality life for the individual, their family members and the individual in the working environment. From its establishment until today, the department has rehabilitated a total of 300 clients.

Participants

Center for education and rehabilitation 'Vinko Bek':

- Valentina Devčić - Psychologist
- Emina Šišić Anđelić - Educational rehabilitator
- Ana Petrinec - Occupational therapist
- Marina Kulfa - Educational rehabilitator
- Ida Poljan - Psychologist
- Mira Sajković - Educational rehabilitator

Other organizations:

- Hrvoje Handl, MD, specialist in psychiatry from Zagreb, Croatia

Rittmeyer Institute for the Blind, Trieste, Italy

The Rittmeyer Institute for the Blind was founded in 1913, thanks to the munificent donation of Baroness Cecilia de Rittmeyer, who was very sensitive to the issue of visual impairment, in the spirit of Protestant patronage. The Institute's path has been marked by scientific and social progress and the changing needs of its users. Having started out as a welfare centre for the blind, around the 1920s and 1930s, Rittmeyer underwent a gradual transformation into an educational institution. In the mid-1970s the multi-morbid nucleus was established, which later led to the activation of an occupational workshop to give children with multiple disabilities a perspective for the maintenance and further development of their abilities.

Today, the institute has entered a new phase. While maintaining many of the already consolidated activities - support for school and university students, vocational training, the occupational workshop, the day recreation centre for the elderly - it has progressively abandoned the boarding school approach as the only effective response for rehabilitation and the achievement of autonomy in the visually impaired. In fact, the action of Rittmeyer's specialists is mainly focused on customised projects, characterised by a multidisciplinary approach with bi-weekly interventions. A result achieved thanks to the professionalism of its educators and the creation of a multifunctional team, capable of providing a global response to the problems posed by users on a daily basis. They include, among others, specialists in typhlopedagogy, psychology, psychomotricity, physiotherapy, music therapy, speech therapy, visual rehabilitation, basic stimulation, pet-therapy, multihandicap, horticultural therapy, personal autonomy, orientation and mobility.

The Rittmeyer's team has by now consolidated this approach of wide-ranging methods and paths, carefully planning the educational itinerary in families, working closely with schools, acting as a guide and reference in identifying the most suitable aids and guiding the choice of means, technologies and materials. In particular, Rittmeyer has developed an effective pathway in support of school integration, with specialised intervention in favour of the children, presence in schools, support for support teachers, and the planning of activities in parallel with and to complement those conducted in the classroom.

In addition to the functions regularly carried out by the Institute, in recent years the activity of the Residence for the Visually Impaired elderly has been added, a concrete and articulate response to the multiple needs of the third and fourth ages.

The Rittmeyer's purpose is to provide services and interventions for the visually impaired of any age, recognised by law, to promote education, re-education, rehabilitation, education, social and work integration, and the recovery and development of the abilities and autonomy of the blind and visually impaired, without distinction of sex, language, religion, race, political opinions, or personal and social conditions. The above-mentioned aims are pursued in particular through:

- organisation of centres specifically equipped for the visual, functional and social rehabilitation of the blind and visually impaired;
- organisation of pre-school, school and post-school support activities not dependent on the Ministry of Education, University and Research and of specific supplementary activities necessary for the full autonomy and integration of visually impaired students;
- organisation of forms of accommodation for visually impaired students attending schools or training and refresher courses in Trieste, outside their habitual residence;
- organisation of forms of accommodation to support initiatives for the social and work integration of visually impaired people;
- identifying, promoting and supporting training and refresher courses for the visually impaired;
- organisation and promotion of initiatives to foster the school, social and work integration of blind and visually impaired people with additional disabilities;
- setting up residential and semi-residential centres for the visually impaired elderly;
- promotion and organisation of training, refresher and specialisation activities for personnel working in the field of rehabilitation, re-education, education and assistance for the visually impaired;
- promotion and organisation of initiatives for the prevention of blindness and visual impairment;
- promotion and organisation of research initiatives in the field of ophthalmology and typhlology;
- maintenance and development of experiences of school and social integration between visually impaired and sighted people;
- dissemination of specific information aimed at visually impaired users, health, care and education professionals;
- financing and developing social and work integration activities for visually impaired people, including those with additional disabilities, possibly through consortia or participation in social cooperatives in accordance with the relevant laws in force.

Participants

Regional Institute Rittmeyer for the Blind:

- Mr Hubert Perfler – President
- Mr Ralph Rocktaeschel – Vice President
- Mrs Elena Weber – General Director
- Mrs Giorgia Valenti – Administrative assistant for the Promotion and Project Office

- Mrs Giuliana Marin – Psychologist
- Mrs Anna Calacione – Psychologist and psychotherapist, assistant educator and rehabilitation technician in orientation and mobility for visually impaired people
- Mrs Emanuela Franzutti – Assistant educator
- Mrs Corstanza Tersar – Psychologist and administrative assistant
- Mrs Marta Miniussi – Administrative assistant for the Promotion and Project Office

Other organizations:

- Mr Nicolò Di Summa – Educator and expert in the management of educational services for I.Ri.Fo.R. Institute for Research, Training and Rehabilitation of Friuli Venezia Giulia
- Mr Tiziano Agostini – Psychology professor at the Life Sciences Department of the University of Trieste
- Mrs Ginevra Montesi – Psychology student at the Life Sciences Department of the University of Trieste.

Berufsförderungswerk Halle, Germany

The BFW Halle is a regional and national working social service company, which offers a variety of vocational rehabilitation and accompanying services for visually impaired and blind persons and cares for their reintegration into the job market. It's a private company with public associates. Founded more than a hundred years ago in 1898 as „Königlich Preußische Provinzial Blindenanstalt“ (Royal Prussian Home for the Blind), the institution has been established as Berufsförderungswerk in 1991, after the wall came down. It is now one of 4 special institutes in Germany for retraining blind and visually impaired adults, being the only one in East Germany, with approximately 70 staff persons and 120 clients.

The BFW Halle has long term experiences in individually counselling for the visually impaired and their special concerns of getting back into a job. The BFW has both special competence in training the blind and vision impaired and coaching them on the job. There is special knowledge and equipment concerning assistive technology, as well as accompanying services like Low Vision treatments and psychologists. We offer e.g. consultancy on devices and preventive measures at one‘s individual workplace, new professional orientation (complete professional education, additional qualifications and individual trainings) and an integration into the labour market and follow-up care.

There is special expertise in educating and training adult persons with vision impairment and psychological disorders. The BFW Halle is deeply embedded in national and transnational networks on vocational educational trainings. It has gained experiences in running several transnational projects since 1998.

Participants

BFW Halle:

- André Kunnig - Psychologist
- Yvonne Drambyan - Psychologist
- Johannes Werres - Psychologist
- Timo Greiner - Psychologist
- Holger Stoek Integration-Manager
- Frank Kiessling – Low-Vision-Specialist

BFW
BERUFS
FÖRDER
UNGS
WERK
HALLE (SAALE)

Robert Coppes Foundation, Vught, The Netherlands

With 160 (paid) employees the Robert Coppes Stichting (founded in 1984) is a foundation that supports about 250 to 270 adults (including elderly) with visual impairment and multiple additional disabilities (mainly psychiatric impairments, but also brain injury, hearing impairment, autism, addiction etc.). The RCS is one of the three service providers for visually impaired people in the Netherlands and the only one specialised in this specific target group (about two-thirds have at least an additional psychiatric disorder). RCS is mainly active in the South of the country. The main office is situated in Vught (near 's Hertogenbosch). In that town RCS has seven residential facilities and two day care facilities. In addition there are four regions for outpatient counselling with offices in Sittard, Nijmegen, Breda and Vught, two of whom also have day care facilities (Nijmegen and Sittard).

The Robert Coppes Stichting offers support to an extremely problematic group of multiple impaired people (1) who are not able to compensate for their vision loss because of the comorbid psychiatric (and other) disabilities, (2) who are not able to compensate for their psychiatric challenges because of the visual impairment and (3) who suffer from an increased psychological vulnerability. RCS offers support to increase the quality of life of these people and to increase their possibilities for societal participation. This support ranges from 1 hour a week in the own living environment of the client to 24/7 support in one of the residential facilities and every possibility in-between, including day care facilities. The skills and expertise involved regard the full range of necessary knowledge to offer support because of the blindness or partial sight, a broad range of psychological and psychiatric problems, and the (often conflicting) interaction between these problem fields.

Participants

Robert Coppes Foundation:

- Dr. Hilde van der Aa (project leader) – Senior researcher
- Dr. Marit van Buijsen (project leader) – coordinator Expertise, Innovation and Knowledge
- Drs. Peter Verstraten – Psychologist
- Drs. Edine van Munster – PhD-student
- Drs. Debby van Vught – Mental Health Psychologist
- Drs. Annie van den Heuvel – Outreaching support worker
- Drs. Dorien Zwegers - Psychologist
- Pascale Dammers – Psychodiagnostic worker
- Marieke Langenkamp – Outreaching support worker
- Drs. Dominique van Rooij – Psychologist
- Drs. Lisanne Leenders – Teunissen – Mental Health Psychologist
- Dr. Lia van der Ham – Senior researcher
- Vicki Quirijns – Staf member Knowledge & Implementation
- Monique Beukers – Former CEO
- Marian van Heerebeek – CEO
- Arla Heins – Senior policy officer
- Henriette Hofmeijer – Outreaching support worker
- Peter Willems – Client
- Avilla Haller – Client
- Theo Charpentier - Client

Other organizations:

- Prof. Dr. Ruth van Nispen – Professor Visual functioning and health at Amsterdam UMC
- Drs. Helga Saez – Psychiatrist at Reinier van Arkel Group

Explanation of the chosen terminology

Depending on the context we will speak of care providers (usually as organizations, sometimes as persons), care professionals or caregivers (may also include parents e.g.). Sometimes, again depending on the context, we will use the term support workers.

Where persons of the target group are concerned, we will usually speak of 'clients', since that will always be in the context of care or support. Though we would like to refer to them as individuals with their own qualities (strengths and weaknesses like any other person) many presentations and case studies would be cumbersome to read (and write). That is why we chose the word 'client' for this Book of Good Practices.

In many case presentations we also used fictitious names to address the person concerned.

Further glossary:

1. An ophthalmologist is an eye doctor.
2. In some countries professional's names start with 'typhlo-' meaning that these professions regard (people with) visual impairment. E.g. a typhlologist is someone specialised in (optical) aids for people with visual impairment and a typhlopedagogue is a pedagogue (or child psychologist) specialised in people with a vision impairment.
3. Behavioral scientist refers to either a psychologist or pedagogue, or both.

THEME 1

Attachment, Charles Bonnet Syndrome, Personality Disorders and Psychoses

Theme 1: Attachment, Charles Bonnet Syndrome, Personality Disorders and Psychoses

Robert Coppes Foundation – Vught – The Netherlands, January 2020

In this first meeting four sub-themes have been discussed, subsequently: (1) Attachment issues in persons with visual impairment; (2) the Charles Bonnet Syndrome; (3) Psychoses in people with visual impairment; and (4) Borderline Personality Disorder (BPD) in people with visual impairment. For each topic an overview is given with background information, case discussions and general conclusion.

Topic 1: Attachment issues in persons with visual impairment

Background information

Definition attachment

An attachment disorder is a type of mood or behavioral disorder that affects a person's ability to form and maintain relationships. These disorders typically develop in childhood. They can result when a child is unable to have a consistent emotional connection with a parent or primary caregiver.

Expert's talk on attachment

'See me, hear me, feel me', Attachment and visual impairment' from Marit van Buijsen, behavioural scientist of the Robert Coppes Foundation. See also appendix 2: PowerPoint Presentation for Attachment.

Attachment is the ability to have an effective connection with and find comfort in a caregiver. Being sensitive and responsive to a child's needs and requests is important to form a healthy attachment between a caregiver and a child. This healthy attachment is an important base for adulthood, such as having more ability to develop a positive self-image, ability to deal with impulses and with stressful situations, development of logic thinking, having insights in own and others' feelings and the ability to build a (long term) relationship with yourself and with others. When a child is not able to develop a healthy attachment, they are more at risk for developing mental problems in later life.

The visual impairment is a risk factor in developing attachment problems. Because of a lack of non-verbal communication this is difficult; not able to make use of eye-contact; not seeing social identification marks (mutual smile, hand sign or movement of the head); feeling of emotional un-involvement. Caregivers of a child with a visual impairment need more than average skills in responding sensitive and responsive to their child. Therefore, early recognition of visual problems in young children is very important.

For professionals it is important to support parents in accepting the visual impairment of their child and learning how to make contact with their child when eye contact is not possible. Empowering parents to perform the heavy task to connect to and raise a child with visual impairment (and possibly other problems) should be a main focus.

In adult clients, problems in attachment can be an important underlying cause of their mental problems. Being aware of attachment status (and mental / social-emotional development) gives

information to explain certain problems that clients face. When there is more insight in the attachment pattern of a client and this has taken into account in the support, this can help clients to build trust and overcome problems.

Quotes

Two professionals from The Netherlands, who are also the mother of a blind child confirm the difference and difficulty in responding sensitive and responsive to their child. One said:

"My son was always waiting for someone taking the initiative to touch or make contact. When we knew his eyes were bad, we started to touch him and to tell him what was happening, an extra effort to keep contact and give him safety."

The other added:

"My son needed constant verbal and physical contact because he panicked with new sounds of unexpected situations. It took a few years before I came in contact with doctors who were specialised on this problem and took us seriously. In my professions, I have met parents that didn't accept the child after the diagnosis of visual problems, not because of the child but because of the difficult task to take care of these children. It is important that parents are empowered to do this job, to have good attachment and good development of the child."

Professionals from Croatia added:

"Parents have an important role in the youth of children. Experience of talking, touching, walking. It is important to know as soon as possible that there are visual problems so you can respond to this in your behaviour (attachment). It is important to see the child as a normal child and not as a child with a disability."

Case discussions involving attachment problems

Case 1 - Attachment

Fictitious case based on different clients, by Robert Coppes Foundation - The Netherlands

Case description

Elle is a 32-year-old woman. In addition to her mild intellectual disability, she is visually impaired. Elle has lived in various foster families from an early age. In one of the foster families there was physical and emotional abuse. In the past she has tried to live independently. However, she got into serious problems due to alcohol abuse and financial problems. Elle's eye disease also appeared to be progressive, so the Robert Coppes Foundation seemed to be the right place to offer her guidance. In order to get Elle's financial situation under control, she was put under administration. Although it was a difficult step for Elle, she understood that this was probably better for her. Elle has now been living at the Robert Coppes Foundation for five months.

In the first respect, Elle is a friendly woman. She can go along well in simple conversations that can be very pleasant. She then looks relaxed and is, whenever possible, helpful to fellow residents. There are two residents with whom she has a nice contact every now and then. However, when things get tricky and/or confrontational, Elle gets angry and starts crying, followed by a tantrum in which her whole body is tense and she walks around with her bare feet. From that moment on she will stop any kind of guidance and sometimes does not show up for three or four days. Elle does send notes that she is still angry and that she hates everyone in the world. When her anger has subsided, she sends a note that

she is no longer angry. The counselor may then return to her apartment, which is sometimes very dirty. Empty beer and wine bottles are scattered throughout her apartment. Elle's arms and legs are also full of scratches and bruises. It is difficult to talk to her about the last few days.

Advices on support and/or treatment mentioned in the group discussion

Emotionally Elle reacts comparable to the emotional stage of a toddler (anger/tantrums), her ability to act in a social way can be compared to a teenager/young adult. Problems in attachment can be an underlying cause for these difficulties. She grew up in foster families and therefore did not experience a safe haven. She can make short, superficial contacts, but has problems to build a meaningful relationship with a person.

Options for support and/or treatment:

- Provide psychoeducation to make her more aware of her own problems, why she reacts the way she does (due to possible intellectual disability, attachment problems, personality disorder).
- Find out her motivations, what is important for her.
- Reduce the number of care professionals. This could help in developing a trusting relationship with one or two people.
- Provide clear structure and daytime activities within a protective environment.
- When a trusting relationship and more structure is established, possible treatments can be started, such as for alcohol abuse, a personality disorder or how to cope with past trauma.

Challenges due to the visual impairment:

- Psychoeducation can take longer as you are not able to use drawings to explain a person's challenges. It takes more time as well to understand what is going on inside the head of the person.
- A person can show inappropriate attachment behavior to a professional, due to intellectual or visual impairment. Such as hugging and kissing a therapist.
- Building a trusting relationship takes more time, due to the visual impairment you need other ways to be sensitive and responsive to the needs of a client.

In Croatia, they have similar cases such as:

- A woman who has problems with eating and she doesn't talk. She has a visual impairment and some intellectual problems. She rejects the support workers who take care of her on a daily basis. Approach: trying to create positive moments, trying to let her open up.
- A boy with attachment issues, he does not want to go home (stigmatised where he lives – a small island – mother is ashamed of her child). In this case it is important to first support parents and then parents may be able to help the child. In Croatia, it is not possible to provide much support for parents. Parents are left alone. This is also recognised by colleagues from Hungary.

Case 2 - Attachment

By Budapest School for the Blind - Hungary.

Case description

Among other care services, the institute has a children's home for the visually impaired children in foster care. The children living in the children's home are very heterogeneous in their age, abilities,

conditions, and the way they got in the institute. Some of them live there since they joined the kindergarten when they were 3 years old. Most of them were in a very bad condition, they showed signs of severe behavioural and emotional problems. Some children were removed from their families and moved in the children's home during their school age, therefore the connection and attachment to their families has changed, got very rare or in some cases it ceased. Some children are orphans. Naturally this influences the children's social abilities, how they can connect to adults and/or to their peers. All these children have attachment problems in different extent.

Because of the heterogeneity of the children, the problem cannot be standardised. In many cases the children become auto aggressive or aggressive to others; they try to connect to everyone (anyone who is willing to spend time with them) or just the opposite: they close themselves off and resist to any connections ('just leave me alone').

Kata is a 17-year-old girl. She has multiple impairments, including a severe intellectual disability and a visual impairment. After her birth her parents gave her to foster care, but her grandmother took her in. When she got 12 years old, her grandmother could not care for her anymore, because of her own health problems. Kata moved in the children's home. Her grandmother took her home occasionally, but less and less. After a while she did not take her home anymore. In the past season she came to visit Kata only once.

Kata cannot talk, she uses a few gestures. By using some gestures, she can answer adequately to very simple questions about her needs. We experience that besides her grandmother she cannot really attach to anyone in her environment. She is not looking for anyone's company. She is not connecting either to her peers or to the teachers. No one is important for her. Recently she had cumulative aggressive manifestations. We think these are related to the things we wrote above.

Advices on support and/or treatment mentioned in the group discussion

- It is important to try to create positive moments, trying to let her open up.
- It is important that she has one person to connect with, who she can trust - perhaps a person who reminds her of her grandmother – low voice is important – a smell might be important as well as food. Talk to the grandmother and try to find out how she interacted with the girl, to transfer this to therapy.
- Her age should be taken into account. At 17 years a lot is happening in the minds of teenagers.
- It is important to find out what the right diagnosis is. What is the exact problem? There is a lot of aggression involved. How to deal with aggression?
- Sometimes pets can be useful to show emotions. Some children do not like people because they have bad experiences, but they like to connect with pets. Perhaps a small pet can work for her or even a kind of robot (pet robot). Or even music.
- Providing structure may also help, trying to fix regular moments to visit her.
- It is important to first help/support parents and then, parents will help the child. In Croatia and Hungary support for parents could be increased.

Good Practice

for persons with a VI and attachment problems

Being aware of a person's attachment status gives information to explain other problems. Clients can be supported in developing more trust in others, but this asks for time and specific skills in the professionals that provide support to these clients.

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Topic 2: Charles Bonnet Syndrome

Background information

Definition CBS

The Charles Bonnet Syndrome (CBS) is not a psychiatric syndrome. It is about visual hallucinations with no psychiatric origin, that visually impaired people may have.

Expert's talk on CBS

From Peter Verstraten, psychologist at the Robert Coppes Foundation. See also appendix 3: PowerPoint presentation Charles Bonnet Syndrome

Charles Bonnet was a Swiss philosopher. He was the first one who wrote about these hallucinations. His grandfather saw things that were not really there but did not have a psychiatric problem. He was however visually impaired.

Some say it is a pseudo hallucination, but in fact it fits in the definition of a true hallucination. It really looks like a real perception of something. People do not dare to speak about it, because they think that others may think they are becoming crazy.
Because people are visually impaired they usually know right away that the images they see are not real because they cannot see (enough). However, people often cannot make that judgement in the beginning and may experience the hallucinations as frightening.
The frequency and duration of hallucinations is different; usually with eyelids open, sometimes integrated in actual environment, sometimes not; usually not moving along with eye movement, compared with normal images just as clear or even more clear, usually normal colour. What they see can be objects, persons, animals, chairs, bicycles, etc. – usually without much relevance. Sometimes they are not complex but more elementary (dots/stripes/worms).

Essential in diagnoses is that one has to have insight into unreal nature of the hallucinations. For differential diagnoses there are a number of other types of hallucinations without a psychiatric background that need to be excluded. It's usually older visually impaired people who suffer from CBS. There are many risk factors like e.g. neurological, physiological, psychological, medication, like beta blockers, etc. Most people have these hallucinations during night (when it is visually boring) – the less input the brain has, the more the brain will provide for its own input.

About 72% of people with CBS don't experience distress because of the hallucinations. The others do, related to the frequency, the duration or the unpleasant content of the hallucinations.

There are a few theories why these hallucinations occur. When you bring these together they all concern people with a visual impairment. Apparently, their brains are not much triggered. Then there is change in the activity of the brain, like external triggers (e.g. turning on the light). The brains is then aroused to give meaning to what it gets as input. People who were born blind can never have CBS because this filling in by the brain is based on visual memory.

Clients will most often not tell about the hallucinations, it can be helpful to ask clients if they experience hallucinations. There is no evidence based approach to treat CBS. What you can do is pass away hallucinations. Main treatment options: re-assurance by explaining; passing techniques to stop hallucinations; ABC scheme (from cognitive therapy). There is evidence of medication working in

hearing impaired persons with auditory hallucinations. Application of this medication in CBS clients seems to work with some of them.

Peter Verstraten developed a questionnaire to investigate if clients do suffer from CBS. See appendix 4: Questionnaire Charles Bonnet Syndrome.

Quotes

"Charles Bonnet syndrome presentation was very interesting – I did not find people with this yet, but apparently there must be. I will pay attention now – very useful for my work."

"To realise how important it is to have the right diagnosis. What is really the problem and what does it mean for treatment/care. I hope that this will enable us to do something around:

- ***Assessment;***
- ***Creating of awareness;***
- ***Bringing experiences together."***

Good Practice

for persons with a VI and Charles Bonnet Syndrome

It is important to be aware that hallucinations occur more frequently in people with visual impairment. It is important that clients know that this is not strange and that this is an official syndrome (and not a sign of a psychiatric disorder / you're not going crazy).

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Topic 3: Psychoses in people with visual impairment

Background information

Definition psychosis

The word *psychosis* is used to describe conditions that affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way, it is called a psychotic episode. During a period of psychosis, a person's thoughts and perceptions are disturbed, and the individual may have difficulty understanding what is real and what is not.

Expert's talk on psychosis

From Helga Saez, a psychiatrist working at Reinier van Arkel Group.

Reinier van Arkel Group is one of the oldest psychiatric hospitals in the world. Helga works with Robert Coppes Foundation (RCF) for about 14 years as a consultant. She is not responsible for treatment but gives advice and support to the professionals of the RCF on psychiatric problems.

There is hardly any literature on the combination of visual impairment and psychotic disorders. There are different types of psychoses (schizophrenia, schizoaffective, brief psychotic episodes, delusional disorders, shared psychoses, psychoses due to something else.).

First point of attendance in treatment/seeing patients with these combined problems is 'how do I make contact?'. Normally the first step for psychiatrics in making contact with patients is making eye contact and looking at and studying response. With visually impaired persons eye contact is not possible so other methods have to be chosen. Advice is to discuss with the client how he wants to be approached and start working on trust.

A second challenge is to make the right diagnosis. Sometimes there will be doubts about hallucinations or psychoses. Yet, is it important to have the accurate diagnosis. If it is not schizophrenia, but e.g. stress, the therapy is different.

You first try to stabilise the situation, but then only the process starts. Psychosis is just a symptom. Assessment is crucial. In diagnosis there should be more space for considering the context/ background. You will need more time for diagnosis.

Clients often have had a lot of bad experiences in life, are sometimes hospitalised. In a psychiatric hospital the situation is complicated for patients with visual impairment. Professionals are not used to working with these patients.

With visual impaired persons it is important to pay attention to background, history and earlier experiences. When you know more about this you will be more able to study what the main problem is that makes this client not functioning well or why he is anxious/ psychotic etc.

Psychotic episodes are most often seen in clients using drugs, with delirium, personality disorders. For visually impaired persons it is difficult to get out of a psychotic episode especially when being in a psychiatric hospital. This situation can make patients very anxious because they do not know the environment. Intention is to protect these clients from new impulses and put them back in their natural environment (in our case at the RCF) as soon as possible.

Aggression is often a problem in psychoses of schizophrenia. This can be very scaring and traumatizing for other visually impaired people when they are around, living in the same facility. Response to medication is the same in visually impaired as in not visually impaired persons.

Case discussion involving psychoses

Case 1 - Psychosis

By Robert Coppes Foundation - The Netherlands

Case description

Lucy is a lady of 53 years old, born in Aruba. She was orphaned at the age of 4 and had no other family who could or would take care of her. Therefore, she lived on the streets for a while until she became completely blind caused by a car accident. After that, she was brought to the Netherlands and placed in a foster home. Although stability came into her life as a result, she did not experience this home as warm or safe. Therefore, the contact was broken when Lucy became an adult. As an adult, she led a turbulent life. She lived on the streets although she had a house, had many contacts and was a regular user of alcohol and drugs. When she came into care at the Robert Coppes Foundation, she needed help with keeping her finances in order, assistance in contacting other organisations and assistance in using a computer and other devices. At first, this contact was friendly and there were only vague indications of the use of alcohol, drug and medication and of a psychiatric background. However, after a few years she developed several physical complaints, i.e. weight gain, fatigue, pain and balance problems, and therefore decided to completely stop taking her medication without discussing this with a physician. After that, her condition went downhill. She started to distrust others, got aggressive, broke contacts and started to remember negative experiences from her past. She also had delusional thoughts, i.e. psychotic episodes, and thoughts of ending her life. She rejected new medication from her GP and the help from mental healthcare professionals. Luckily, she trusts the professionals at the Robert Coppes Foundation and we were able to contain a stable situation.

- Question 1: How should we deal with the risk that she poses for her own life and that of others?
- Question 2: How could we help her expand her network while she is very distrustful to others?
- Question 3: How can we deal with other healthcare professionals who don't want or know how to support this client?
  Lucy regularly asks us to check things. She thinks, for example, that things in the house have been destroyed, she asks us to check this (with our eyes), but usually there is nothing wrong. However, confronting her with this will immediately trigger her distrust and anger. Therefore, we developed a strategy to prevent her asking our opinion or we formulated our opinion in a way that it neither confirms nor denies anything.
- Question 4: Are there other ways we could deal with this?

Advices on support and/or treatment mentioned in the group discussion

- Important: what is it what client wants? What are his/her needs? And to create a resource group around the client. Difficult to get a grip on this because of a personality disorder. As long as we go on with 'we need to do this and that', clients will not have ownership of their own process.
- Who is determining what the best treatment is for this client? Now, you are approaching it as you would approach her as family member. The situation is not changing – we keep

continuation the same situation – there is not real intervention to change the situation, to break the cycle.

- Question: would you have another approach because she has a visual impairment? People around her, accept more from her, because she has VI and people feel pity for her. A solution might be to get your hands off, but you don't do that with VI people. Perhaps if you lose her, she might get treatment for her psychiatric condition.
- Is it possible that clients suffer from psychoses/schizophrenia and CBS? It is possible but not likely at the same time. It is often difficult to find the cause of psychoses.
- What kind of research needed? Psychotic disorders are very broad. And people have a lot of other diseases like autism. We have to look more at common comorbidities: which treatment is most effective for which comorbidity (impact assessment)? It is important to try to create positive moments, trying to let her open up.

Good Practice

for persons with a VI and psychoses

It is important to find out the cause of a psychosis to understand the best way to help the client to manage the situation. Psychoses are only a symptom. The fact that psychoses can have different causes, which need different types of treatment, shows the urge to find out how we can come to better diagnoses. A good assessment of the problems helps to choose a good treatment. There are different treatment methods being used to treat psychoses/psychiatric disorders that should also be applicable for visually impaired persons. This asks for adaptations; it is worthy to invest herein. One must be to be aware that treatment of this special group of patients takes more time.

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Topic 4: Borderline Personality Disorder in people with visual impairment

Background information

Definition BPD

Borderline personality disorder is a mental health disorder that impacts the way you think and feel about yourself and others, causing problems functioning in everyday life. It includes self-image issues, difficulty managing emotions and behaviour, and a pattern of unstable relationships.

With borderline personality disorder, you have an intense fear of abandonment or instability, and you may have difficulty tolerating being alone. Yet inappropriate anger, impulsiveness and frequent mood swings may push others away, even though you want to have loving and lasting relationships.

Borderline personality disorder usually begins by early adulthood.

Expert's talk on BPD

From Debby van Vught and Dorien Zwegers, psychologists at the Robert Coppes Foundation. See also appendix 5: PowerPoint Presentation Borderline Personality Disorder.

Borderline Personality Disorder (BPD) in combination with a visual impairment leads to a complicated set of problems. Main characteristics are mood swings and heavy emotions. Crises come and go. Furthermore, people with BPD tend to think in black and white. Other symptoms could be:

- personalising, in relation to themselves;
- disaster thinking: my life is a mess, I have no future;
- this negativism is always there, in every conversation, in everyday life.

Normally human beings get warm feelings while connecting with others (social situations). You can imagine this as a kind of 'heather inside', but in the case of persons with BPD it's not functioning properly. 'Better feeling pain than feeling nothing'.
The symptoms of BDP in persons with VI could deviate. For instance, persons with VI could live a more isolated life. Getting and keeping a client stable is a great challenge for professionals.

See appendix # for the PowerPoint Presentation.

Case discussion involving Borderline Personality Disorder

Case 1 - Borderline Personality Disorder

By Robert Coppes Foundation - The Netherlands

Case description

Gerda is a lady of 75 years old with Usher syndrome (hearing impaired and completely blind after menopause). She has been a widow for 5 years. In the past, her husband took care of her of whom she was completely dependent. She has one brother (also with Usher syndrome) with whom she has occasional contact. Gerda is physically healthy, active and creative, and finds it difficult to "do nothing". However, her mood can change instantly. She has been in care at the Robert Coppes Foundation for a

year now. During her stay with us at one of the housing facilities, this has proven extremely difficult because she has problems with almost all professionals, is unable to work with volunteers and continues to seek confrontation with everybody around her, also other clients. Although there is no formal diagnosis, she appears to have (at least characteristics of) BPD. However, discussing this with her is not possible because she will not accept this. She needs practical support in administrative tasks and financial matters. She also needs our support to be able to express her wishes and anger to other organizations and volunteers. This regularly puts us in a difficult position with regard to other care providers and authorities. Gerda feels very lonely in an environment that she experiences as being hostile to her. Because of her behaviour, she pushes people away, while she is actually in need of intimate, reliable relationships. We have the impression that this feeling of loneliness only further reinforces her negative behaviour.

- Question 1: How can we get a better understanding of her complaints, and the underlying psychiatric problems?
- Question 2: Why is diagnosing her complaints (if possible) important?
- Question 3: If diagnosing her complaints is not possible, how can we best support her in the current situation?

Advices on support and/or treatment mentioned in the group discussion

Two cases on BPD were discussed. Main topics were:

- When everything is stable when people are growing up, there is less chance to develop BPD. Attachment problems as a result of abandonment at a young age could for example be a trigger for BPD. Factors with positive influence are intelligence, a stable family and certain skills. Neurotransmitters also play a role. This makes it for clients 'easier' to accept (that they just had bad luck).
- Diagnosing is difficult, there are often a couple factors together which lead to the diagnose BPD. You could use the DSM (Diagnostic and Statistical Manual of Mental Disorders). Nine factors are relating to DSM. If you're diagnosed with five of them then it's more or less sure you suffer from BPD.
- Win trust! It's important to reach stability first, then work on problems (this will cost time and patience). It can take two years to make real/profound connection. Also look behind the usual/normal treatments. It can be useful to make connection with the area of interest of the client. Look for motivation in the client himself, what will motivate him/her? For instance if someone likes riding a bike, then go for a tour together. Work on building a theory and unravel it, step by step.

Good Practice

for persons with a VI and BPD

The treatment for BPD is based on a long-term perspective. There's no single medicine. As a professional you have to work on trust first. It's important to work with therapists, experts on VI and psychologists, together. Ambulant care is preferred because persons with BDP often don't fit in in groups, like in residential homes. Social workers play often a saviour/helper role. Sometimes, it's better doing nothing. Set limits, you can be too much involved. You don't have to be the best. Let the client discover his/her own strength.

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THEME 2

Addiction and eating disorders

Theme 2: Addiction and eating disorders

Center for education and rehabilitation 'Vinko Bek' – Zagreb – Croatia, June 2021

Background information

The second meeting was held online and the main goals were to bring professionals and members of the target group together to share knowledge and experience on addiction and eating disorders in people with visual impairment. For both topics an overview of the background information has been given by experts in the field, case discussion from every country member, discussion and general conclusion.

Definition addiction and eating disorders

Addiction is a compulsive, chronic, physiological or psychological need for a habit-forming substance, behavior or activity having harmful physical, psychological or social effects. Symptoms of substance use disorders fall into four categories: impaired control, social problems, risky use and physical dependence.

Eating disorders are a range of psychological conditions characterized by severe and persistent deviation related to feeding and body weight. They might start with an obsession with food, body weight or body shape.

Expert's talk on eating disorders

By Hrvoje Handl, MD, specialist in psychiatry from Zagreb, Croatia

Eating disorders are characterized by disturbances in eating or eating-related behaviors that lead to changes in the intake or absorption of food, which significantly harms physical health or psychosocial functioning. According to the DSM-5 there is proposed diagnostic criteria for eating disorders: anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), other specified feeding and eating disorder (OSFED), pica, rumination disorder, avoidant/restrictive food intake disorder (ARFID), unspecified Feeding or eating disorder (UFED) and other: muscle dysmorphia and orthorexia nervosa (ON).

Eating disorders are dangerous behavioral disorders that result from the interaction of a number of factors, which may include emotional and personality disorders, family pressure, possible genetic or biological predisposition, and a culture in which there is an abundance of food and an obsession with thinness.

Bulimia, which is more common than anorexia, is characterized by cycles of excessive intake and deliberate elimination of food. It usually begins in early adolescence when young women try restrictive diets and, in case of failure, react by overeating. After that, the food is expelled either by vomiting or by taking laxatives, diet pills or drugs to reduce body fluids. Patients diagnosed with bulimia have about 14 episodes of binge eating and purging of food each week. People with bulimia who do not suffer from anorexia are normal or slightly overweight, which can fluctuate more than 20 kg due to cycles of overeating and eliminating food. Bulimia affects 1% of young women between the ages of 12 and 25.

Men are often less affected and it is more common in Western culture societies. Bulimia is equally present in different social classes and affected people are usually normal weight, some of them are in slightly subnormal weight and rarely obese.

Anorexia nervosa is a disorder that causes the sufferer to starve and lose weight, losing from 15% to even 60% of their normal body weight. Half of these patients, who are known as restrictive anorexia sufferers, lose weight through strict diets; the other half, bulimic patients, maintain thinness by eliminating food. Although both types of illness are serious, bulimia patients are often at greater risk because bulimia is an additional stressor for an undernourished body. Anorexia has a prevalence of 0.28 - 1% in the adolescent age, 90-95% off affected are women. After the age of 13, the frequency of occurrence increases, the maximum lies between the ages of 17 and 18. Anorexia is also less often in non-Western culture and it is equally present in different social classes.

The third category of eating disorders are unspecified disorders, which cannot be defined as either anorexia or bulimia. This category includes binge eating without purging, infrequent episodes of binge eating and purging (less than twice a week or such behavior lasting less than three months), repeated chewing and spitting without swallowing large amounts of food, or normal weight in people with anorexia nervosa. This disorder occurs more often in women than in men. In men, compulsive overeating disorder is the most common of all eating disorders. The first association with the concept of compulsive overeating is an obese person, but this is not always the case. Repetitive episodes of overeating include eating at certain times (e.g. every 2 hours) a larger amount of food than is usual for other people in similar situations, and a feeling of lack of control over eating during such an episode (feeling that the person cannot stop eating, cannot control the amount, as well as the food consumed). An episode of binge eating includes: eating much faster than usual, eating to the point of feeling uncomfortably full, eating large amounts of food despite the absence of physical hunger, eating alone due to feeling ashamed in front of others due to the amount of food eaten, feeling disgusted with oneself, depressed mood, or great guilt after such an episode. This disorder has pronounced agitation that is present even after an episode of overeating. Binge eating occurs frequently, at least once a week for three months.

Treatment of mentioned disorders are weight gain – 1 to 2 kg per week, BMI value 18.5-20 psychotherapeutic techniques, inclusion of a family, group therapies, individual therapy, cognitive-behavioral therapy, psychopharmaceuticals, antipsychotics, antidepressant and anxiolitics.

The DSM-5 recognizes substance-related disorders resulting from the use of 10 separate classes of drugs: alcohol, caffeine, cannabis, hallucinogens, inhalants, opioids, sedatives, hypnotics or anxiolytics, stimulants (including amphetamine-type substances, cocaine, and other stimulants) and tobacco. Mentioned drugs have in common the fact that they directly activate the rewarding system in the brain, involved in reinforcing behavior and creating memory. Because the rewarding feeling can be so profound, users can neglect other normal everyday activities in favor of taking the drug. But not all people who are using drugs are automatically or equally vulnerable to developing substance-related disorders. Some people have lower levels of self-control that predispose them to develop problems if exposed to drugs.

It is important to mention that both of these groups of disorders can be a supporting factor for another. Alcohol, drug and medication addictions prevalence in patients with eating disorders are significantly high: in bulimia 50 - 60%, anorexia 40 - 50%, alcohol is the most common addiction of bulimia 55%, anorexia 23%, marijuana 41%, cocaine and amphetamines 10%, hallucinogens and heroin 28% and benzodiazepines 30%.

Presentations on addiction and eating disorders

Hungary

See also appendix Presentation eating disorder, Hungary

Colleagues from Hungary gave a presentation on how eating attitudes and problems in children can be a sign of eating disorders in adulthood. The causes of eating disorders - organic and inorganic - are listed.

We eat when we are nervous, happy, worried… Eating is more than a physical or organic need for food. The beginning of feeding occurs in the womb, and it affects how the child eats when it is born. After the birth of a child, an attitude towards feeding is created. A certain percentage of eating disorders occur in childhood, but the question arises about the meaning of it for adulthood. It is a predictor of later eating disorders. People are learning through sight, but if the child is visually impaired it certainly affects the diet (due to interaction and self-feeding). In an online questionnaire for parents developed in Hungary, the results show that more than half of the parents surveyed said that their children had problems with feeding/eating. Multiple impairments are severe, so in addition to other difficulties, eating disorders occur often, many certainly need help and support.

The Netherlands

See also appendix 7: PowerPoint Presentation addiction, NL

Colleagues from Netherlands gave a presentation about addiction and eating disorders in adults with visual impairment and what we know about it from practice (see also appendix . Visually impaired people are more vulnerable due to the risk factors for both addiction and eating disorders. Data has been found in the American literature that says that 30%, and even up to 50%, of a visually impaired person has a prevalence of addiction risk. The references are old, but still very interesting data and it would be good to have newer data. From case reports in The Netherlands there is obviously a lot of cases of an eating disorder among people with visual impairment. In The Robert Coppes Foundation professionals are using a model of motivational interviewing in treatment. Motivational interviewing (motivation for assessment) has four principles: partnership, acceptance, compassion and interest. The basis of the model is to know the importance of understanding the other person and their needs, find strengths and set goals together. It is important to offer them a safe environment and establish trust between the client and the therapist, work on self-confidence and self-esteem. The challenge is to involve the social environment and get the client involved.

Quotes

Professionals from Hungary concluded their presentation about eating attitudes and problems in children by saying that:

“Many times, eating difficulties are overshadowed with other problems such as visual impairment, gross motor problems or other problems with health. It is important to deal with these children properly as early as possible because maybe we could prevent eating disorders in later life.”

Another point of view was given from professionals in Croatia.

“We have cases of overprotective parents of children with visual impairments and multiple disabilities when it comes to feeding. Even when there is no medical reason and children can physically eat on their own and there is not objective reason, parents are often very overprotective and feed their children.”

In Hungary they have that similar problem, adding:

“Parents can often see the problem differently than the teacher or professionals does, so it is necessary to discuss this as well.”

To summarize, participants agree on the statement from professionals in The Netherlands:

“Problem can be with the child, eating disorders and maybe some other difficulties that can play a role such as autism, but is also important to look at the parents and see how their behavior influences child's eating habits.”

Also:

"Motivational interviewing is very much about seeing the person, having respect for the person and not telling her you are wrong. Because, when you have been told you are wrong for some period, you start to believe it."

Professionals from Croatia added:

"It is important to see the person, not just the addiction or some other problem they have. You are more than that. You have a lot of qualities, not only problems."

Case discussions

Case 1 - Addiction disorder

By BFW Halle - Germany

Case description

Client is a 34-year-old man. He suffers from retinitis pigmentosa. At the moment, his field of vision is good enough for classification as visually impaired but not blind. Client states in his admission interview a heavy substance addiction in the past, including methamphetamines like Crystal and several other substances. At the time of the initial assessment, he lived in a rented apartment, which he shares with several other people. Because of a significant lag in rental payment, he is threatened by homelessness, as was already the case earlier in his life. During assessment he assured not to take drugs anymore but found it difficult to keep distance from people he knows from his past and the drug scene. That's why he strives for a relocation to another city. During his initial assessment, the client tells us that he wants to achieve a professional qualification as he abandoned several vocational educations and never worked longer than a few months in temporary jobs. During the assessment, although he has average intellectual abilities and is generally interested in educational possibilities, he often refused to work on tasks he is not specifically interested in. He easily gets angry and several times thought about the possibility of cancelling the assessment.

During the next years of professional qualification, the client managed to improve his skills and achieved good to very good results in most of the relevant subjects. After a preparatory course, he enrolled in a course to become a clerk. Despite managing his financial issues and moving to another city, with support from a social worker, he repeatedly got involved into heavy drinking and following disagreements and quarrels during his stay at the BFW. While being interested during lessons for as long as he is in a good mood, he still lacks emotional control when getting angry. Several classmates felt threatened by him and at some point, requested his exclusion from lessons. After several occurrences and written warnings, he was obligated by his insurance (educational qualification cost unit) to take part in psychological counseling on a regular basis. While attending these counseling appointments, he states that he isn't in need of any psychological help. In his opinion the ongoing involvement in heavy drinking isn't part of the problem.

Advices on support and/or treatment mentioned in the group discussion

- It is suggested that the client should be engaged in anger management treatment to achieve emotional stability;
- It is suggested that the client should be engaged in meditation and a psychologist treatment;
- Another given advice was to engage this client in hobby from interest or activity;
- Find a motivation for client's education and a better engagement with rehabilitation programs.

Case 2 - Eating disorder

By Vinko Bek - Croatia

Case description

The client has been practically blind since 2006. He is 39 years old and lives with his mother and stepfather. He stayed at our facility for a few months and we had a good insight into his eating habits, as well as his general daily functioning. The client suffers from Bardet-Biedl Syndrome, hypothyroidism, hypertension, dyslipidemia and hyperuricemia and goes to regular endocrinological and ophthalmological checks. On paper, there is no diagnosis of an eating disorder, but the client has metabolic syndrome.

In a conversation with a psychologist, his preoccupation with diet and physical appearance was emphasized. He avoided numerous foods and skipped meals during his rehabilitation stay, even though no doctor advised or prescribed him to eat the way he did. When asked why he skips meals and why he does not consume various foods, the client answers that he himself, observing his body, concluded that certain foods harm him and that he feels bad after consuming them. He was advised to contact his doctor about proper nutrition, due to his health condition, but he said he did not see the need for it because he knew what was good for him. In everyday situations he did not have various diets, but he still claimed that he knows what is good for him and does not need the advice of a nutritionist, psychologist or any other expert.

During his stay at our center, due to numerous diagnoses, he was monitored by our medical service. It was evident that he was often very weak, there were difficulties with blood pressure and sugar levels, and such conditions often followed he would not eat (he would skip a meal, despite eating foods he earlier says that he eats). As he did not move much and did not exercise, he thought that his diet could affect his physical appearance, which was a big problem considering his diagnoses.

Advices on support and/or treatment mentioned in the group discussion

- With this client the question is whether this problem is a medical or behavioral background and it is difficult to determine what the right diagnosis is.
- The description of behavior shows that eating problems are present. Considering that this is an adult client who had a structure in getting meals, during rehabilitation programs, apart from verbal encouragement, we could not have an influence on the way he consumed his meals.
- It is of great importance to get the correct diagnoses for the client to have regular everyday functioning.
- It is important for us to have a correct diagnosis and something objective that we can rely on during treatment/rehabilitation.
- It is suggested that the client should be sent for additional tests (nutritionist, psychiatrist, etc.).

Case 3 - Eating disorder

By Robert Coppes Foundation - The Netherlands

Case description

Client is a creative woman born in 1963. She has been blind since 2008. This is (or has been) a great loss experience for her, which she is constantly confronted with. This, in addition to other physical and psychological complaints, makes life complicated for her. Her physical complaints consist of stomach complaints, for which a cause has never been found. For a few years now, she has been diagnosed with type 2 diabetes and is dependent on insulin. She also has limited mobility due to pain in her hip. In the past there has been alcohol abuse, which is hardly negotiable. Client has average cognitive abilities. However, her orientation in time, place and person is good. A neuropsychological test was conducted in 2012 and an additional personality survey was conducted in 2013. Her personality profile and behavioral pattern seem to correspond in particular to the dependent and depressive personality and is less

recognizable in the avoidant personality disorder. She seems to avoid situations, but this varies and seems to depend on her mood and physical symptoms. These disturbances in her personality may explain her difficulties in daily functioning.

As a result of her visual impairment in combination with her other impairments, she is dependent on others in all areas of life. However, she has her own daily routine; she can plan and structure her day independently. Her autonomy is very important to her. She wants to do and decide independently as much as possible. However, she does need help solving problems, making more complex decisions, and coping with stressful events.

On a daily basis she has a number of short contact moments with a supervisor; for medical assistance, having a chat or taking a walk. These chats allow her to vent and help her to put things into perspective. Still, she thinks that she is not always taken seriously; she gets along better with one supervisor than with another. Because of her negative self-image, she seems to benefit mostly from supervisors that approach her positively and provide confirmation so that she feels heard, seen and wanted.

Once every two weeks, she also has contact with a psychologist from the Robert Coppes Foundation to explain what is on her mind. These conversations do not cover a full psychological treatment; external mental health care is indicated for this. It has been advised to start working on insight into the pattern of thinking and behavior, e.g. by means of intensive cognitive behavioral therapy. However, she does not want to receive external treatment.

Supervisors notice problems with her eating habits. She seems to buy a lot of unhealthy food and drinks, such as alcohol, a lot of candy and chocolate. In addition, when she eats with the group, she eats little or no vegetables. She likes to eat fries and more unhealthy meals. At times when her sugar level is high, she says she has not eaten, while supervisors notice that unhealthy foods are gone every week. She has stopped working with a dietician because she does not believe her. She also threatens to stop working with the diabetic nurse because the nurse confronts her with insulin values that do not match with what she says she has been eating and drinking.

Advices on support and/or treatment mentioned in the group discussion

- Autonomy is very important to the client and that could be the key to have contact with the client and to motivate her.
- Engaging in treatment that would not destroy a client's autonomy was suggested, such as group treatment/support to motivate her to get a healthier lifestyle.
- Another way in work could be engaging the client in some creative activities that would be used as a connection to a healthier lifestyle. Also, it is important to find out which art activities she finds interesting.
- Since this client is having problems with trusting other people, phone apps or technical devices that are controlled by phone could be of help.
- Another suggestion in working with this client might be biofeedback. That would be a good way of helping since she is in denial and has a great sense of shame.
- Work on her self-esteem is very important and because this client is very creative it would be good to use that in order to achieve better self-esteem. For example, maybe the client could be the one teaching others how to express their creativity as an art teacher of some kind.

Case 4 - Eating disorder

By BFW Halle - Germany

Case description

Client is a 41-year-old woman. She has been diagnosed with visual impairment with myopia and nystagmus. In addition, she has been suffering from a binge eating disorder with morbid obesity (183 kg.) since her youth and, as a result, arterial hypertension as well as dysfunctions of the lumbar spine and knee. She needs a rollator as a walking aid. Client has already received several rehabilitation treatments because of her eating disorder, and in 2008 a sleeve gastrectomy was performed. During her stay at the BFW her diagnosed anxiety and depression showed a moderate level.

Client is a trained geriatric nurse and initially worked in this position for a few years. Then there was a 4-year period of unemployment. Most recently, she had worked part-time for 5 years in a residential community for dementia patients. However, for the past 3 years she was unsuccessfully looking for work. Due to her visual impairment, activities with higher demands on her eyesight need to be avoided in the future and her general resilience was also significantly reduced due to being overweight. In result to that she is interested in a professional reorientation.

Client completed a 6-week assessment with good results. She is now able to formulate a professional goal, the realistic desire to train as a healthcare clerk. She also wanted to use the time of vocational rehabilitation to significantly reduce her weight and thus improve her overall health.

Despite a good performance during her training, she constantly had to cope with problems in her private life, which associated with increased personal stress. This kept her from a balanced level of self-care and regularly required socio-educational or psychological support. The long separation from her life partner, who fully depends on her, stressed her hard. Client, for example, took care of all administrative work for a private household and had to manage the financial situation and organized the entire move to another apartment all by herself. Besides that, she had to take care of her own health as she had neglected doing so for a long time. So, her teeth were gradually restored and after a long hesitation she finally got into the necessary treatment with lymphatic drainage twice a week.

Client regularly participated in exercise classes at BFW, installed a pedometer app, and noticeably improved her overall fitness during the 2.5 years of training. Inside the buildings, she was eventually able to move around without the rollator. By mutual agreement, she came to the psychological service weekly for weighing and regularly took advantage of individual meeting topics as possibilities for weight reduction. We also managed discussing its obstacles. Her best result in weighing was 169 kg.

Unfortunately, she was unable to achieve the desired permanent weight reduction. In times of stress at home or in training, she constantly fell back into old patterns. Then she did not pay enough attention to her diet and ate more sweets. It was difficult for her to muster the necessary self-discipline and she always had "good reasons" for not keeping to her resolutions and plans (missing sneakers, etc.). Client did not succeed in accepting the additional offers we made, such as participation in water sports or in a medically supervised nutrition plan with weight loss program. Overall, at the BFW the client showed a rather low level of suffering from being overweight. She was well integrated into the class group, was able to represent her opinion and could clearly articulate her needs. In an internship, a client managed to prove her acquired expertise and received a binding job offer after successfully completing the vocational training.

Advices on support and/or treatment mentioned in the group discussion

- The question is how to raise a client's motivation to work on weight loss, because none of the activities she engaged proved successful.
- The suggestion is to engage client in some group work, where there would be people with similar problems.
- Another suggestion is to find some hobbies and interests (art, music) and connect these interests with movement, which would encourage her to activate herself.
- Engagement in professional sports training or instruction in sport and nutrition could be a good strategy.
- Since this client has different symptoms that could indicate some other mental health problem, psychotherapeutic treatment could be of help to the client.

Case 5 - Addiction disorder

By BFW Halle - Germany

Case description

Client is a 34-year-old man. He suffers from Retinitis pigmentosa. At the moment, his field of vision is good enough for classification as visually impaired but not blind. Client states in his admission interview a heavy substance addiction in the past, including methamphetamines like Crystal and several other substances. At the time of the initial assessment, he lived in a rented apartment, which he shares with several other people. Because of a significant lag in rental payment, he is threatened by homelessness, as was already the case earlier in his life. During assessment he assured not to take drugs anymore but found it difficult to keep distance from people he knows from his past and the drug scene. That's why he strives for a relocation to another city. During his initial assessment, the client tells us that he wants to achieve a professional qualification as he abandoned several vocational educations and never worked longer than a few months in temporary jobs. During the assessment, although he has average intellectual abilities and is generally interested in educational possibilities, he often refused to work on tasks he is not specifically interested in. He easily gets angry and several times thought about the possibility of cancelling the assessment.

During the next years of professional qualification, the client managed to improve his skills and achieved good to very good results in most of the relevant subjects. After a preparatory course, he enrolled in a course for becoming a clerk. Despite managing his financial issues and moving to another city, with support from a social worker, he repeatedly got involved into heavy drinking and following disagreements and quarrels during his stay at the BFW. While being interested during lessons for as long as he is in a good mood, he still lacks emotional control when getting angry. Several classmates felt threatened by him and at some point, requested his exclusion from lessons. After several occurrences and written warnings, he was obligated by his insurance (educational qualification cost unit) to take part in psychological counseling on a regular basis. While attending these counseling appointments, he states that he isn't in need of any psychological help. In his opinion the ongoing involvement in heavy drinking isn't part of the problem.

Advices on support and/or treatment mentioned in the group discussion

- It is suggested that the client should be engaged in anger management treatment to achieve emotional stability. Emotional stability seems to be the base for starting a treatment (because of the issues with the anger management).
- It is suggested that the client should be engaged in mediation and a psychologist treatment. Also discussion with the classmates could help to find a solution.
- Find an activity or hobby of interest for the client so that he could feel successful.

- Find a motivation for the client's education and the way of motivation to have better engagement with rehabilitation programs.

Case 6 - Eating disorder

By Robert Coppes Foundation - the Netherlands

Case description

Client has been living with the Robert Coppes Foundation for decades and has been overweight for years. He has a troubled past and psychiatric problems, for which he receives medication that also affects his weight. He also has a mild intellectual disability.

Many attempts have been made to lose weight. Multiple pathways with dieticians and different diets. The psychologist from the Robert Coppes Foundation tried to stimulate a better eating pattern and ultimately losing some weight. However, all these attempts have yielded no results and these failure experiences did not increase the self-confidence of the client. Recently, the client had applied to a nearby obesity clinic. This brought new concerns, because the Robert Coppes Foundation feared another failure experience. The trajectory at the obesity clinic is an intensive trajectory with weekly conversations with a dietician and psychologist and monthly moments of weighing and physical checks. To be able to optimally support the client in this trajectory, the Robert Coppes Foundation worked together with the obesity clinic and agreed with them on the following course:

• Let the psychiatric problem rest and not stir it up or treat it; the client had already followed that route at a mental health institution and already received medication.
• Set the goals very low. Every step in the right direction is one; no matter how small.
• Make the goals as concrete and practical as possible. For example, don't say; eating chocolate is not good for you, but agree on what he can eat as a snack in the evening.
• Build on positive experiences. Emphasize that a lot has gone well. Give compliments.
• Keep it simple so the client can understand it.
•Take into account the visual disability in conversations and goal setting.
• See client often and briefly; both dietician and psychologist spoke to the client for half an hour every week. For half an hour the concentration and attention span were okay.

The dietician and psychologist of the obesity clinic worked closely together on the same goals. A support worker from the Robert Coppes Foundation was present during all appointments to make the translation to the domestic situation in the living group. Based on this approach, the client completed the entire process and did not drop out prematurely; that already was a huge success for him. In addition, he has been able to learn and follow some nutritional advice and now has more structure in his diet, which also positively influences his psychiatric problems.

Advices on support and/or treatment mentioned in the group discussion

- It is efficient to take small steps in approach to work with clients. Small steps would help clients in achieving a sense of success.
- Steps should be as concrete and practical as possible, so the clients could experience small successes that will make them feel better - a subjective experience of success even for small shifts forward.
- Instead of focusing on what clients cannot do or eat, focus on what they can.
- The support worker could motivate the client to make progress and help set achievable goals.
- Implementation of sport, such as group sport would be a good way of motivation for the client.
- Another strategy would be using an app to track daily goals to get some feedback on progress.

- Involving in some group activities can be useful (group therapy could be a very successful strategy in some cases).

Case 7 - Addiction disorder

By Robert Coppes Foundation - the Netherlands

Case description

Client is a 52-year-old woman with a troubled past. She became visually impaired shortly after birth and has been completely blind since 2012. She was married and has one child from this marriage. She has a good contact with her ex-husband and son.

She has been living with the Robert Coppes Foundation since 2012. On admission, she was diagnosed with blindness, borderline personality disorder (BPD), autism spectrum disorder (ASD) and attention-deficit hyperactivity disorder (ADHD). There was also excessive alcohol, weed and cocaine consumption. Between 2012 and 2017 she was admitted twice to a crisis department of a mental health institution because of incidents in the living group. During that period, she was also voluntarily admitted to a clinic for addiction care, for treatment based on the diagnosis of drug dependence in combination with a borderline personality disorder. However, she was not intrinsically motivated since she only cooperated because the Robert Coppes Foundation deemed it necessary. This is probably why this did not lead to a decrease in her unruly and hot-tempered behavior. Nor did she stop using excessive alcohol and drugs.

In the autumn of 2017, her situation at the living group went wrong. She was completely lost, unapproachable and verbally aggressive. She even threw an ashtray at one of the caregivers. Fortunately, this caregiver was not hit. The immediate cause of this crisis turned out to be a combination of excessive use of alcohol, cannabis and cocaine. The mental health crisis service was called in. When the client was sober again, she indicated that she wanted to be hospitalized for a rehab programme. She now seemed to be intrinsically motivated for this.

During her stay at the clinic, she managed to become abstinent from alcohol and drugs. The psychodiagnostic examination showed that there were complex traumas causing complex post-traumatic stress disorder (PTSD). Trauma treatment was started at the clinic. After four months she was discharged from the clinic, returned to her apartment at the Robert Coppes Foundation and continued trauma treatment on an outpatient basis for almost a year. She also followed a treatment program to support the recovery of self-management and good self-care. This involved multi-disciplinary collaboration between client, counsellor and behavioral scientist from the Robert Coppes Foundation and an external outpatient practitioner. This treatment program ended at the end of 2018. At the moment, the client is still abstinent from alcohol and drugs. She can also live with her traumas, which she says have no more sharp edges.

Case 8 - Addiction disorder

By Robert Coppes Foundation - the Netherlands

Case description

Client is a 53-year-old man, who has received ambulatory care from the Robert Coppes Foundation since 2001. He is blind and a chronic alcohol and cannabis abuser. He comes from a family where there was a lot of substance abuse and violence. He grew up in a working-class neighborhood (and still lives there), where there is a lot of social control, but other norms and values apply here than what is "normal". Think of a lot of (verbal) aggression, substance abuse and poverty/ unemployment. Client has a history of criminal activities and has been in detention for this once. There is still regular contact with the police.

Client has been in a relationship twice, both partners are deceased. He indicates that he has processed this grief but does not want to enter a new relationship to avoid the risk of losing her again.

After his detention, client came into care at the Robert Coppes Foundation. Initially, the care mainly consisted of building trust and offering practical support, such as sorting out mail and supporting the client in his contact with authorities. Despite his blindness, client is quite independent. Until recently, he had many social contacts and hobbies such as woodworking and working on his car. However, in recent years he has lost many contacts and his health has deteriorated. He suffers a lot from tension and anger, but also from sadness. Because of this, he can become very emotional and even aggressive. He has sleeping problems and regularly doesn't sleep all night. He can also act very threatening when he feels mistreated. This often gives rise to conflicts.

We see that his situation is deteriorating and that more and more protective factors, such as social contacts and daytime activities, are disappearing as a result. While his health problems increase, he refuses medical care. He values his autonomy and wants to be in control. There is a relationship of trust with the ambulatory care worker who offers him guidance and practical support. She is there for the client when he needs it and helps him regulate emotions and tensions and tries to stimulate healthy living habits and reduce substance abuse. Given the complexity of the situation, a psychologist from the Robert Coppes Foundation is also involved and the case has been discussed several times with care providers from addiction care. However, the client keeps refusing external support from addiction care workers.

Good Practice

for persons with a VI and addiction or eating disorders

People with visual impairment and eating disorders or addiction problems should be looked at with an overall view. Taking into account psychosocial, physical and emotional factors, but also their possibilities, qualities and positive sides. It is important to see the person, not just the addiction or some other problem they have. "You are more than that. You have a lot of qualities, not only problems".

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THEME 3

Behavioral disorders

Theme 3: Behavioral disorders

Budapest School for the Blind – Budapest – Hungary, October 2021

In the third meeting three presentations were discussed, an expert's talk about externalizing disorders in adolescence and two additional presentations of which the first concerns understanding “problem” behavior and the second on aggression specifically in vocational rehabilitation. Five case presentations and general conclusions were discussed.

Background information

Definition behavioral disorders

A recurring and persistent pattern of behavior in which the basic rights of others or important age-appropriate social norms and rules are violated.

Expert’s talk on behavioral disorders

From Dr. Judit Balazs (psychiatrist), a presentation about externalizing disorders in adolescence.

Her presentation core was about ADHD: if this disorder is not well treated or get the right treatment it can cause much more problems later on, in adulthood e.g., aggression or auto aggression.

In the presentation we could hear some information about ADHD. It is a neurodevelopment disorder, children are born with it, they never get it from how parents treated them. It has a very strong genetic biological background. If it is untreated, it causes additional disorders, even depression and anxiety. It manifests itself with different degrees of severity in each generation.

ADHD statics is that 3-5% of school-age children are estimated to have this disorder. ADHD is a treatable disorder. ADHD characteristics are inattention, impulsivity, and overactivity. For the diagnosis it is very important that a minimum of 6 symptoms occurred during the past 6 months. E.g.: lacks attention to detail, makes careless mistakes, has difficulty organizing tasks, is distracted easily, talks excessively. And these symptoms are present at abnormal levels, interfering with, or reducing the quality of social, school, or work functioning. An additional criterium is that several symptoms are present in two or more settings

ADHD persists into adulthood 75% of the time. Up to 4% of adults suffer from it. It can be quite crippling, depending on the severity of the disorder. Characteristic problems with ADHD in adulthood are disorganization, distractibility, restlessness, impulsivity, labile mood, quick temper, oppositional behavior, job stress, unemployment, divorce, loneliness, smoking. The impact of ADHD on people is that e.g. 40-50% will engage in antisocial activities, experience depression, or a personality disorder.

Treatment if not pharmacological:

- psychoeducation;
- parent team;
- home modification;
- parent- teacher teamwork;
- consistency of parent- teacher- doctor team;
- cognitive behavior therapy.

Presentations on behavioral disorders

The Netherlands

Presentation from Dr. Marit van Buijsen on understanding "problem" behavior. See also appendix 8: PowerPoint Presentation 'Understanding problem behavior'

Main points of the presentation:

There are different views on "problem" behavior. In the Netherlands there are more books on that topic (e.g. Geert Bettinger: Moving on by standing still). Bettinger's book states we should take a different view on a "problem" behavior.

- A service user is care-dependent: the user is always in a dependency. Most service users have several disabilities (like mental disabilities or dementia), so they have difficulty to express themselves. Maybe they cannot say if they have pain or a problem. It can be difficult to share their feelings because it is too painful.
- Unable to express dissatisfaction and/or pain, so they give a signal with behavior. It bothers us, but the service user must make it stop.
- We should see it as a signal behavior, that we must try to understand.
- Moving on by standing still: we should focus on why the service user is showing this behavior. How can we ensure that the service user does not have to show this behavior again? We need proper assessment.

Assessment factors that play a role (complex)

In the Netherlands there is institute of expertise. Professionals can consult with them about the complex problem. They say, different factors play role in "problem" behavior: there are different factors within the service user: biological and psychological. Behavior is also connected to the social context: how the family, professionals, and other people react to the behavior.

Assessment needs to consider:

- Physical context: building, decoration, light and sound.
- Organization: vision, policy, education.
- Multifaced: what other facts do we have, experience, interpretation, values and norms, and interests.

Attitude of the professional: Mentalization based support

What attitude of the professional does the service user need? College organization developed mentalization based support, to help persons deal with this behavior. It is based on mentalization based treatment. It is developed mainly for people with borderline syndrome (BPD). It helps people to recognize and deal with their emotions and feelings.

Mentalizing: Seeing yourself from the outside and the other from the inside. A human ability that allows us to judge or explain our own and other behaviors. Behavior is motivated by mental state: feelings, thoughts, desire, belief, intention. It is important to know and imagine why the service user is showing this behavior so better care can be offered.

Not mentalizing state:

- Stress influences our ability to mentalize.
- A lot of service users have difficulties adapting to a mentalizing state.

- They are more quickly stressed.
- They show “problem” behavior.

It is important to learn how to reflect on our actions, to mentalize our actions and feelings.

Key skill: you have to use your mentalizing skills to help a person to regulate his emotions and teach him this mentalizing approach. The key skills to do that are:

- Being a mirror for the behavior and feelings of a service user (“I see that…”).
- It is important to stand still and look behind the behavior.
- This is only possible when you are feeling calm inside.

Mentalization based attitude: calm inside, don’t judge, be open minded, be honest, be flexible and willing to reconsider your opinion, do not make a disagreement with a service user too personal but keep on looking at it with some distance.

Germany

Presentation by Andre Kunnig on aggression specifically in vocational rehabilitation. See also appendix 9: PowerPoint Presentation Aggression 1

Aggression is quite normal and part of human behavior. We can find aggression in the whole human history. The definition is that aggression is on purpose intentionally and the victim wants to avoid this.

Ther are different views on what causes aggression. One is that this behavior can be biological. A very old theory is the “steam boiler model”. If it is too much the boiler explodes. Another view is more genetic; that it is a part of our aggressive behavior heritage.

Also, culture influences the way we act out aggression. Another view is the neurobiological aspect, that there is brain damage or a malfunction of neurotransmitters.

Psychological approaches are another theory. Frustration causes aggression, especially if a person has learned that aggression is a successful behavior. The learning history, that if I have experienced a positive reaction to aggressions in my childhood. In a role model was successful an aggressive behavior.

Personal conditions can be a cause also, that aggressiveness as a personality trait. Usually, men are more violent, and women show more bullying. Situational conditions are alcohol and high temperature and violence in media.

Psychiatric disorder and aggression. There are differences in the expression of symptoms by men and women with depression. Men show atypical symptoms: fury, anger, aggression, alcohol or drug abuses. Schizophrenia is a psychiatric disorder with impulsive aggressiveness because of the feeling of threat. Mental retardation also causes aggression, because of less ability for emotional regulation and impulse control.

Holger Stoek presents a typical case about a visually impaired male with aggression and behavioral disorder. See also appendix 10: PowerPoint Presentation Aggression 2

- Male;
- born in 1960;
- vocational training as a machine operator;
- no PC knowledge, no typewriting;
- diabetes: no tactile sense – getting Braille is restricted;
- weak resilience and motivation.

Reactions:

They had team consultation every week, but they didn't find the right treatment for him, so finally they changed the persons who treated him. It was the first time they handled the problem this way, but they couldn't manage it otherwise.

Quotes

"I will be more aware of some behaviour that could be passive aggressive and the possibility to use 'mentalisation' (the process by which we make sense of each other and ourselves, implicitly and explicitly, in terms of subjective states and mental processes)."

"No matter the country, problems are similar."

"Aggression is a very broad subject, with many aspects; aggressive behaviour can have many manifestations and origins."

Case discussions

Case 1 - Behavioral disorders

By Vinko Bek - Croatia

Case description

The client is a 25-year-old blind woman, who usually comes in our Center twice a week. (Due to the aggravating circumstances caused by the pandemic, she is not currently coming for rehabilitation). Along with her visual impairment, the client has some other difficulties – slow speech development, moderate to severe intellectual disabilities, impaired development of motor functions, sensory and behavioral disorders, pathological EEG.

The client is not independent in performing daily activities. She doesn't move independently, she doesn't use a white cane, instead she moves by means of a seeing guide. She needs help when she goes to the toilet. She eats on her own, but all her food should be prepared and placed in front of her on a plate. There are great difficulties in communication, she keeps repeating the same sentences all over again and meaningful dialogue is very difficult to establish, almost impossible. She prefers independent activities, finds it difficult to cope in society and she does not develop close friendly relations. She is often in a very changeable and unpredictable mood and there are present unpredictable reactions to certain situations.

Her aggressive behavior is present in situations that she finds stressful. It is difficult to conclude objectively which situations will cause stress, because sometimes even completely benign situations she finds dangerous or stressful. Consequently, it is very difficult to prevent an aggressive outburst. Some triggers of aggressive behavior are noise or an individual she does not like. Or sometimes she comes from her home to our Center already upset. When this is the case, it takes a very long time for her to calm down. Reactions in these and some other situations are crying, yelling, and hitting people and things. In one situation she was walking in the yard with an assistant/ rehabilitation professional. When entering the room, the assistant asked her if she needed help. Our client grabbed the assistant's head and did not let go for about ten seconds (a colleague's help was needed to separate them). Sometimes the very presence of a certain person makes her angry and then she shouts.

In situations of aggression or increased nervousness, we put our client in a quiet room where she can engage in some activities that she usually finds cheerful and relaxing. We then isolate her from other

clients, to protect them, and make sure that she does not have the things she can throw away and destroy or that way injure herself or others.

Advices on support and/or treatment mentioned in the group discussion

One case on attachment was discussed (see appendices), presented by our colleagues from Croatia. The main topics in the group discussions was how to prevent the aggressive behaviour.

Here are some of the solutions or techniques that may help in these situations:

- Ask yes and no questions: they are easier to understand for the client and for the workers, from the answers it is easier to understand what the problem or trigger for the aggression could be.
- Time-table-routine: it helps for the client to understand where she is, what will happen with her.
- Safe environment: it is important to have an environment where the client can be (alone as well) and where she can't harm herself. Just the objects that are really needed are in the room.
- Be aware in which mood she comes in: it is important to have a routine when she arrives to the building. It can be always with the same person she trusts, and they go through a few questions that they always talk about (routine), so they know what moods she is in.
- She can learn basic object signs for easier communication like pillow means tired, plastic glass means thirsty.
- Alternative and augmentative communication: basic sign language, object signs, yes or no questions.
- It is important to know the client: her favourite activities, what can make her calm e.g. music, some subject.
- Routine: e.g. morning routine when the client arrives, 10-15 minutes with the helper she can trust. like a „transit" between home and the workers
- ABC observation.
- Narrate more what is happening with her, around her so she has a better understanding during the activities
- Take videos for the parents about the activities, so they can see what we do with her and maybe they can do those activities at home as well.

Case 2 - Behavioral disorders

By BFW Halle - Germany

Case description

Uwe is a 58-year-old man. He suffers from myopia and glaucoma and is severely visually impaired (visual acuity 0,05-0,08). Uwe reports in our admission interview an extensive history about conflicts regarding child custody for his physically disabled daughter and contentions with officials/agencies including several lawsuits in the past. Due to these circumstances, he is threatened by personal insolvency. As he is aware, that he is psychologically heavily stressed, he enrolled for psychotherapeutic treatment for a few sessions, but then quit, as he didn't find it to be helpful.

Uwe also reports in our assessment, due to his visual and orthopaedic illness he is no longer able to work in his original profession (gardener). He seems to be in sincere need of an occupation and takes part in all the subjects of the assessment, but several times attracts attention by his aggressive tone and behaviour. When he is not content with the tasks, he falls into abusive language. Moreover, he cancels several interviews by slamming the door when confronted with uncomfortable subjects. As a result of

the assessment, we advise a special training for coping with stress as well as psychotherapy and social counselling during professional qualification.

During integration training Uwe's behavioural problems persisted. He has problems controlling his temper and impulses, raises his voice inappropriately, leaves consultations unexpectedly, slams doors and insults trainers and rehabilitation students. His participation is deficient, he leaves classrooms without warning to take 'important' phone calls, does not show up to appointments etc. He only accepts external offers of help as a condition in connection with the right of access to his daughter. This still causes conflicts for further consultations with psychologists. He regularly attends appointments at the psychological department at BFW. On these occasions he shows being overload and stressed on private 'self-made' problems. He always blames other people for his situation and never realizes his own contribution.

In searching for a specific internship respectively a future job Uwe behaves inconsistently. Often, he denies himself but in the same situation he claims to be highly motivated to find a good job and to receive a corresponding salary. He overrides the concrete advise from BFW against an activity in social consulting areas. In fact, he finally succeeds in finding an internship after some – partially unpleasant – interviews with companies.

The internship itself went well due to his own positive attitude, motivation, and ability to work. He also could manage to control emotions and temper while on the job. Nevertheless, Uwe lacks the necessary sensitivity in consulting situations, he says inappropriate things at the wrong time. Often, he inappropriately mentions his concern as a father of a physically handicapped daughter. He cannot keep enough distance from it. His social competences are not sufficient for the desired job description and lacks often in the ability to work in teams. He was not chosen for a job at the company the internship took place, although Uwe's conclusion in the end of the integration training is he "has learned quite a few things".

Advices on support and/or treatment mentioned in the group discussion

Here are some of the solutions or techniques what were discussed about this case:

- What mental disorder might be the base for this deviant behavior?
  We discussed if it is really a behavior disorder because we are not sure if he had these problems before all the bad things that had happened to him.
- How could he reach a better impulse control?
  What could be helpful for reducing his aggression or handling stress management? He was offered training in stress reduction management, like progressive muscle relaxation during his stay at BFW. We offered him mindfulness-based therapy.
- What are appropriate actions to improve his social skills?
  Because he was lonely, we thought they should create smaller groups where he can participate e.g., participants from the BFW. Also, it would be helpful for him to participate in more practical activities like pottery or basket case making.
- How can a counselor best protect himself from possible verbal and/or physical attacks by participants of such training units or in class?
  It is important to keep yourself calm, not to get emotionally affected by his emotional breakout. Make sure to have a way to exit from the room if needed.

Case 3 - Behavioral disorders

By Budapest School for the Blind - Hungary

Case description

Diagnosis: Aplasia papillae, Amblyopia

Family background: Right now, the grandmother is the legal guardian. The father's lifestyle was not harmonious in terms of raising his son. Grandmother was trying to balance for a long a time and split her “services” between her son and grandson. She then formally asked for help of local social services to keep the child in touch with the parents.

He was 10 years old when the mother left them because of the father's drug problems. She couldn't take her son with her; the husband wouldn't let her. The boy told me that his mother had left in secret: she took him into bed in the evening, and by the morning she was gone, without even saying goodbye. Since then, he has been in touch with her by phone and occasionally meets her in person at the school reception. According to him, he accepted the situation, as he still has his father and grandparents - he is fine with them. As a student he lives in the school dorm during the weekdays. Living with his grandparents has a positive effect on him, his emotions are more balanced, he loves his family very much, he sticks to them.

First, he was angry with his mother for leaving, but then he said he has forgiven her but “something broke inside” him when she left. Sometimes he knows nothing about his father which is hard for him. His grandparents don’t tell him everything about his father and he feels there is some secret in the family he doesn’t know. For his teacher it is hard to communicate with the father.

School characteristics: He is the oldest among the classmates, the others listen to him, he is easily influenced by his leadership role. He's got friends from the class, but also from other classes he keeps in touch in dormitory. Discipline is difficult for him to bear; he is a bit lazy in studying. His thinking is characterized by understanding and logical inference, his interest is versatile, he is very active in classes. Grandma says he's in a growing need for independence.

Aggressive behaviour occurred mainly during the evening and morning dormitory periods (e.g., for being bullied, he threw a sharp object at someone). In addition, aggressive behaviour occurred during the breaks between the classes (e.g., when the school radio was cancelled, he smashed a wall soap dispenser). He hits his mates several times because they're making noises, or they talk a lot. He is usually disturbed by too loud noises and when there is a lot of chatter during classes. (Maybe overly sensitive hearing?)

Behavioural characteristics: Impulsive boy. According to his teachers, he often teases his peers for no reason. He is a slightly hyperactive. His self-control is weak. Auto aggression (banging his head against the wall, choking himself) has happened before when something happens that he doesn't like. He has strong tempers, often followed by outward aggression. He's weak in waiting, in patience. During our two-person meetings, he cannot sit in one place without doing something, he always needs some objects or play equipment during a conversation to keep his hands busy. He usually tries to solve everything with aggressive behaviour. If he doesn't find something, after a long search, he'll throw everything away, starts smashing and crushing. Frustration tolerance is low.

Strengths and hobbies: He is curious, kind, loving, friendly, communicative, respectful with adults, helpful and trustful. He is interested in the digital world; he is good in using the digital tools. He likes sports, he attends some afternoon sport activities. His knowledge in everyday topics is extensive, so his friends like

to chat with him, sometimes he gives practical advice to them. He likes to share his own belongings with others.

Experiences during personal psychological help: His coping strategies are not developed because of his age and bad examples. He is strongly connected to his mother, who sticks to his son in an overprotective way. He says he tries to do what they agreed with his teacher (count to 10 before acting, thinking of his grandmother, so she will not be sad because of his actions), but at the end those things don't work. He says when he is angry, he feels dizzy. His relationships with his friends are usually not balanced: either he or the other one is always more dominant. He learnt his fighting attitude from his father: "because he cannot see, that is the way he can protect himself." He plays aggressive games on the computer. He feels bad that he can't be alone because of his aggression he is always under a strong surveillance. He started to feel jealous of people who can see because they can do more (e.g., they can drive, they can find things easily) He feels it is hard to communicate with others of his age who are not visually impaired.

Advices on support and/or treatment mentioned in the group discussion

Here are some of the solutions or techniques what were discussed about this case:

- Give more feedback about his positive characteristics. Some kind of (team) sport would help him with his social interactions like judo.
- He needs a role model in his life for example of a teacher who can set good examples for him. Maybe it would help if his psychologist would be male.
- A new psychiatrist is needed because of the ADHD and aggression.
- He needs psychotherapy to process his relationship with his mother, and the frustration caused by his low vision.
- Although it is hard, parents need to be involved in psychotherapy.
- There was a disagreement about the video games he plays, if it causes aggression or used as an aggression relief. It is important to find out which one so we could act accordingly.
- His family background problem needs to be solved step by step:
    - he should have regular and predictable meetings with his mother;
    - he may feel guilty or think that his mother left because of him, it's important to strengthen that it's not his fault. It must be said out loud by his parents;
    - parents should be involved in the student dorm's life.

Case 4 - Behavioral disorders

By Budapest School for the Blind - Hungary

Case description

She is a 20-year-old young woman with multiple disabilities (intellectual, visually impaired, mobility, behaviour and sleeping difficulties). She was born from a twin pregnancy by week 29; unfortunately, she was the only one who survived. Her disabilities are known from birth.

She has an unbalanced mental state. She is aggressive a lot (scratch, tear subjects and other's hair or clothes), hysterical, and unpredictable. Typically, she is aggressive when she doesn't like the task or has to do what she is not used to doing, or maybe something doesn't turn out as she wanted it.

She takes almost everything in her mouth what she can touch around her. She chews her shirts or her hair. She is constantly giving noises with her mouth, or she repeats words or sentences that she heard from fairy tales. Her speech is lisping but clear, but her speaking is not adequate. Her verbal

communication is mostly the repetition of the fairy tale sentences, but rarely she whispers-asks something like going to the bathroom or for water, but it is hard to recognize it.

If she is happy or likes something, she makes strong back and forth swing moves while she claps and screams happily. Her connection with others depends on her mood, the situation, how well relaxed she is.

She hardly starts any connection with others, if she does, she turns to that person and starts to repeat a piece of fairy tale, sometimes she comes near to the other person, or gives her walkman and says: “I turn it on”, which means she asks for turning it on.

Her behaviour and sleeping problems come mostly from her parents’ lifestyle. They work at home, and they work mostly at night in their office which is in their flat where she should sleep as well. They also have 8-10 cats in the flat, and they are not well-cared, so they also cause sleeping and hygienic problems. Her teachers can see the signs of hygienic problems and exhaust of the parents. Her father is always telling that he is tired of taking care of her daughter, he always steps in other’s aura during conversations, his speaking style is back-slapping. His connection with his daughter: earlier he accepted her and took care of her nicely, but now he is tired of that, “what should we do with her?”. That’s what he feels.

Her mother doesn’t accept other opinions, she doesn’t hear the others, or what they want to tell her. She doesn’t fully accept her daughter with her disabilities, she has an imaginary, idealistic picture of her daughter, and she cannot see her daughter real abilities and status. Most of the time she doesn’t see her physical abilities (like what she can or cannot do in clothing).

The parent don’t accept any help (not even mental/psychological help). During conversations they don’t listen to the teachers; just telling their problems.

Advices on support and/or treatment mentioned in the group discussion

Here are some of the solutions or techniques what were discussed about this case:

- Keep small steps in mind.
- Giving simple instructions in a quiet but very firm voice accompanied by action.
- Establishment of a daily routine to follow, use of a child transport service.
- It's critical to enter in the girl's stories. This is the method, how we can connect with her. Then we can push her to connect with the ‘real world’.
- Imitation - shock by the power of surprise.
- Rewrite her favourite story, stitched with real elements. Motivate her with her favourite tale and music.
- Organize programs for parents so her parents can meet with other parents who experiencing similar difficulties.
- Gaining the trust of the parents: listening to them, feeling that we fully understand them, summarizing their own thoughts, always taking the conversation forward with one question. Once the wanted relationship of trust has been established, it is nice to slowly involve a psychologist in the conversation.
- Provide childcare so that parents can have time off where they can concentrate to themselves.

Case 5 - Behavioral disorders

By Robert Coppes Foundation - the Netherlands

Case description

Client is a 44-year-old man. He is an only child in the family. Client was born with cataracts. As a child, client had surgery on his eyes, during which both his lenses were removed. Due to a metabolic disease, a thin layer of protein and calcium keeps growing on his cornea, which can only be removed surgically. Client has already undergone several corneal transplants. This leads to great fluctuations in his visual functioning. Also, he is known with cramp seizures, which probably can be explained by epileptic activity.

Client lives in one of the residential care facilities of the Robert Coppes Foundation since 1999. During this time, he has followed day care activities at different organisations. Due to his fluctuating visual acuity and seizures, he was not able to perform day care activities, and this stopped in 2009.

According to client, he has good contact with both parents. Client indicates that he is somewhat like his father, who is also an 'insider'. Client says he has not been able to cry for a long time, he keeps everything "inside". He indicates that he has been unhappy all his life and that he hates his life. According to client, this is mainly due to his physical limitations. Because of this he cannot do the things he would like to do. Client says he also has a "dark side" that surfaces regularly and that he has been suicidal in the past. Client states that there are only a few people he trusts in the world. In the past, his trust has been abused several times. People came late or did not keep appointments. Because of this he finds it difficult to trust people. The client indicates that he hates other people and would rather have nothing to do with them. He also avoids social contacts when he is not feeling well. At moments like this he does not trust himself and he is afraid that he might hurt people physically.

Client mostly spends his time at his apartment, playing video games. He has very little contact with the outside world. He has no friends and only contact with his support workers and immediate family. Client never attends social gatherings, such as coffee drinking or meals. Client avoids group meetings as much as possible. Client can communicate in a one-on-one contact in a fun and pleasant way, often also with humour. However, he only does this when he feels comfortable and has known the other person for a long time. Sometimes, it only remains a contact in the door opening or he does not open his door or closes the door immediately without saying anything. Also, when meeting the client in the hallway, he can ignore the support workers. In a larger group the client avoids all contact and isolates himself. In a small group, he can make a pleasant contribution to the conversation, but only on his own terms. People must listen to each other and keep agreements, when this does not happen, he is quickly disappointed. He then ends contact and isolates himself.

Advices on support and/or treatment mentioned in the group discussion

Here are some of the solutions or techniques what were discussed about this case:

- Find some activities or topics that interest him with information that he can manage. Try to communicate with him through his favorite video game. It is important to find out if playing video games is a hobby or a game addiction?
- His symptoms may point at a typical male depression. It is important to find if that is the case so maybe therapy could start.
- He may be distant because he had many losses in his life (his favorite teacher passed away; his psychotherapist changed). Could he have personality disorder? His psychotherapy continued so now he's slowly opening up
- He has passive-aggressive behavior. He keeps his feelings inside because he's afraid of his aggressive feelings.

- He has strict expectations about how the others should behave.
- Does he have his daily routine? We discussed how important it is for him to have a routine not just always playing with videogames, but plan to have at least one activity outside or within a group. He needs more positive experiences.
- Start positive experiences with family (he has a good relationship with his parents), then extend it to other parts of life.

Good Practice

for persons with a VI and behavioral disorders

It is important to recognize and diagnose ADHD in time, because it can cause aggressive behavior in adult age. It is important to explore what signal the person is trying to give with his aggressive behavior. To understand the behavior, take a broad and multifaced approach. By taking a mentalization based attitude we can help service users to release stress and regulate their emotions leading to a decrease in the need to show 'problem' behavior.

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THEME 4

Autism Spectrum Disorders

Theme 4: Autism Spectrum Disorders

Rittmeyer Institute for the Blind – Trieste – Italy, May 2022

Background information

Definition ASD

In this fourth meeting – the first in presence after the COVID pandemic lock-downs – different subjects were discussed: General overview on autism and visual impairments; Autism experience circuit; Autism, visual impairment and relations, intimacy & sexuality; and the impact of orientation and mobility on clients with visual impairments and comorbidities in the field of psychiatric and psychological disorders.

Expert's talk ASD

Prof. Tiziano Agostini – professor of general psychology at the University of Trieste, Life Sciences Department – Psychologic Unit.

Prof. Agostini highlighted the opportunities for cooperation between University of Trieste and Istituto Rittmeyer in the field of support towards people with visual impairments and comorbidities in the field of psychiatric and psychological disorders and the activities already realized in this field. Also, he focused his attention on the importance of the results achieved during Psycovia project.

Presentations on ASD

Italy

Autism and visual impairments in Italy (see also appendix 11: PowerPoint Presentation Autism Spectrum Disorder of Italy that focused on the definition and the situation concerning person with autism and visual impairments in Italy.

Croatia

Autism and visual impairments in Croatia (see also appendix 12: PowerPoint Presentation Autism Spectrum Disorder, Croatia) that focused on the definition and the situation concerning persons with autism and visual impairment in Croatia

The Netherlands

Autism Experience Circuit: it is an interactive opportunity to sensitize citizens and professionals and also participants to the world of persons with visual impairments and comorbidities in the field of psychiatric and psychological disorders through personal and concrete activities to be exploited.

Autism, visual impairment and relations, intimacy & sexuality (see also appendix 13: PowerPoint Presentation Autism and relations, NL) that analyses the way to gain knowledge and experience about autism spectrum disorder and relationships, intimacy and sexuality in combination with a visual impairment.

Quotes

"It is important to involve parents and other people in the environment of the client."

"I have learned about the steps and rules in dealing with autism and sexuality."

"Organizing the case-discussion in groups by language resulted in having feedback on each of the cases from different 'cultural' backgrounds. This is an interesting approach."

Case discussions

Case 1 - Autism spectrum disorder

By Robert Coppes Foundation - the Netherlands

Case description

Background information

Our client, Joost, is 24 years old and lives with his parents and sister. He became completely blind around the age of 13 within a period of six months. Before that there were no indications that this could happen. Also, the cause was only discovered after he was already blind. He was in special education because he has autism.

Joost has an above average intelligence and a great interest in science subjects. He had a lot of trouble putting energy into subjects he was not interested in. Because he became blind, he went to special education for visually impaired children. This was not tailored to children with his form of autism. Nevertheless, he thinks back of it with pleasure, because it challenged him intellectually, but he also liked the contact with the other students.

What is the problem/dilemma?

He obtained his diploma and is not sure what he wants or can do with his future. Gradually it became clearer that he also lacks skills that are necessary for him as a blind person to move around independently, both literally and figuratively. Part of this is the issue of mobility. For a long time, he lacked the motivation because he finds it useless to do something that does not directly benefit him. Learning a route just to be able to do it is not enough for him. It must lead somewhere. When the bigger picture became clearer, he was willing to take the step to get training. The mobility instructor did not know him personally but did know the background.

Joost clearly found it very nerve-racking. If you know him for a longer period of time, you will notice that because he falls back on logic. The result can be that he keeps discussing steps, agreements, goals, etc. that make sense to him. This did not make it any easier for the instructor.

It was agreed that he would learn a route to a building. That seemed to be useful to him. Joost walked independently with his cane. The instructor walked behind him. Part of this route was a busy crossing with a zebra crossing and a rattle ticker. The audible pedestrian signals signalled that the traffic light had turned green. Joost started walking. A motorist decided he could drive on. The instructor saw the danger and grabbed Joost by the arm to pull him back.

This intervention was so violent for Joost that he refused to participate in training afterwards. Being touched is extremely difficult for him. Unannounced physical contact is unacceptable.

Still, Joost has the need to become more independent (and then he thinks back to the time when he could still see and do what he wanted). He wants to participate in an activity outside the home. He sees this also as an encouragement to take up travelling again.

Questions

How can we make the training as good and safe as possible?

Advice on support and/or treatment mentioned in the group discussion

This is how the discussion went. The representative from The Netherlands presented the chosen case. After listening to it, the participants had some minutes to discuss together in sub-groups, in order to

prepare some questions, they should have for the contributor and with regards to the case and wrote them down. Each question was written on a different piece of paper. The questions have then been collected by the contributor, who read them all in front of all participants. The contributor made three sub-groups: Hot, Cold and Neutral and decided to put each question in one of the three groups. A question is Hot when it is an eye-opener, a new question to think about. A question is Cold when the contributor already knows how to answer. A question is Neutral if it is a new question of which the contributor does not yet know exactly what to do with. The contributor tried then to answer to the questions and participants could then reformulate in sub-groups (hot, cold, neutral) the problem based on the answers given by the contributor. Only at the end of the process there was a moment dedicated to a common discussion, during which the contributor listened while the other participants talked about what they had noticed about the case and the way the contributor dealt with it and talked about it.

No substantive notes have been received from the host of this meeting.

Case 2 - Autism spectrum disorder

By BFW Halle - Germany

Case description

Background information

Michael, age 30, male, Berlin, single no children, parents emotional distant but caring – living 200 km away.
3 days assessment in June 2012 - question: recommendation for return to work; client: pension insurance.
Macular dystrophy, Asperger's autism (mild symptoms), anxiety disorders, allergies.
School/profession/work: 10th grade with good results - professional qualification as IT specialist (2001) - website maintenance - training for the unemployed – 2004 - 2012: Call centre agent Deutsche Bahn (DB): 150 – 180 phone calls per workday (8 hours), open plan office with 120 persons, rolling shift work (3 shifts, few weekends), metrics: quality, speed, error rate always too slow, often criticized by boss, problems with colleagues, increased vision problems, circulatory problems/ collapses with emergency medical service, illness notes, exemption from work since May 2010.
2010: DB started employee assistance program, psychological and psychiatric reports (can't work in a call centre), Disabled Representative involved, legal dispute about a home office (not possible), last: application for occupational rehabilitation at BFW Halle 2012.
Assessment Results: verbal intelligence: above average, high accuracy, concentration and memory: good performances, needs optical and electronic aid/devices, needs psychotherapeutic treatment, RTW: internal transfer to archive or library e.g. – alternative: retraining as specialist for media and information services (collect, manage and maintain databases, classify, check, maintain and secure information = low demands for social interaction).
Then our job was over, we don't know how it went on.

What is the problem/dilemma?

In Germany there is actually good but fragmented system of support for health problems at work, as can be seen in this case. Help often comes late for complex cases like Michael K.

Questions

1. How would such a case go in your country?
2. How would Michael find a suitable job?
3. Which support would be available for Michael in your country?

Advice on support and/or treatment mentioned in the group discussion

The discussion went as described above in the Dutch case.

No substantive notes have been received from the host of this meeting.

Case 3 - Autism spectrum disorder

By Robert Coppes Foundation - the Netherlands

Case description

Background information

Client is an intelligent and active woman from 72 years of age. She has a visual impairment due to a birth trauma. Furthermore, she is hard of hearing (wears hearing aids), has diabetes mellitus type 2, osteoarthritis and experienced several cerebral visual impairments (CVI's). She has two sisters with whom she has a good relationship. Client went to special education and therefore grew up only partly at home with her family.
She lives in one of the residential care facilities of the Robert Coppes Foundation.
Structure and clarity are very important to client; she has an autism spectrum disorder.
Client experiences tensions in life; she tries to deal with these as best as she can. Her religion helps in this respect, as does taking trips on public transport to random places in the country.

What is the problem/dilemma?

Predictability is very important for the client, when situations don't go as planned it causes her a lot of stress. As a result of the Covid pandemic, this predictability can be less fulfilled. For example, care workers have to call in sick more often, which results in more changes in the timetable. In addition, there is a lack of personnel, which means that fixed moments of care cannot always be provided on time (for example, the joint coffee time starts 5 to 10 minutes later). This gives the client a lot of stress and makes her even more fixated on these moments. For example, 15 minutes before coffee time she is pacing in front of the office, and she repeatedly asks whether the coffee is ready. When the tension rises too high, the client loses control and may raise her voice, swear and hit. She can be easily guided in this and goes to her own apartment to calm down when the situation escalates.
Client finds it very frustrating that this happens and has decided to take daily tranquillizers, to reduce the tension. In addition, she has requested new sessions with her psychiatrist. I myself wonder how we can adapt elements in her system, so that she experiences less inconvenience from these changes/ uncertainties in the planning of the day.

Questions

1. How can we meet the client's need for predictability without that this becomes a rigid set of premises?
2. Are there other ways to help client in their need of predictability?

Advice on support and/or treatment mentioned in the group discussion

The discussion went as described above in the first Dutch case.

No substantive notes have been received from the host of this meeting.

Case 4 - Autism spectrum disorder

By Vinko Bek - Croatia

Case description

Background information

The client is a woman who was born in 1997. She has been blind since birth and lives with her mother and brother. She is very dependent on the help of family members in performing most of her daily activities. She completed the special education program for acquiring competencies in everyday life

activities. She is not able to work, and she attends our Center in order to maintain the acquired skills and abilities.
She is focused on her routines, from which she often finds it difficult to deviate. She likes religious topics and listening to biblical and other stories, which she then mechanically repeats without understanding the content. She repeats various other phrases and always addresses the same people in the same way. She does not want to participate in new activities or learn new content that would allow her to function more independently. Deviations on the emotional level are also visible in the form of expressing a certain indifference when talking about emotional experiences, for which an emotional reaction is expected, or she is expressing her emotions too intense (adequate emotional reaction is missing, not expressed in an expected way). If something upsets her (deviating from the routine or encouraging something she does not want), the client has a very emotional reaction, shouting and intensifying the otherwise present stereotypical waving of arms and rocking the upper body.
The client has a problem with sensory perception in certain work activities, she does not accept materials: clay and felted wool. She is selective and picky in her diet. From her friends in the group, there are people with whom she is more connected (they are the ones with whom she spent her childhood in primary school), while she respects older users in the group, but does not show interest in socializing. It should be noted that she sings beautifully and participates in support programs: music therapy, physiotherapy, and kinesitherapy.

What is the problem/dilemma?
The biggest problem in her functioning is returning to the Institution after a long absence, which is manifested by vomiting while driving and refusing meals. Since it has been her fourth year in the program, the driving episode is repeated and lasts up to approximately three weeks. The client is looking forward to returning to the group, the cooperation with her mother is excellent and with all the efforts of preparing to return to the program, she always reacts in the same way.

Questions
1. How to encourage the client to accept changes in the environment?
2. How to expand her interests and encourage the client to try some new activities that will allow her greater independence?
3. How to make it easier for the client to deal with intense emotions (expressing emotions in an adequate way)?
4. how would you help her return to the group after a long absence (to avoid psychosomatic problems, vomiting)?

Advice on support and/or treatment mentioned in the group discussion
The discussion went as described above in the first Dutch case.

No substantive notes have been received from the host of this meeting.

Case 5 - Autism spectrum disorder
By Budapest School for the Blind - Hungary

Case description
Background information
John is a 17-year-old boy with low vision. With glasses he can read 14 font size. He does not have autism spectrum disorder diagnosis, but his social and adaptive behaviour shows that he is most likely to be on this spectrum. His intellectual ability is between normal and disordered.
He is living with his parents. He also has 5 adult half-siblings, but they meet with each other every weekends. He is living in a religious family. They have a good relationship with each other, but their parents cannot accept John's maturation. According to his mother, he follows the rules at home, he

doesn't have any grave behavioural problems, but he usually does these things: he takes off his pants in a public place before he enters to the bathroom, he is untidy in his room, he screams a lot, he puts on his clothes inside out and mixes up the shoe sides. He plays on his computer almost all the time, he helps only when asked. At school we also experience the same behavioural problems and more.

What is the problem/dilemma?

He always gives orders to his classmates (he repeats the same things what teachers would expect, but he does not use the sentences adequately). He screams during and between the lessons. He always argues with teachers and student about basic facts (e. g. 5x4 is not equal to 20 but to 18). He always puts his hand into his pants.

He is very unorganized, he leaves his belongings (waste, books, leftover food, dirty napkins etc.) on the table. He also forgets where he put his things and he also looses them. He chews a lot of things (pencil, earphone's cable).

We use lots of visual assistance, "yelling scale", step by step description (written and pictures), class rules, and reward systems. Visual assistance for organizing his belongings in the classroom.

Questions

1. How can we manage him to understand that he causes issues for his social environment with his behaviour problems?
2. How can we manage the parents to understand and accept their son's social difficulties?
3. What else can we do to help him fit in his class?

Advice on support and/or treatment mentioned in the group discussion

The discussion went as described above in the first Dutch case.

No substantive notes have been received from the host of this meeting.

Good Practice

for persons with a VI and autism spectrum disorders

Having a combination of a visual impairment and autism spectrum disorder can be experienced as a challenge. Visual ques cannot (or only partly) be used within this client group. Therefore, looking for other ways to present concrete and clear information is very important.

BFW BERUFS FÖRDER
RITTMEYER
Robert Coppes Foundation
Co-funded by the Erasmus+ Programme of the European Union

THEME 5

Depression and anxiety

Theme 5: Depression and anxiety

BFW – Halle – Germany, September 2022

Background information

Definition

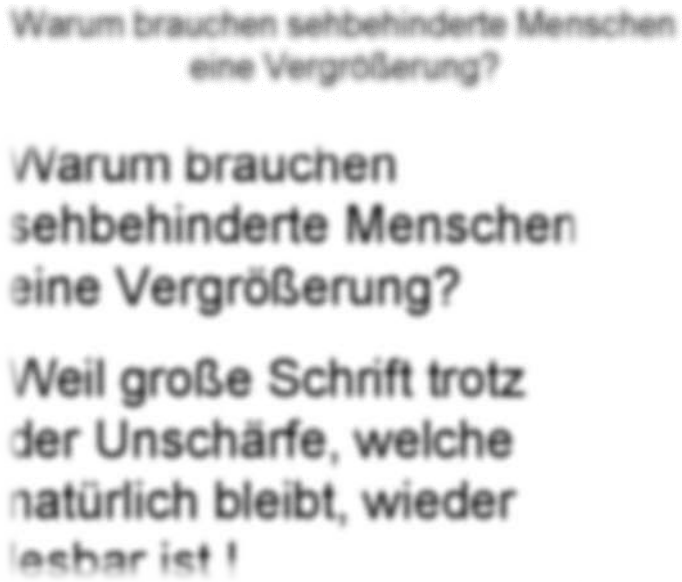
Affective disorders are changes in moods. Thinking, feeling, and acting are subject to depressed or manic moods. We do not talk about the opposite - mania:

1. intense high feeling,
2. excessive and often unfounded good mood,
3. increased personal performance
4. persons suffering from Mania perceive themselves as extraordinarily powerful and creative and
5. have only a very low need for sleep and rest.

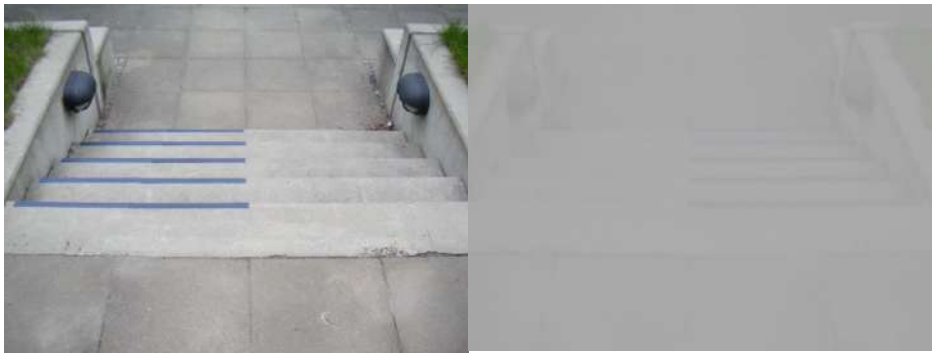
Expert's talk

Frank Kieβling, BFW, Influence of mental illness on visual functions

Why do visually impaired people need an enlargement? Because larger fonts are better recognized!



However, not only the size is important. People who suffer from depression have lower contrast vision than people who are not affected by it. Contrast vision disorders: In everyday life, information is seen worse…one Example…

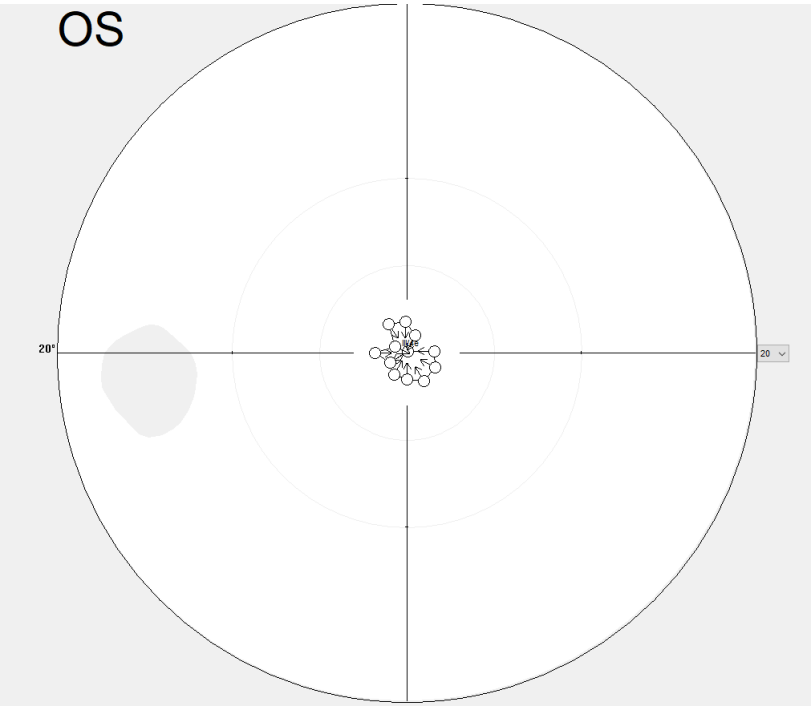


People who suffer from depression have functionally lower vision in all everyday situations, such as:

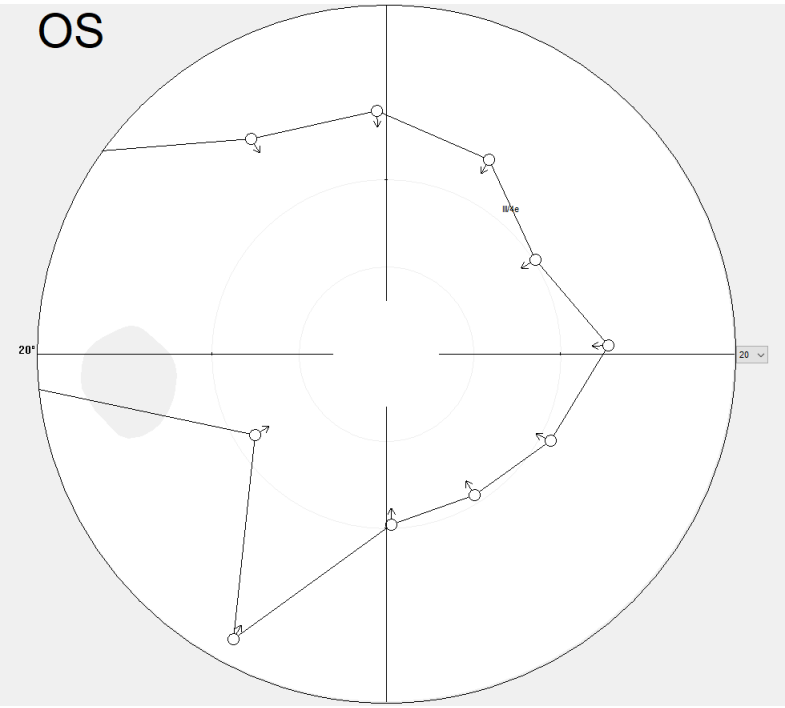
- worse results in visual field examinations
- slower reading
- disturbed accommodation
- mobility in everyday life

In the case of the depressed, the measured response was on average only half as strong as in healthy control subjects (Bubl, E. et al.: Seeing Gray When Feeling Blue? Depression Can Be Measured in the Eye of the Diseased. In: Biological Psychiatry 10.1016/j.biopsych.2010.02.009, 2010)

Visual field participants with depression and after treatment retinopathy pigmentosa showed worse results with depression due to slowed reaction …



… and better results after a depression treatment



We can find the same results with measure the reading speed using Irest.

Likewise, medications affect vision. Basically, all centrally acting drugs such as

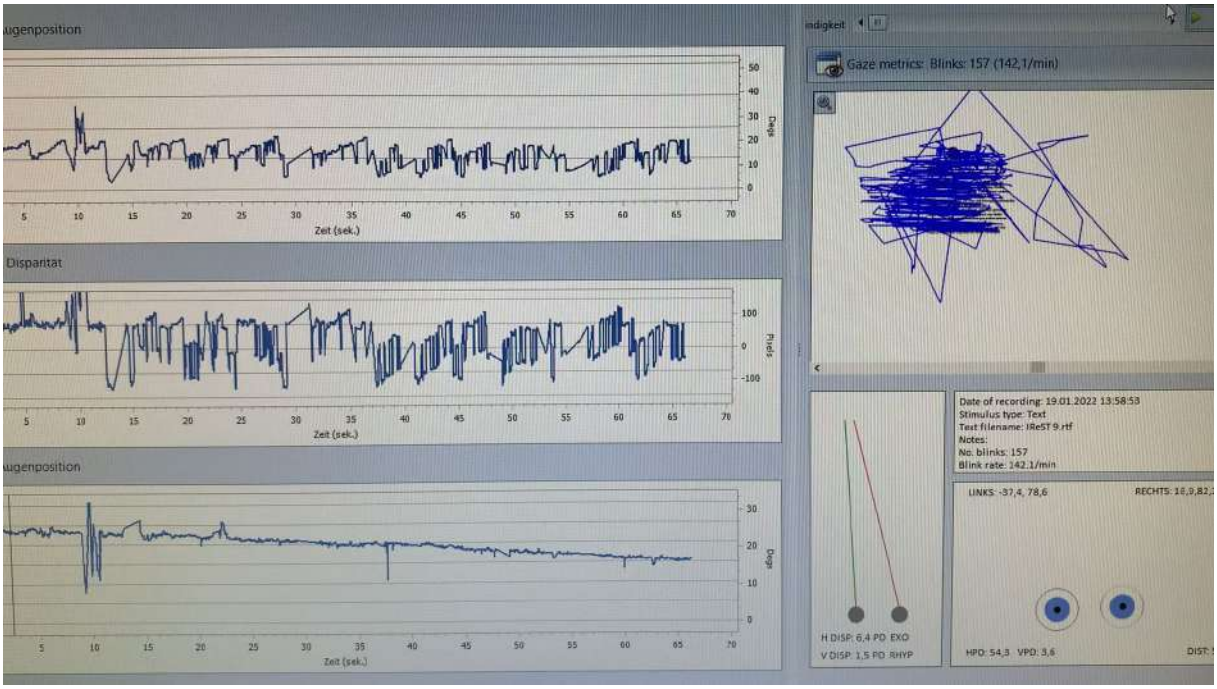
- anticonvulsants;
- psychotropic drugs;
- drugs,

... cause eye movement disorders, such as

- slowed saccades;
- excessive saccades;
- paresis;
- convergence spasms.

We have good experience with functional measurements with eye tracking.

- A good way to measure and compare eye movements is eye tracking.
- Data on eye movements provide valuable insights into written language comprehension.



What should be considered when measuring visual functions?

- Always work together interdisciplinary.
- Always question your results.
- Carry out several measurements and not only the visual acuity is important.

Presentations

Germany

André Kunnig, BFW, Understanding depression

What is a mental disorder?

- Pathological changes in experience and behavior.
- It may be accompanied by abnormalities in perception, thinking, feeling, or even self-perception.
- Mental disorders are typically associated with significant personal distress or stress and problems in several areas of life.

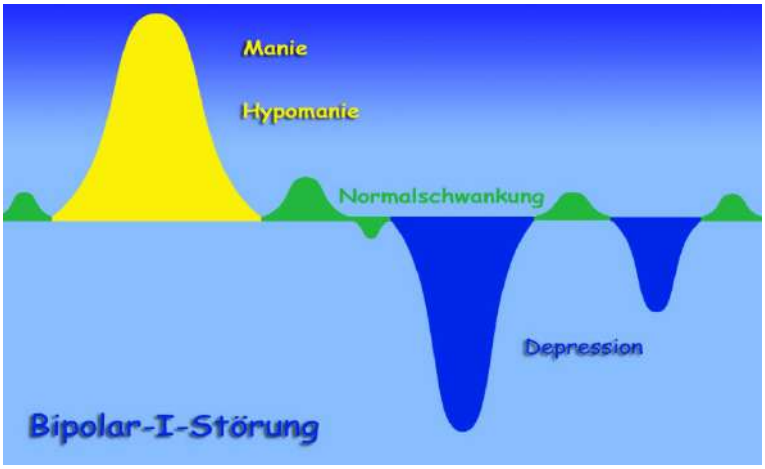
Essential

- Reduced self-regulation competence.
- Self-regulation means ''having ourselves in control'' and making decisions about our actions Impulse and affect control, as well as hierarchization of intentions.
  It is about the extent to which we not only react to external conditions or follow the impulses of our needs, but how we decide for or against one or another behavior. Self-regulation, then, is the process by which we control and direct our own behavior in order to achieve desired goals, thoughts, and feelings.
- You can only influence the disease with difficulty or not at all, even through increased efforts, self-discipline.

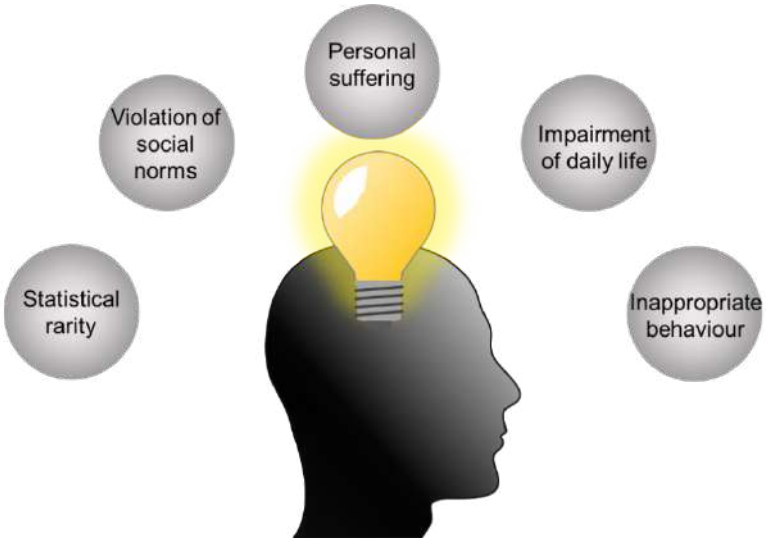
Consequences

- Problems in coping with everyday life; or
- Impaired social relationships;
- Difficulties filling social roles as before.

Not every deviation from what is considered as a normal experience is a disorder with disease value



So, the question is: What constitutes a mental illness?



So, what is depression?

- Depression is a serious mental illness that can occur at any age;
- patients feel down, low-spirited;
- … lose their interests and are exhausted and unmotivated, lethargic;
- the illness persists for a long time and usually does not improve on its own without treatment.

Depression causes

- emotional: depressed, sad mood;
- cognitive: negative self-concept, self-blame, rumination, loss of concentration;
- behavioral: change in activity level (retarded vs. agitated);
- motivational: loss of interest and drive, inability to make decisions;
- vegetative: insomnia, loss of appetite and libido.

Male Depression! There are differences in the expression of symptoms by men versus women with depression; men show atypical symptoms: fury, anger, aggression, alcohol or drug abuses.

Depression is

- one of the most common diseases;
- the causes and mechanisms of development are still unclear;
    - the peak of the disease is now between the 18th and 20th year of life (previously between 30th and 40th);
    - women are twice as likely to suffer from depression as men;
    - other factors: physical illness, poverty, no relationship;
    - there are neurobiological connections;
- but in the end – depression is always multifactorial: there are psychosocial AND neurobiological factors: a genetic predisposition interacts with a stressful and overwhelming situation.

What does depression mean in the field of visual impairment? There are different ways.

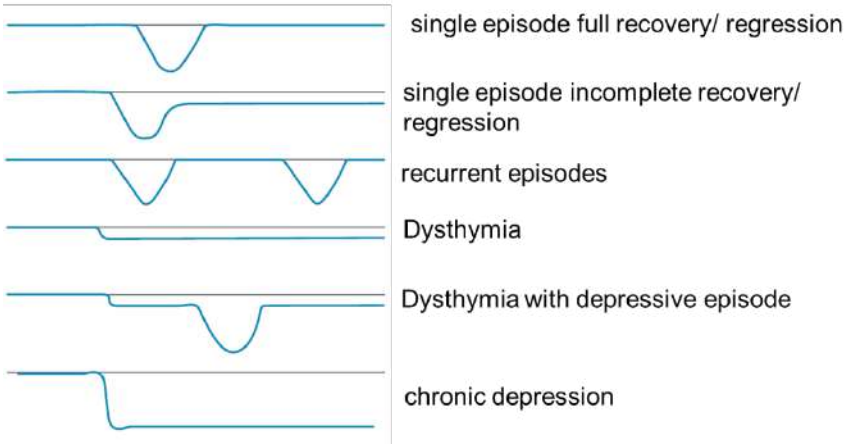
- You can have both independently of each other - depression and visual impairment.
- You can get a depression because of a visual impairment: Loss of opportunities, loss of one of the most important senses, loss of job, relationship ...
- You can have a depression and a visual impairment due to a physical disease (brain damage).
- You can have a depression and a visual impairment due to permanent psychophysical stress (stress leads to depression and affects some eye diseases too (glaucoma, diabetes, central vein occlusion in the eye).
- You can have vision problems due to a drug treatment against depression (dry eye, hormonal changes).

This can be an important indication for focusing the therapy or treatment. There is not only one type of depression - there are many different ones! So, it is important to have a good diagnosis:

- to distinguish depression from normal fluctuations of emotions;
- and to get an indication of more genetic and physical causes or of strain, stress, a loss or bereavement.

Different approaches are needed for the same external disorder pattern.

Depression – different courses are possible.



What kind of treatment would help?

- Important are drug treatment and psychotherapy.
    - Drug therapy is still trial and error - it is not known how, if and which medication can help.
    - Psychotherapy often has a longer-term effect.
    - A combination is often good.
- Basically, different factors of psychotherapy are assumed to be effective:
    - First and foremost, a functioning therapeutic relationship;
    - In addition: resource activation, problem actualization as well as problem solving and motivational clarification.

These are mechanisms that can be used effectively against depressive symptoms - independent of the various therapeutic approaches.

Germany

Johannes Werres, BFW, Anxiety

What types of anxiety disorders are there? International Classification of Diseases, 10th Revision Chapter V: “Mental and behavioral disorders”

F40 Phobic anxiety disorders (great fear is evoked in certain well-defined situations that are not currently dangerous e.g. elevators).

Examples:

- Agoraphobia: Situations that are not currently dangerous; intense fear of being overwhelmed or unable to get help (e.g. leaving home, shops, crowds and public places, public transportation).
- Social Phobia: Fear being judged or scrutinized by others leading to avoidance of social situations.
- Specific (isolated) phobias: Phobias restricted to highly specific situations such as proximity to particular animals (e.g. dogs - cynophobia), heights (akrophobia), flying (aviophobia), dentistry (dentophobia), or the sight of blood (haematophobia).

F41 Other anxiety disorders (not restricted to any particular environmental situation e.g. recurrent attacks of panic).

Examples:

- Panic disorder: intense, sudden panic attacks - unpredictable.
- Generalized anxiety disorder: extreme and unrealistic worries about various topics, including health, work, school, family etc. You may feel that the worry continues from one thing to the next.

Prevalence: How often in 12 months/ lifetime; US epidemiological surveys 2012 (rounded):

	within 12 months	**lifetime**
Specific Phobia	10%	14%
Social Phobia	8%	13%
Panic Disorder	3%	5%
Agoraphobia	2%	3%
Generalized A. D.	3%	6%

How often does this occur in blind people or persons with visual impairment. A study from Germany (Nelles, M. 2015, doctoral thesis) found clinically relevant symptoms (rounded):

- Social fears 42%
- Depressions 40%
- Generalized anxiety 35%
- Panic 7%

The numbers show once again how important our common PsyCoVIA topic is. We also have gender differences: 2 (female) : 1 (male). Women are twice as likely to be diagnosed with an anxiety disorder than men.

Why? (theories)

- Women talk more about mental health problems.
- Men face more fear-inducing situations (role-specific) = “exposure therapy”.
- Biologically induced stress appears to be more pronounced in women (Olff et al.,2007).
- Men have stronger beliefs that they can control their situation (gender-specific education)

How does a mental disorder work? How does an anxiety disorder work? In any mental disorder we can distinguish four components.

1. behavior that is visible from the outside;
2. physical reactions/body (pulse, breathing, vision, pain, etc.);
3. our feelings; and
4. our thoughts.

Now, thinking back to our little experiment, including my previous tip about collapsing, what did you feel and think? Now imagine a person whose heart is beating faster and who thinks they are going to have a heart attack. What do you think will happen? If you were treating a person with an anxiety disorder, where would you start?

- Behavior
- Physical reactions
- Feelings
- Thoughts

Dysfunctional cognitive schemas: The physical reactions are interpreted mentally and confrontation and exposure.

The Netherlands

Edine van Munster, RCF, Detection of depression and anxiety – How to deal with underdetection?

There are barriers in detection and recognition of depression and anxiety in visually impaired and blind adults

Patient Health Questionnaire – 4

- Screening instrument
- No knowledge needed
- Translated to 25 languages

	Over the past two weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half of the days	Nearly every day
Anxiety	Feeling nervous, anxious or on edge	0	1	2	3
	Not being able to stop or control worrying	0	1	2	3
Depression	Little interest or pleasure in doing things	0	1	2	3
	Feeling down, depressed or hopeless	0	1	2	3

0 – 2
No complaints

Over the past two weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half of the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed or hopeless	0	1	2	3

0 – 2
No complaints

3 – 5
Mild complaints

Over the past two weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half of the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed or hopeless	0	1	2	3

0 – 2
No complaints

3 – 5
Mild complaints

6 – 8
Moderate complaints

Over the past two weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half of the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed or hopeless	0	1	2	3

0 – 2
No complaints

3 – 5
Mild complaints

6 – 8
Moderate complaints

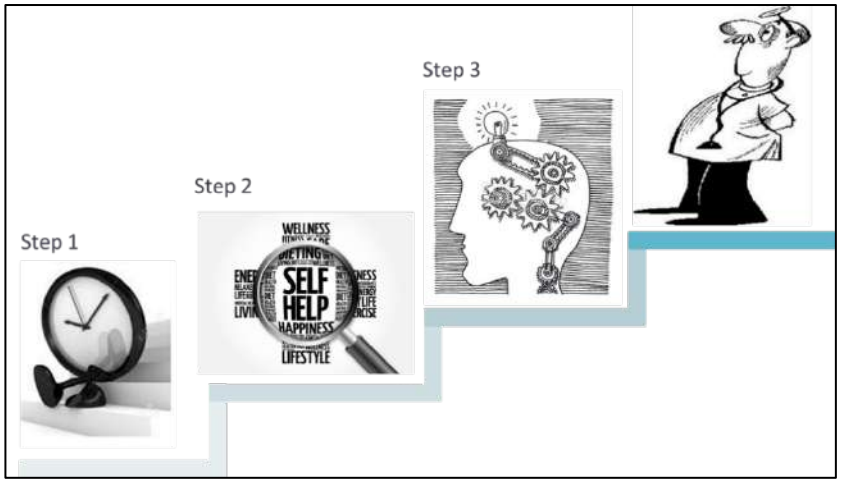
9 – 12
Severe complaints

Over the past two weeks how often have you been bothered by the following problems?	Not at all	Several days	More than half of the days	Nearly every day
Feeling nervous, anxious or on edge	0	1	2	3
Not being able to stop or control worrying	0	1	2	3
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed or hopeless	0	1	2	3

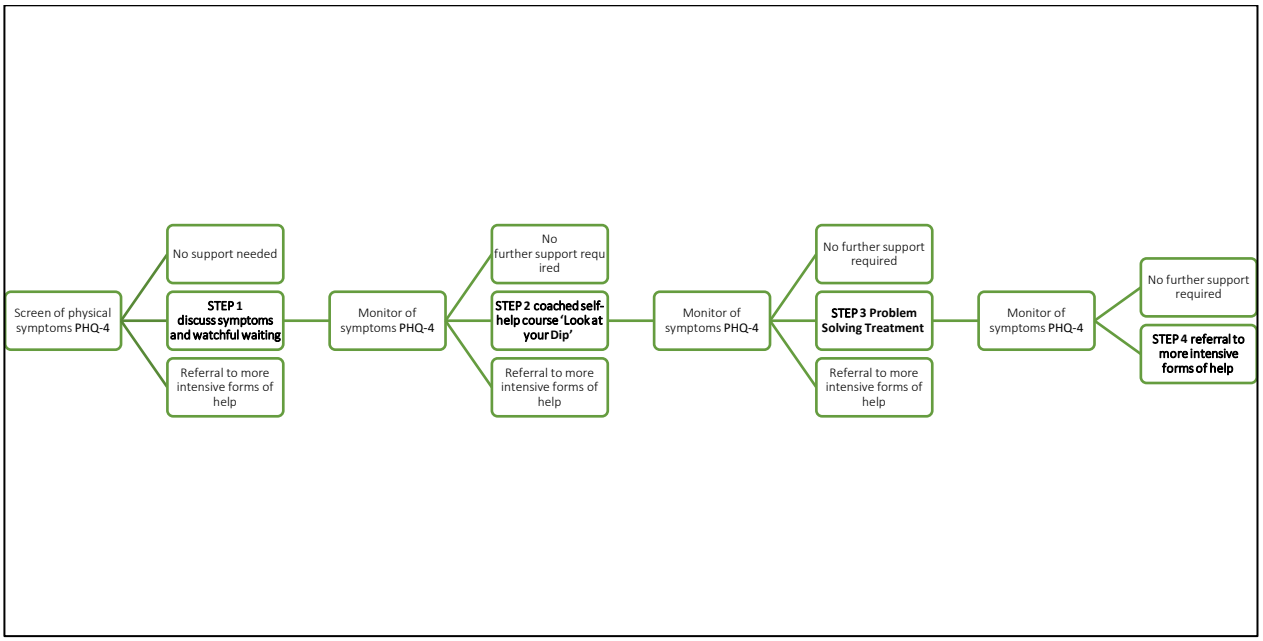
The Netherlands

Pascale Dammers, RCF, Stepped-care for adults with visual impairment and depression and/or anxiety symptoms.

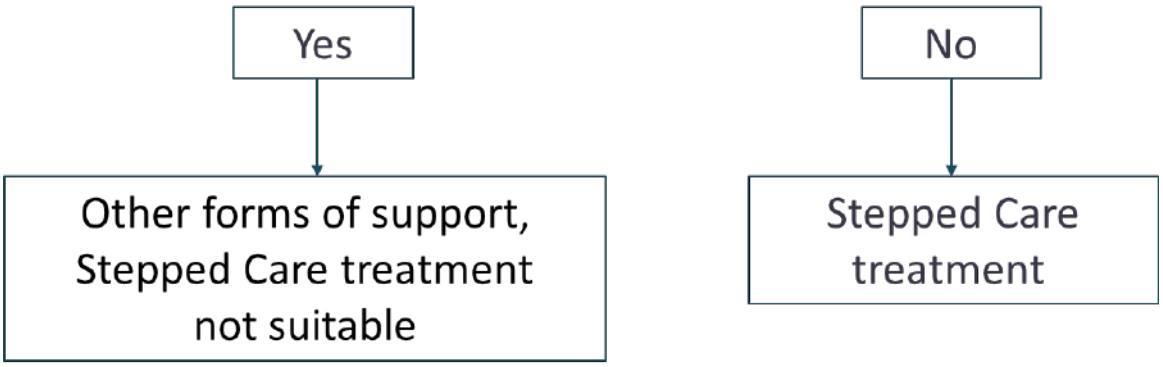
A step by step treatment for older adults with visual impairment and depression and/or anxiety symptoms



Decision tree:



Have you had a diagnosis of depression or anxiety disorder in the past?



Step 1 Watchful waiting

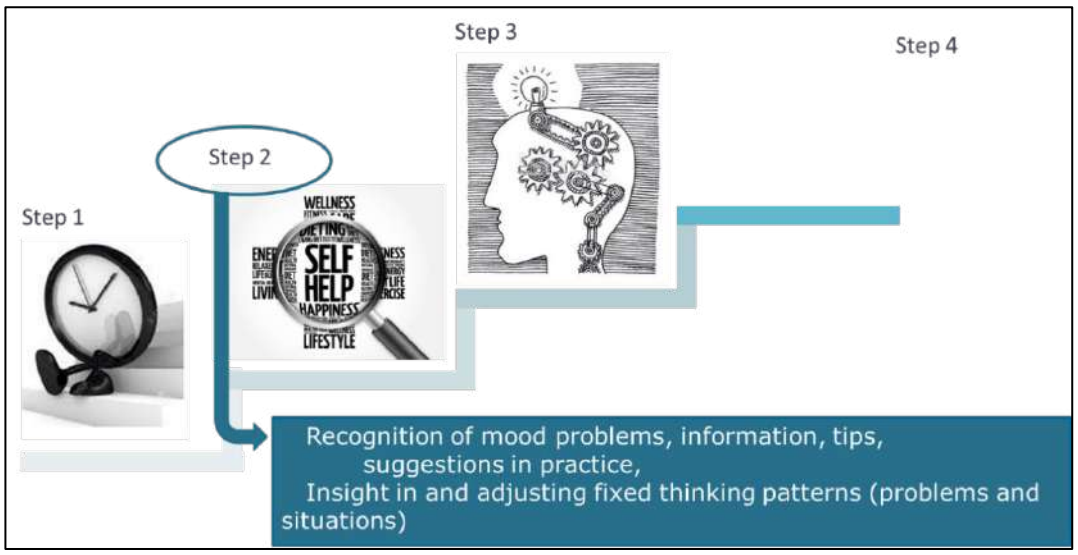
Starts with a period of watchful waiting.

Mood complaints can improve spontaneously.

Acknowledging the feelings is a very important first step for reducing these feelings. Take time for this.

This period of time is 1 month.

Step 2



A custom course for the elderly with complaints of depression and anxiety.

Available in book form (big font style), on Daisy CD, in Braille and digital (YouTube).

"Look at your Dip" follows a programme of 7 weeks, but clients may also take longer. We assume that the majority of clients have completed the course within three months. They can set the pace themselves. Every week they read about new insights and skills and can learn from them.

The weeks are divided as follows:

Week 1: **How do you feel?**

Week 2: **Recreation**

Week 3: **Enjoyable activities**

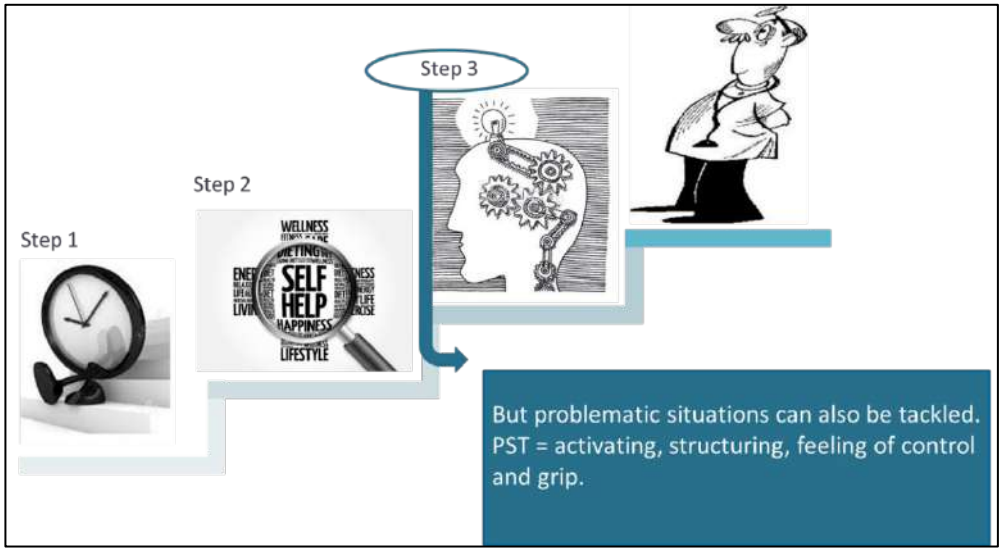
Week 4: **Thinking and feeling**

Week 5: **From negative to positive thinking and feeling**

Week 6: **Resilience**

Week 7: **Facing the future**

Step 3



Problem Solving Treatment

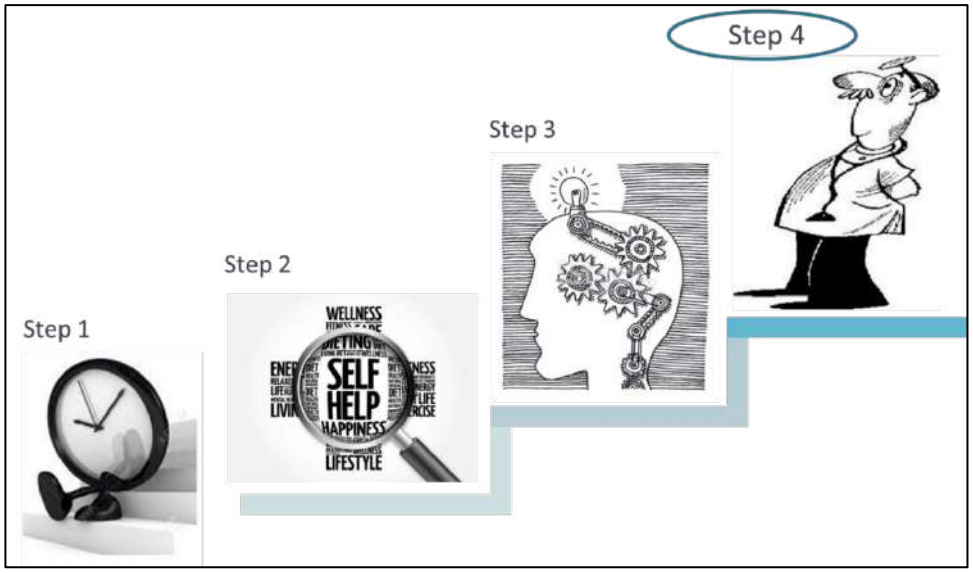
In the case of PST, problems are investigated and viewed, via seven steps, or address them or can be (partly) solved. Surprisingly more often than one thinks is to exercise some control on situations where this was previously the case seemed impossible.

The 7 steps of PST

- Explanation of rational and treatment;
- Problem definition;
- Setting achievable goals;
- Generating solutions, brainstorming;
- Discussing pros and cons;
- Choosing solution(s) and creating an action plan;
- Evaluate.

Step 4 – Refer

- Discuss in multidisciplinary consultation
- Referral General Practioner (GP)
- Use referral letter



Quotes

"The presentations and discussions helped me to categorize the knowledge of anxiety and depression."

"It was a great working atmosphere; the group worked well together; there were good theory inputs and a good alternation between theory, case discussions and other experiences."

"While there is often a connection between VI and depression or anxiety disorders, both influence each other. However, a strong manifestation of the mental illness makes it very difficult for VI people to cope with everyday life, so that their treatment must be a first priority."

"The awareness that colleagues in other countries are struggling with the same issues."

Case discussions

Case 1 - Depression

By BFW Halle - Germany

Case description

Mr. K. is 37 years old. He suffers from Leber Hereditary Optic Neuropathy - a hereditary disease that leads to a change in the nerve cells of the eye and a rapidly progressing deterioration of vision (regular visual acuity at the beginning of 2019, currently only perception of hand gestures). Further diagnoses are recurrent depressive episodes, condition after alcohol withdrawal 12/2019, nicotine abuse and hypothyroidism. Mr. K. is single and, due to his illness, is now living again with his parents in a medium-sized city, as he is very dependent on their help. Besides contact with his sister, he additionally has a supportive circle of friends. Since the beginning of 2020, he has been training with a long cane. He continues to find it difficult to get around in unfamiliar surroundings, and he is not yet able to use public transport independently. Given his medical diagnosis, he was first retired, but later started his vocational rehabilitation at BFW Halle in January 2022. Currently, his main interest is to learn the profession of a state-examined masseur. In his free time, he regularly goes jogging on a well-known route. He also enjoys traveling and active holidays.

What is the problem/dilemma?

Describe the problem or dilemma in the case

Mr. K. has been suffering from depression for a long time. The additional blindness is another heavy burden for him. Not being able to do things by himself is quickly frustrating him - "the blindness is annoying". Asking for help as well as talking about himself is generally difficult for him. However, he is quite capable of implementing professional recommendations and acting upon them. In addition, Mr. K. often feels uncomfortable in performance and group situations. Despite medication and regular professional support (including psychological services at the BFW, psychotherapist sessions every 14 days and psychiatrist appointments every 2 months), his mood continues to fluctuate. There are repeated absences from training (approx. 25%) and thus there are learning gaps that could only be closed with additional support. In June 2022, he was recommended another stay at the clinic for stabilization and medication adjustment. However, he’s requested to be hospitalized earliest in January 2023 (which marks the end of the blind-technical basic rehabilitation training at BFW Halle), in order not to miss his vocational rehabilitation training. Because of his eye disease Mr. K. takes part in an innovative gene therapy. He has very high hopes of a successful outcome. So far, however, there has been no improvement in his vision - which again is very disappointing for him.

Questions

1. To what extent do you see the success of Mr. K.'s rehabilitation currently at risk?

In your opinion, is a stay in a psychiatric hospital a priority at this point in time?

2. Is the profession of a state-examined masseur suitable for Mr. K? What speaks for it, what speaks against it?

3. What possible resilience factors could help Mr. K. in dealing with his blindness (in particular: how could he lower his high self-expectations and increase his frustration tolerance)?

4. Is the ongoing gene therapy - with open result - hindering or helping him to cope with his disease?

Advices on support and/or treatment mentioned in the group discussion

Question 3: What possible resilience factors could help Mr K. in dealing with his blindness (in particular: how could he lower his high self-expectations and increase his frustration tolerance)?

Answers: Gene therapy. Explain meaning to him, define goals, strengthen his acceptance of the situation. Promote peer work. Mobility training (sudden success is guaranteed).
Situation related learning. Make clear he is not the only one in such a situation. Doing some work can be helpful.

Case 2 - Anxiety disorder

By Rittmeyer Institute - Italy

Case description

Background information

Andrea is 28 years old, he is a computer scientist, broke up with his girlfriend a few months ago, his parents live in another region. His parents are very caring and visit him as soon as they can. A. has an older sister with two young children with whom he has always had a difficult relationship. The sister lives near their parents who are now retired and have decided to move to help her with the children. A. has glaucoma in both eyes discovered in early 2020: this condition has been quite aggressive in the last years and is leading him to severe peripheral low vision in a short time. The glaucoma, together with the pandemic situation and the risk of job loss, led A. to suffer from anxiety disorders that have been driving him to isolate himself for some time. A. has more difficulties getting around the city using public transport (he has not been using a car for the last 3 months) as there has been a consistent reduction in his visual field. A. also has always been a sporty boy and has played tennis competitively, but since he has lost much of his sight, he leads a rather sedentary life.

What is the problem/dilemma?

Andrea's employer (in agreement with the boy) has approached Rittmeyer to support the boy undergoing rehabilitation in the field of typhlology. They would like to support A. since the boy is no longer able to come to work independently and cannot perform his duties adequately. A., however, has great difficulty accepting his medical condition.

Questions

1. How would you deal with the situation?

2. Try to identify the steps you would follow to investigate the case further.

3. How could A.'s passion for sports be used for therapeutic purposes?

4. What kind of planning would you propose to the boy's employer and family?

Advices on support and/or treatment mentioned in the group discussion

Question 3: How can his sports passion be used for therapeutic purposes?

Answers: Depending on the kind of glaucoma: find a sports community, define sports as a meaningful part of your life. Find a peer with or without a handicap. Move to family. Promote his independency. Work from home possible? Cognitive and behavioural therapy useful?

Case 3 - Anxiety disorder

By Robert Coppes Foundation - the Netherlands

Case description

Background information

Lis is a woman of 44 years with a visual impairment, who always looks very well groomed.

She has several physical problems such as bladder problems, iron deficiency, chronic asthma, sleep problems, weak ankles and knees and a spastic gut. She receives medication for her physical problems as well as antidepressants and sleep medications. She has had psychiatric treatment to help her deal with her traumas in the past. This has helped in part.

Her personality has been shaped by a traumatic past. Lis has an anxiety disorder which causes her to experience limitations in all areas of life. Because of this she needs a clear and predictable life. She has individual day care 2 times a week. When she was younger, she worked at a day care center for a few years, but this became too heavy for her emotionally.

Lis is not able to solve problems by herself. Often, she has thought of a solution but is unable to arrange it without guidance. Lis suffers from a lot of stress. Especially when things do not go according to her expectations. Lis experiences the most trouble because of her dependence on others, due to her limitations. This keeps her from doing things. She feels burdened because she must ask others for help with certain things.

Lis has broad interests; she follows the news, soccer and politics. Equality is very important to Lis. Lis is an intelligent woman, but she is uncertain in life. Lis can be sociable and has a sense of humor. She has a very small social network. There is no contact with the family.

What is the problem/dilemma?

Lis has lived in a residential facility for almost 30 years and will most likely live there her entire life. Because of her complex psychiatric problems, she is unable to live independently. She is intelligent and very well aware that her life is different from that of most women of her age. She says she has no perspective; “in 10 years' time my life will still look exactly the same”. Nothing is going to change. Sometimes she says that life is no longer necessary for her. She has no vital depressive features but does find life difficult.

Questions

1. Do you recognize this problematic picture and does it occur to your clients.

2. How do you deal with it?

3. Do you have tips/ideas on how to deal with this client?

4. Would you treat this client? Have conversations with her? What kind of treatment?

Advices on support and/or treatment mentioned in the group discussion

Question 3: Do you have ideas how to deal with this client?

Answers: Define realistic goals. Cognitive therapy. Concentrate on the 4 parts of anxiety theory. Other forms of therapy like animals, music, future work, writing…
Make friends, non-handicapped as well. Activities outside her residential facility. Meet the family. What about religion?

Case 4 - Depression

By Vinko Bek - Croatia

Case description

It is about a woman aged 44. She is visually impaired and in addition to visual impairment, she also has a hearing impairment (she wears a hearing aid). When she came to stay at our Center, she was taking antidepressants, a very small dose. She said that she went to see a psychiatrist privately when she realized that she "wasn't going any further". She describes a period of time lasting approximately two years, when she was tied to the house and didn't do anything, didn't go anywhere, didn't socialize and didn't have the will to do anything. She did an administrative job in a private company, but her eyesight deteriorated, and she could no longer work. After the termination of the employment relationship, a state occurred that she herself calls a depressive state. In addition to the depressed mood, there was also a loss of interest in activities that used to make her happy (traveling, socializing with others, going out, etc.), there were also difficulties with sleeping (insomnia), and there was psychomotor restlessness (agitation, she could not calm down, find her peace). Her self-image is very damaged, she has fragile self-esteem, and she has a constant need to prove her own worth, which often leads to inappropriate behavior.

She is university-educated, in a very good financial situation, lives with her parents and brother who run a restaurant (family business), but she also has her own apartment in Zagreb, which she rents out.

What is the problem/dilemma?

The client was included in the psychosocial rehabilitation program, during which she was accommodated in our Center. The adjustment was difficult due to her resistance to the Center's rules, but she got along well with another client who was staying at our Center during that period, so this somewhat helped her to adapt more easily.

The client had a hard time accepting the long white cane and was visibly uncomfortable when using it. In traffic and in public spaces, when using a cane, she behaved quite frivolous and immature, joking about the situation, waving the cane or leaning on it as if she were supporting herself. She would deliberately hit people who passed by or things the outline of which she could still see, just to see how someone would react in that situation.

Sleep difficulties were still present, which is why she was taking pharmacotherapy, but since we were not in contact with a psychiatrist, we could not monitor whether the client was following the expert's instructions. As the time of her stay in our Center passed, she reduced the use of medication, saying that she felt better and no longer needed the amount she was taking initially. In the end, she stopped taking the therapy altogether.

During her stay at our Center, the client had a constant need for activities. She was very restless and in addition to the activity schedule that was agreed with her, she often asked for additional activities, additional dates for rehabilitation programs, etc. She had a hard time coping with the free time she had for herself, with her thoughts, and had a hard time relaxing.

Her unstable self-image and very fragile self-esteem required constant confirmation of her worth, and she tried to achieve this in inappropriate ways. Thus, she flirted with some employees and clients in a completely inappropriate and unpleasant way, looking for confirmation that she is attractive and interesting to others; she did the tasks of other clients and helped them even in situations when they should have done it themselves for the purpose of their rehabilitation, etc.

Questions

1. What is the correct diagnosis? Or even more diagnoses?

2. What do you think is the priority in working with the person described?

3. How would you approach such a client and how would you set boundaries?

4. How to prepare the client to return to her home and prevent the return of depressive symptoms?

Advices on support and/or treatment mentioned in the group discussion

Question 3: How would you approach a client and how would you set boundaries.

Answers:

- Check Borderline Diagnosis; Check thoughts of suicide.
- Create a team to support her.
- A treatment plan is needed; a psychiatric treatment needed.
- Avoid a divided care team; the team must be a unit.
- Maybe the environment in Zagreb is better; maybe also the support given by parents and siblings is.

Case 5 - Anxiety disorder

By Budapest School for the Blind - Hungary

Case description

John, 17-year-old, 9th-grade blind (dg.: Retinoblastoma) obese boy. He is currently a student at an elite high school and has been studying integrated for a year. His academic results are outstanding. He is a boy of high intelligence, quick perception, excellent memory. He is extremely sensitive. His urge to talk is very strong, and he tends to exaggerate. Due to his illness, he receives constant medical control. John is interested in everything that happens in the world, and specifically looks for news about disasters and accidents. He is prone to being phlegmatic and swearing and has a great sense of humor. While he studied in a segregated school, he was a college student for a while. Since he didn't like being a college student (he was afraid of the fire alarm at night, and he missed his family a lot), his mother started to bring him to and from school every day (so his fears of traveling intensified). Since he does not take elevators or subways; they had to use detours.

When John was in high school, he was strongly confronted with his addiction, his vulnerability, and the disadvantages of his blindness ("it annoys me that others can see," he said). He was extremely jealous of his rich mates. Now that he has successfully integrated, he has calmed down a bit, but he is learning a lot, and his desire to prove himself is huge. Listening to music, listening to the radio, and running calms him down. From this school year, he is playing goalball again. He is excellent at using the computer. He was a school radio operator at the school for the blind and currently works with a sighted colleague.

Family situation: The family lived together until John was 5 years old, quarrels and acts of violence happened. They moved a lot and lived in poor condition (he was afraid at one time that the house would collapse on him).

Now he lives with his mother and stepfather and has a 10-year-old half-brother who is severely mentally impaired. He has a good relationship with his stepfather. Quarrels occur between the parents,

and they also drink. Their financial situation is bad. The stepfather works a lot, and the mother is at home with their joint child. His mother has epilepsy and is generally in very poor physical condition.

John worries a lot about his mother's health. He loves his mother very much, her word is final in everything, but at the same time he sees through when his mother is wrong, etc., he is mentally on a higher level.

What is the problem/dilemma?

His anxiety is also manifested in the tearing of the skin on his fingers (his fingers are often wounded), and recently he also chews his nails. He has many fears: closed places (elevator, subway), fire alarms, if the train he is traveling with stops for reasons unknown to him (actually, all situations where he does not receive immediate information about what is happening), etc. - reports panic attack-like symptoms in these situations. His latest fear came during a storm. According to his mother's report, he had a panic attack when there was lightning and thunder, and the only way he could calm down was to go down with him to the street after the storm to see if everything was okay. When studying in front of others, anxiety manifests itself in eating in front of others and using the toilet. He prefers not to eat or use the toilet while he is at school. Due to his strong desire to prove himself, he studies until late at night and gets up at dawn to study more. He compensates a lot by eating and is now extremely obese. A psychologist deals with him.

Based on the anxiety test, he doesn't show social anxiety but physical symptoms, avoidance behavior, panic symptoms appear.

Based on the Rotter's Incomplete Sentence Test: his desires are formulated, he wants everyone in his family to be healthy, he is afraid of losing his mother. He envisions IT as a future occupation. He wants to control his life sometimes.

Questions

1. How can we strengthen his basic sense of security and reduce his anxieties?

2. How can we motivate him to eat healthier?

3. How can we make the family's life easier?

Advices on support and/or treatment mentioned in the group discussion

Question 1: How can we strengthen his basic sense of security and reduce his anxieties?

Answers: Exposure therapy. Change relationship to mother. Getting independent in housing. Find a solution regarding obesity.
Cognitive therapy. Aware of anxiety, alcohol problems. Realise that he can achieve impact with his behaviour.

Good Practice

for persons with VI and depression or anxiety disorders

Interdisciplinary cooperation and good diagnostics are very important, do not trust any single measurement result but take several and different ones.

Watch out for misinterpretation of symptoms, especially male depression.

The eye disease and its effects have an impact on the psyche, but depression and anxiety also have an impact on visual performance.

Co-funded by the Erasmus+ Programme of the European Union

THEME 6

Post-traumatic stress disorder (PTSD)

Theme 6: Post-traumatic stress disorder (PTSD)

Robert Coppes Foundation – Nijmegen – The Netherlands, October 2022

The meeting started with a digital tour through the Robert Coppes Foundation. See appendix : PowerPoint Presentation Digital tour Robert Coppes Foundation

Background information

Definition PTSD

Post-traumatic stress disorder is diagnosed using the DSM-5 which contains the following indicators:

- Stressor (event);
- Intrusive symptoms (nigthmares/ flashbacks);
- Avoidence (for example fireworks);
- Negative changes in thoughts and mood;
- Arousal and activity (heart pounding);
- Duration; at least one month;
- Functional significance (not able to participate in);
- Psychoses.

Expert's talk on PTSD

'The risks and treatment of PTSD in persons with a visual impairment' from Lia van der Ham and Edine van Munster. Lia van der Ham is researcher, consultant and trainer at Lost Lemon. Edine van Munster, researcher at the Robert Coppes Foundation.

See also appendix 15: PowerPoint Presentation Expert's Talk PTSD

Little is known about the combination of visual impairment (VI) and trauma. Therefore, a qualitative study by Amsterdam UMC and the Robert Coppes Foundation has been carried out for two years. The study is aimed at the risks and treatment of PTSD in persons with VI. The results of the study are presented in five key messages. **The first one** is that persons with VI may be more likely to experience traumatic events: the role of abuse is prominent. According to the literature found, persons with VI likely have an increased risk of certain traumatic events, for example falls, traffic accidents and abuse. In addition, exposure to other events is possibly influenced by VI through low self-esteem, lack of connectedness, dependency on others and missing visual information.

The second key message is that VI shapes the way people experience traumatic events. VI influenced experiences by:

- Suddenness; Not seeing it coming
- Powerlessness; Not being able to respond/ defend oneself
- Lack of control; Not knowing how to get out of the situation

PTSD is at least as common in people with VI vs. without VI symptoms; they are very similar, but the impact is bigger; this is **the third key message**. There are some indications that PTSD is more prevalent

among people with VI, compared to people without, however no solid evidence is found yet. Reported symptoms generally consistent with symptoms of PTSD, but seem to differ slightly in severity and impact, for example:

- VI increased the feeling of unsafety and anxiety due to lack of visual information (about the environment and other people intentions) and being aware of one's vulnerability and dangers.
- VI strengthened avoidance and isolation due to lack of trust in others and reduced mobility.

The fourth key message is that regular PTSD care is also suitable for people with VI if attention is paid to separate and combined impact of PTSD and VI. Based on the following factors: prevention, support and self-help. Examples for prevention are normalization of events and fear and preparing for potentially dangerous situations. According to support, one can think of social support and clarity. Lastly self-help contains of structure, activities and writing. VI is never a reason for not initiating treatment, but pay attention to underdiagnosis, support system and referral between low vision centre and mental health care. Therapies which are potentially suitable for people with VI are: EMDR, trauma-focused cognitive behavioural therapy and psychomotor therapy. During the therapy attention should be paid to:

- adapting modality;
- negative life experiences;
- real versus excessive fears;
- intensity of (EMDR) treatment.

In relation to the VI one should pay attention to accessibility, materials, communication and length of treatment.

The last key message is the fact that more knowledge and tools are needed. Therefore, during the study of Amsterdam UMC and the Robert Coppes Foundation the findings were translated into a training module. The module can be followed by low vision professionals from all three low vision organisations in the Netherlands. The next research project will be a study about determining prevalence and risk in Dutch adults with VI.

Presentations on PTSD

During the TPM in Nijmegen each participating country presented the current situation of PTSD in combination with VI in their country. In most countries no exact numbers of persons with a combination of VI and PTSD are known on national level. There are people with symptoms of PTSD, but an actual diagnosis is missing.

The participants from Germany explain that anxiety disorder is frequently diagnosed, therefore the possibility is present that PTSD is less diagnosed. They elaborate with the fact that it is important to state the difference between the beginning of the symptoms (before and after VI). In that way the difference can be made between the various diagnoses. A specific guideline is useful here.

Causes of traumatic events in the different countries could be war experience, exposure to natural disasters, traffic accidents and abuse.

See appendix 16: PowerPoint Presentations of situation description in own country for the different PowerPoint Presentations of the countries.

Quotes

On Monday during the TPM in Nijmegen Marit van Buijsen has conducted a dialogue by propositions. One of the statements was: I know how to provide treatment or support to a person with PTSD. One said:

"I support people to achieve better self-esteem (for example mobility fear of traffic), in addition I try to provide coping ability and help with exposure exercises."

The other added:

"I would send the client to a colleague who is EMDR specialised, so I am aware of treatment options."

The following statement is: EMDR is an adequate treatment for vulnerable clients. One participant said:

"When EMDR was introduced, there were a lot of no's but if there is a support system, it is an adequate treatment for vulnerable clients. Length of the treatment depends on the complexity of the trauma."

Case discussions

Case 1 - Post-traumatic stress disorder

By Robert Coppes Foundation - the Netherlands

Case description

Jody is a woman, born in 1953 in Thailand. Father did not declare her birth until 1956, which is now her official birth year. She is probably diabetic from birth, but this was not diagnosed until she was 23. Because it was noticed so late, she has vision impairment, deteriorated heart and kidney function. Diagnosed with proliferative diabetic retinopathy ODS and Macular edema. She must receive regular painful laser treatments for the latter. Due to poor kidney function, she must go to the hospital several times a week for dialysis. Jody has Thallessemia minor, a disease that is especially common in Asian people. As a result, she gets intestinal bleeding that leads to reduced HB levels. She receives EPO injections to stop the bleeding. Sometimes psychotic episodes attributed to the fluctuating blood sugars. Psychologically, we see several problems. Currently most prominent is a picture reminiscent of paranoid schizoaffective disorder.

Jody grew up in a poor family and barely attended school. She had to start working early to support the family. As a result, Jody has difficulty reading and writing. Mother died when she was 10 years old immediately after the birth of her youngest brother. The family then fell apart. Jody took care of the siblings still living at home. When she was 14, her father also died. When Jody was 16, her aunt forced her to marry a man 40 years old. From this marriage a daughter was born. Jody left husband and daughter shortly after birth. She went to live with her cousin. She had to clean his house, if she went to work outside the house she was beaten with a stick. Later she went to live and work with an aunt. Jody told us that about this time she had a serious accident. She was allegedly hit by someone who had raped her. When Jody was 20 years old, she met a Dutch man. He supported her financially. When she was 25 years old, she married him and from this marriage a daughter was born. This daughter was placed by Jody youngest sister in Thailand.

Then she and her husband went to live in the various European countries where he went to work. After a few years, Jody came to live with her husband in the Netherlands where she also got a job as a

cleaning lady. She learned to speak Dutch. After 9 years, her husband got into a relationship with another woman and the marriage came to an end. Her daughter continued to live with her ex-husband. She received alimony and also worked as a cleaning lady. Meanwhile, she met another man whom she started living with. While she continued to work, he did nothing and became addicted to alcohol and drugs. When he got a girlfriend, she left. As of 2009, Jody stopped working due to health reasons. There is no contact with the oldest daughter at all but there is still contact with the youngest daughter. By the way, both daughters are in contact with each other. By her own account, there are several people in Jody's family who showed psychiatric problems. Grandfather, according to her, jumped out the window in a crazy mood and died. Father abandoned the children after mother's death. Jody's sister was said to be regularly psychotic. About mother we received no information. Jody's daughter keeps away from everything and it is difficult to communicate with her. She is not open to contacting us.

Advices on support and/or treatment mentioned in the group discussion

Support workers at the residential location where she lives are regularly accused of stealing jewelry, clothing, money, etc. She barricades doors and is very suspicious of people who enter her home. She then puts a heavy trash can in front of her door, for example. Sometimes a temporary solution is found, for example by fitting extra locks but that is always short-lived because she becomes suspicious again. For example, she has not been able to find her keys for a while and then thinks someone has copied them. She collects things, especially clothes. She loses the overview which leads to great agitation. Self-care is good but her apartment gets dirty. She absolutely does not like it when you help her clean up. This puts her at risk of getting food poisoning, for example. Directive approach is counterproductive, she then immediately puts her foot down. Negotiating with her sometimes works. "What goes around comes around." In the house she has reasonably good contact with fellow residents but does not make friends. She does enjoy taking care of people and cooking, for example. She can be very petulant and angry. You recognize this because she makes repelling gestures with her hands. She becomes short-tempered and changes her voice. Financially she always has a problem. She has no real debts but is never satisfied, it is never enough. There is a strong suspicion that she has been psychologically damaged in the distant past. As a result of sexual abuse and multiple rapes, already at a young age, pregnancy in a forced marriage did not contribute to a healthy emotional development. Anxiety, strong need for control, psychosis (she sees people in her room who are not there), suspicion, periods of poor sleep.

The dilemma, to my mind, consists in the fact that there are so many factors intertwined, both psychological and physical, in addition to a different cultural background, that making a solid diagnosis is not easy to do. Sometimes one problem is in the foreground and sometimes it is another problem that demands attention. Ms. also shows characteristics of cluster B problems, sometimes splitting, sometimes manipulating etc. She was never diagnosed with borderline but still it helps with her to put responsibility back with her for example unambiguity in counseling etc. is very important with her.

Options for support and/or treatment:

The overall conclusion of this case is to focus on the quality of life. Some contestants mention that it is not necessary to discuss the diagnoses of PTSD because of the different problems she has, EMDR could be suitable. It is important to take the background of the client in the approach of treatment. Some contestants suggest treating the psychotic symptoms first, because they are quite prevalent. If treatment of psychotic symptoms is not possible, then EMDR is possibly a fitting treatment. To get a change of perspective, an advocate group (for EMDR) in the Netherlands could get involved.

During the case discussion people asked about the motivation of the client in life, other questions were about the treatment of psychological problems. Also, someone asked about the reason for thinking about PTSD, because there are no signs of reliving the events, of avoidance etc.

Case 2 - Post-traumatic stress disorder

By Vinko Bek - Croatia.

Case description

The client was born in 1988 (age 34) in Zagreb in a family of six: parents, an older brother and sister, and a younger brother. He was diagnosed with amaurosis, moderate intellectual disability and ADHD. He completed his education under a special program that lasts until the age of 21 (special programs for acquiring competencies in the activities of everyday living and work with individualized approach). He lives with his parents and because of the severity of his diagnoses there is no possibility for him to live and work independently. He requires continuous increased care, nursing and supervision by his parents. Both parents are very caring and included in his life. He comes to our Center "Vinko Bek" for rehabilitation three times a week in a group of clients with multiple disabilities. He is sensory sensitive, reacts to smells, seeks touch and stereotypical actions are present (rocking or stereotypical manipulation of objects). When he is coming to rehabilitation, almost always verbalizes a certain topic or problem that does not apply to him or can affect him, but he is visibly upset by it. He recounts events from the media, from politics to entertainment and absolutely everything he hears in his family. The topics he recounts are always negative. The situation at home is currently very sensitive because his father suffers from coronary disease, which additionally negatively affects the mood of all family members. The mother is quite cooperative and realistic in her communication with the employees.

He is extremely emotionally sensitive to interpersonal relationships, which we believe is a consequence of the trauma he experienced in childhood. About 20 years ago, the client stayed at an accommodation in the Caritas home and stayed at that same home for 5 years. After 5 years of his stay in the Caritas home, it became known about the abuse of clients in the home by the staff and the head manager, which was also covered by the media. It is known with certainty that our client was also exposed to a certain type of violence/abuse, although it was not possible to obtain reliable information from him specifically, neither regarding what exactly he experienced, nor exactly what kind of emotional state he was in there (there is no possibility for him to describe the stated above). What showed that he was traumatized, is his behavior. The client became very agitated and upset at the mention of certain people or places associated with a traumatic event. In such state it is difficult to get him back to the "here and now" (possible flashbacks or dissociative reactions). He showed and verbalized the fear of having to return to the Caritas home, he had very poor concentration and his complete attention was on the traumatic experience he had experienced. Difficulties arose on a physical level as well, problems with high blood pressure occurred, which is why he went to the hospital for an emergency room. In general, he showed (and still shows) a very low limit of tolerance for frustration (he reacts very strongly).

The findings and opinions of experts do not indicate a diagnosis of PTSD, but the client's behavior shows symptoms of PTSD related to a specific traumatic experience. Considering the general psychophysical condition of the client, we believe that it is necessary to protect him from unnecessary negative situations and news.

Question from the case contributors: What to advise parents and family members in approaching a client with these difficulties? How to deal with that situation?

Advices on support and/or treatment mentioned in the group discussion

- Advice in relation to the parents: start with a low-level approach (for example a coffee moment) so they don't have the feeling they are doing therapy.
- Advice in relation to the client: he talks a lot in a negative way, so let him express himself in a different way, for example art therapy, to distract from the negative.
- Temporarily move the client to another environment, away from the family. In the meantime, support the family with some kind of education about acceptance of the client. Possible result in paradigm change. Reaction: good advice but then the budget is a problem. Is a similar center not causing new traumas considering the past situation? The client has to be prepared and must be convinced that not all the care facilities are the same.
- Parents must motivate their son to cooperate in the daily structures in life.

Case 3 - Post-traumatic stress disorder

By BFW Halle - Germany

Case description

At the beginning of her vocational rehabilitation Mrs P. is aged 30 yrs. She suffers a severe visual impairment due to optic atrophy, myopia, and a nystagmus. She is reliant on devices for blind people. Beside this she has PTSD, recurring episodes of depression, as well as a combined personality disorder (with dependency and anxiously avoiding parts). Temporarily her mental resilience undergoes a massive restriction. So, she is psychotherapeutically supervised in an ambulant manner.

Mrs P. is unmarried and lives in a rental flat in a city. Mainly she cares for herself. She uses the municipal transport system. In surroundings she is unfamiliar with she occurs a lot of problems. Because of her emotional affections she cannot work as masseuse and her last job as a waitress in a dark room restaurant. Her relationship to mother and sister is shattered. Besides she can count on friends.

In the BFW Halle she made a 6-week assessment with work shadowing in several vocational jobs. Subsequently she graduated a prolonged basic training course for the blind. Although she accomplished week results, she wanted to become a merchant in public health. Within her training she faced many emotional ups and downs. So, she moved to another town, she started and broke up a partnership, acquired and abolished a guided dog, experienced the death of a close relative, and received diagnoses of new physical diseases.

Given that Mrs P. was the only student in her course, she mostly was on her own when learning. This means she had to be disciplined. For all barriers and sickness absence she finished her training successfully. She used all offers of our institutes: mobility training, training for daily living skills, support by social workers, conversation with our psychological service. She steady participated. A traineeship is part of vocational rehabilitation. By reason of Covid Mrs P. couldn't find a traineeship. This had a negative impact on her self-confidence and motivation.

Right after finishing her training, she rewarded herself and bought two cats. Now she was not mobile anymore. So, although she graduated quite well, and applied a lot, she couldn't find a job yet. Because of her pets - she won't leave them alone – she has some doubts to take part in a labour market integration measure in the BFW Halle.

Question from the case contributors: What could be helpful for her to find a job eventually?

Advices on support and/or treatment mentioned in the group discussion

- Perhaps the client fears the work opportunities and she uses the cat to hide. The thought of going to work could be a big step, therefore small steps to start with could be taken.
- An advice for the organization is to help her by finding a job. The BFW has already done this, but she is not open to this. Starting with small steps, like activities near her home, could help.
- The cats could be an excuse to stay at home, maybe there is something underneath the problem. The cats may give her comfort, she could possibly be suffering from anxiety.

Case 4 - Post-traumatic stress disorder

By Rittmeyer Institute - Italy

Case description

Mr. M. is 64 years old man. Total loss of sight due to a car accident that left his face disfigured, severely affecting also his ability to pronounce words. He presents manic depressive obsessive syndrome as a defence against depression. Before the accident he was in charge of a work team in a large company in Friuli, he was married, but was also involved in an extra-marital relationship. Father of an adult son and grandfather, he described himself as an 'eternal Peter Pan' before the accident.

Mr. M. presents relational difficulties with his son caused by the concealment of his extra-marital relationship from the family. Mr. M.'s psychotherapy is therefore focused on the following topics:

1. Analysis of the behaviour of the family of origin;

2. Targeted meetings with family members and partner;

3. Emotional management in view of the return to the home country;

4. Work on rapprochement with their son;

5. Clarification of the current emotional situation and the possibility of possible cohabitation with the partner.

Question from the case contributors:

What steps would you put in place to implement in Mr. M. a pathway of acceptance of his or her disability?

Advices on support and/or treatment mentioned in the group discussion

- Start rehabilitation specific for him (deaf/blind), therefore he can discover new activities.
- He is now dependent on someone, this could be a possible problem. So stick with daily activities where he is/ becomes more independent.
- Try to find a part of his life which was not affected by the accident, what he can do individually and independently.
- You could try to involve the company he used to work for and discover if he can do/ get tasks.
- Perhaps the manic symptoms could get treated first.

Case 5 - Post-traumatic stress disorder

By Budapest School for the Blind - Hungary

Case description

Emese is 18 years old. Her eye diseases: myopia, astigmatism, retinopathy of prematurity causes, strabismus convergens, nystagmus and other irregular eye movements, photosensitivity, dyschromatopsia, narrowing of right-sided visual field. Others: emotional disturbance in childhood, problems affecting the primary living space. IQ: borderline, learning disability (mild dyslexia, dysgraphia).

Family situation: She lives with her mother and two healthy younger adolescent siblings. At home her brother is the boss who is a violent type, fights also happen. She loves her mother and sister very much, but it is difficult for her to get along with her brother. Her father molested her when she was a teenager (about 12 years old), beat her family and went to prison. She doesn't know anything about him right now. They live in modest circumstances with little money, her mother works in several shifts.

Education: Emese is going to be a baker at the end of this school year at our vocational school. She is skillful in her profession, hardworking. She fits into her class and dormitory. She is verbally aggressive with one of her classmates (a student with autism). There are many conflicts between them. Her teachers noticed symptoms of depression, increased irritability, and anger outbursts in her. She requires constant feedback and attention. She is dating a blind young man who is in state care, their relationship is unstable.

She already went to a psychologist in elementary school and to a psychiatrist, but due to the covid epidemic, her care was interrupted. This also contributed to the fact that her trauma was not processed, she continues to carry her burden. She developed her own self-defense strategy, she has an imaginary, split world. This seems to serve a self-defense function.

During our meetings, it often seems as if she wouldn't be there. She has low energy level, she is anxious, depressed. She has an extremely high need for affection (initiates hugs). She is also suspicious, distrustful towards most people. Each time she brings her own fantasy world (she has an imaginary family). Often, the change is not even clear, when she is in the fictional and when in the anxiety-relieving reality. She often complains about dizziness, memory problems, migraine, and a strong aggressive urge that she finds difficult to control. She tears the skin off her finger when she talks about her past. In my opinion, she is dangerous to herself and others, and can easily drift into deviant groups. Physicality is a problem in her relationship.

Emese is writing a book called Legends. I have the feeling that she processes the things that happened to her through her story. Writing a book about it is a self-healing process. Also, she distances the matter from herself, by telling it through the lives of other people. It is unclear whether this is a split fairy tale world or a sometimes-split hallucinatory state for self-defense?

She has a very strong temper, a desire for revenge towards her father, and says: "I want to kill people such like him so that this does not happen to others." She is currently receiving supportive care.

Results of psychiatric consultation: Impulse and rule management difficulties, auto- and hetero-aggressive manifestations, increased emotional and mood lability, attachment insecurities are characterized. Infantile and regressive elements alternate with adequate manifestations in her behavior. She has narcissistic complaints, constantly tries to be the center of attention. Increased self-uncertainty, self-assertion tendencies and impulsivity, reduced frustration tolerance and failure

tolerance, incomplete reality control. Projection tests have not been recorded yet. Contacting the parent has been unsuccessful so far.

Question from the case contributors: Is it okay if I try to give her the opportunity to bond?

Advices on support and/or treatment mentioned in the group discussion

- It is not your job; it is a problem to have such a strong bond. It is necessary to clarify the diagnosis. Is it borderline or PTSD? There is a large problem with the environment, she feels a lot of frustration. Frustration causes aggression. Give her anger and frustration control training. Maybe it makes the aggressive situation a little bit better.
- The question is still unanswered if she needs medical therapy. This needs to be clarified. This could be a first step. She lives in a dysfunctional environment; how much should she distance herself from the family if they are not open for therapy? She has some other family in Budapest. Maybe it is better to work with them. Involve this part of the family and cooperate with her. Because her mother is not there.
- We will search for a good psychiatrist to get a clear diagnosis and medication. And looking for other family members to bond with.

Good Practice

for persons with a VI and Post-traumatic stress disorder

Persons with VI may be more likely to experience traumatic events: the role of abuse is prominent. VI shapes the way people experience traumatic events. PTSD is at least as common in people with VI than without VI symptoms; they are very similar, but the impact is bigger. Regular PTSD care is also suitable for people with VI if attention is paid to separate and combined impact of PTSD and VI. VI is never a reason for not initiating treatment, but pay attention to underdiagnosis, support system and referral between low vision center and mental health care. And, last but not least, more knowledge and tools are needed.

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End conclusion

Impact of the project

The evaluation results of the project clearly show that care professionals express a need for support in their further professional development to be able to provide effective care and treatment to persons with a visual impairment and mental health problems (as was assumed when developing the project). Through six TPM's, organized in five different countries (the Netherlands (2 sessions), Italy, Croatia, Hungary and Germany) participants with various professional backgrounds yet all involved in the care and treatment to this specific group of clients could gain new knowledge and insights on how to provide care and treatment to this specific group of clients. Each training session covered one or more specific psychological and psychiatric disorders. For these training sessions, a format was developed based on core building blocks, i.e.:

- Interactive sessions with peer-exchanges on concrete cases (intervision).
- Theoretical input from experts on the themes of each session.
- Presentation of the national/regional situation in relation to the target group and the themes.
- Workshops and/or self-experience sessions to further explain tools/instruments or specific support approaches for this group of clients.

The most useful parts of the TPM's were the learning through exchange with colleagues through the case-discussions gaining new perspectives on the own case, through the presentations of theoretical background on the different themes and through background information on how the participation institutions organize and offer care and treatment. The material presented during the training sessions was assessed as very helpful as well as the discussions on the importance of an effective diagnosis.

The participants involved in the training (between 21 and 30 for each session) had various professional backgrounds, while all working with this specific group of clients, e.g. psychologists, occupational therapists, behavioural scientists, vocational rehabilitation specialists, etc. In the two training sessions during which experience experts from the target group were present, they had a specific role in the training, which was assessed as very positive. It would be relevant to further discover how client participation could bring further added value to this type of transnational training sessions.

The relevance of the TPM's was very positively rated, with even a slight upward trend in the scores over the life-cycle of the project. The project responded to the needs and expectations of the participants to acquire more knowledge, to refresh knowledge and to gain new insights in their work facing the complexity of providing support and care to this particular client group (who have only their visual impairment in common). It is the combination of (theoretical background) presentations on themes with the case-discussions on these themes and eventual workshops that make the training sessions relevant for the participating professionals.

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Learning experiences of the participants

With thanks to the external evaluator, Dominique Danau.

Current state of the art

During six transnational project meetings knowledge and experiences were exchanged on the care and treatment of adults with a visual impairment and comorbid mental health problems. This was experienced as an effective approach to build a first knowledge base on this subject and provided different professionals the opportunity to gain knowledge and expertise. During the case discussions it became clear that each case has its specific aspects and a taking a general approach is difficult. However, based on the discussions and experiences of the participants the following general conclusions about the care and treatment of this client group could be made:

- It is important to be aware on mental health problems in persons with a visual impairment.
- Persons with VI are more at risk for developing specific psychiatric disorders or the manifestation of the psychiatric problems is different compared to persons without a visual impairment.
- General treatments for specific psychiatric disorders cannot be one-to-one applied to persons with VI, specific adaptations for the visual impairment need to be made.
- The care and treatment for visually impaired adults with comorbid mental health problems is based on a long-term perspective.
- Professionals need to take a holistic approach and to see the psychosocial and/or emotional problems behind the disorder.
- Psychiatric disorders are frequently underdiagnosed in persons with a visual impairment, general diagnostic assessment is difficult due to the inability to use general diagnostic tests. Specific assessment tools for detecting mental health problems in persons with a visual impairment are needed to be able to gain a proper diagnose for persons with a visual impairment.

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Appendices

1: Standardized formats for case discussion

For the case discussion two documents were used, a format that could be used for describing the case and a protocol used to discuss the case. Both documents are included in this appendix.

Format used to provide a description of the case

Case description

Describe in max 1 A4 the following:

Background information Think about: Age, gender, Eye condition, Other medical information, Social/emotional/behavioural information, Living condition, Education/ work, Family situation, Important live events.

What is the problem/dilemma? Describe the problem or dilemma in the case

Questions What questions do you have about the case for the meeting?
1. **2.** **3.** **4.**

Protocol used to discuss the case

Procedure Case Discussion PsyCoVIA

60 minutes

Step 1 Reading the case and formulate 2 open questions (20 min)

The participants read the case and discuss in sub-groups which questions they have for the contributor and write down a maximum of two open questions on two different sheets and hand them to the contributor.

Step 2 Hot, cold or neutral (during 20 min)

The contributor makes three columns: Hot, Cold and Neutral.

- Hot is: an eye-opener, a new question to think about.
- Cold is: a question he has been asking himself for a long time and knows the answer to.
- Neutral is: a new question of which the contributor does not yet know exactly what to do with.

Step 3 Answer questions (5 min)

The contributor answers the hot questions. He/she may also choose to answer the neutral questions.

Step 4 Participants reformulate the problem (10 min)

Participants discuss in sub-groups the problem and their answer to the main question based on the answers given in step 3 by the contributor.

Step 5 Participants answer the main question (10 min)

Each group presents their answer to the main questions to the contributor.

Step 6 Open discussion (10 min)

The contributor asks questions based on the advises given by the groups and all persons are open to contribute to the discussion.

Step 7 The contributor now reformulates his own problem (5 min)

The contributor then gives his/her own view on the problem and talks about how he or she is going to deal with the problem.

2: PowerPoint Presentation for Attachment

‘See me, hear me, feel me’

Attachment & Visual Impairment

Marit van Buijsen, MSc.

Robert Coppes Foundation

Born Blind

Blind children from the beginning of life lie in their cribs waiting, waiting for sound to come nearer, then fade away. They learn to know those who touch them and to distinguish how they touch. Slowly, they begin to connect certain sounds to certain people. They develop a sense of familiarity with the manner in which their needs are met. Theirs is a world of waiting, listening, and receiving the touch through their body-as-a-whole; they cannot take in through their eyes.

Sometimes, even the familiar sound/touch person moves and touches them in frightening ways. They may resort to even more stillness and/or repetition of their own movement, which they can maneuver and control at will. They invent rhythmic hand movements that soothe them when upset and sometimes they create shadows with which to play. They may try less often to venture into the unknown darkness around. Their “Golden Age” is without pictures and images. There are only formless shadows. They have no notion that others have arms, legs, or bodies like their own. Their hands become their eyes - making the process of learning about themselves and about others a slow, tedious puzzle. They might ponder (if they could), “Arms of the other are in different places than the last time. How many are there? Do I have enough? What makes those sounds I hear? Can part of me make those sounds too?”

Content

Attachment

- What is attachment and why is it important?
- How is an attachment relationship established?
- Risk factors when having a visual impairment

Social Emotional Development

- Phases
- Risk factors when having a visual impairment

What is attachment

- Affective connection
- Find comfort

Responsiveness

- Being sensitive for signals
- Respond to this signals
  - Notice the signals of the child
  - Correctly interpretate these signals
  - (Intuitively) know how to respond
  - Willing/being able to react
  - React effectively

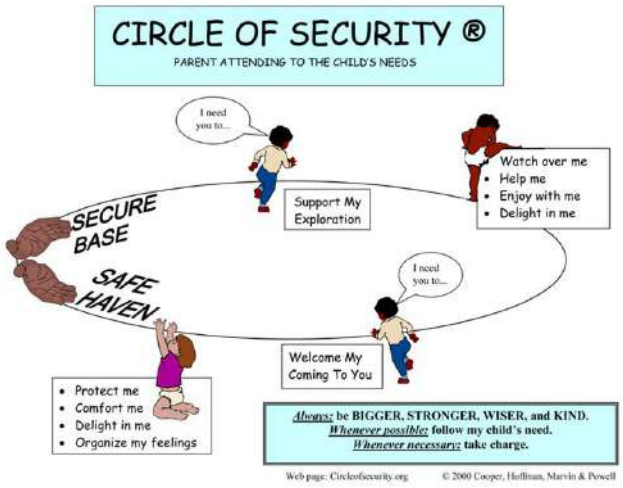
Essential messages

- You exist for me
- You exist on your way for me
- I will always be there for you, when you need me

Basic trust in self and others

Healthy attachment

- Positive self-image
- Dealing with impulses
- Dealing with stressful situations
- Optimal brain development
- Development of logic thinking
- Insights in own and others feelings
- Developing conscience
- Able to build a (longterm) relationship with self and others



Attachment styles

Thoughts of Partner \ Thoughts of Self	Positive	Negative
Positive	**Secure** Comfortable with intimacy and autonomy	**Preoccupied** Preoccupied with relationships
Negative	**Dismissive** Dismissing of intimacy Strongly independent	**Fearful** Fearful of intimacy Socially avoidant

DSM 5

- **Disinhibited Social Engagement Disorder (DSED)**
- **Reactive Attachment Disorder (RAD)**

Attachment & Visual impairment

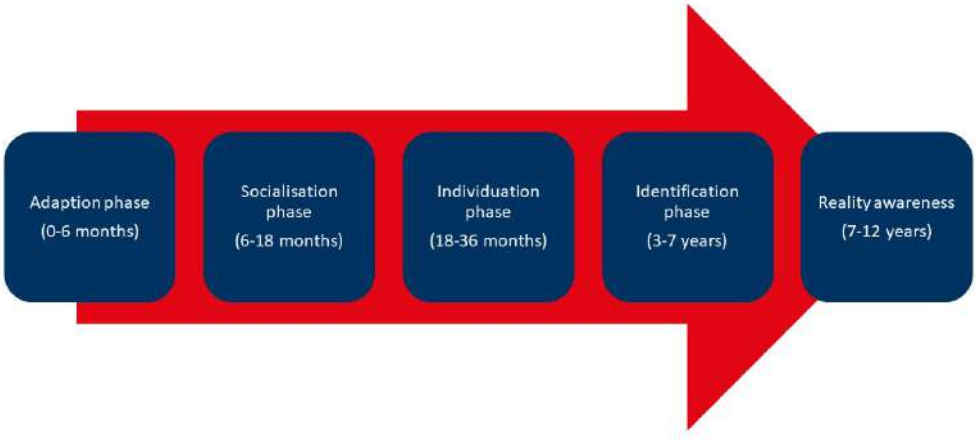
- Non-verbal communication is different;
- Not able to make use of eye-contact;
- Not seeing social identification marks (mutual smile, hand sign or movement of the head);
- Feeling of emotional uninvolvement.

Caregivers need more than average skills in responding sensitive and responsive to their child.

Social Emotional Development

- Form meaningful relationships
- With others or self
- Always connected to each other

Social Emotional Developmental Phases



Adaptation phase (0-6 months)

- Adapt to life outside
- Basal life necessities
- Peace, Cleanliness, Regularity

Socialisation phase (6-18 months)

- Explore their surroundings
- Egocentric
- Secure base, Trust, Predictability

Individuation phase (18-36 months)

- Autonomy
- Tantrums
- Build trusting relationship

Identification phase (3-7 years)

- Independency
- Being accepted
- Responsibility, Identity, Socialisation

Reality awareness (7-12 years)

- Self esteem
- Social rules
- Stimulate independence, self esteem

Visual Impairment

- More time
- Way of learning
  - Mutual learning
  - Cannot make use of modeling/imitation
- Awareness of being different/ having special role
- Less positive experiences
- Parents being overprotective/more cautious
- Less use of trying

3: PowerPoint presentation Charles Bonnet Syndrome

Charles Bonnet Syndrome

Enviter's PsyCoVIA project
January 2020
Peter Verstraten

Robert Coppes Stichting

Scheme of presentation

- Diagnostic criteria
- Prevalence
- Characteristics
- Examples
- Risk factors
- Consequences
- Treatment options
- Towards a model for understanding CBS

Robert Coppes Stichting

Charles Bonnet (1720 - 1793)

Essai analytique sur
les facultés de l'âme
(1760)

Robert Coppes Stichting

Definition of hallucination

Perception of visual, auditory, tactile, olfactory, or gustatory experiences without an external stimulus and with a compelling sense of their reality

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Diagnostic criteria CBS

- Complex visual hallucinations
- Insight into unreal nature of the hallucinations
- Absence of hallucinations in other sensory modalities
- Absence of delusions: irrational or intense belief(s) or suspicion(s) which a person believes to be true

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Differential diagnosis

- Hallucinations of widowhood
- Hypnagogic hallucinations
  half awake → half asleep: when falling asleep
- Hypnopompic hallucinations
  half asleep → half awake: when waking up
- Hallucinations as symptoms of epileptic or migraine attacks
- Hallucination due to the use of hallucinogenic drugs
- Hallucinations in exceptional stressful situations
- Hallucinations during PTSD re-experiences
- Hallucinations in case of delirium
- Hallucinations in case of dementia

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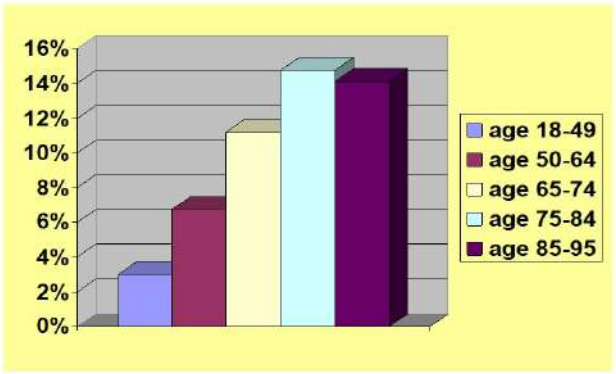
Prevalence CBS in 300 low vision patients of different age groups



Age 18-64: 5,1%
Age >64: 13,1%

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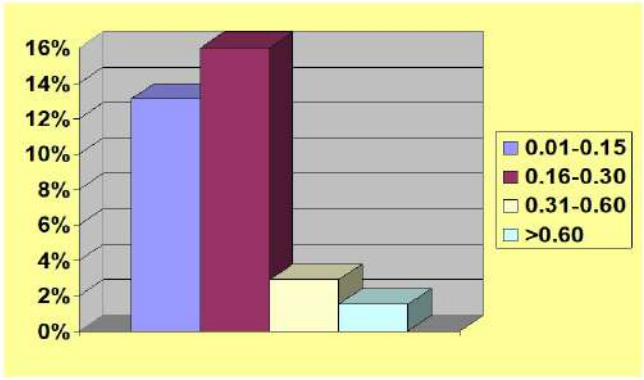
Prevalence CBS in older low vision patients with different visual acuity



0.01-0.30: 14,4%
> 0.30: 2,1%

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Formal characteristics according to Teunisse

- Frequency and duration are variable
- Usually with eyelids open
- Sometimes integrated in actual environment, sometimes not
- Usually not moving along with eye movements
- Compared with normal images just as clear or even more clear
- Usually normal colour

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Formal characteristics according to Schultz et al

- Alert
- Eyelids open
- Sharply focused image
- Appears suddenly
- No apparent trigger
- No voluntary control
- Present for seconds
- No movement
- Vanishes suddenly

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Content characteristics according to Teunisse

- Hallucinated objects can be:
  - Persons
  - Animals
  - Plants
  - Trees
  - Buildings
  - Landscapes
  - Utensils
- Intrinsic movement or not
- Recurring objects or not
- Usually unfamiliar objects
- Usually personally irrelevant

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Content characteristics according to Ffytche

- Hallucinated objects can be:
  - Simple unformed: flashes, lines, dots
  - Geometrical: grids, lattice, fence, brickwork
  - Disembodied faces: grotesque, distorted
  - Figures: costumes, uniforms, hats
  - Branching forms: trees, branches, shrubs
  - Polyopia: multiple copies of same objects in rows/ columns
  - Perseveration: veridical object persists on looking away
  - Text: letters, notes
  - Particulate: visual field covered by dots, particles
  - Vehicles: cars, lorries, buses

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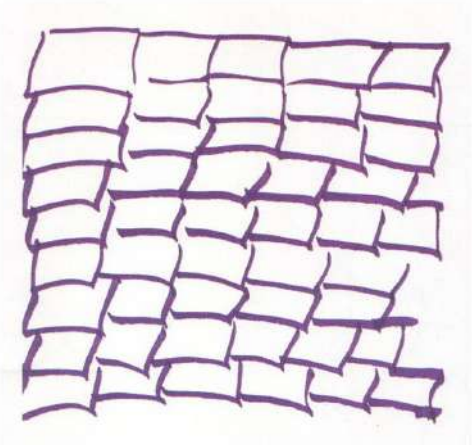

Drawing from collection of Lylas Mogk

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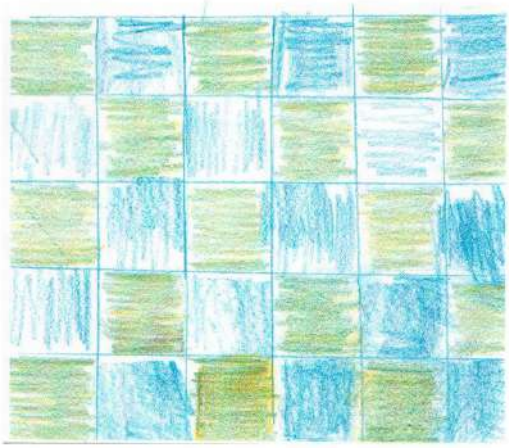

Drawing from collection of Lylas Mogk

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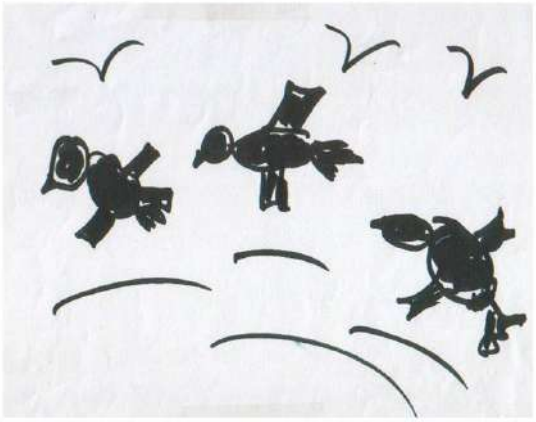

Drawing from collection of Lylas Mogk

Robert Coppes Stichting

Drawing from collection of Peter Verstraten

Robert Coppes Stichting

Drawing from collection of Lylas Mogk

Robert Coppes Stichting

Drawing from collection of Lylas Mogk

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Drawing from collection of Lylas Mogk

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Drawing from collection of Lylas Mogk

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Risk factors (Ffytche et al., 2010; Jenner, 2006; Aleman & Laroi, 2008; Verstraten & Vandermeulen, 2008)

- Physiological: age, sleep onset/offset, sensory deprivation, photic stimulation, comorbid somatic disorders
- Neurological: lesions in the visual pathways, epilepsy, migraine, Parkinson's disease, neurodegenerative processes
- Psychiatric: delirium, Alzheimer, Lewy Body dementia, psychosis, schizophrenia
- Iatrogenic: anti-cholinergic medication, L-dopa, Beta-blocking medication
- Psychological: stress, loss of energy, loneliness, low extraversion, anxiety, shyness, bereavement

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Risk circumstances according to Teunisse

- Evening / night
- Less light intensity
- Being alone
- Domestic environment

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Levels of distress

- No distress 72%
- Some distress 18%
- Severe distress 10%

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Reasons for distress

- High frequency of hallucinations
- Long duration of hallucinations
- Unpleasant content of hallucinations

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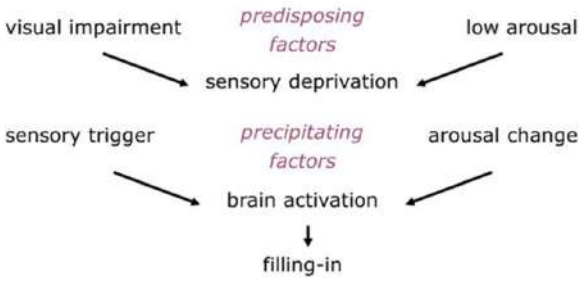
A model for the onset of CBS-hallucinations



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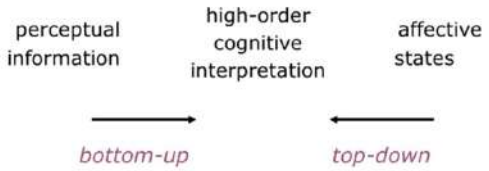
Neural network approach to the nature of delusions (Chen & Berrios)



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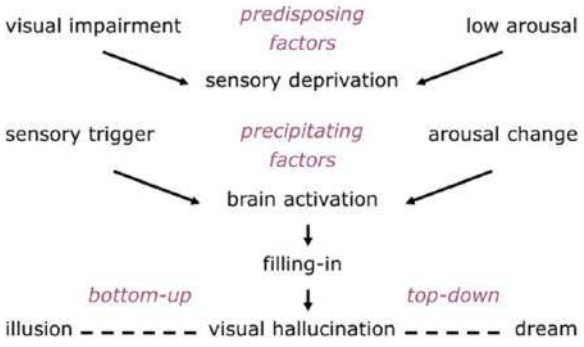
A model for the onset of CBS-hallucinations



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Neural network approach to CBS-hallucinations

Direction	Bottom-up	Top-down
Source	External sensory triggers	Changing visual attention
Content	Related to sensory circumstances	Related to psychological affects
Close to	Illusions	Dreams

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Treatment options

- Anti-psychotic medication does not work!
- No proven effective interventions
- However:
  - Visual treatment
  - Pharmacological treatment
  - Psycho-social treatment and psychotherapy

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Visual treatment

- Improving acuity
- Optimizing residual vision

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Pharmacological treatment

- Replacing beta-blocking medication
- Optimizing physical condition
- Carbamazepine
- Valproate
- Ondansetron
- Cisapride

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Psychological treatment

- Psycho-education
  - Individual
  - Group approach
- Traditional psychotherapy
- Cognitive behaviour therapy (CBT)

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Psycho-education

- Reassurance by explaining:
  - Many older people with sight loss experience these visual hallucinations
  - It's an official syndrome, called the Charles Bonnet syndrome
  - It is not a sign of a psychiatric disorder, you are not going crazy
- Passing techniques to stop hallucinations

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Techniques to stop hallucinations

- Closing eyes
- Opening eyes
- Blinking
- Moving eyes swiftly
- Looking away or walking away
- Approaching the hallucinated object
- Visual fixation on hallucinated objects
- Putting on a light
- Concentrating on something else / looking for distraction
- Hitting the hallucinated object
- Shouting at the hallucinated object

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Group approach: content

- Aim: reassurance and opportunity to share experiences
- Information about:
  - Characteristics of CBS
  - Risk factors
  - Techniques to stop hallucinations
- Sharing and exchange of experiences with CBS
- Sharing and exchange of experiences to stop hallucinations

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Group approach: structure

- Open structure
- Build-up is the same every meeting
- Usually clients only participate once, though some want to attend more than one meeting
- Total meeting takes about two hours
- Conducted by a psychologist and a social worker

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Group approach: experiences

- A group-size of 8 persons would be ideal, but in practice we had small groups of 4 or 5 participants
- The planned frequency for these groups was once every month, but the actual frequency turned out to be once every three months
- The groups were originally planned for visually impaired elderly with CBS, but we included their spouse too.

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Traditional psychotherapy

- Exploration of symbolic content of CBS-hallucinations
- Aimed at emotional coping with vision loss

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Cognitive behaviour therapy

- ABC-scheme in which the hallucination is the activating event (A), the meaning attached to this hallucination is the belief (B) and distress through fear or anxiety is the consequence (C)
- By discussing and trying to change B, also C will be changed

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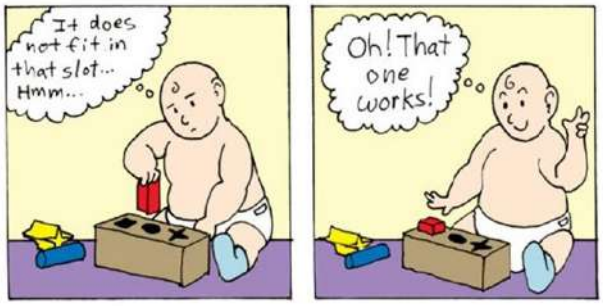
Not one evidence based approach



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4: Questionnaire Charles Bonnet Syndrome

Charles Bonnet Syndrome Questionnaire
Characteristics of hallucinations and circumstances

Name or number or code:

Age:

Gender:

Eye disease / diagnose:

Since	O	birth
	O	youth
	O	adult age
	O	old age (> age 65)
Onset	O	suddenly
	O	gradually
Visual acuity	VOD:	
	VOS:	

Visual field		OD	OS
	Central:		
	Peripheral:		
	Hemianopia:		

Physical comorbidities / additional diseases:

Use of medication:

Name	Dose	Frequency	Since (date)

MMSE-score: or CST-score: or other cognitive screening:

Suspect of cognitive problems? Yes / No

Is it about *complex* visual hallucinations? Yes / No

Is it clear that it is not about illusions? Yes / No

Is it clear that the person is awake during the hallucinations? Yes / No

Is it clear that the hallucinations are not triggered by the person himself? Yes / No

Are simultaneous auditory (and other sensory) hallucinations absent? Yes / No

Are delusions excluded? Yes / No

Does the person have insight in the unreal character of the hallucinations? Yes / No

O very probably CBS
O possibly CBS / doubt, because:
O not likely CBS, because:

Description of the hallucinations

Content of the hallucinations

- O persons
  - O adults
  - O children
  - O faces
  - O (large) groups
  - O miniature people
- O animals
- O plants / trees
- O buildings
- O landscapes
- O other objects

Content familiar?	yes / no
Integrated in normal environment?	yes / no / sometimes
Intrinsic movements?	yes / no
Recurring objects?	yes / no

Frequency: How often did you have these hallucinations last month?

- O never
- O once every two weeks
- O once a week
- O once a day
- O twice or three times a day
- O once per hour
- O constantly

How long do these hallucinations last?

- O 1 - 4 seconds
- O 5 seconds - 1 minute
- O 1 - 30 minutes
- O 30 - 60 minutes
- O > 1 hour

How much do you suffer from these hallucinations emotionally?

1	-	2	-	3	-	4	-	5	-	6	-	7
not at all						somewhat						very much

How would you describe your affective reaction?

- O anxious
- O irritated
- O amused
- O indifferent
- O sad
- O surprised
- O happy
- O other:

To what extent are these hallucinations annoying in a practical sense?

1 - 2 - 3 - 4 - 5 - 6 - 7
not at all somewhat very much

Localisation in the visual field:

Moving along with movements of the eyes? yes / no / sometimes
Clearer images than normal? better / worse / the same
Colour? colours / black and white

- O only with eyes open
- O only with eyes closed
- O both

The time on the day the hallucinations usually appear

- O morning ± ..... o'clock
- O afternoon ± ..... o'clock
- O evening ± ..... o'clock
- O night ± ..... o'clock

Where were you at the time the hallucinations appeared?

- O at home
- O somewhere else, namely:
- O both are possible

Were you
- O alone
- O with company
- O both are possible

What were you doing at the time the hallucinations appeared? Were you active or not?

- O visually active
- O auditory active
- O other sensory activity

Description of environmental conditions:

Explanation in terms of external triggers

- O visually
- O auditory
- O tactile / motorial
- O olfactory
- O gustative

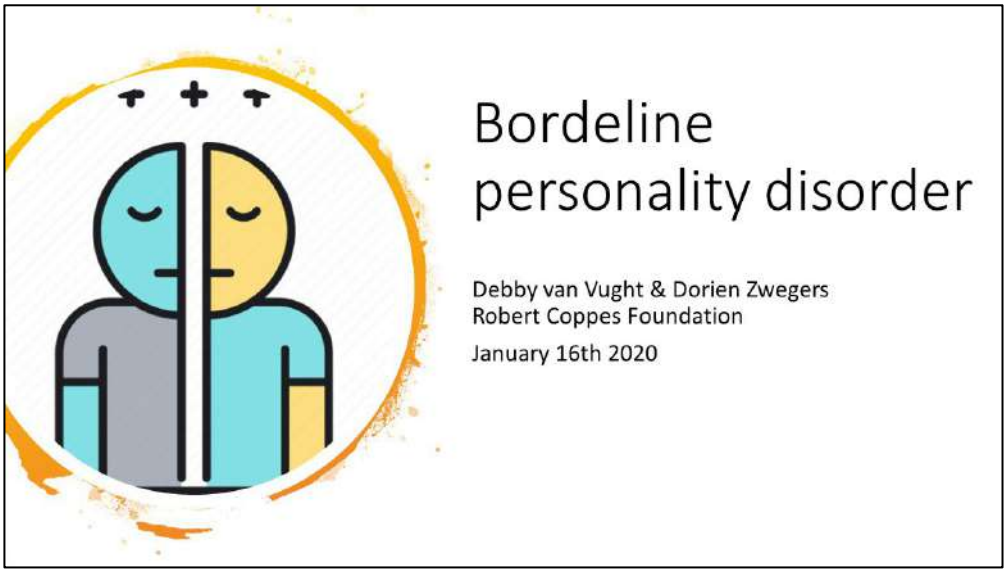
Techniques used to stop the hallucinations

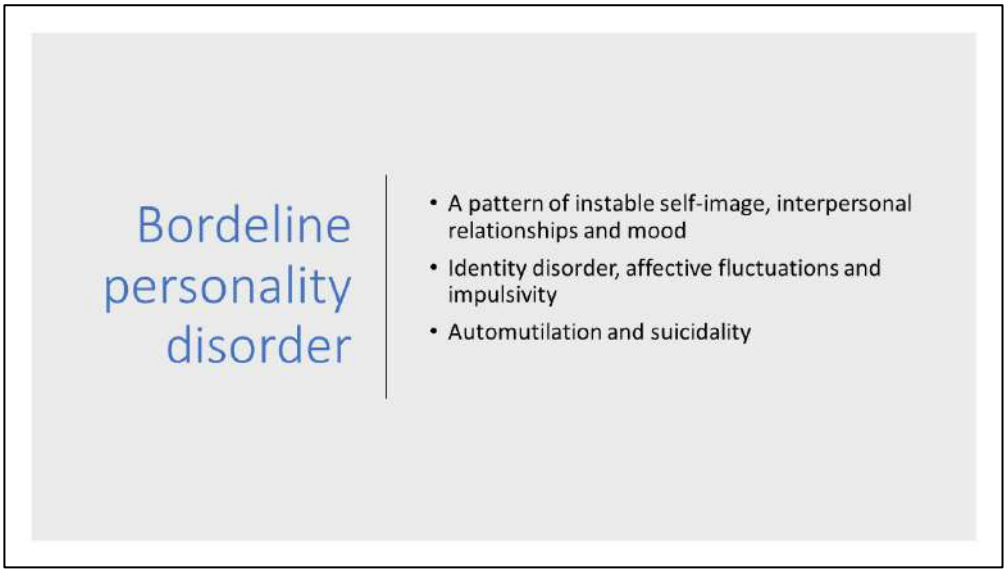
- O Closing eyes
- O Opening eyes
- O Blinking
- O Moving eyes swiftly
- O Looking away or walking away
- O Approaching the hallucinated object
- O Visual fixation on hallucinated objects
- O Putting on a light
- O Concentrating on something else / looking for distraction
- O Hitting the hallucinated object
- O Shouting at the hallucinated object

Additional remarks concerning:

- O fatigue
- O stress
- O shyness
- O introversion
- O loneliness
- O other, namely:

5: PowerPoint Presentation Borderline Personality Disorder





Bordeline personality disorder

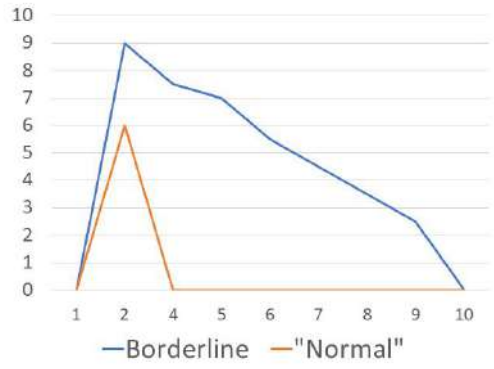
Strong changes in:

- Mood
- Thoughts
- Behaviour

Mood, thoughts and behavior

- Fear of being abandoned
- Unstable relationships: idealize and belittle
- Identity disorder
- Mood swings
- Intense anger
- Impulsive behavior
- Suicidal behavior, self-harm
- Chronic feeling of emptiness
- Dissociative or paranoid symptoms

Emotional response



Thoughts and cognitions

- Think in black and white
- Negative thinking
- Idealizing versus devaluing
- Personalize (relate to yourself)
- Disaster thinking
- Generalize
- Magical thinking
- To read minds
- Emotional reasoning
- Having to do things

Possible causes: biological

- Inherited traits such as impulsiveness and mood instability
- Reduced serotonin activity (regulates emotions and impulse control)
- A biological susceptibility to strong, sudden mood disorders, with an extreme sensitivity to events in the environment

Possible causes: psychological

- Physical and emotional neglect in childhood
- Sexual traumas
- Divorce experiences at a young age

Possible causes: social

- Social changes
- Living conditions

Treatment

The main focus is on long-term management of complaints and not on short-term crisis management

Treatment

- Long-term
- Ambulant care preferred over clinical
- Individual or group therapy
- Relationship or Family Therapy
- Pharmacotherapy

Medication

There is no pil for Bordeline personality disorder!

Medication

- Neuroleptics
- Antidepressants
- Benzodiazepines

Mechanisms in contact

- Defective objectconstant
- Trust is a precarious concept
- Attachment-Detachment
- Distance-Proximity
- Transfer-Countertransfer
- Splitting
- Denial

Mechanisms in contact

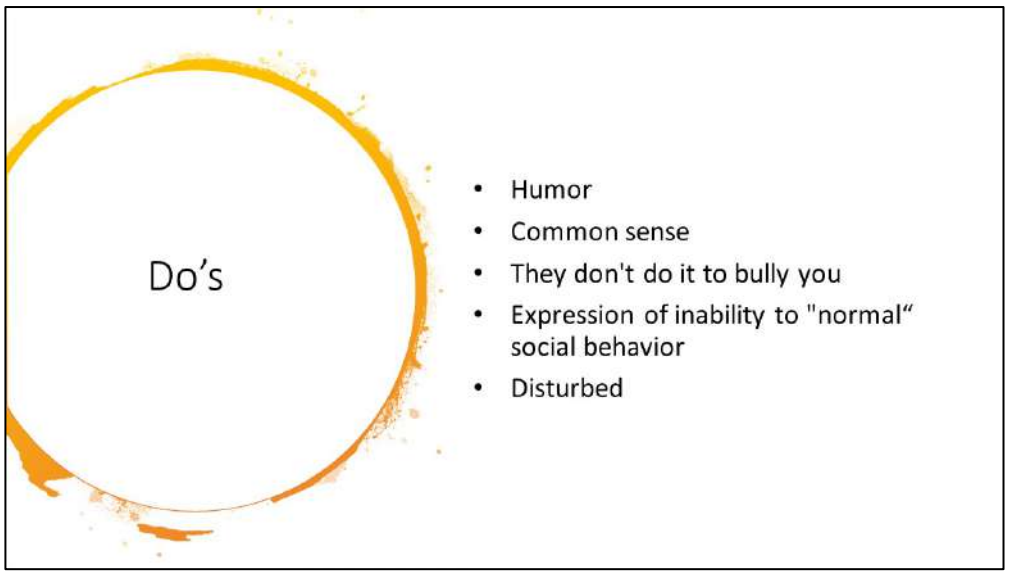
- Projection
- Manipulation
- Powerless induction
- Conflicts with authority
- Idealize-Disqualify
- Black and white
- Lower-Upper position
- The familiar is safe

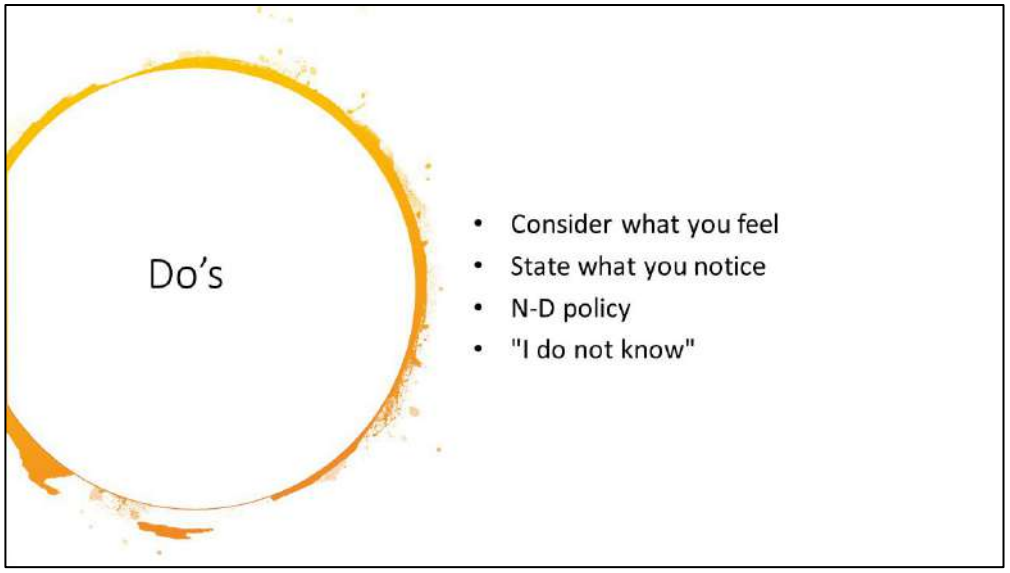
Do's and don't's

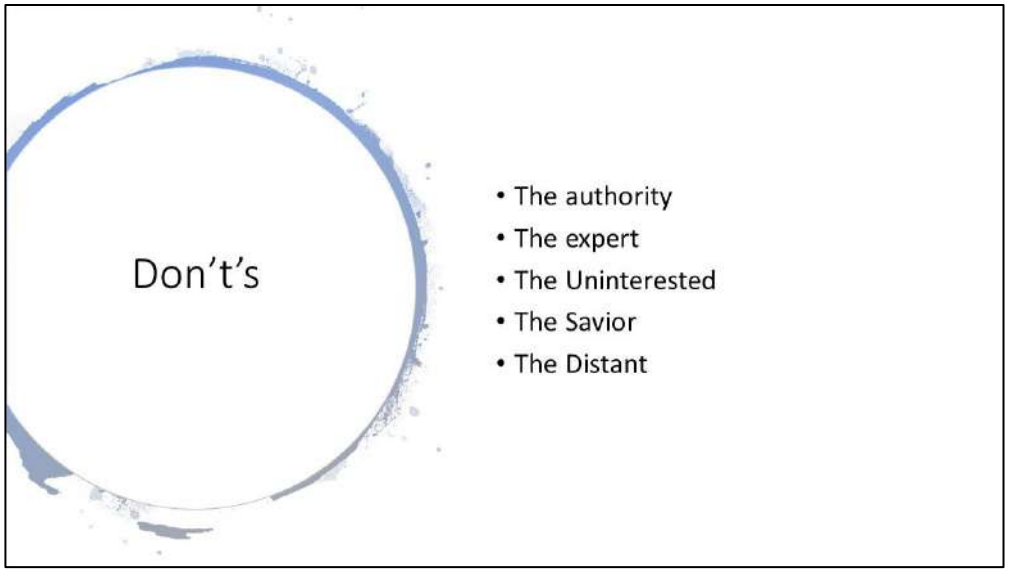
The Non-Specific therapy factors

Do's

- Authenticity, functional openness
- Transparency, Honesty
- Autonomy, Respect
- Clarity, Sincerity
- Limits !!!


Do's
Humor
Common sense
They don't do it to bully you
Expression of inability to "normal" social behavior
Disturbed


Do's
Consider what you feel
State what you notice
N-D policy
"I do not know"


Don't's
The authority
The expert
The Uninterested
The Savior
The Distant

Your task

Help the client to discover his/her strengths and build on this, so that the client can feel better about himself and his/her life.

How to survive?

- "It's a hell of a job."
- Negative transfer is inevitable
- Be aware, talk about it, share with each other
- Team safety and permission for team differentiation is needed
- Dose distance/proximity, be careful with coming too close; or being too distant
- Humor is indispensable - keep smiling despite the misery
- Learn to do "nothing" but not from "laisser fair" culture
- Ask for supervision / intervision
- Set limits

Handling guidelines

- Acceptance
- Communicate transparently
- Set limits (know your own limits)
- Continue to see your own mistakes and shortages
- Search for "triggers"
- Be clear
- Be consistent

Handling guidelines

- Recognize the feelings of the other
- Discuss the facts
- Stay calm, take some distance
- Ask for different behavior
- Use the identification plan
- Seek support from colleagues
- Use a transparent team of professionals

Tips during a crisis

- Implement the crisis plan
- Stay calm
- Be clear
- Respect autonomy
- Be fair and honest
- Limits !!!!!
- Common sense
- She / he does not bully you
- Listen

Marilyn Monroe 1926-1962

- Addictions
- Countless relationships
- Changes of mood
- Suicide attempts

6: Presentation eating disorder, Hungary

Can eating attitudes and problems in children be a sign of eating disorders in adulthood?

Anna Váró, Hungary

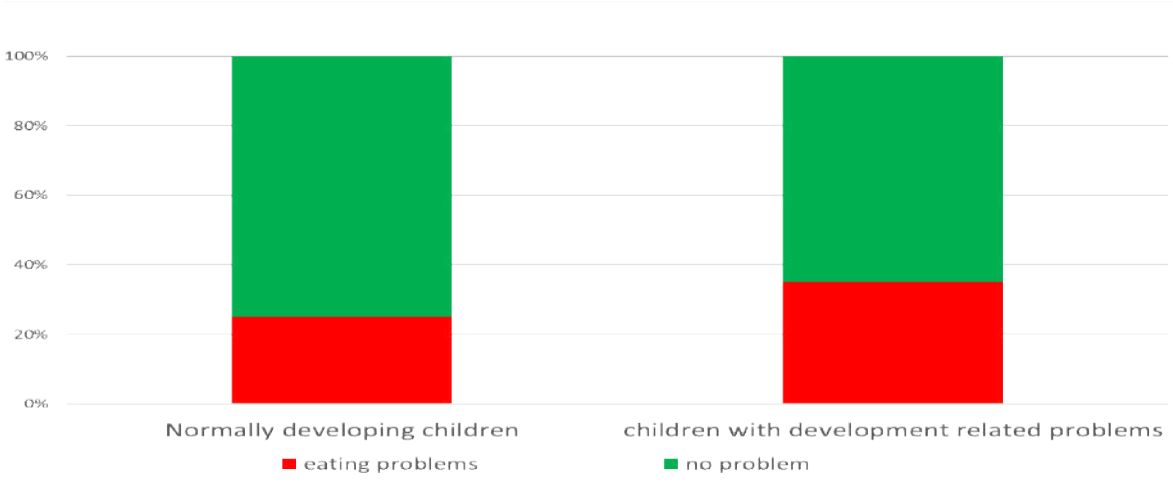
In our institute we have children from 3 years old to young adults. We have more than 200 students and approximately 75% of them are multiply impaired. This means that if we look at the eating problems, disorders the cause can be organic and non organic.

To begin with, let's look at why we eat. We don't only eat to stay alive. We eat when we are bored, sad, happy, nervous, or we don't eat when we are hungry but too nervous. Eating is much more than our organic needs. If we are healthy adults our eating attitudes change according to our psychological state.

Where does it start? The eating skills start to develop in utero. One of the first sensations of the foetus is the taste of the amniotic fluid. The taste buds on the tongue with distinctively mature receptors noted at 12 weeks gestation. The foetus drinks the amniotic fluid. The taste of the amniotic fluid changes according to what the mother eats.

The psychosocial interactions during feeding which occur between the infant and caregiver (usually the mother) begin at birth. The give and take exchange is necessary for the emergence not only of adequate feeding skills, but also positive behavior and attitudes toward eating.
Traditionally the good mother feeds the child well. The good baby eats and thrives well. If so, the mother feels proud and confident. If the child does not eat well the mother starts to feel bad which affects the baby's feeding attitude The child learns that through eating or not eating he can control his environment. He can cause happiness or sadness. This force can take over the body sensations, and the child will not eat because of hunger, but to control his environment. He eats if he loves and refuses to eat if he wants to criticize.

It has been estimated that 25% of normally developing children have eating, feeding problems and that this percentage increases to 35% when the population is restricted to children with development related problems (prematurity, specific deficits). Severe eating disturbances like

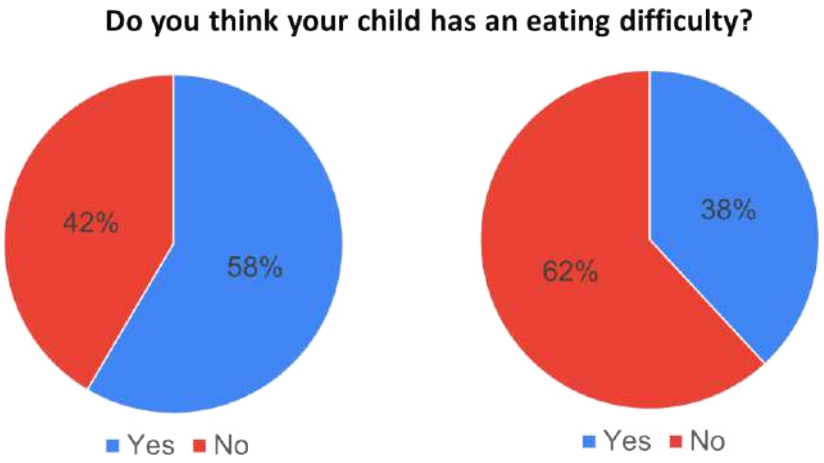


persistent food refusal can result in a failure to thrive and require hospitalization. In particular, failure to thrive is determined by nonorganic causes in 50-58% of cases. On the other hand, 6% of infants in the 6-15 months range of age are reported by their caregivers to have feeding difficulties, arising to about 25-40% during latter phases of development. These percentages include aspecific patterns (colic, vomiting, slow-feeding) as well more structured restrictive or hyperphagic behaviors, and even well-codified disorders such as pica and mericism. Marchi and Cohen traced maladaptive eating patterns of 800 toddlers during a 10-years follow-up. Picky eating and selective alimentation were found to be predictors of a subsequent Anorexia Nervosa, while prospective risks for a later Bulimia Nervosa implicated pica and irregular meals. Moreover, the historic studies of Anna Freud and the investigations of C. Keller detected a connection between feeding and eating disturbances of infancy and later onset of behavioral and personality disorders.

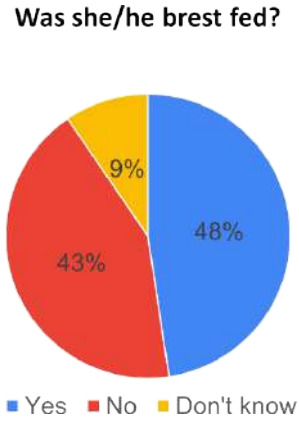
What is the case with visually impaired children? It is primarily through vision that the infant normally learns the significance of stimuli in his environment. When a child has a visual impairment, particularly if it co-exists with motor and/or learning difficulties, this will have a huge impact on the acquisition of eating and drinking skills. It is estimated that over 40 percent of the brain is devoted to visual function.
The visual impairment can affect interactions between the child and his carer as well as the development of independent eating and the enjoyment of food. Being able to see food greatly enhances our ability to anticipate and enjoy mealtimes. The child with visual impairment requires particular help to learn how to eat and drink.

To assess the eating difficulties, problems, attitudes in our institute we made a questionnaire. This was filled out by the parents. We would like to share some of the results.

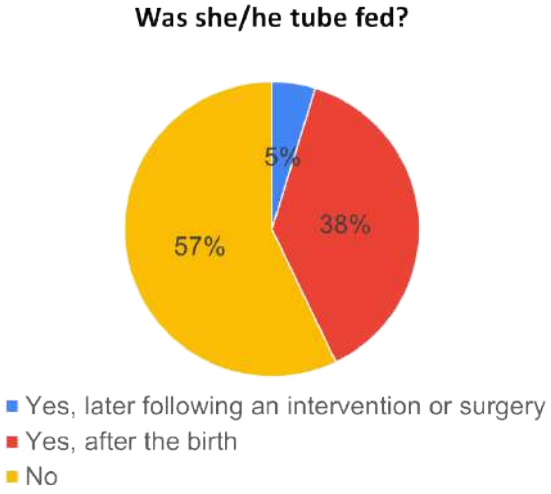
As in our institute, a lot of differently affected children are represented in our sample. Some children are only visually impaired, and some are multiply and severely affected. We found that almost half of the children had some problem, difficulty with eating. Some children have organic problems with eating due to their impairment. To sort them out we excluded the children with severe gross motor function and other severe difficulties except visual impairment. Still 38 % of the students have eating problems regarding their parents.



Early experiences affect later attitudes, so we had some questions that could reveal these. One of these was if she or he was breastfed or not. In Hungary most of the mothers try to breastfeed their baby so 48% is a low number.



On the other hand a lot of the children 43% were tube fed sometime in their life. Tube feeding is a trauma for the child especially the nasogastric tube, and usually if the tube feeding is only temporary they use nasogastric tube. Just imagine that someone puts the tube through your nose into your stomach.



Only 50% of the students eat independently with cutlery, 15% need verbal support, 30% need support with the cutleries, and 5% need more help during eating.
24% of the students eat slowly, but we have children who eat too fast.
All these are not eating disorders but they can be a problem.

Also drink habits are interesting, because 40% of the students don't drink enough by themselves.

If we look at the irregularities we have students that reject new food or reject eating, or are disturbed by food stains, some binge eat, gag during eating, or have over-stimulated motor movements. A few students are afraid of gaining weight, and also we have a student who eats inedible things (pica).
I think the risk is high for these children to develop eating disorders.

It would be interesting to make a control group with normally developing children and compare the data.

Many times eating difficulties are overshadowed by other issues. We think it is important to deal with these children and their eating problems properly as early as possible, to prevent eating disorders from developing later on.

References:

1. Sacrato et al., Emergent factors in Eating Disorders in childhood and preadolescence, Italian Journal of Pediatrics 2010
2. J. C. Arvedson, L.Brodsky Pediatric Swallowing and feeding, DC Learning New York, USA 2002
3. A. Winstock, Eating and drinking difficulties in children, Speechmark Oxon Uk, 2005

7: PowerPoint Presentation addiction, NL

Addiction and Eating disorders in adults with visual impairment: what do we know from the literature and practice

Marieke Langekamp & Hilde van der Aa

Robert Coppes Foundation

Agenda

- What do we know from the literature?
- How do we deal with these problems in our daily practice?
  - Model: motivational interviewing
  - In practice at the Robert Coppes Foundation
- TED talk: inspiring view on addiction

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Addiction

Drug addiction, also called substance use disorder, is a mental health disorder that affects a person's brain and behavior and leads to an **inability to control the use of a legal or illegal drug or medication**. Substances such as alcohol, marijuana and nicotine are also considered drugs. When you're addicted, you may continue using the drug despite the harm it causes. People struggling with addiction usually deny that their drug use is problematic and are reluctant to seek treatment.

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Risk factors

- **Family history of addiction:** drug addiction is more common in some families and likely involves genetic predisposition.
- **Mental health disorder:** if you have a mental health disorder such as depression or post-traumatic stress disorder, you're more likely to become addicted to drugs. Using drugs can become a way of coping with painful feelings, such as anxiety, depression and loneliness, and can make these problems even worse.
- **Peer pressure:** peer pressure is a strong factor in starting to use and misuse drugs, particularly for young people.
- **Social support:** a lack of a bond with your parents or siblings may increase the risk of addiction, as can a lack of parental supervision.

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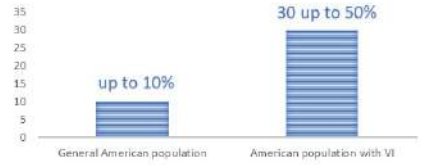
Addiction in people with VI

People with VI are more vulnerable:
- at a higher risk of mental health disorders
- experience more difficulty in social interactions, vulnerable for peer pressure
- receive less social support, often small social network

Lifetime prevalence higher than general population*



* Buss and Cramer (1989), Moore and Li (1994), Nelipovich, Wergin, and Kossick (1998)

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Eating disorders

An eating disorder is a mental health disorder defined by abnormal eating habits that negatively affect a person's health, emotions and ability to function in important areas of life. Eating disorders can harm the heart, digestive system, bones, and teeth and mouth, and lead to other diseases. Most common eating disorders include **binge eating disorder**, where people eat a large amount in a short period of time; **anorexia nervosa**, where people have an intense fear of gaining weight and restrict food or overexercise to manage this fear; **bulimia nervosa**, where people eat a lot and then try to rid themselves of the food by throwing up.

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Risk factors

- **Family history:** eating disorders are significantly more likely to occur in people who have parents or siblings who've had an eating disorder.
- **Mental health disorders:** people with an eating disorder often have a history of an anxiety disorder, depression or obsessive-compulsive disorder.
- **Dieting and starvation:** dieting is a risk factor for developing an eating disorder.
- **Stress:** whether it's moving to another home, taking a new job, or a family or relationship issue, change can bring stress, which may increase a person's risk of an eating disorder.
- **Cultural standards of attractiveness:** concerns with body image are epidemic in Western societies mainly influenced by the media which imply that especially women should be thin.

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Eating disorders in people with VI

People with VI are more vulnerable:
- at a higher risk of mental health disorders
- more susceptible to experience stress due to their impairment

No prevalence estimates found (mostly case studies)

Specific risk factors:
- Not being able to see how you look and having to rely on others for that, may lead to increased insecurity and dissatisfaction of one's own body and increased risk of eating disorders over time (Thomas et al., 2012; Vandereycken, 1986)

- Congenitally blind women appear to have lower body dissatisfaction and more positive eating attitudes compared to women blinded later in life, which may be due to the fact that they are less susceptible to cultural standards from the media. (Baker et al. 1998)

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The Robert Coppes Foundation (RCF)

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Model: motivational interviewing

Motivational Interviewing (MI) a conversation style focused on collaboration with special focus of eliciting and strengthening intrinsic motivation for change.[1]

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In practice at the RCF

- Being there for the client, make connection, build trust
- Offering a safe environment in which someone can change
- Work on self-respect and own strength of the client
- Working together with addiction care and provide thim with information on visual impairment
- Group-based treatment often does not work
- Looking at possible underlying trauma/psychiatric problems
- Challenge to involve social network (family/friends), more focus/effort on involving them may be needed

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https://www.ted.com/talks/johann_hari_everything_you_think_you_know_about_addiction_is_wrong

8: PowerPoint Presentation 'Understanding problem behavior'

Understanding 'problem' behavior

Ways to look at behavior

Dr. Marit van Buijsen

19 October 2021

Robert Coppes Stichting

Problem behavior

How do you see problem behavior?

Take your smartphone:
Go to menti.com and use the code 9878 3574

A different view on 'problem' behavior

- Service user is care-dependent
- Unable to express dissatisfaction and/or pain
- Gives a **signal**
- It bothers us, but service user must make it stop

→ See it as **signal behavior**, that you must try to understand

Moving on by standing still

- What is the underlying reason for the behavior?
- How can we ensure that the service user does not have to show this behavior again?

→ Assessment

- What does the service user need from us?

→ Attitude of the professional

Goal

Assessment	Attitude of the professional
• Factors that play a role	• Mentalization-based support

Assessment

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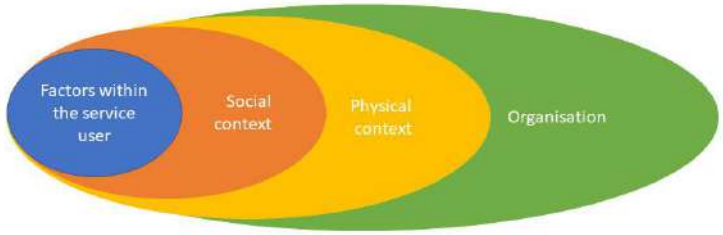
How to look at behavior?

centrum voor consultatie en expertise

Different factors play a role
- Broad
- Multifacet

Broad



• Biological factors • Psychological factors	• Family • Professionals • Fellow service users	• Building • Decoration • Light/sound	• Vision • Policy • Education

Multifacet

- Facts
- Experience
- Interpretation
- Values and norms
- Interests

Attitude of the professional

Mentalization based support

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Mentalising

- Seeing yourself from the outside and the other from the inside
- Behavior is motivated by your mental state
  - ...I feel (feelings)
  - ... I think (thoughts)
  - ...I want (desire)
  - ...I wish (belief)
  - ...I hope (intention)
- Human ability that allows us to judge or explain our own and others behavior

Importance

- Able to understand your own and others behavior
- Regulate your emotions
- Resilience to deal with difficult situations and cope with problems

Not-mentalizing state

- Stress influences our ability to mentalize

→ A lot of our service users have difficulties to adapt a mentalizing state
→ More quickly stressed
→ Show 'problem' behavior

Key skill

- Help release stress by **being a mirror** for the behavior and feelings of a service user
- I see that...
- Important to stand still and look behind the behavior
- Only possible when you are feeling calm inside

Mentalization based attitude

1. You are calm "inside" and have learned to check that with yourself.
2. You do not judge the other person but have an open attitude.
3. You are curious and show interest in the other person.
4. You cannot know for sure what the other person is thinking or feeling (you have the position of not knowing), but you want to explore that. To children you can say: "I can't tell from your nose how you feel or what you think.

Mentalization based attitude

5. You are yourself and honest.
6. You are flexible and willing to reconsider your opinion.
7. You are transparent and therefore react predictably for the other person.
8. You do not make a disagreement with your service user too 'personal' by looking at it with some distance.

Closing remarks

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Key message

- Do not judge the person for his behavior but stand still and try to explore what signal the person is trying to give us with his behavior
- To understand the behavior take a broad and multifacet approach
- By taking a mentalization based attitude we can help service users to release stress and regulate their emotions leading to a decrease in the need to show 'problem' behavior.

Want to know more?

https://cce.nl/about-cce

https://www.bartimeus.nl/sites/default/files/downloads/mentalization_can_be_learned.pdf

mvbuijsen@robertcoppes.nl

9: PowerPoint Presentation Aggression 1

BFW BERUFS FÖRDER UNGS WERK HALLE (SAALE)

KOMPETENZZENTRUM
RUND UM DAS SEHEN

Aggression

André Kunnig
Psychologist/ Head of RehaAssessment/Education
BFW Halle/ Germany

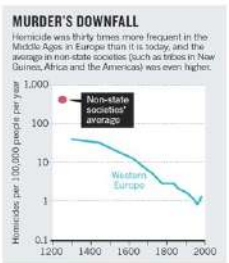
AGGRESSION – A (SOCIAL) PSYCHOLOGICAL VIEW

WHY DO WE HAVE AGGRESSIONS?

What is aggression

A historical view

- Aggression is quite normal and part of the human behavior
  - War, terrorism, violence
  - Bullying in school, at work or in relationships
- We find aggression in the whole human history and also the attempt to taming and avoiding this behavior



What is aggression

A definition

Aggression is

- On purpose, intentionally
- Wants to hurt
- The victim wants to avoid this

A behavior by accident or by mistake or if I want it (surgery) is not an aggression!

Why do we have aggressions?

Causes for aggressive behavior

Biological approaches

- A Steam boiler Modell:
  - We always produce aggressive energy, if it's too much the boiler is exploiting and we act it out
  - It's old and not the state of the art anymore
- Genetics: a little part of our aggressive behavior inheritable
- Influence of hormones (testosterone): but the link is weak
- Influence of culture in the way, how we do act out an aggression
- Neurobiological aspects: brain damages or a malfunction of neurotransmitters

Why do we have aggressions?

Causes for aggressive behavior

Psychological approaches

- Frustration causes aggressions, especially if I have learned that aggression is a successful behavior
- My learning history in general:
  - If I have learned that aggression is a successful behavior
  - If I have experienced a positive reaction to aggressions in my childhood
  - If a role model was successful with an aggressive behavior

In sum we have more evidence for the psychological approaches

Why do we have aggressions?

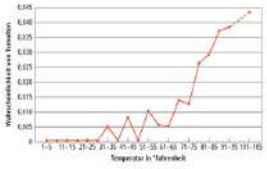
Personal and situational conditions

Personal Conditions

- Aggressiveness as a personality trait
- Hostile attribution style
- Gender:
  - men show more violence
  - women show more bullying

Situational Conditions

- Alcohol
- High temperature
- Violence in media



Why do we have aggressions?

Psychiatric disorders and aggression

Male Depression

- There are differences in the expression of symptoms by men versus women with depression; men show atypical symptoms: fury, anger, aggression, alcohol or drug abuses

Schizophrenia

- Impulsive aggressiveness because of the feeling of a threat (Threat-Controll-Override)
- Residual symptoms of a schizophrenia

Why do we have aggressions?

Psychiatric disorders and aggression

Mental retardation

- Less ability for emotional regulation and impulse control

Personality disorders

- Psychopathy and antisocial personality disorders or a borderline disorder
- Sometimes a pathological narcissism

Thank you!

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Mobil: + 49 151 467 265 37
Mail: akunnig@bfw-halle.de

10: PowerPoint Presentation Aggression 2

BFW BERUFS FÖRDER UNGS WERK HALLE (SAALE)

KOMPETENZZENTRUM RUND UM DAS SEHEN

Aggression and Behavioral Disorders in People with Visual Impairment

Mr P. - description of a case
presentation by Holger Stoek (bfw halle)

Aggression and Behavioral Disorders in People with Visual Impairment

Mr P. - description of a case

- male person, born in 1960, attended school for 10 yrs.
- vocational training as a machine operator
- worked 22 yrs. as a lorry driver

15/02/2023 Holger Stoek 2

Aggression and Behavioral Disorders in People with Visual Impairment

Mr P. - description of a case

- office worker training in BFW (Halle) in 2015
- basic rehabilitation in 2017
- integration training 10 month in 2018

15/02/2023 Holger Stoek 3

Aggression and Behavioral Disorders in People with Visual Impairment

Mr P. - description of a case

- mean intellectual level, German 3 (level C), Mathematics 4 (level D)
- no PC knowledge, no typewriting
- diabetes: no tactile sense – getting Braille is restricted
- no knowledge of devices for vip
- weak resilience and motivation

Aggression and Behavioral Disorders in People with Visual Impairment

Mr P. - description of a case

- problems:
  - choice of measure
  - white cane training
  - research for work experience

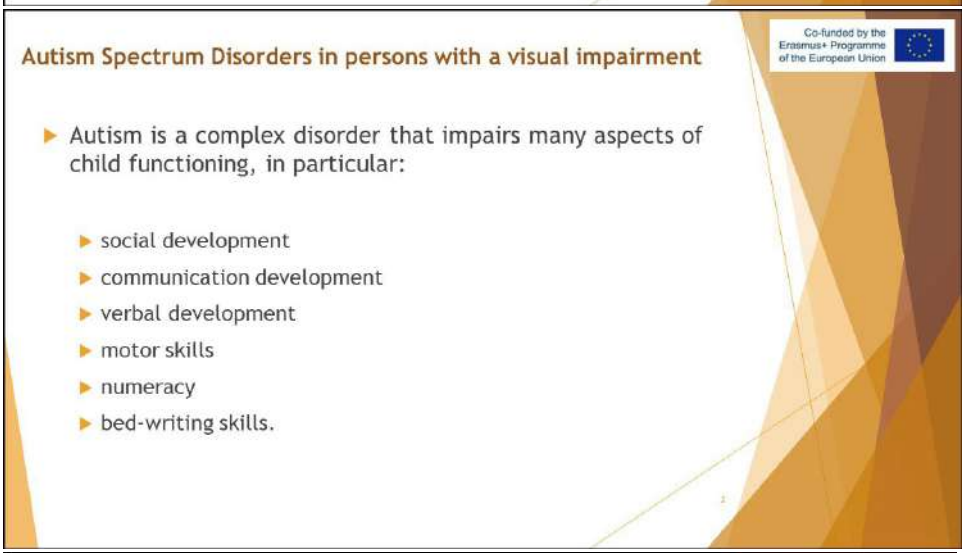
Aggression and Behavioral Disorders in People with Visual Impairment

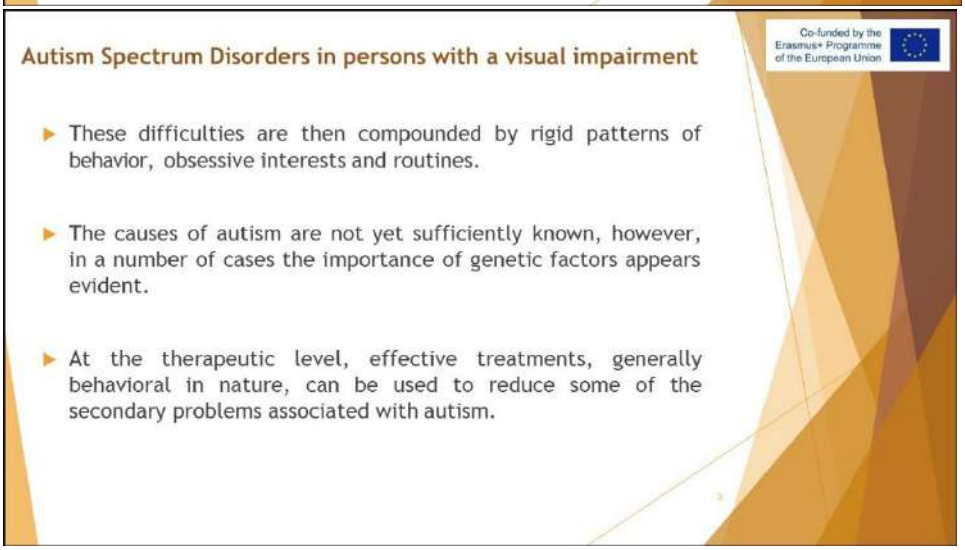
Mr P. - description of a case

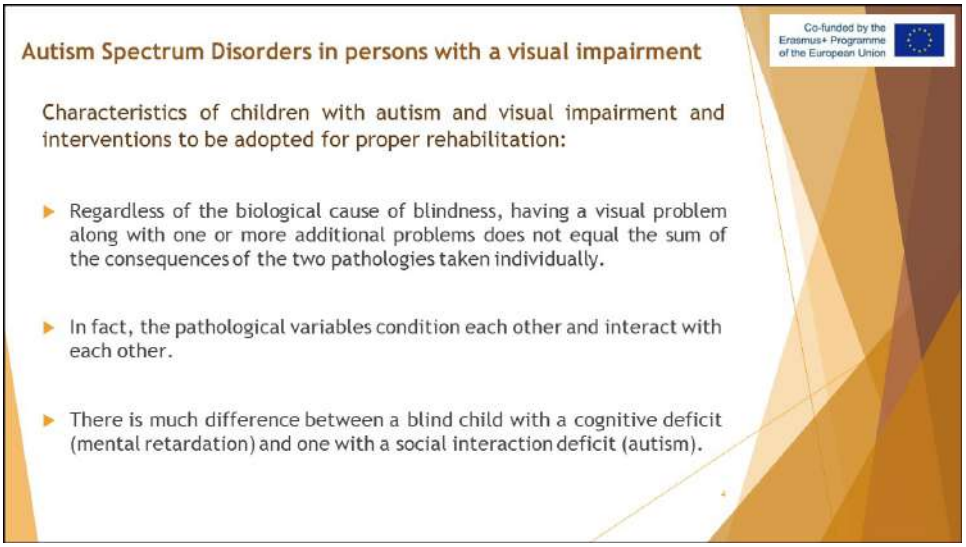
- reactions:
  - bold, insultingly behaviour
  - threated to bash

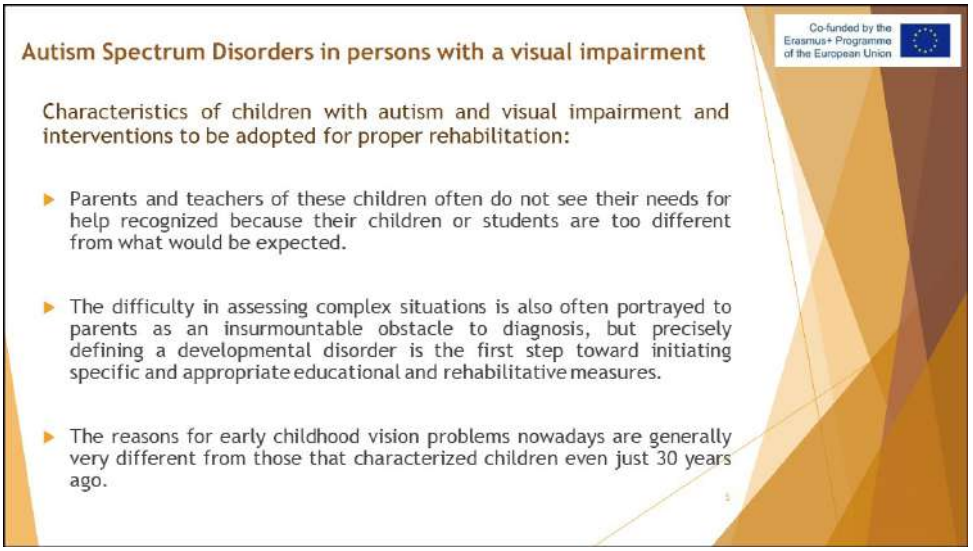
Thank Youy!

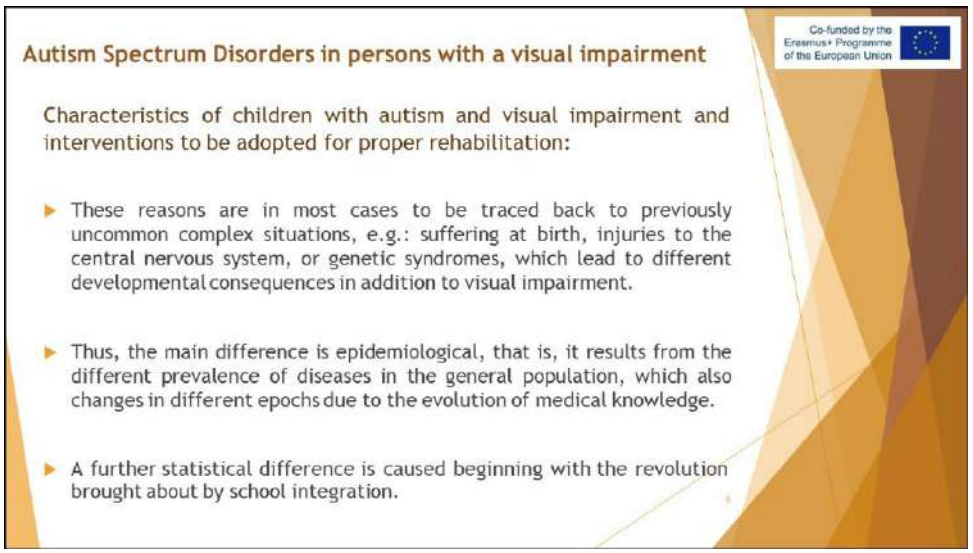
11: PowerPoint Presentation Autism Spectrum Disorder of Italy

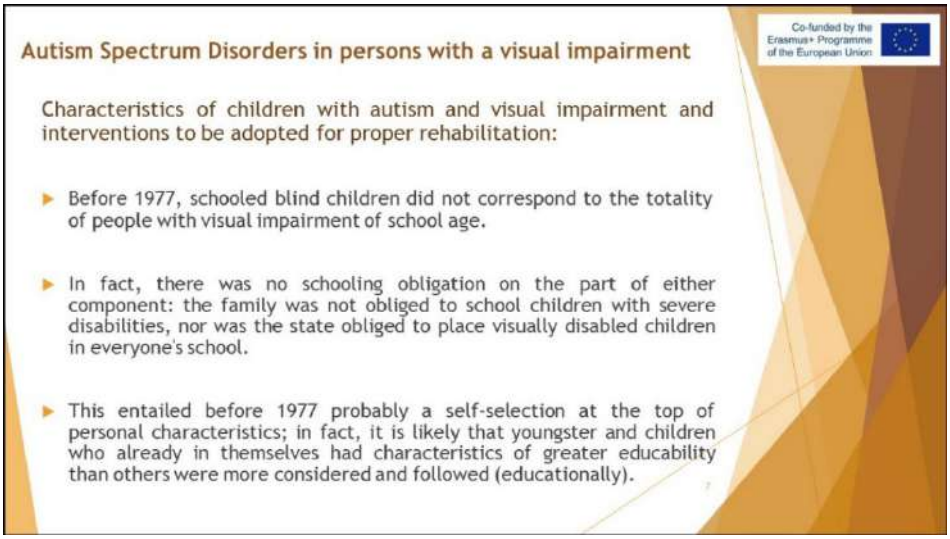


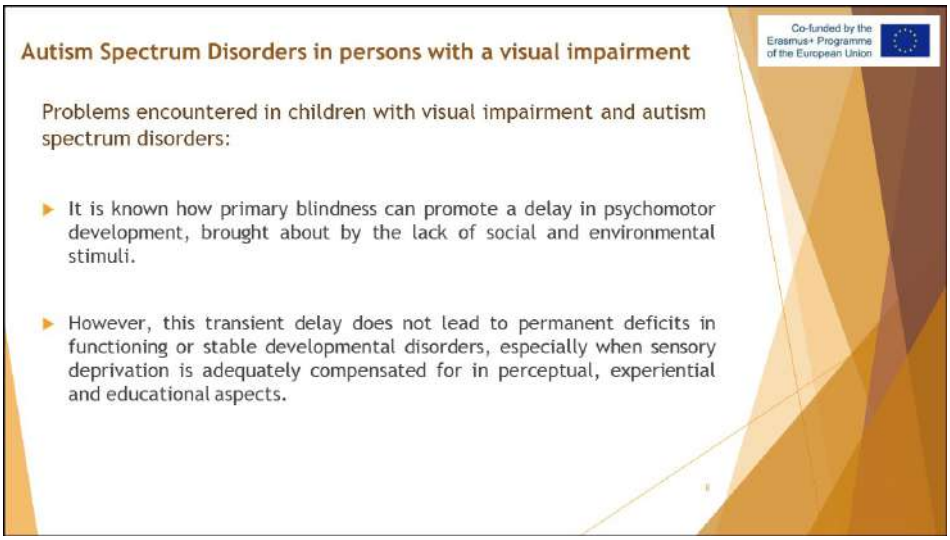


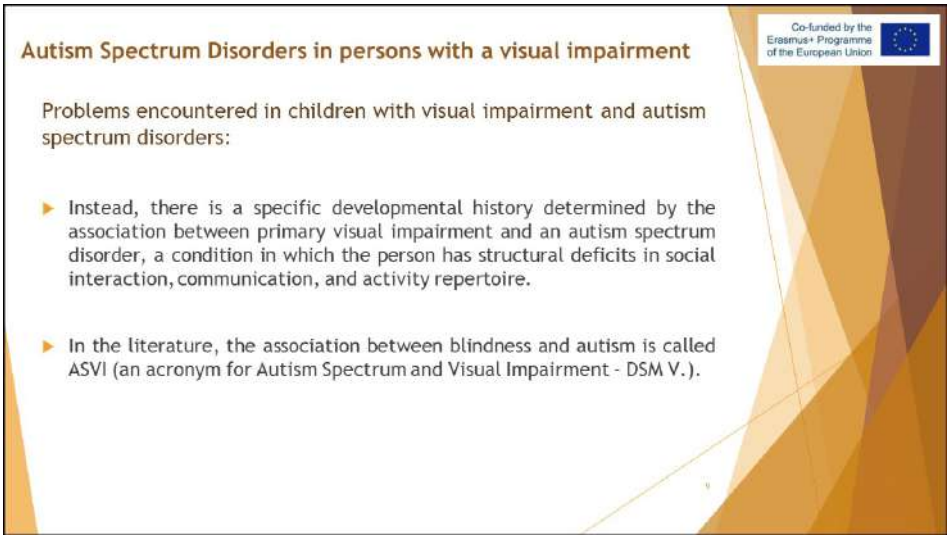

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Characteristics of children with autism and visual impairment and interventions to be adopted for proper rehabilitation:
Regardless of the biological cause of blindness, having a visual problem along with one or more additional problems does not equal the sum of the consequences of the two pathologies taken individually.
In fact, the pathological variables condition each other and interact with each other.
There is much difference between a blind child with a cognitive deficit (mental retardation) and one with a social interaction deficit (autism).

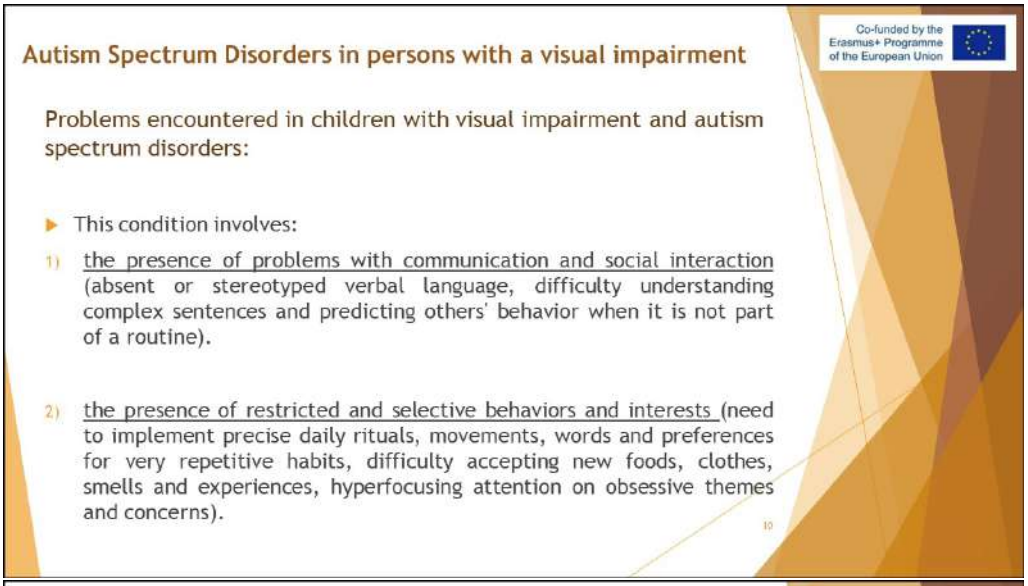

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Characteristics of children with autism and visual impairment and interventions to be adopted for proper rehabilitation:
Parents and teachers of these children often do not see their needs for help recognized because their children or students are too different from what would be expected.
The difficulty in assessing complex situations is also often portrayed to parents as an insurmountable obstacle to diagnosis, but precisely defining a developmental disorder is the first step toward initiating specific and appropriate educational and rehabilitative measures.
The reasons for early childhood vision problems nowadays are generally very different from those that characterized children even just 30 years ago.

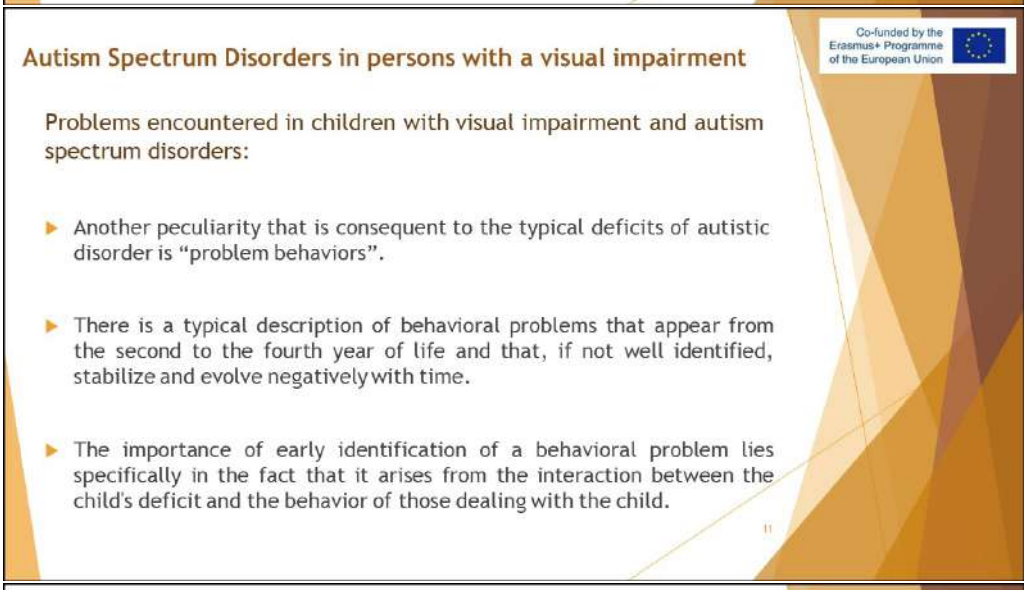

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Characteristics of children with autism and visual impairment and interventions to be adopted for proper rehabilitation:
These reasons are in most cases to be traced back to previously uncommon complex situations, e.g.: suffering at birth, injuries to the central nervous system, or genetic syndromes, which lead to different developmental consequences in addition to visual impairment.
Thus, the main difference is epidemiological, that is, it results from the different prevalence of diseases in the general population, which also changes in different epochs due to the evolution of medical knowledge.
A further statistical difference is caused beginning with the revolution brought about by school integration.

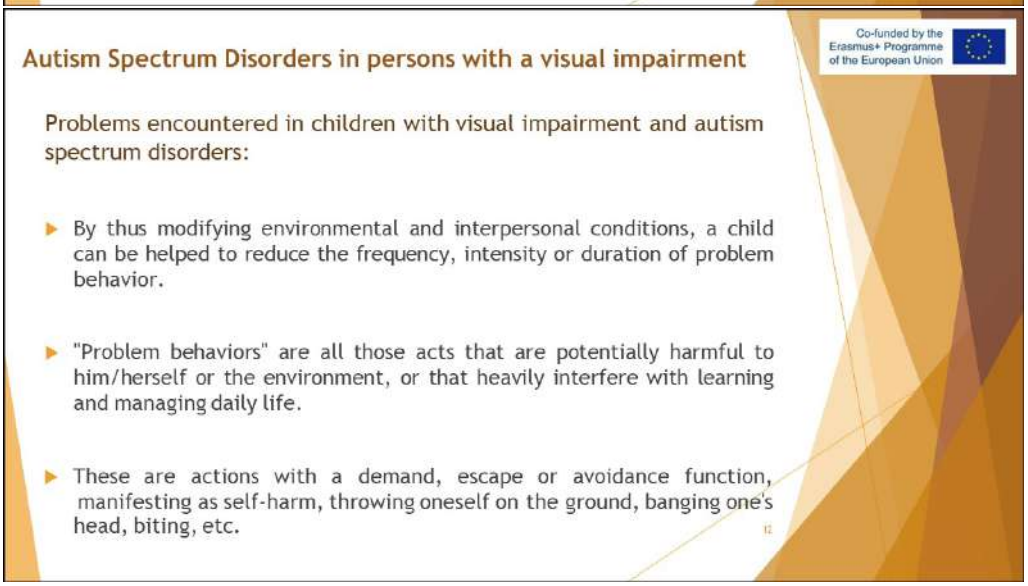

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Characteristics of children with autism and visual impairment and interventions to be adopted for proper rehabilitation:
Before 1977, schooled blind children did not correspond to the totality of people with visual impairment of school age.
In fact, there was no schooling obligation on the part of either component: the family was not obliged to school children with severe disabilities, nor was the state obliged to place visually disabled children in everyone's school.
This entailed before 1977 probably a self-selection at the top of personal characteristics; in fact, it is likely that youngster and children who already in themselves had characteristics of greater educability than others were more considered and followed (educationally).

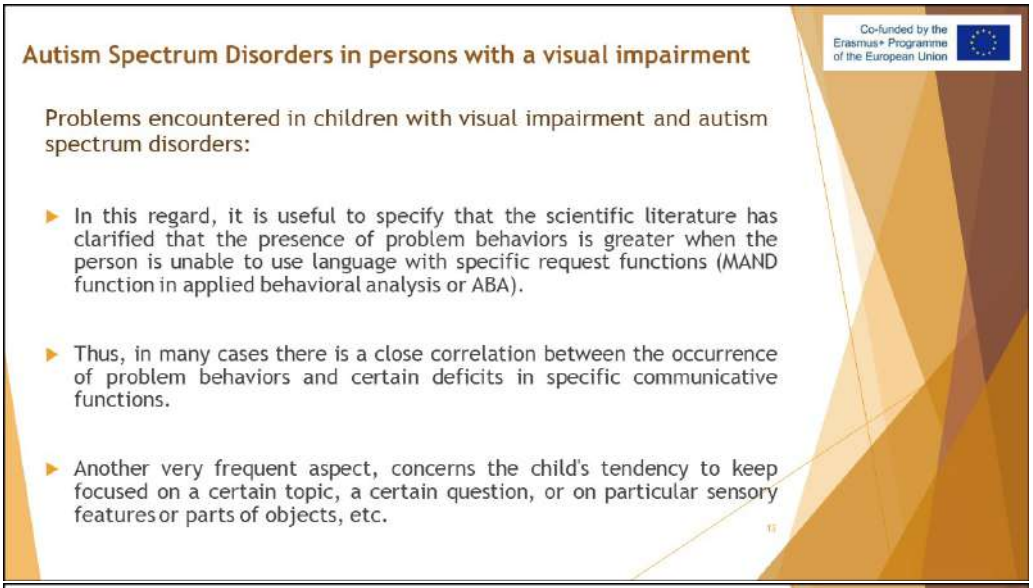

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
It is known how primary blindness can promote a delay in psychomotor development, brought about by the lack of social and environmental stimuli.
However, this transient delay does not lead to permanent deficits in functioning or stable developmental disorders, especially when sensory deprivation is adequately compensated for in perceptual, experiential and educational aspects.

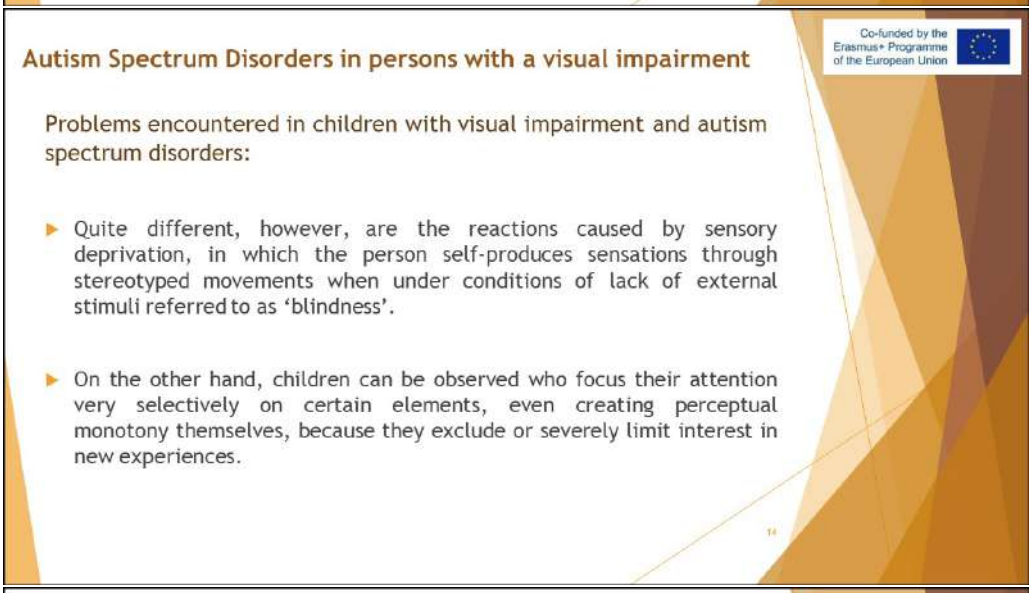

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
Instead, there is a specific developmental history determined by the association between primary visual impairment and an autism spectrum disorder, a condition in which the person has structural deficits in social interaction, communication, and activity repertoire.
In the literature, the association between blindness and autism is called ASVI (an acronym for Autism Spectrum and Visual Impairment - DSM V.).

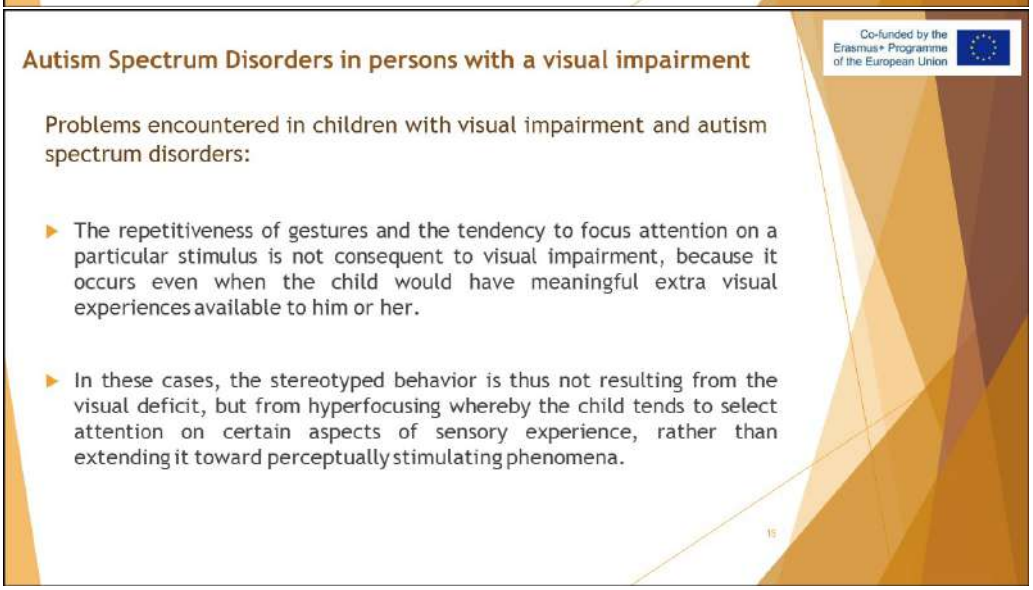

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
This condition involves:
1) the presence of problems with communication and social interaction (absent or stereotyped verbal language, difficulty understanding complex sentences and predicting others' behavior when it is not part of a routine).
2) the presence of restricted and selective behaviors and interests (need to implement precise daily rituals, movements, words and preferences for very repetitive habits, difficulty accepting new foods, clothes, smells and experiences, hyperfocusing attention on obsessive themes and concerns).
10

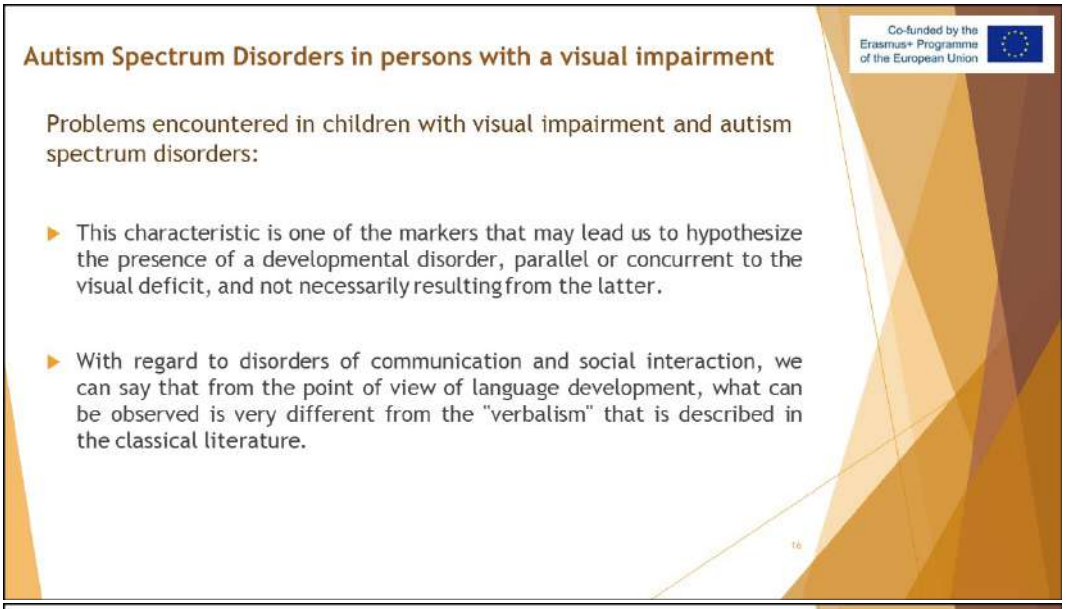

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
Another peculiarity that is consequent to the typical deficits of autistic disorder is "problem behaviors".
There is a typical description of behavioral problems that appear from the second to the fourth year of life and that, if not well identified, stabilize and evolve negatively with time.
The importance of early identification of a behavioral problem lies specifically in the fact that it arises from the interaction between the child's deficit and the behavior of those dealing with the child.
11

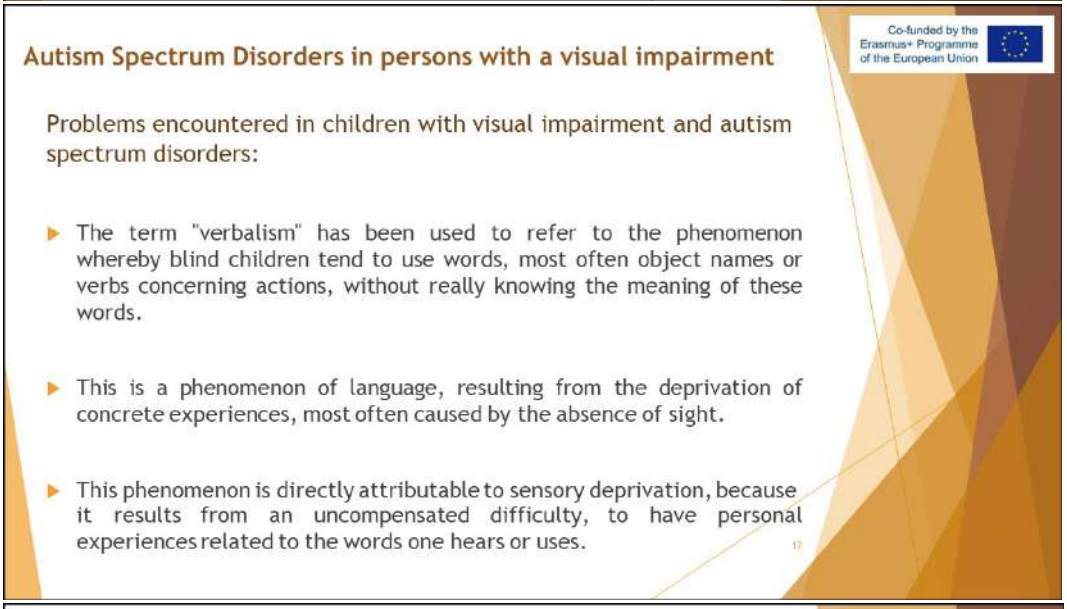

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
By thus modifying environmental and interpersonal conditions, a child can be helped to reduce the frequency, intensity or duration of problem behavior.
"Problem behaviors" are all those acts that are potentially harmful to him/herself or the environment, or that heavily interfere with learning and managing daily life.
These are actions with a demand, escape or avoidance function, manifesting as self-harm, throwing oneself on the ground, banging one's head, biting, etc.
12

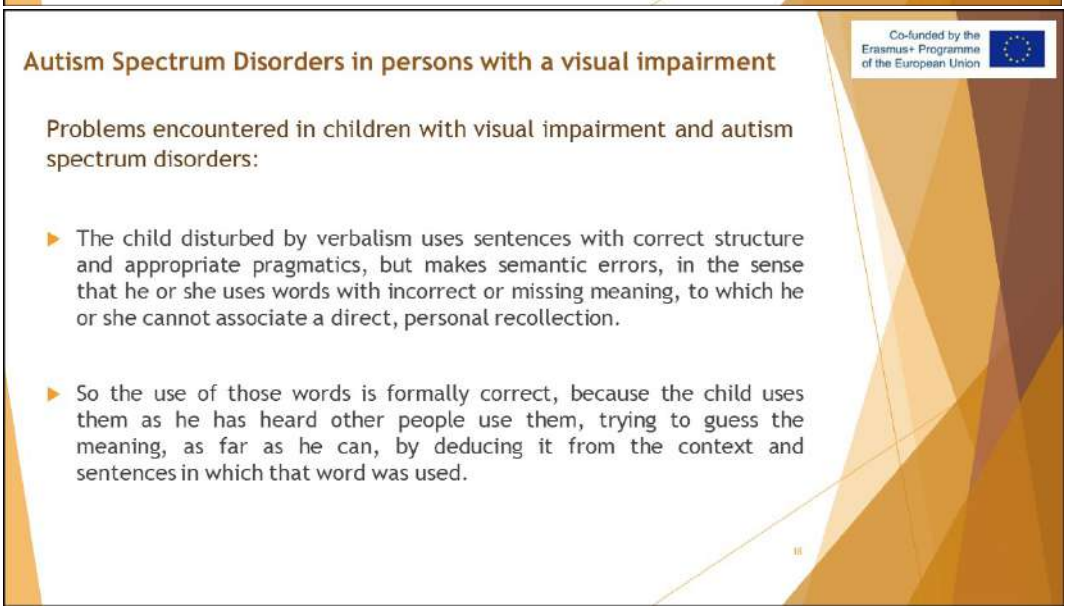

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
In this regard, it is useful to specify that the scientific literature has clarified that the presence of problem behaviors is greater when the person is unable to use language with specific request functions (MAND function in applied behavioral analysis or ABA).
Thus, in many cases there is a close correlation between the occurrence of problem behaviors and certain deficits in specific communicative functions.
Another very frequent aspect, concerns the child's tendency to keep focused on a certain topic, a certain question, or on particular sensory features or parts of objects, etc.

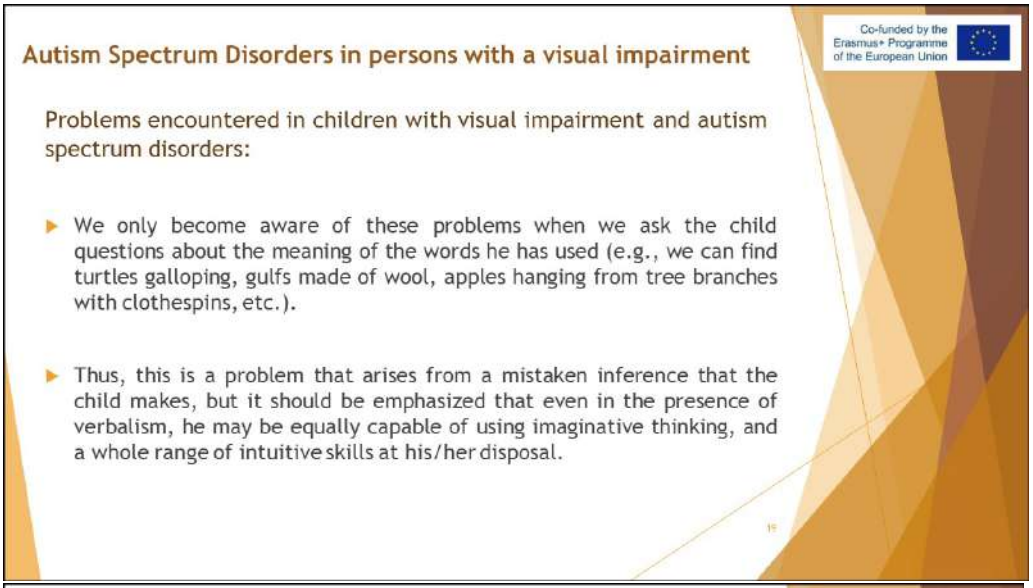

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
Quite different, however, are the reactions caused by sensory deprivation, in which the person self-produces sensations through stereotyped movements when under conditions of lack of external stimuli referred to as 'blindness'.
On the other hand, children can be observed who focus their attention very selectively on certain elements, even creating perceptual monotony themselves, because they exclude or severely limit interest in new experiences.

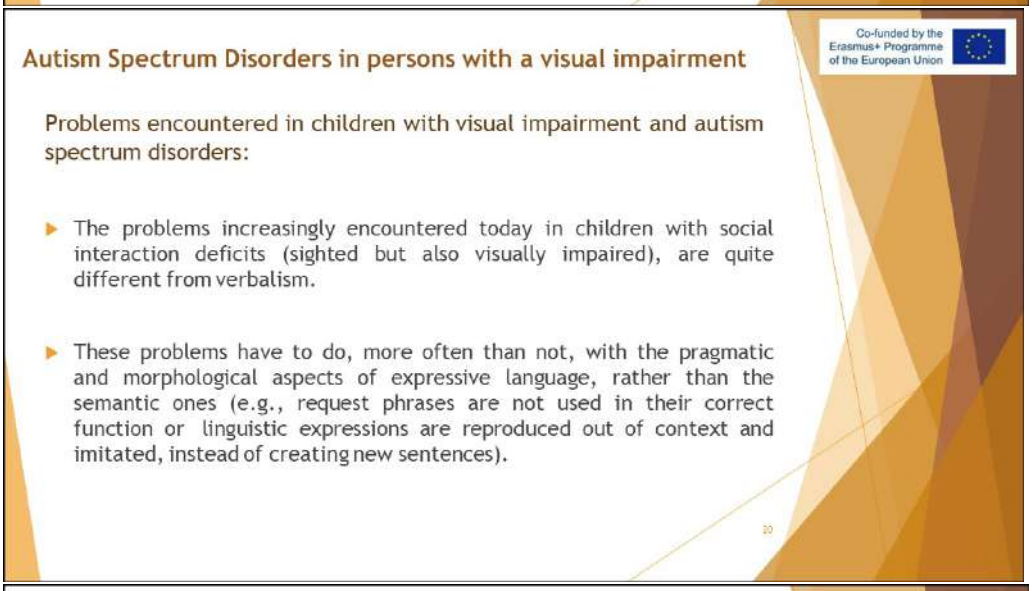

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
The repetitiveness of gestures and the tendency to focus attention on a particular stimulus is not consequent to visual impairment, because it occurs even when the child would have meaningful extra visual experiences available to him or her.
In these cases, the stereotyped behavior is thus not resulting from the visual deficit, but from hyperfocusing whereby the child tends to select attention on certain aspects of sensory experience, rather than extending it toward perceptually stimulating phenomena.

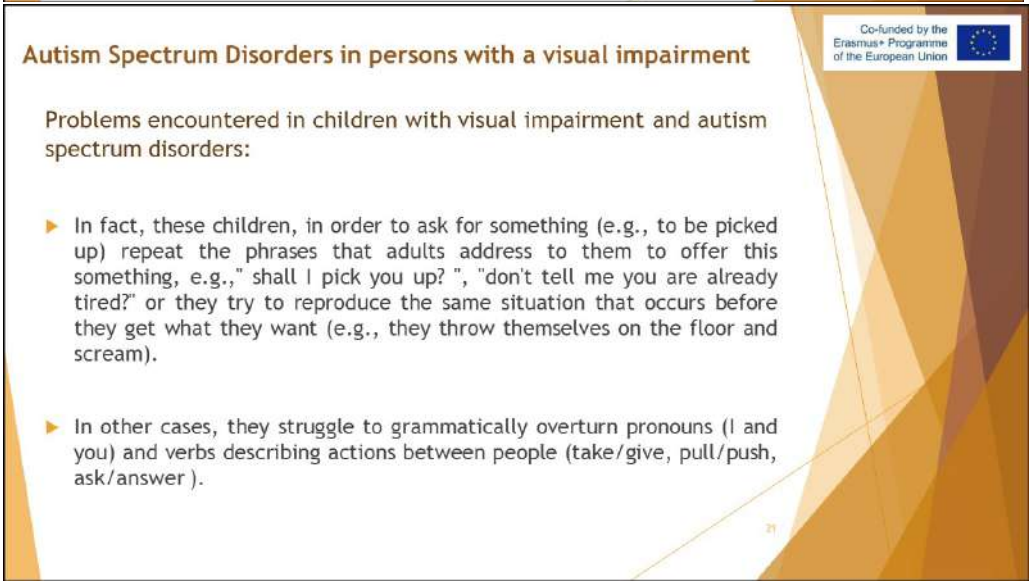

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
This characteristic is one of the markers that may lead us to hypothesize the presence of a developmental disorder, parallel or concurrent to the visual deficit, and not necessarily resulting from the latter.
With regard to disorders of communication and social interaction, we can say that from the point of view of language development, what can be observed is very different from the "verbalism" that is described in the classical literature.
16


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
The term "verbalism" has been used to refer to the phenomenon whereby blind children tend to use words, most often object names or verbs concerning actions, without really knowing the meaning of these words.
This is a phenomenon of language, resulting from the deprivation of concrete experiences, most often caused by the absence of sight.
This phenomenon is directly attributable to sensory deprivation, because it results from an uncompensated difficulty, to have personal experiences related to the words one hears or uses.
17


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
The child disturbed by verbalism uses sentences with correct structure and appropriate pragmatics, but makes semantic errors, in the sense that he or she uses words with incorrect or missing meaning, to which he or she cannot associate a direct, personal recollection.
So the use of those words is formally correct, because the child uses them as he has heard other people use them, trying to guess the meaning, as far as he can, by deducing it from the context and sentences in which that word was used.
18


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
We only become aware of these problems when we ask the child questions about the meaning of the words he has used (e.g., we can find turtles galloping, gulfs made of wool, apples hanging from tree branches with clothespins, etc.).
Thus, this is a problem that arises from a mistaken inference that the child makes, but it should be emphasized that even in the presence of verbalism, he may be equally capable of using imaginative thinking, and a whole range of intuitive skills at his/her disposal.
19


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
The problems increasingly encountered today in children with social interaction deficits (sighted but also visually impaired), are quite different from verbalism.
These problems have to do, more often than not, with the pragmatic and morphological aspects of expressive language, rather than the semantic ones (e.g., request phrases are not used in their correct function or linguistic expressions are reproduced out of context and imitated, instead of creating new sentences).
20


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Problems encountered in children with visual impairment and autism spectrum disorders:
In fact, these children, in order to ask for something (e.g., to be picked up) repeat the phrases that adults address to them to offer this something, e.g.," shall I pick you up? ", "don't tell me you are already tired?" or they try to reproduce the same situation that occurs before they get what they want (e.g., they throw themselves on the floor and scream).
In other cases, they struggle to grammatically overturn pronouns (I and you) and verbs describing actions between people (take/give, pull/push, ask/answer).
21

Autism Spectrum Disorders in persons with a visual impairment

Co-funded by the Erasmus+ Programme of the European Union

Importance of the relationship between diagnostic accuracy and targeted rehabilitation:

- In recent years we have acquired reliable information on the effectiveness of some approaches and treatments with respect to some deficits characteristic of autistic disorder, particularly on the quality of communication and problem behaviors.
- The Italian *Istituto Superiore di Sanità* has conducted an extensive analysis of research on the effectiveness of various treatments, and has compiled a detailed document for use by technicians and a popularized version for parents.

22

Autism Spectrum Disorders in persons with a visual impairment

Co-funded by the Erasmus+ Programme of the European Union

Importance of the relationship between diagnostic accuracy and targeted rehabilitation:

- This is Guideline Number 21, "The Treatment of Autism Spectrum Disorders in Children and Adolescents," issued in October 2011.
- The guide aims to produce information useful in directing the decisions of clinical and nonclinical practitioners toward greater effectiveness and appropriateness.

23

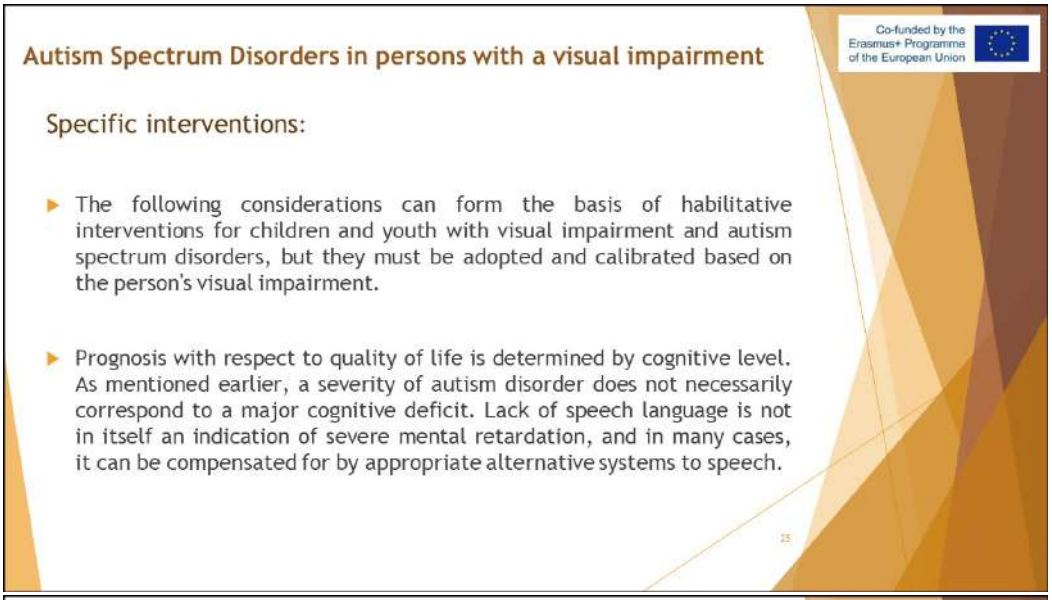
Autism Spectrum Disorders in persons with a visual impairment

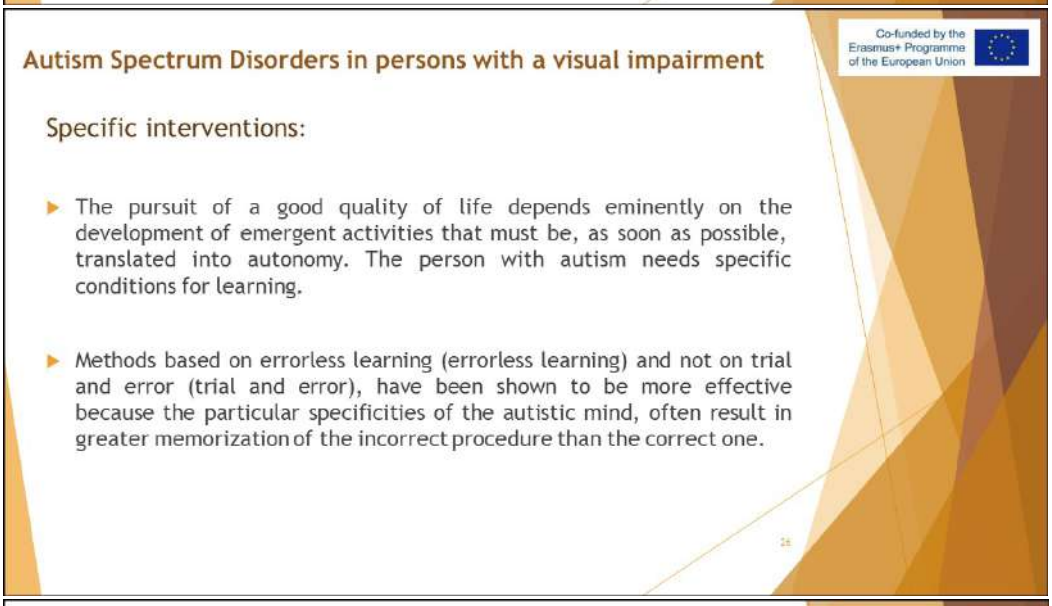
Co-funded by the Erasmus+ Programme of the European Union

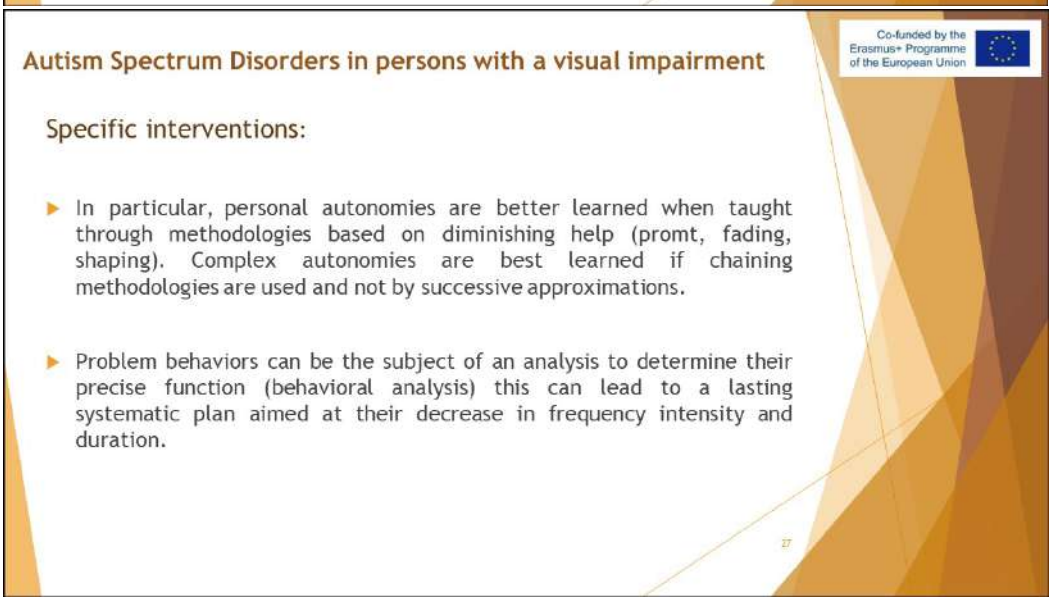
Importance of the relationship between diagnostic accuracy and targeted rehabilitation:

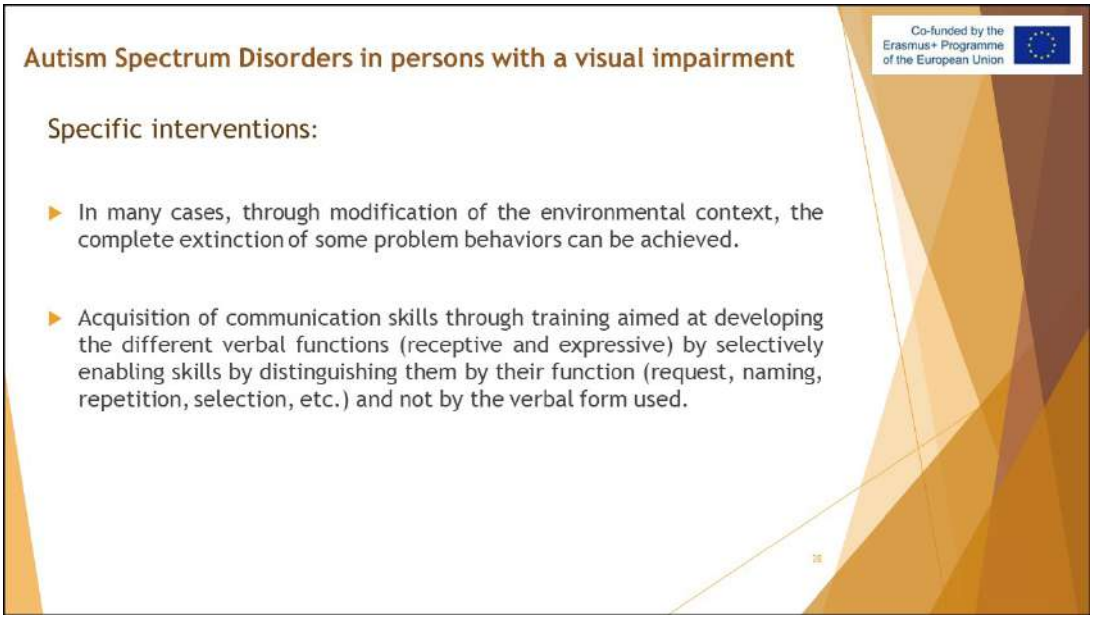
- This writing contains recommendations, formulated on the basis of an analysis of efficacy studies, produced for each treatment, that can guide in adopting (or not) a certain therapy to intervene in autism spectrum disorders in children and adolescents.
- Efficacy evaluation acquires greater relevance when it involves educational and habilitative services aimed at people with disabilities, since it involves individuals who are by definition "not curable" but who can still improve quality of life and functioning, activity and participation.

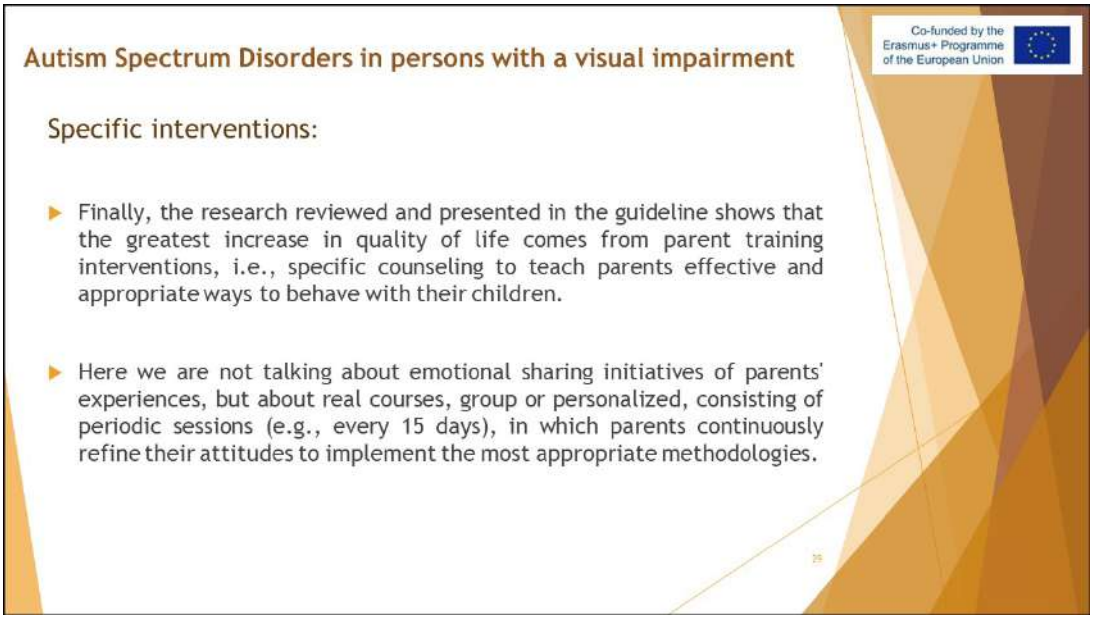
24

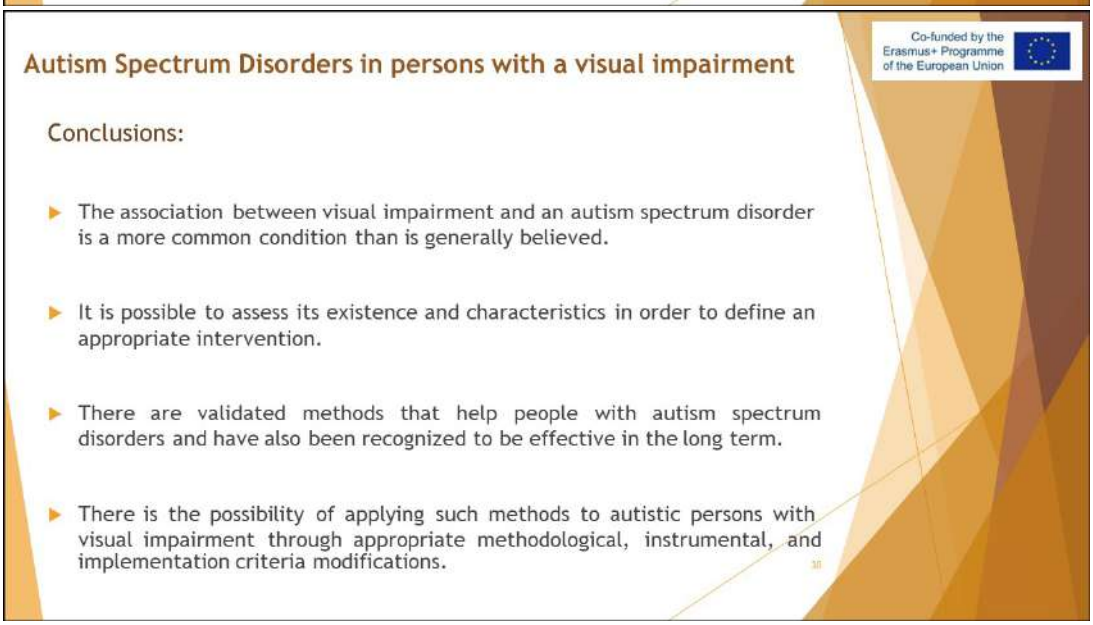

Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Specific interventions:
The following considerations can form the basis of habilitative interventions for children and youth with visual impairment and autism spectrum disorders, but they must be adopted and calibrated based on the person's visual impairment.
Prognosis with respect to quality of life is determined by cognitive level. As mentioned earlier, a severity of autism disorder does not necessarily correspond to a major cognitive deficit. Lack of speech language is not in itself an indication of severe mental retardation, and in many cases, it can be compensated for by appropriate alternative systems to speech.


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Specific interventions:
The pursuit of a good quality of life depends eminently on the development of emergent activities that must be, as soon as possible, translated into autonomy. The person with autism needs specific conditions for learning.
Methods based on errorless learning (errorless learning) and not on trial and error (trial and error), have been shown to be more effective because the particular specificities of the autistic mind, often result in greater memorization of the incorrect procedure than the correct one.


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Specific interventions:
In particular, personal autonomies are better learned when taught through methodologies based on diminishing help (promt, fading, shaping). Complex autonomies are best learned if chaining methodologies are used and not by successive approximations.
Problem behaviors can be the subject of an analysis to determine their precise function (behavioral analysis) this can lead to a lasting systematic plan aimed at their decrease in frequency intensity and duration.


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Specific interventions:
In many cases, through modification of the environmental context, the complete extinction of some problem behaviors can be achieved.
Acquisition of communication skills through training aimed at developing the different verbal functions (receptive and expressive) by selectively enabling skills by distinguishing them by their function (request, naming, repetition, selection, etc.) and not by the verbal form used.


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Specific interventions:
Finally, the research reviewed and presented in the guideline shows that the greatest increase in quality of life comes from parent training interventions, i.e., specific counseling to teach parents effective and appropriate ways to behave with their children.
Here we are not talking about emotional sharing initiatives of parents' experiences, but about real courses, group or personalized, consisting of periodic sessions (e.g., every 15 days), in which parents continuously refine their attitudes to implement the most appropriate methodologies.


Autism Spectrum Disorders in persons with a visual impairment
Co-funded by the Erasmus+ Programme of the European Union
Conclusions:
The association between visual impairment and an autism spectrum disorder is a more common condition than is generally believed.
It is possible to assess its existence and characteristics in order to define an appropriate intervention.
There are validated methods that help people with autism spectrum disorders and have also been recognized to be effective in the long term.
There is the possibility of applying such methods to autistic persons with visual impairment through appropriate methodological, instrumental, and implementation criteria modifications.

Autism Spectrum Disorders in persons with a visual impairment

Co-funded by the Erasmus+ Programme of the European Union

Bibliography for further readings:

- Autism Spectrum Disorders (ASD) in Blind Children: Very High Prevalence, Potentially Better Outlook - Rubin Jure, Ramon Pogonza, Isabelle Rapin - Published online: 25 September 2015, Springer Science+Business Media New York 2015.
- Child psychiatrist who transformed understanding of autism. Nature, Vol 599, 25 November 2021.
- George Frankl: an undervalued voice in the history of autism - Filippo Muratori, Sara Calderoni, Valeria Bizzari - Published online: 27 August 2020 (European Child & Adolescent Psychiatry (2021) 30:1273-1280 https://doi.org/10.1007/s00787-020-01622-4).
- Il processo maturativo. Studi sul pensiero di Winnicott | Gaddini De Benedetti Renata e Remondi G. (cur.) | CLEUP (unilibro.it).
- https://www.ibs.it/autismo-psicosi-infantile-libro-frances-tustin/e/9788866773757 .

Autism Spectrum Disorders in persons with a visual impairment

Co-funded by the Erasmus+ Programme of the European Union

Bibliography for further readings:

- Bion W.R. (1970): "Attenzione e interpretazione". Una prospettiva scientifica sulla psicoanalisi e sui gruppi. Armando Roma 1973.
- Bion W.R. (1977): Taming wild Thoughts, tr. It. "Addomesticare i pensieri selvatici", Franco Angeli Ed., Milano 1998.
- Maiello S. (1993): "Il corpo di risonanza", Note sul versante dell'ascolto analitico, PM 1/93.

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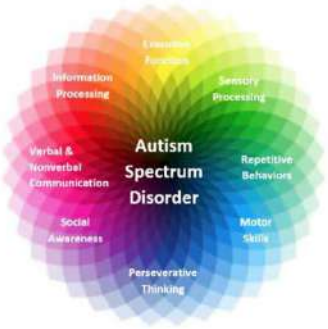
12: PowerPoint Presentation Autism Spectrum Disorder, Croatia

Autism and visual impairment

Centar za odgoj i obrazovanje „Vinko Bek"
Kušlanova 59a, Zagreb, Hrvatska

- In our Center "Vinko Bek„, in a group of clients with multiple difficulties, we have 5 clients who, in addition to visual impairment, also have some form of autism spectrum disorder.



https://youtu.be/K2P4Ed6G3gw

- These are clients who require the extremely large engagement of various experts. We therefore use a multidisciplinary approach in our work.
- In working with these clients, we make sure that everyone stick to clear, well-defined structures
- Clients insist on routines, if they do not have them, they fall into frustrations and undesirable behaviors from which they often find it difficult to get out.
- The activities are precisely arranged by days and of a precisely determined duration.

- We use an individual and holistic approach.
- No case of autism is completely identical, the diagnosis is the same, but the difficulties within the diagnosis are manifested in different ways, so it is very important to approach it individually.
- It is important to look at the overall difficulties in the physical, cognitive, emotional and all other fields.

- We encourage socialization, expansion of interests and activities, and sensory empowerment of the client to encourage the acceptance of new materials in the work.
- Through cooking the client accepts new flavors and textures of food (the gustatory sensory part)
- Through activities in the garden we encourage the recognition and acceptance of various odors, as well as tactile sensations (developing sensory perception in the olfactory and tactile area)

- Cooperation with parents/guardians is extremely important in working with clients.
- They are going through a lot of stress and the support of experts is very important to them (as well as quality cooperation is for us). Parental stress has a negative impact on parental mental health and self-efficacy, and also affects the level of the child's functioning.

- In various studies, parents of children with disabilities say that the support of professionals is important to them, not only their child but the whole family.
- It is important to encourage inclusion and integration of clients into society and high expectations of professionals and continuous work to strengthen clients confidence. It is important for them to know that we believe in the client and the abilities/possibilities he/she has, no matter how small those are.
- Parents appreciate professionals who are additionally engaged and who are intrinsically motivated to help them and their children, and who educate parents and inform them about the rights they and their children have.

- We work with clients in a described way, and cooperation with parents is important to us because of maintaining a structure that is important to clients.
- If we come across uncooperative parents or parents who are dealing with too many of their own problems (and sometimes this is the case), working with the client himself is much more difficult.

- Clients with autism like to come to our Center and this is the best indicator that we are doing well and with quality. Although concrete progress is extremely slow, clients satisfaction motivates us.

- Thank you ☺

- Ana Petrinec, occupational therapist
- Emina Šišić Anđelić, educational rehabilitation
- Valentina Devčić, mag.psych.

13: PowerPoint Presentation Autism and relations, NL

ASS, RIS & VI

Just a little different!

Debby van Vught & Annie van den Heuvel

Co-funded by the Erasmus+ Programme of the European Union

PsyCoVIA

Robert Coppes Foundation

ASS, RIS & VI

ASS: autism spectrum disorder
RIS: relationships intimacy and sexuality
VI: visual impairment

Goal

Gain knowledge and experience about **autism spectrum disorder** and **relationships, intimacy and sexuality** in combination with a **visual impairment**

What are we going to do

- Explanation VI-ASS & RIS
- Tips and Tools
- 3 Cases
- Feedback
- Dare to ask

What is different?

- Slower
- Difficulty watching
- Less experience in social contacts
- Lack of feedback
- Attachment process is more difficult

What is different?

- Body image influences sexual contacts and sexual behavior
- Information of body image is partly dependent on parents, siblings, friends and supervisors
- Risks of uncertainty, negative coloration of appearance instead of self-knowledge, self-esteem and self-confidence

ASS & RIS

People with ASS have sexual feelings and desires.
But it's not so easy for them to turn these into sexual behaviors that are acceptable to both them and the environment.

What do persons with ASS need?

- People with ASS don't need less info, but more!
- Not only fact-based knowledge, but also language
- Social rules, concrete
- Learn skills
- Make it visual/tangible
- Pay attention to generalisation

Order of information

TOP 3

1. How does the person with ASS (detail thinking) think

1. Detail thinking

2. How are stimuli experienced?

3. Use the 10+ rule

The 10+ rule is that you learn behaviors and skills at a very young age that are still acceptable if these children are over 10 years old

Discrimination skills

Learning about what behavior belongs where.
This is also the first step in the information

Above all, learn what is allowed.

Be explicit in your language

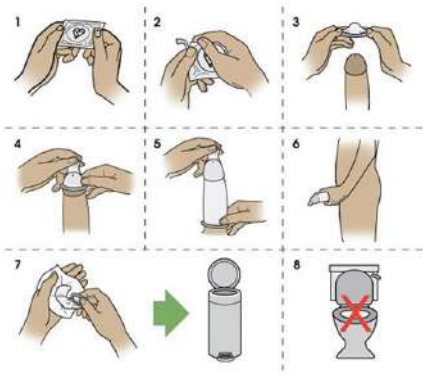
TAFELVOETBAL (Table football)

Work on transfer

For example:

- Home
- Work/school/daytime activities
- Friends
- Clubs

Is this a good educational picture for people with ASD?
Why or why not



3 cases

1. What can you say about the VI? How should you take the VI into account?
2. What can you say about detail thinking. How does the person with ASS think? How should you take detail thinking into account?
3. What can you say about the processing of stimuli? How should you take this processing of stimuli into account?
4. Does the 10+ rule apply here?

Case 1: Sophie

Sophie is 5 years old and has a visual impairment and ASS. She lives at home with her parents and her brother (9 years old).

During the day Sophie goes to a child care facility at her place of residence. Sophie loves to puzzle, play outside with friends. She likes to take a bath and loves having a massage, especially in the evening when the whole family is sitting on the couch watching TV.

Sophie has a lot of trouble falling asleep at night.
Now her mother suggested massaging her every night before bed.

Case 2: Tygo

Tygo is 15 years old, he has a VI and ASS. Tygo lives at home with his parents, brother (17) and sister (12).

Tygo has been talking a lot lately about girls, sex, and dating. Tygo has also been quite irritable lately and arguing a lot with everyone.

When starting up the computer, his father stumbled upon a porn site and with searching the history they found out many porn sites had been opened in recent months. It all turned out to have been sought by Tygo.

Short feedback and closure

Key message

Start and continue the conversation about RIS!

14: PowerPoint Presentation Digital tour Robert Coppes Foundation

Digital Tour Robert Coppes Stichting

Marit van Buijsen

PsyCoVIA

Robert Coppes Foundation

Co-funded by the Erasmus+ Programme of the European Union

Care organisation

Care and treatment for adults with a visual impairment (VI) and multiple additional problems

Care Programmes

Healthcare act	Care programme		Teams
Care insurance	Treatment	Intermittent Visual Treatment	Teams Outreaching support
Act for Social Support (municipalities)	Specialist outreaching support		
Act for long-term care (government)	Modulair Package at Home		
	Day care facility		Teams Day care facility
	Full Package at Home (FPH)		Teams FPH
	Residential care facilities		Teams for Residential care

Residential care facilities


Aloysiuslaan 25, 5262AH


Salahutuplein 40, 5262ZN


Taalstraat 154e, 5261BJ


Steenweg 18-24, 5261CZ


Bisschop Zwijsenplein 38, 5262JL


Diepenbrockstraat 2, 5262HT


Vijverhof Merpatistraat 19, 5262ZX

Day Care Facilities


Coppes Couleur, Helvoirtseweg 167, 5263 EC Vught


Prof. Cornelissenstraat 8, 6524 PJ Nijmegen

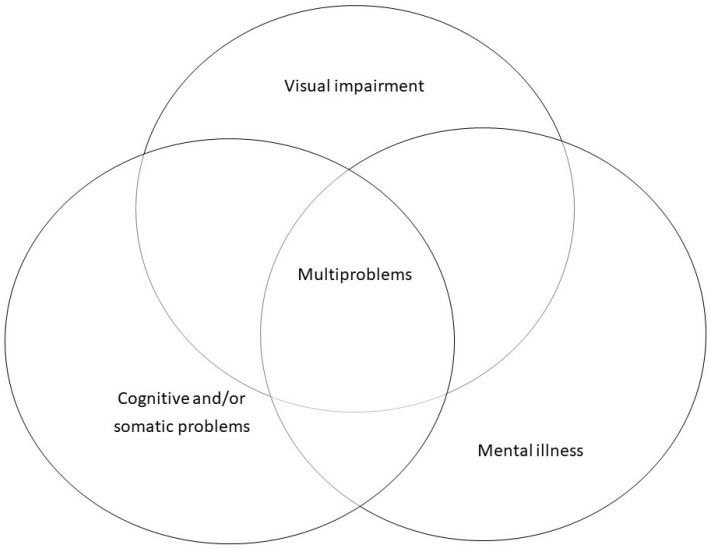

Diepenbrock, Diepenbrockstraat 2, 5262 HT...

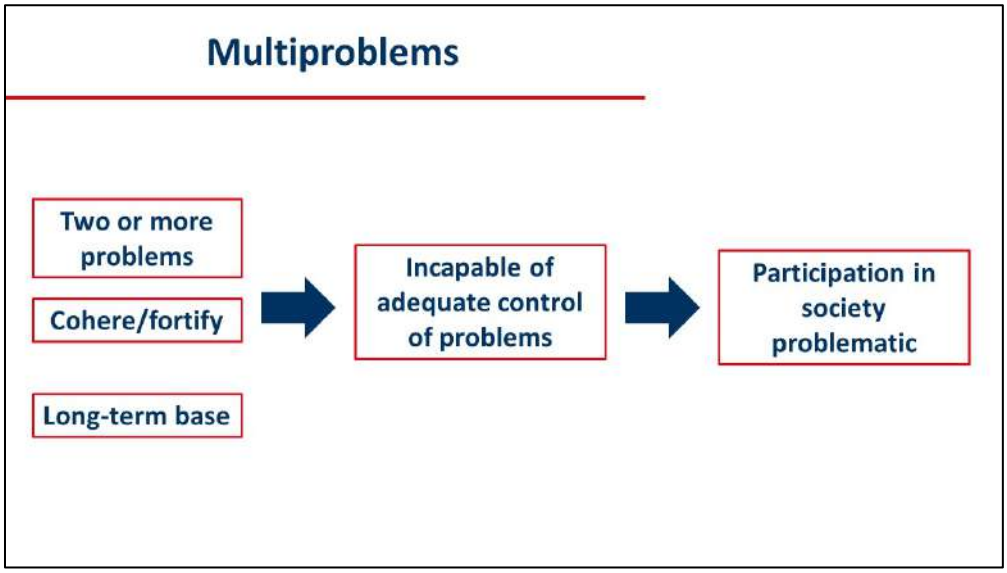

Spaubeek-Schoolstraat 3, 6176 BZ Spaubeek

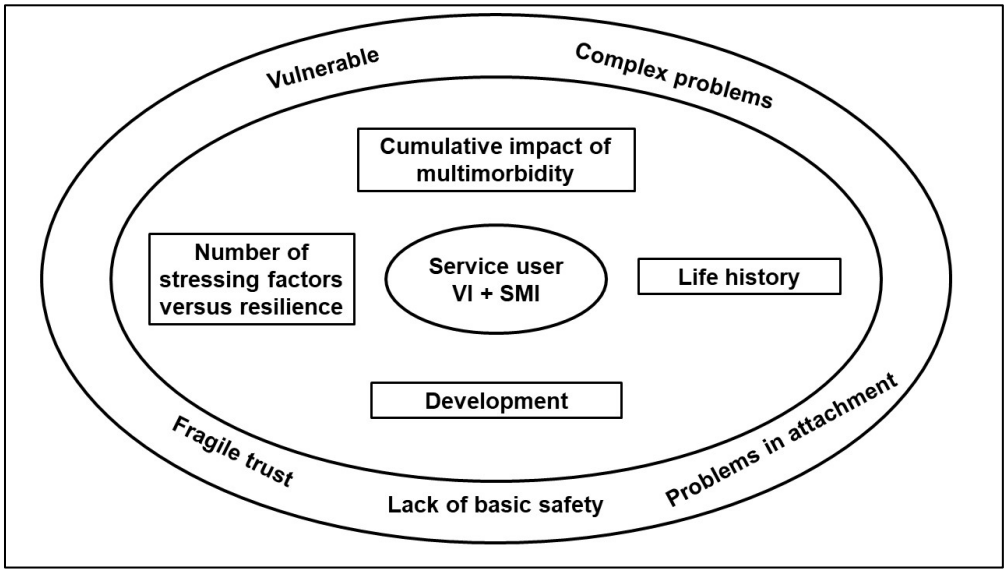
Outreaching support

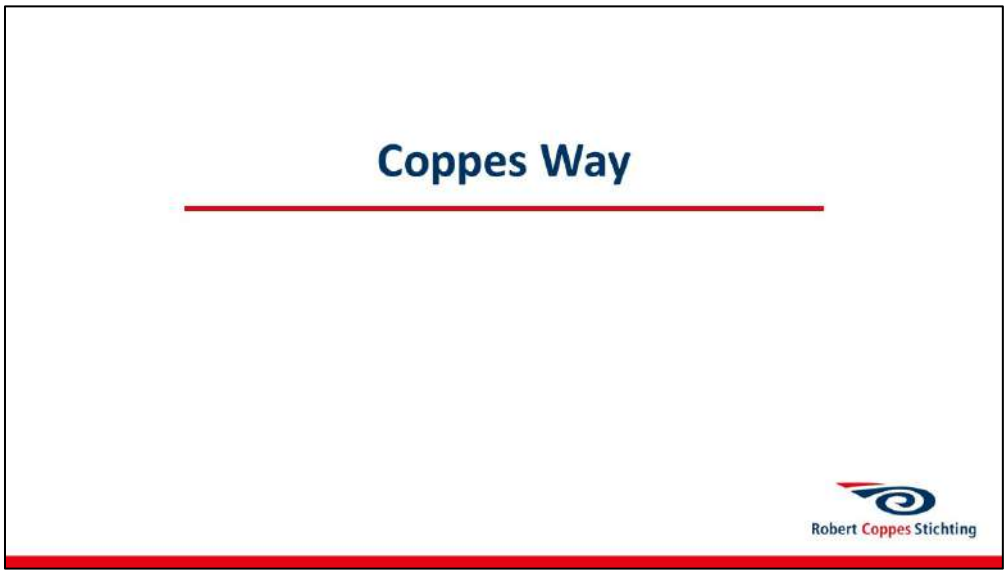
Client group

Robert Coppes Stichting




Multiproblems
Two or more problems
Cohere/fortify
Long-term base
Incapable of adequate control of problems
Participation in society problematic


Vulnerable
Complex problems
Cumulative impact of multimorbidity
Number of stressing factors versus resilience
Service user VI + SMI
Life history
Development
Fragile trust
Lack of basic safety
Problems in attachment


Coppes Way
Robert Coppes Stichting

Logic model

Theory behind the intervention (why)
- Trust and safety essential
  - More time needed
  - Long-term process
    - Impact VI

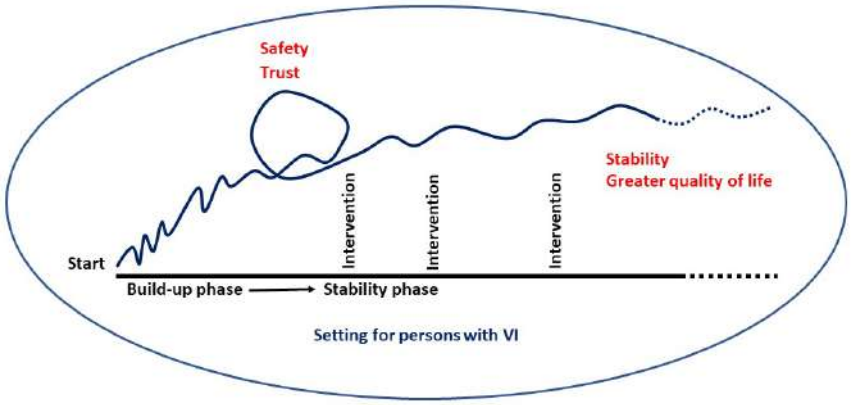
Activities (how)
Phases
- Build-up;
- Stability;
- Intervention

Intermediate outcomes
- Trust, safety, stable balance
- Flexible care
- Continuity in care

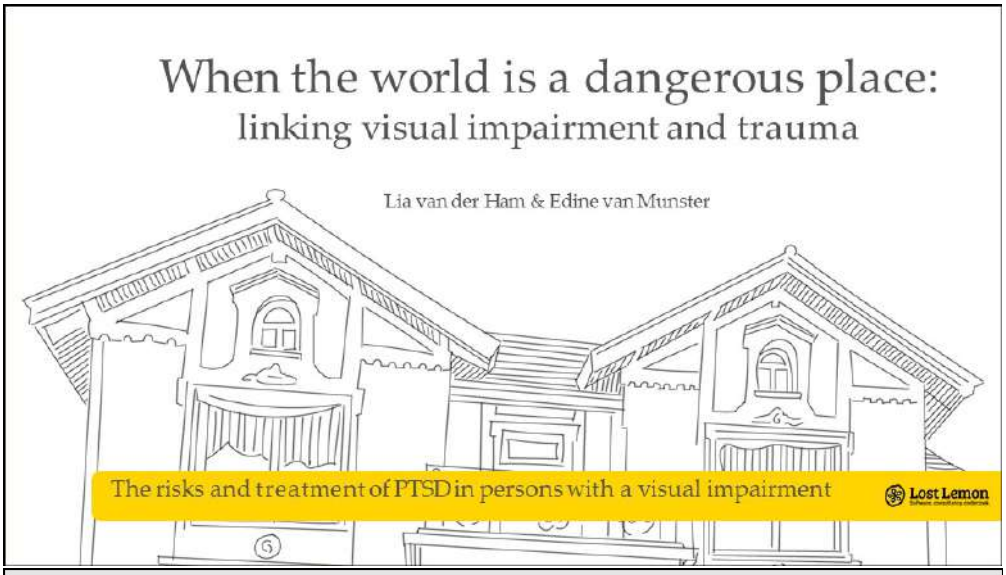
Final outcomes
- Stability (mental health problems)
- Greater sense of well-being/ more life satisfaction

Contextual factors (what)
- VI-setting with intensive collaboration mental health care
- Inapplicability of standard protocols or programmes
- Cultural standards RCF: unconditional availability, freedom from organisation

Care process and outcomes



15: PowerPoint Presentation Expert's Talk PTSD



Key messages

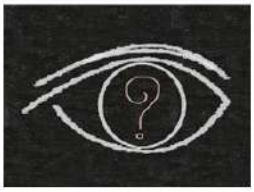
1. Persons with VI ***may be*** more like to experience traumatic events; the role of abuse is prominent
2. VI shapes the way people experience traumatic events
3. PTSD is at least as common in people with VI vs without VI; symptoms are very similar but impact can be bigger
4. Regular PTSD care is suitable if attention is paid to separate and combined impact of PTSD and VI
5. More knowledge and tools are still needed

On what are our key messages based?

- 2 year qualitative study by Amsterdam UMC and Robert Coppes Stichting:
  - **Review of literature**
  - **Interviews with people with VI and PTSD (n=18)**
  - **Group discussions with care providers**
  - **Community of Practice**
  - **Development of training module**

#1

Persons with VI *may be* more like to experience traumatic events; the role of abuse is prominent



Risk of traumatic events in literature

- **Persons with VI likely have an increased risk of certain traumatic events**
  - Falls, traffic accidents, abuse
- **Exposure to other events possibly influenced by VI through:**
  - Low self-esteem
  - Lack of connectedness
  - Dependency on others
  - Missing visual information

Trauma among our interviewees

- **16 cases of complex / multiple trauma:**
  - mostly involving sexual, physical and/or emotional abuse in childhood in family settings and/or institutions
- **2 cases of single trauma**
  - a fall and case of kidnapping
- **Several 'odd' events**
  - guide dog accident, vision loss, treatment by doctor, etc.

➔ **Certain events among interviewees may not have occurred**

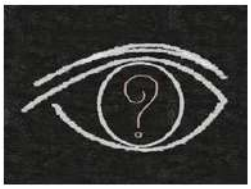
- abuse at institution, guide dog accident, fall, bus accident

24 yr old women with complex trauma

"... you have to trust others, because you are partly dependent when you are in a strange environment [...] and it happened that someone said 'I am going to leave you here' and used that as a threat [...] well, you have nowhere you can go..."

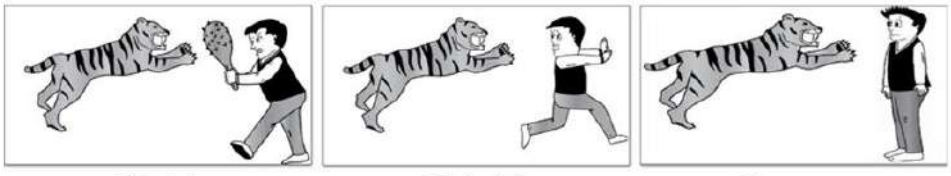
#2

VI shapes the way people experience traumatic events



With a VI, would you fight, flight or freeze?

Trauma Responses



Fight Flight Freeze

Experiences during events

VI influenced experiences by:

- Not seeing "it" coming *(suddenness)*
- Not being able to respond/ defend oneself *(powerlessness)*
- Not knowing how to get out of a situation *(lack of control)*

63 yr old man who fell in a hole

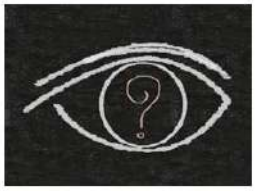
"I suddenly thought of the world as a dangerous place. I literally could not oversee things. And when I went outside, I noticed everything, every loose tile in the pavement."

31 year old women who was kidnapped

"At certain moments I wanted to try to get out of the van, but I did not see how I could open it and I think this may have stopped me from trying. Plus, had I gotten out, where would I go?"

#3

PTSD is at least as common in people with VI vs without VI; symptoms are very similar but impact can be bigger



PTSD in persons with/without VI

- **Some indications that PTSD is more prevalent among people with VI, compared to people without**
  - No solid evidence yet
- **Reported symptoms generally consistent with symptoms of PTSD, but seem to differ slightly in severity and impact**

PTSD symptoms and impact

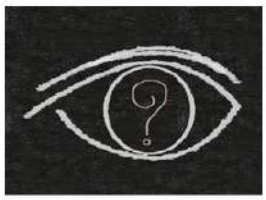
- **Visual impairment increased feelings of unsafety and anxiety due to:**
  - Lack of visual information about the environment and other people's intentions
  - Being aware of one's vulnerability and dangers
- **Visual impairment strengthened avoidance and isolation due to:**
  - Lack of trust in others
  - Reduced mobility

43 year old woman with complex trauma

"It clashes, on the hand you need help because of your disability and your PTSD and on the other hand you distrust everybody, you're angry at everybody and you want everybody to go away."

#4

Regular PTSD care is suitable if attention is paid to separate and combined impact of PTSD and VI



PTSD care: from prevention to treatment

Prevention

Support ⟷ **Self-help**

Treatment

Prevention

1. *Normalization of events and fear*
2. *Preparing for potentially dangerous situations*
3. *Rehabilitation*
4. Control and self-confidence
5. Positive approach
6. Social networks

Support

1. Structure and activities
2. *Social support*
3. Clarity
4. Asking and listening
5. *Signaling and monitoring stress*
6. Acknowledging complaints
7. *Psycho-education*

Self help

1. Structure
2. *Activities*
3. *Writing*
4. Relaxation
5. Talking and sharing
6. Taking control
7. *Animals*
8. Looking for professional help

Treatment: starting treatment?

- Visual impairment is *never* a reason for not initiating treatment
- Pay attention to:
  - underdiagnosis
  - support system
  - referral between low vision center and mental health care

Treatment: which treatment?

- EMDR, (trauma-focused) Cognitive Behavioral Therapy and psychomotor therapy are potentially suitable for people with VI
- Pay attention to:
  - adapting modality
  - negative life experiences
  - real versus excessive fears
  - intensity of (EMDR) treatment

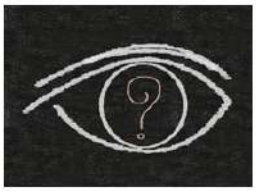
Treatment: how to facilitate it?

- Support and treatment can be provided in low vision centers and/or in mental health care
  - collaboration recommended!
- In relation visual impairment pay attention to:
  - accessibility
  - materials
  - communication
  - length of treatment

Questions so far?

#5

More knowledge and tools are still needed



Training for low vision professionals

- During the Amsterdam UMC/ RCS study findings were translated into a training module
- The module consists of an e-learning (knowledge) and interactive session (exchange)
- The module can be followed by low vision professionals from 3 low vision centres in the Netherlands
- The module is part of a larger training program on mental health and VI provided by the RCS

New research project!

Determining prevalence and risk in Dutch adults with VI

- Background: quantitative evidence on prevalence and risk factors in persons with VI is limited
- Methods: Cohort study (n=1474) comparing prevalence and risk factors for PTSD in people with and without VI
- Starting: May 2023

Questions for you:

1. Based on your experience, which factors might make people with VI more vulnerable to experience trauma/ PTSD?
2. How could you use information about prevalence and risk factors in your work?
3. Which practical outcomes/ tools would you need to be able to use information about prevalence and risk factors in your work?

Want to know more?

Contact:

➔ Edine van Munster: evmunster@robertcoppes.nl

Read:

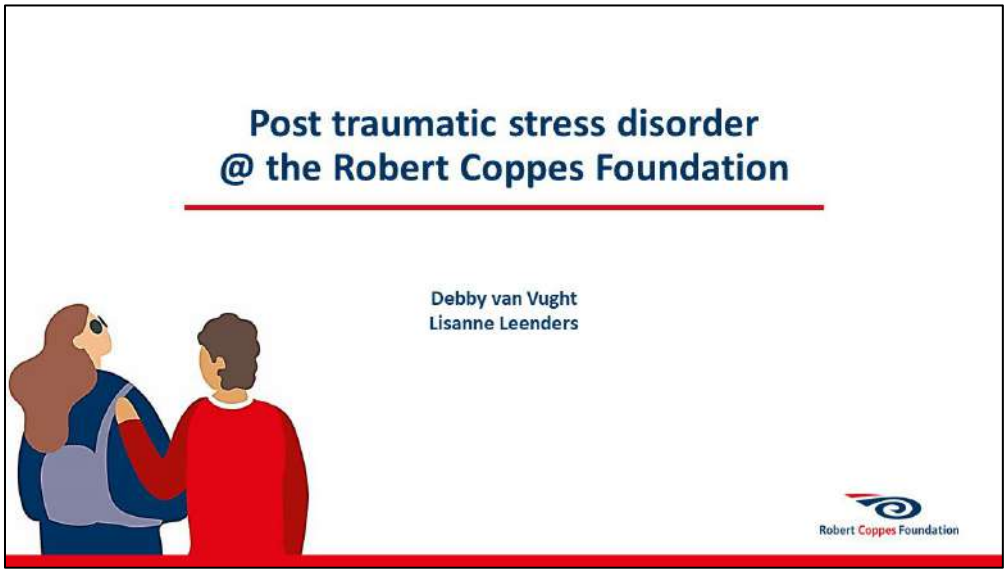
- van der Ham, A. J., van der Aa, H. P., Brunes, A., Heir, T., de Vries, R., van Rens, G. H., & van Nispen, R. M. (2021). The development of posttraumatic stress disorder in individuals with visual impairment: a systematic search and review. *Ophthalmic and Physiological Optics*.
- van der Ham, A. J., van der Aa, H. P., Verstraten, P., van Rens, G. H., & van Nispen, R. M. (2021). Experiences with traumatic events, consequences and care among people with visual impairment and post-traumatic stress disorder: a qualitative study from The Netherlands. *BMJ open*, *11*(2), e041469.

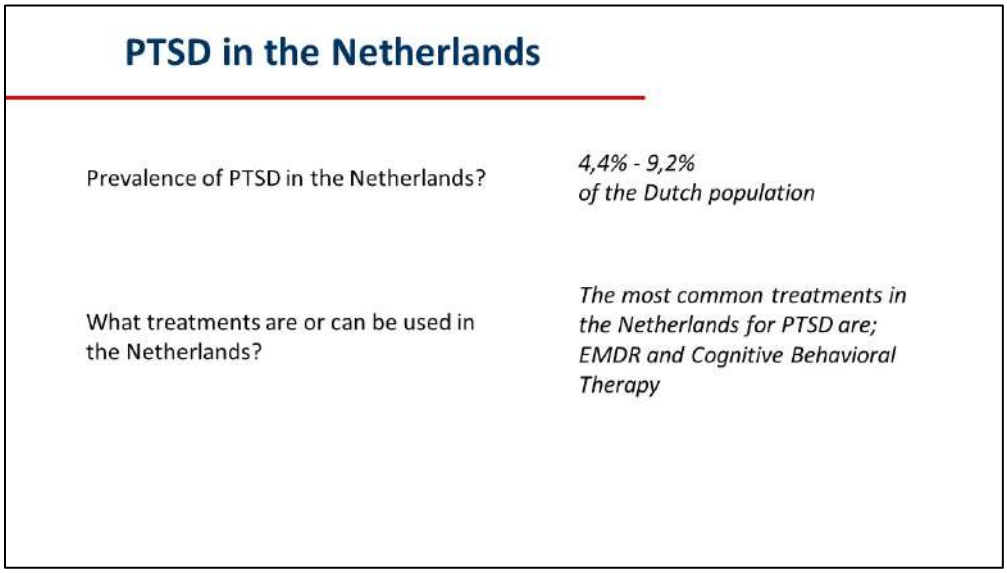
Thank you!

Lost Lemon
Software, consultancy, onderzoek.

16: PowerPoint Presentations of situation description in own country

The Netherlands





PTSD in the visual sector

How many persons with VI are known to have a diagnosis of PTSD in the visual sector?

10% - 16%

What treatments can be used for persons with VI?

Cognitive behavioral therapy
EMDR therapy
This is possible with adjustments!

PTSD @ RCS

Table 5.9

Mental disorder indicated for service users of the RCF (n=63).

Mental Disorder	Number of service users (n)
Personality disorder	12
Pervasive development disorder	10
Depression	9
Psychotic disorder	8
Post-traumatic stress disorder	5
Anxiety disorder	5
Schizophrenia	2
Adjustment disorder	2
Attention deficit hyperactivity disorder	2
Obsessive compulsive disorder	1
Social phobia	1

Note. A service user can have multiple diagnoses.

Our experiences

Are there clients that have symptoms but aren't diagnosed?

How is dealth with the treatment of PTSD in your organization?

One of our clients story

A video was shown

Thank you for your attention!

More information:

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Robert Coppes Foundation

Germany


BFW
BERUFS
FÖRDER
UNGS
WERK
KOMPETENZZENTRUM
RUND UM DAS SEHEN
Post Traumatic Stress Disorder –
The situation in Germany
André Kunnig
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Post Traumatic Stress Disorder – The situation in Germany
15.02.2023
André Kunnig
2


Post Traumatic Stress Disorder – The situation in Germany
The situation in Germany in general...
... in the visual sector
... in the BFW
15.02.2023
André Kunnig
3

Post Traumatic Stress Disorder – The situation in Germany

The situation in Germany - prevalence

- 26% of men and 18% of women in Germany are confronted with a traumatic event at least once in their lives
- however, only a comparatively small proportion develop post-traumatic stress disorder
- Lifetime prevalence men 5%, women 10.4%

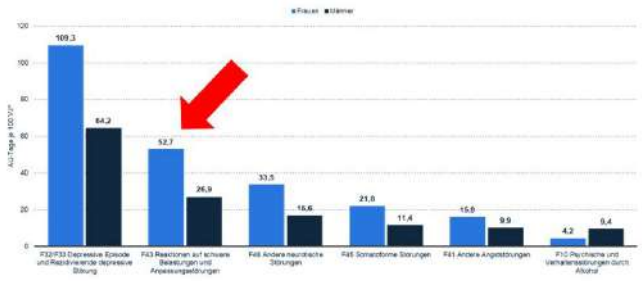
The situation in Germany - prevalence

There are significant differences depending on the type of trauma:

- Rape: highest likelihood of disorder with a lifetime prevalence of approx. 50%.
- other violent crimes approx. 25%
- war trauma approx. 20%
- traffic accidents 10 %; train drivers with personal injuries approx. 20 %
- physical illnesses approx. 15 %

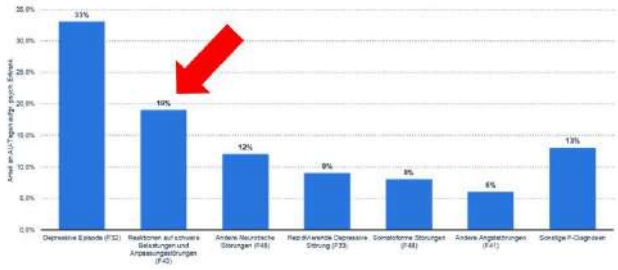
The situation in Germany - prevalence

Most important individual diagnoses of mental illness by gender 2012



The situation in Germany - prevalence

Days of sick leave due to mental illness - individual diagnoses in 2012



The situation in Germany - treatment

Significant deficits at the level of care:

- only 1/3 of mentally ill patients receive any treatment at all
- majority of them are not treated by specialists, but by general practitioners and specialists in somatic medicine
- Almost 40% still go to work
- Average waiting time for a first consultation with a psychotherapist is currently three months – with large differences in the regions

The situation in Germany - treatment

In Germany – a large number of different therapeutic methods that are possible and also evidence-based

1. different cognitive-behavioral therapies
   - differ mainly in the extent to which they are exposure-oriented or cognitively-oriented/imagination-based and
   - in the extent to which the evidence is given for a broad approach or only for use in specific populations
2. systemic trauma therapy
3. EMDR (Eye Movement Desensitization an Reprocessing)
   - explicitly for trauma treatment
   - here we have contacts to a treatment (former colleague) in Halle

The situation in Germany - treatment

Adjuvant, additionally supportive treatment options are:

- Endurance sports,
- medication,
- creative and movement therapy,
- yoga, meditation, mindfulness,
- biofeedback

The situation in Germany – what's important

1. Possibly we have an underestimation of the numbers in Germany
   - it can be assumed that due to the Syrian refugees in 2015 and currently many refugees from Ukraine, the topic will grow significantly; however, the reflection in official statistics and prevalence figures is delayed
2. In science, an inflation of the term trauma in comparison of the term conflict is being observed
   - Perhaps it is a more popular diagnosis

The situation in Germany – what's important

3. There is also a traumatic stress experience in the context of physical illness and treatment; for example, through invasively experienced boundary crossing in childhood
   - here the prevalence seems to be between 15 – 30% and this is possibly another way of underestimation of our numbers ...
   - ... because possibly this is diagnosed under adjustment disorder, anxiety or depression (and therefore possibly wrongly treated)

Post Traumatic Stress Disorder – the visual sector

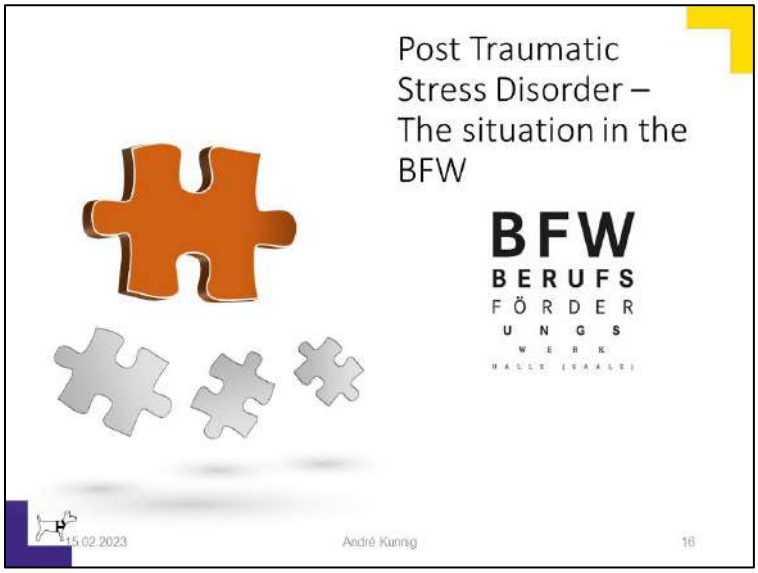
Post Traumatic Stress Disorder – the visual sector

How many persons with VI are known to have a diagnosis of PTSD?

- There are no exact figures available, even the exact numbers of how many people suffer from visual impairment and blindness are difficult to obtain.
- However, based on the facts just mentioned, we may have an underestimation of the actual numbers.

Which treatments used for persons with VI?

- Positive experiences in the past with EMDR


Post Traumatic Stress Disorder – The situation in the BFW
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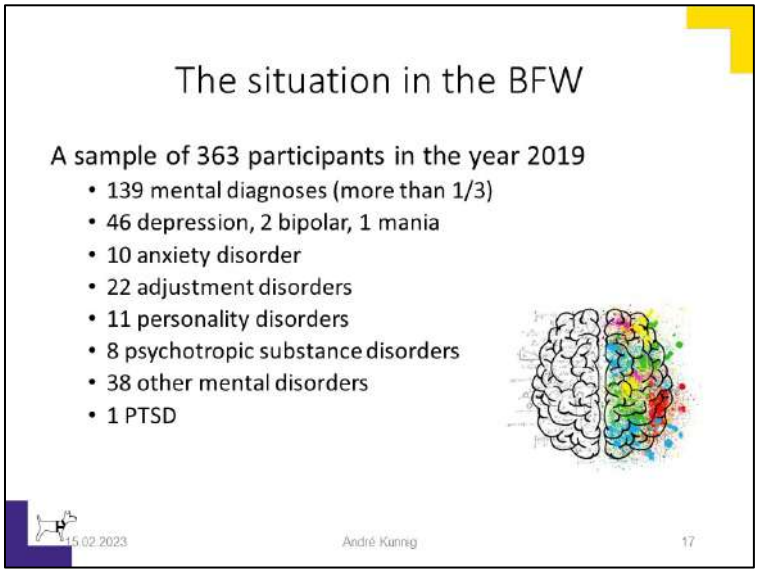
The situation in the BFW
A sample of 363 participants in the year 2019
• 139 mental diagnoses (more than 1/3)
• 46 depression, 2 bipolar, 1 mania
• 10 anxiety disorder
• 22 adjustment disorders
• 11 personality disorders
• 8 psychotropic substance disorders
• 38 other mental disorders
• 1 PTSD
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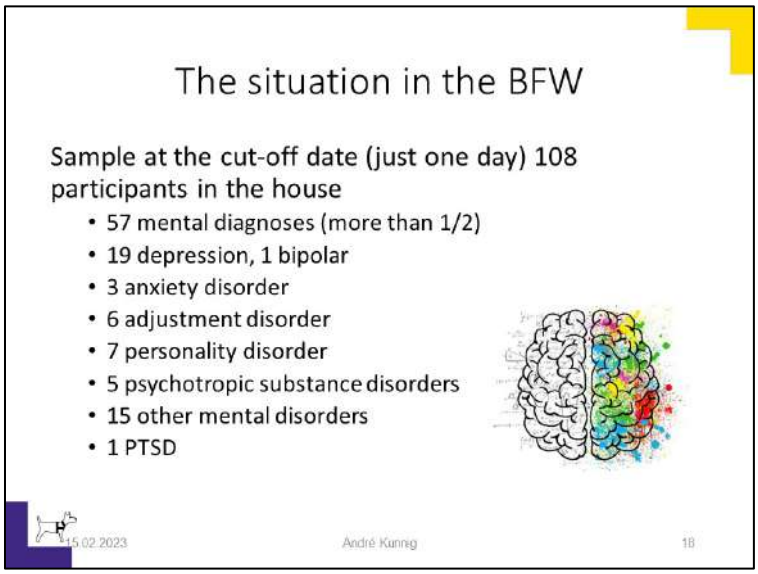
The situation in the BFW
Sample at the cut-off date (just one day) 108 participants in the house
• 57 mental diagnoses (more than 1/2)
• 19 depression, 1 bipolar
• 3 anxiety disorder
• 6 adjustment disorder
• 7 personality disorder
• 5 psychotropic substance disorders
• 15 other mental disorders
• 1 PTSD
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The situation in the BFW – open questions

- Perhaps we have an underestimation of the numbers?
- Perhaps some depression, anxiety disorders, and adjustment disorders are more likely to be a PTSD
- Our way: We would refer to specialized treatment and give supportive treatment until then
- Maybe we learn something about the differential diagnosis here

Thank you!

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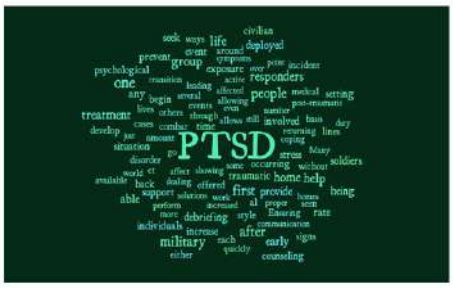
Hungary

PTSD - The situation in Hungary

About PTSD in general…



The prevalence of PTSD in Hungary

25-30% of people who have suffered a traumatic event experience the symptoms of PTSD

It is 6% of the entire population

There is no documenteted data on PTSD in Hungary

Most of these cases are diagnosed with a completely different diagnosis (e. g. depression, panic, anxiety, etc.)

Lack of database

The chief medical inspection system was abolished

Statistical office does not have such data at all

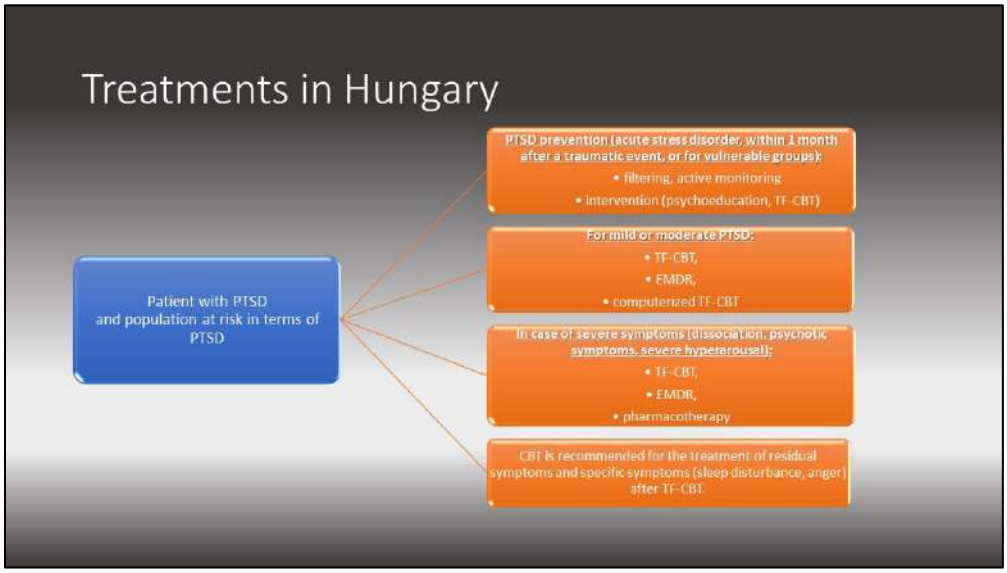
Recognition of PTSD based on NICE guidelines

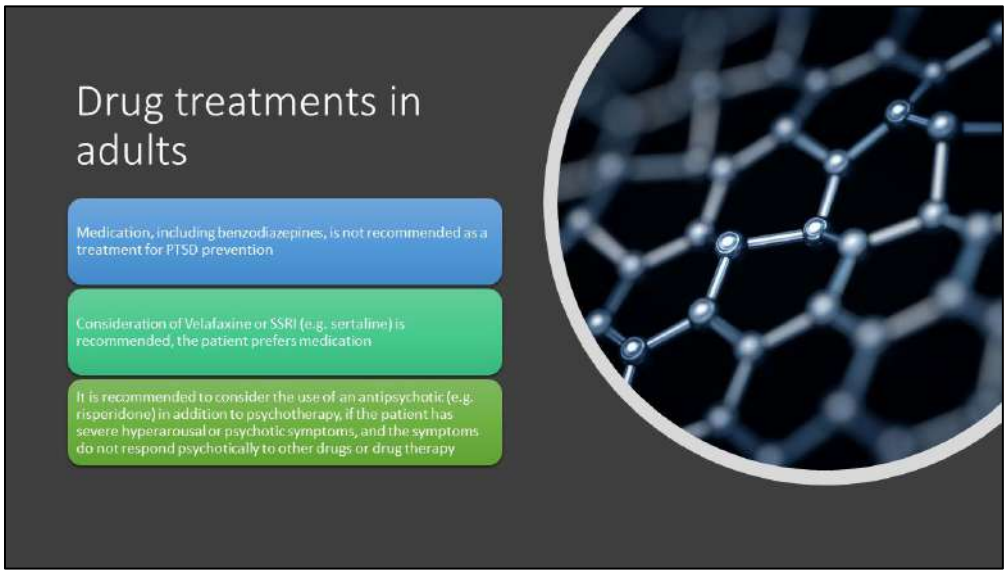
- Questionners in Hungarian:
  - The Impact of Event Scale (IES-R, Weiss and Marmar 1996)
  - Posttraumatic Diagnostic Scale (PDS, Foa 1995)

PTSD treatment in Hungary

- 1. GP (general practitioner) decides wether the pacient shows the symtoms of PTSD
  - Referral to psycologist, psychiatrist
- 2. Complex examination by the specialist care (with special needs and risks)
- 3. Written agreement between primary care and specialist care about who is responsible for monitoring PTSD


Principles in the treatment of PTSD
Supporting patients
Support groups
Creating a safe environment
Involvement of family members and caregivers
Support for family members and caregivers


Treatments in Hungary
Patient with PTSD and population at risk in terms of PTSD
PTSD prevention (acute stress disorder, within 1 month after a traumatic event, or for vulnerable groups):
• filtering, active monitoring
• intervention (psychoeducation, TF-CBT)
For mild or moderate PTSD:
• TF-CBT,
• EMDR,
• computerized TF-CBT
In case of severe symptoms (dissociation, psychotic symptoms, severe hyperarousal):
• TF-CBT,
• EMDR,
• pharmacotherapy
CBT is recommended for the treatment of residual symptoms and specific symptoms (sleep disturbance, anger) after TF-CBT.


Drug treatments in adults
Medication, including benzodiazepines, is not recommended as a treatment for PTSD prevention
Consideration of Velafaxine or SSRI (e.g. sertaline) is recommended, the patient prefers medication
It is recommended to consider the use of an antipsychotic (e.g. risperidone) in addition to psychotherapy, if the patient has severe hyperarousal or psychotic symptoms, and the symptoms do not respond psychotically to other drugs or drug therapy

Treatment of complex PTSD and comorbidities

- In the case of co-existence of PTSD and depression, treatment of PTSD is usually recommended first.
- Do not exclude a patient from PTSD treatment because of a comorbid addiction problem.
- In case of complex PTSD, plan more time to build trust, for this it is necessary to increase the length or quantity of the therapy session.
- Consider the stability and safety of the patient's personal environment (e.g. housing situation) and how this may affect the therapy.
- Help the patient to manage any conditions that may prevent his participation in TF-CBT, e.g. treatment of addictions, dissociation, dysregulation of emotions, interpersonal difficulties or negative self-esteem.
- Let's help the patient to manage the residual symptoms of PTSD or comorbid diseases after the therapy.

PTSD in persons with visual impairment

- We don't have exact numbers of persons with VI + diagnosis of PTSD

Treatments used for persons with VI

- Involving the family
- Consultation with a psychiatrist
- Support group searching

The situation in our institute

1 diagnosed case

3 non-diagnosed case

Question within us

- What can help distinguish PTSD-like symptoms from other psychological illnesses?

Croatia

Erasmus+ PsyCoVia Project

POSTTRAUMATIC STRESS DISORDER IN CROATIA

October 2022 Nijmegen, Netherlands

Presentation by: Ana Petrinec, Emina Šišić Anđelić, Marina Kulfa
„Vinko Bek" Education Centre for the Blind, Zagreb, Republic of Croatia

PTSD in Croatia

- **Croatian War of Independence/*Homeland War*** (from 1991 to 1995) - development of professional and general public awareness
- in war participated 502 678 Croatian soldiers
- due to the consequences of participation in war 57 212 Croatian veterans have physical damage greater than 20% - the established status of **Croatian war veteran**
- first studies were conducted in 1992./1993. - **14% of soldiers had PTSD (Komar, Vukušić, 2004)**

PTSD in Croatia- today

It is estimated that the prevalence of PTSD in exiles and refugees is between 25 and 50%, and among war veterans 25-30% (Croatian Institute for Public Health, 2017)

Treatments and possibilities for people with PTSD

Treatments

- Therapeutic guidelines for PTSD include
- education
- psychosocial support
- psychotherapeutic treatment
- psychopharmacological treatment methods

PTSD and Persons with VI

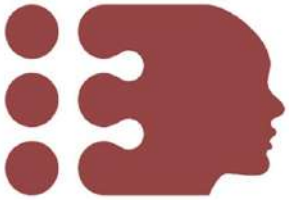
- Register of Persons with Disabilities (October 5, 2022) data is recorded for **20,633 persons** whose cause of disability is visual impairment
- **556 (2.7%)** have a reaction to severe stress/PTSD (F43 according to the ICD10) as a comorbidity diagnosis (Benjak, T.,2022)

Posttraumatic stress dissorder in population of blind invalids of the war in Croatia
(Runjić, Fajdetić & Oberman - Babić, 2007)

- 28 war veterans of *Homeland war* in Croatia were included
- 27 of them (**96,42%**) had complete vision loss due to war events
- 20 of them (**71,43%**) were included in rehabilitation programs in our Department
- **39% had detected PTSD**
- war events were bigger trigger for PTSD than vision loss in this research
- additional simptoms were: difficulties falling asleep, anxiety, hostile feeling, agitation, memory difficulties and depression

„Vinko Bek" Education Centre for the Blind

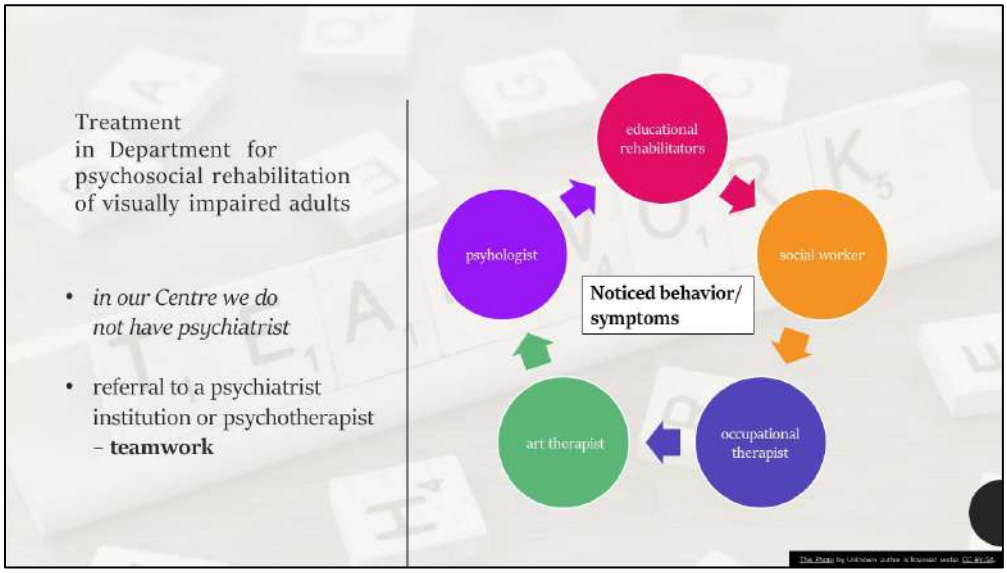
- In **1992** disabled soldiers of war were included in rehabilitation programs on Department for visually impaired persons in later life
- In 1996 a special department for adults with visual impairment was opened (financed by the Ministry of Defense)
- Department for psychosocial rehabilitation of visually impaired adults: **1996-today**



At our Department currently we do not have clients with diagnosed PTSD

Lack of diagnoses?

- trauma experienced during the sudden loss of sight (delay in arrival at our Department and receiving rehabilitation programs and psychological guidance)
- situation in the country regarding people who were directly and indirectly involved in war events
- COVID 19 pandemic (fear, constant state of insecurity, isolation, lack of social contacts, etc.)
- natural events (earthquakes, fires, etc.)


Treatment
in Department for
psychosocial rehabilitation
of visually impaired adults
• in our Centre we do not have psychiatrist
• referral to a psychiatrist institution or psychotherapist – teamwork
educational rehabilitators
social worker
occupational therapist
art therapist
psyhologist
Noticed behavior/ symptoms


Influence of current practice
• one of the most important indicators of the success of the rehabilitation process is independent orientation and mobility of people with VI
• fear of movement, fear of traffic, anxiety, insomnia, sensitivity to sounds, etc. - influence the successful implementation of the rehabilitation program in everyday living
• research shows that visually impaired veterans who underwent the process of rehabilitation achieved much better results than the non-rehabilitated veterans (Runjić, Nikolić & Bilić Prcić, 2003)

Conclusion

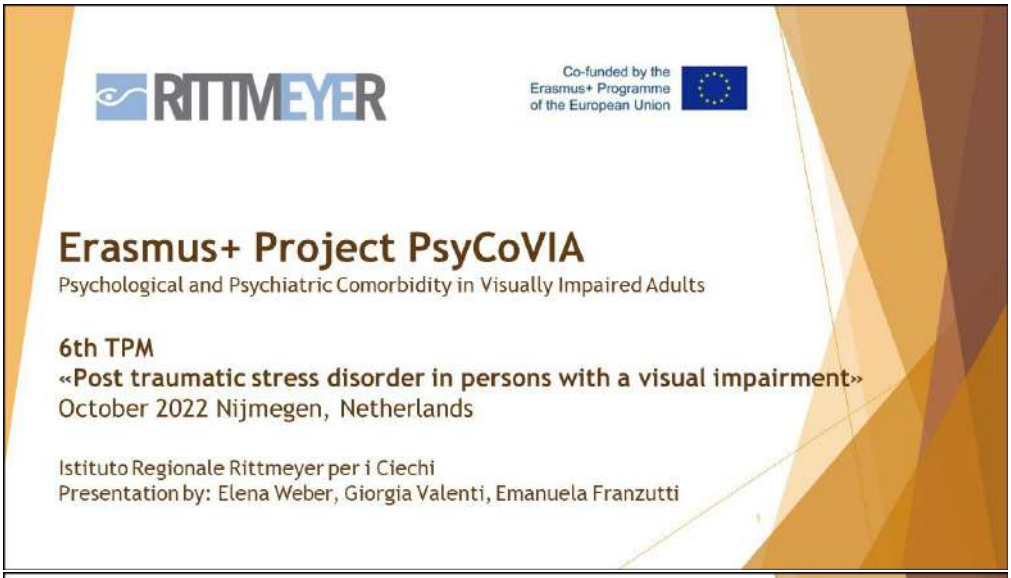
- A significant number of people with VI have PTSD in Croatia
- They are not included in current psyhosocial rehabilitation in our Department
- lack of information about their inclusion in society

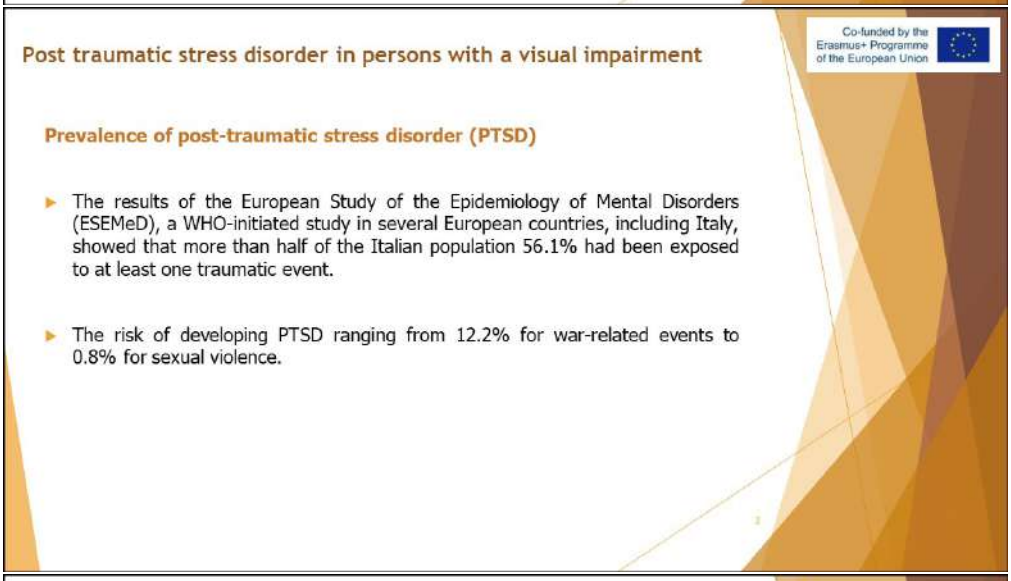
How to correctly direct and encourage clients to involve in psychotherapy/ psychiatric treatment?

How to work with people with VI and multiple disabilites?

Thank you for your attention

Italy


RITTMEYER
Co-funded by the Erasmus+ Programme of the European Union
Erasmus+ Project PsyCoVIA
Psychological and Psychiatric Comorbidity in Visually Impaired Adults
6th TPM
«Post traumatic stress disorder in persons with a visual impairment»
October 2022 Nijmegen, Netherlands
Istituto Regionale Rittmeyer per i Ciechi
Presentation by: Elena Weber, Giorgia Valenti, Emanuela Franzutti


Post traumatic stress disorder in persons with a visual impairment
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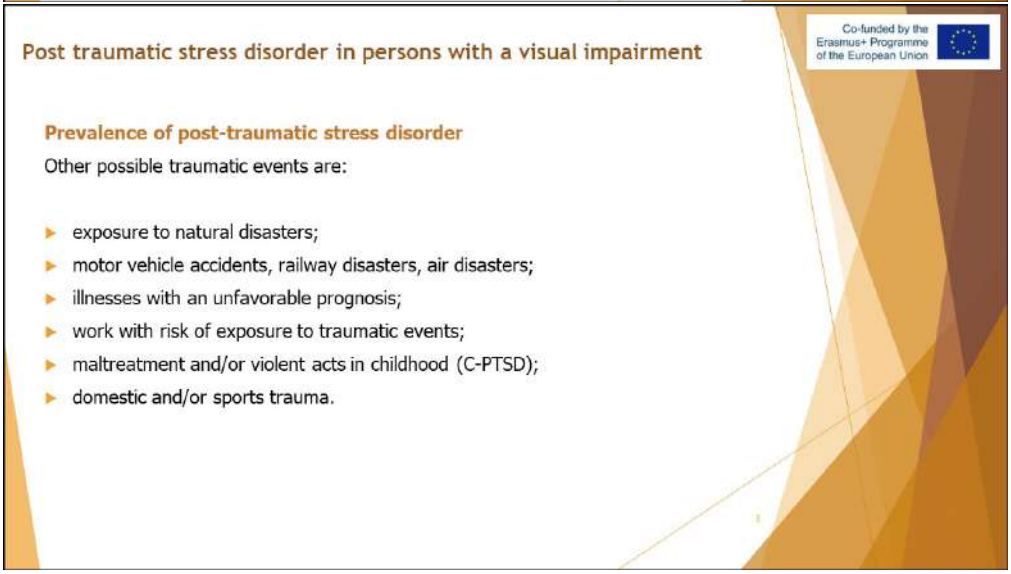
Prevalence of post-traumatic stress disorder (PTSD)
The results of the European Study of the Epidemiology of Mental Disorders (ESEMeD), a WHO-initiated study in several European countries, including Italy, showed that more than half of the Italian population 56.1% had been exposed to at least one traumatic event.
The risk of developing PTSD ranging from 12.2% for war-related events to 0.8% for sexual violence.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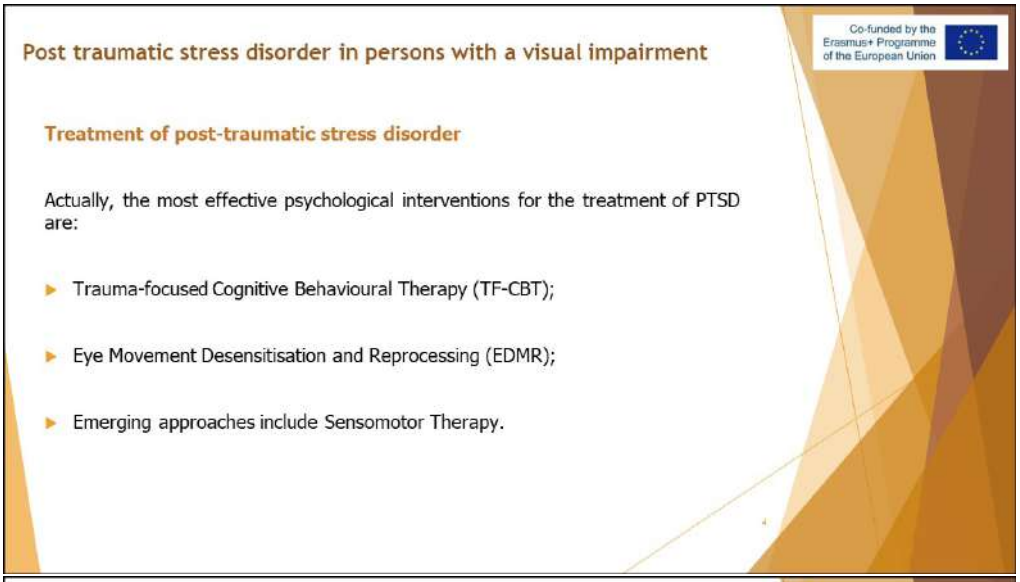
Prevalence of post-traumatic stress disorder
Other possible traumatic events are:
exposure to natural disasters;
motor vehicle accidents, railway disasters, air disasters;
illnesses with an unfavorable prognosis;
work with risk of exposure to traumatic events;
maltreatment and/or violent acts in childhood (C-PTSD);
domestic and/or sports trauma.


Post traumatic stress disorder in persons with a visual impairment
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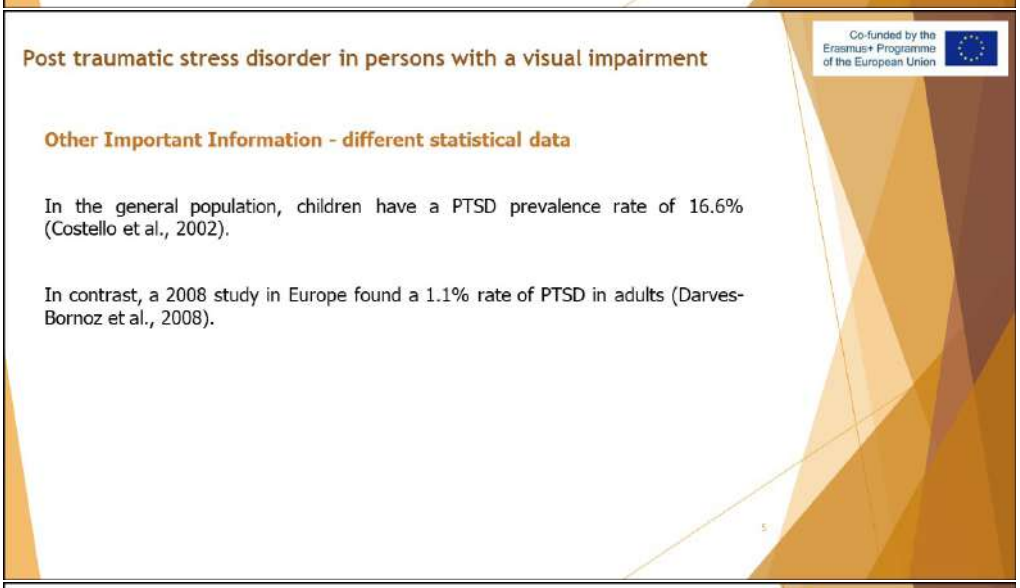
Treatment of post-traumatic stress disorder
Actually, the most effective psychological interventions for the treatment of PTSD are:
Trauma-focused Cognitive Behavioural Therapy (TF-CBT);
Eye Movement Desensitisation and Reprocessing (EDMR);
Emerging approaches include Sensomotor Therapy.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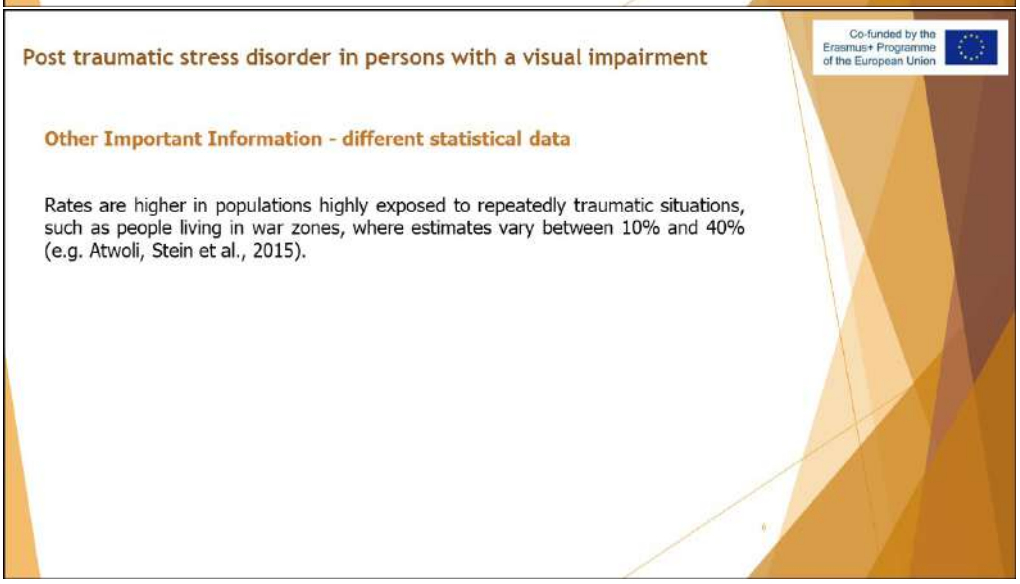
Other Important Information - different statistical data
In the general population, children have a PTSD prevalence rate of 16.6% (Costello et al., 2002).
In contrast, a 2008 study in Europe found a 1.1% rate of PTSD in adults (Darves-Bornoz et al., 2008).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Other Important Information - different statistical data
Rates are higher in populations highly exposed to repeatedly traumatic situations, such as people living in war zones, where estimates vary between 10% and 40% (e.g. Atwoli, Stein et al., 2015).

Post traumatic stress disorder in persons with a visual impairment

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Other Important Information - different statistical data

Or again, PTSD has a high prevalence in adult survivors of childhood physical and sexual abuse with rates ranging from 37% to 44% (Rosner et al., 2014).

These figures are particularly alarming considering that the World Health Organisation estimates that 7-36% of girls and 3-29% of boys have been subjected to sexual violence.

Post traumatic stress disorder in persons with a visual impairment

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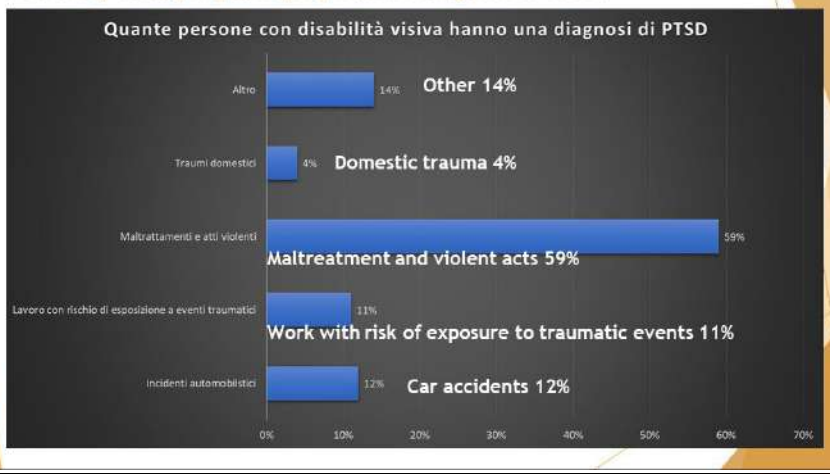
How many visually impaired people have a diagnosis of PTSD?



Post traumatic stress disorder in persons with a visual impairment

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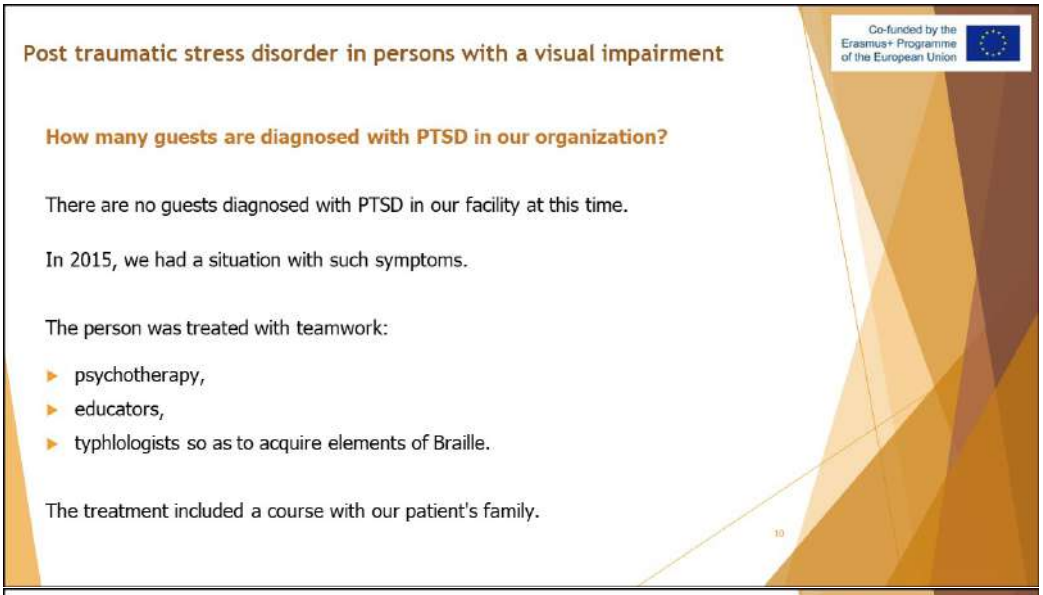
Treatment of PTSD for people with visual impairment

Actually, the most effective psychological interventions for the treatment of PTSD are:

- Trauma-focused Cognitive Behavioural Therapy (TF-CBT);
- Eye Movement Desensitisation and Reprocessing (EDMR);
- Emerging approaches include Sensomotor Therapy.


Post traumatic stress disorder in persons with a visual impairment
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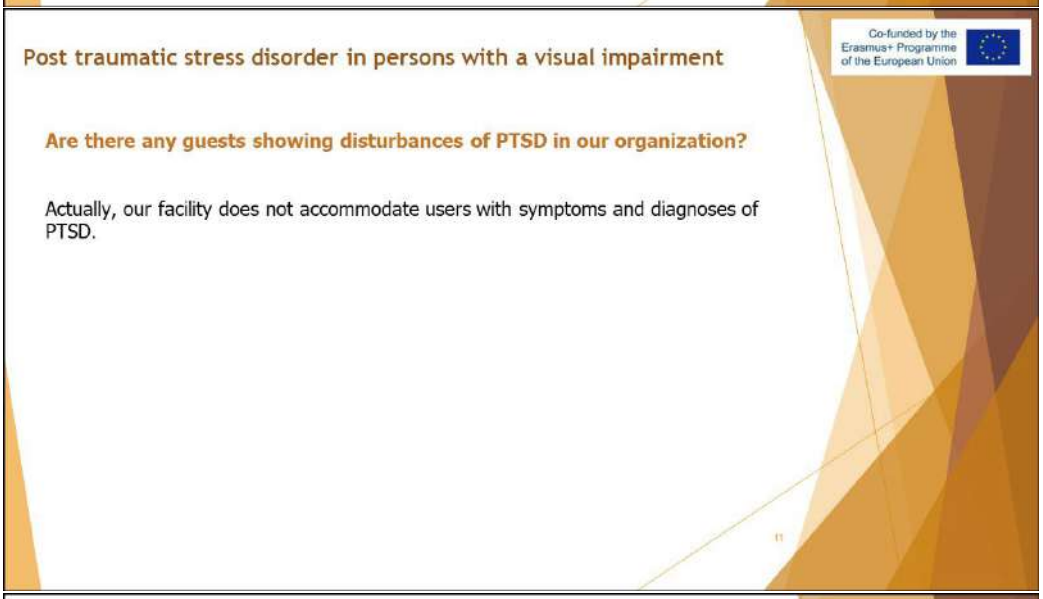
How many guests are diagnosed with PTSD in our organization?
There are no guests diagnosed with PTSD in our facility at this time.
In 2015, we had a situation with such symptoms.
The person was treated with teamwork:
psychotherapy,
educators,
typhlologists so as to acquire elements of Braille.
The treatment included a course with our patient's family.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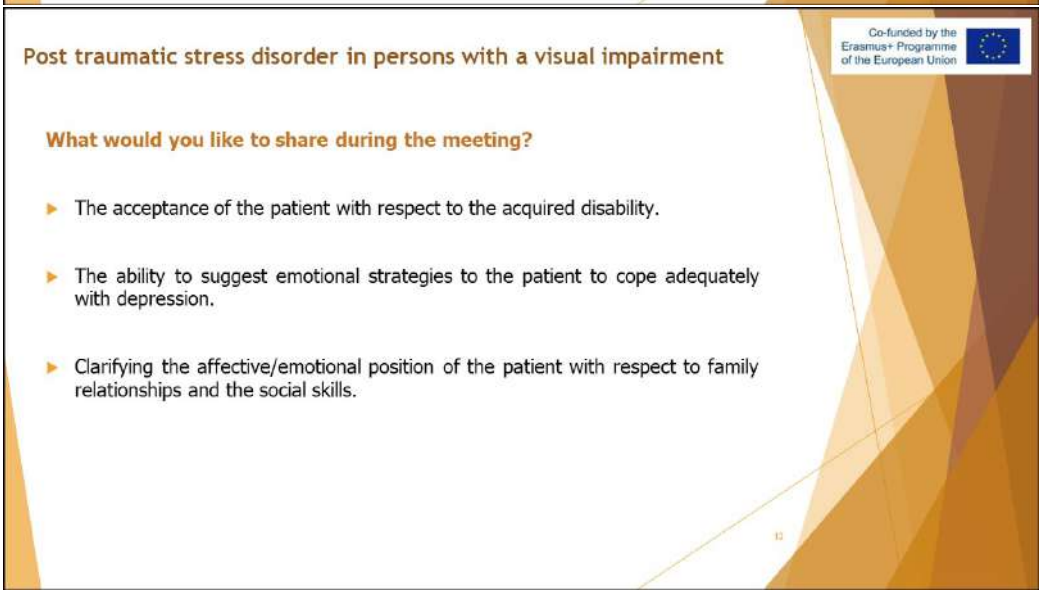
Are there any guests showing disturbances of PTSD in our organization?
Actually, our facility does not accommodate users with symptoms and diagnoses of PTSD.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What would you like to share during the meeting?
The acceptance of the patient with respect to the acquired disability.
The ability to suggest emotional strategies to the patient to cope adequately with depression.
Clarifying the affective/emotional position of the patient with respect to family relationships and the social skills.

Depression and Anxiety in persons with a visual impairment

Co-funded by the Erasmus+ Programme of the European Union

Sitography

- Disturbo da stress post-traumatico - Istituto A.T. Beck (istitutobeck.com)

Istituto Regionale Rittmeyer per i Ciechi

Thank you!

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Book of Good Practices