

Eliminating Social Exclusion EliSE Erasmus+

Nr. 2019-1-LV01-KA204-060427

TRAINING COURSE

INTERDISCIPLINARY NETWORK FOR SPECIAL &
INTERCULTURAL EDUCATION “INCLUDE”

THESSALONIKI, GREECE

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



Self-care and family strategies

SUMMARY

ALTA PANERA, PSYCHOLOGIST - PSYCHOTHERAPIST

EliSe ERASMUS+ TEAM SCIENCE MEMBER

INCLUDE

THESSALONIKI GREECE

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



Stressors of parents with special needs children

- ▶ Mothers of adolescents and adults with autism experience chronic stress comparable to combat soldiers and struggle with frequent fatigue and work interruptions, new research finds. These moms also spend significantly more time caregiving than moms of those without disabilities.
- ▶ Finances are often a source of stress. Frequently one parent, usually the mother, sacrifices her career to attend to the child's needs with a resulting loss of income for the family.



A day in the life of a mother and her disabled son

<https://www.youtube.com/watch?v=YWrSn-fnRtc>

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



Difficulties in families with disabled children

- Issues faced by the families with a child with disability are of a wide range and those who face them might also face difficulties in their social integration
- The presence of problems and their impact on the mental health of members of the family might be misunderstood as internal problems, without taking into account the pressures they are facing
- In order to understand what a member of the family is experiencing it's not necessary to understand the diagnosis or the symptoms the disabled child has, but the obstacles that might arise from it for the other family members

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



Mom Of Autistic Child Walks Through A Day With Her Son

<https://www.youtube.com/watch?v=JGhgcaQ2Tvs>

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



Stressors of parents with special needs children. Emotional impact

- Fear and worry about:
 - The child's pain and suffering
 - The child's future
 - The question of whether you are doing enough or doing the right things to help the child
- Guilt over:
 - The limits of your ability to protect the child
 - The loss of attention toward other children, your spouse and aging parents
 - Your jealousy and resentment of those with “normal” children



Stressors of parents with special needs children

- Feelings of isolation because you:
 - Miss out on many family-oriented activities because your child's disability prevents her/him from successfully participating
 - Encounter criticism and judgment of your parenting from others who don't understand your child's disability
 - Feel like an outsider around parents of typically developing children
- Grief over:
 - The loss of hopes and dreams you had for the child
 - Not having the parenting experience you'd imagined
 - Recurrent reminders of what your child misses out on leading to chronic sorrow



Parents of special needs children mental health

- ▶ Parents of children with physical disabilities are at risk of poor mental health.
- ▶ Parents of children who have a developmental disability experience higher odds of depression or other mental health diagnoses compared with parents of children who do not have a developmental disability.
- ▶ Perceived parental distress is the most important factor affecting parental mental health.

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



Stressors of parents with special needs children

- ▶ Parents of children with special needs are often exhausted and frequently become depressed. Their reserves of time and resources for self-care are even more depleted than those of parents of typical children. Yet their need for refuelling is also greater. To be sustained through the marathon of caring for a child with special needs, it is essential that parents attend to their own needs.

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



The diagnosis

- ▶ https://www.youtube.com/watch?v=Gws_2p3KszU

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



Reflecting on your experience

- ▶ Consider a time in your life where you experienced stress, sleep difficulties, sadness or depression
- ▶ For example, what triggered you, how long did it last, was it simple or complex, was it of internal or external origin
- ▶ What did you find helpful, what was harmful, how did you get over it;

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



How to decrease your negative mood with positive experiences?

- ▶ Although there are many ways to increase your mood, it's been proven most effective to increase the pleasure you receive daily
- ▶ The following steps can help you with this:

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



WEEKLY BEHAVIORAL CHANGE TABLE

BEHAVIOR

- ▶ relaxation
- ▶ exercise
- ▶ nutrition
- ▶ time management
- ▶ sleep
- ▶ Pleasant activities
- ▶ relationships
- ▶ Daily thought diary
- ▶ reading

PLANNING IS IMPORTANT!

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



HOW TO DECREASE NEGATIVE MOOD WITH PLEASANT ACTIVITIES

- ▶ Make a list of pleasant activities. Particularly Include activities you did in the past (and enjoyed) which you no longer do.
- ▶ Include only activities which you can do. For example, you can include “gardening” but it is possible “going to London” is not possible
- ▶ Include activities you have never done, but wish do

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



Ideas for pleasant activities

- ▶ Listening to live music- exercising- going to the beach- making art- playing a musical instrument- watching a sports event- needlepoint- gardening- working on my car- visiting friends- writing an e-mail to a friend- calling a friend- reading a good book- cleaning the house- succeeding in a goal- going to a restaurant- kite flying- going hiking- going for a walk- journaling- going to a place of worship- participating in a theater group- going shopping- sitting in the sun- going to a neighborhood event- going to a museum- going to a bookstore- taking photos- meditating- doing relaxation exercises- cooking- spending time with members of my family- playing card games- exercising

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



HOW TO DECREASE NEGATIVE MOOD WITH PLEASANT ACTIVITIES

- ▶ Make a schedule where you choose at least four of these activities, so you can do them every week. Write down exactly when you will do them.
- ▶ Note the barriers which might arise while doing these activities and write the ways you will overcome them
- ▶ After you do the activities note if you feel better, right after the activity and after a whole week of pleasant activities

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



BE GOOD TO YOUR BODY

Deep breathing

<https://www.youtube.com/watch?v=Wemm-i6XHr8>

- ▶ Take slow, deep breaths
- ▶ Breathe from your diaphragm
- ▶ Notice the contraction of your stomach and try to keep your chest steady
- ▶ Notice the distention of your stomach and try to keep your chest steady while you exhale
- ▶ If you wish, count 4 seconds during your inbreath, hold it for 4 seconds, count 6 seconds during exhale and 2 seconds before you begin again
- ▶ Repeat the word “relax” or “peace” as you exhale
- ▶ Repeat for 5 -10 seconds
- ▶ The more you practice the easier it will be to relax



BE GOOD TO YOUR BODY

Ideal exercise

- ▶ aerobic
- ▶ 4-5 times a week
- ▶ 20-30 minutes a time

Common excuses

- ▶ I don't have enough time (or I don't want to find time)
- ▶ I feel very tired (begin sooner in the day to avoid fatigue)
- ▶ I don't enjoy it (try something different)
- ▶ It's not convenient (try something different)

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



BE GOOD TO YOUR BODY

Nutrition

- ▶ The following is not helpful:
 - ▶ Stimulants: caffeine (coffee, colas, cocoa- maximum 1 coffee or 2 colas a day), nicotine
 - ▶ Salt: decreases potassium, increases blood pressure
 - ▶ preservatives
 - ▶ Meat hormones- decrease your consumption of red meat, pork and poultry- eat fish and vegetables
- ▶ Stressful eating habits- eating too fast, big portions or standing up
- ▶ Avoid sugar, check for food allergies
- ▶ Drink 6-8 glasses of water a day
- ▶ Include one fresh (not canned or frozen) vegetable in your daily meals
- ▶ Supplements: Vitamin B complex (50-100mg) Vitamin C complex (1000mg) with meals



BE GOOD TO YOUR BODY

Regular daily meditation

Benefits: lower heart rate, lower blood pressure, lower tension, lower analytic thought

- ▶ What to do: regular deep meditation exercise for 20-30 minutes a day
- ▶ This will have an effect on the rest of your day and as a result it will: decrease your anxiety, prevent stress, increase energy levels, increase concentration and memory, decrease insomnia and fatigue, prevent headaches and muscle pain, increase self-esteem



BE GOOD TO YOUR BODY

Progressive muscle relaxation

<https://www.youtube.com/watch?v=p54jmkW0RN0>

- ▶ Tense and relax each muscle group in your body. First tense the muscle group for 5 seconds. Then relax it and notice the difference
- ▶ Start with your toes and move up or with your head and move down
- ▶ Usual muscle groups involve: toes, ankles, calves, thighs, buttocks, stomach, shoulders, hands fingers, face
- ▶ When you are done, notice the relaxation
- ▶ Follow the process twice in a row
- ▶ Consider which areas you could do without people noticing you



BE GOOD WITH YOUR BODY

Common obstacles

- ▶ I don't have time (so what is a priority?)
- ▶ I don't have a space to relax (then create one)
- ▶ These exercises are too slow (then you are going too fast)
- ▶ I feel more stressed when I relax (use a shorter relaxation or progressive muscle relaxation)

Down time and time management

- ▶ Time for relaxation or free time: at least 1 hour a day, 1 day a week, 1 week every 4 months
- ▶ Relaxation time, leisure time, relation time
- ▶ Prioritize
- ▶ Delegate
- ▶ Allow for extra time
- ▶ Overcome procrastination

Cognitive distortions

- ▶ https://www.youtube.com/watch?v=_XLY_XXBQWE



REDUCE ANXIETY AND LOW MOOD BY CHANGING YOUR THOUGHTS

The cognitive model:

- ▶ First, it is important to realize that your mood depends on your thoughts. We might experience the same event, but how we think of it will determine how we feel about it.

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



REDUCE ANXIETY AND LOW MOOD BY CHANGING YOUR THOUGHTS

The technique:

- ▶ There are three steps to changing your thoughts.
 - ▶ Identify
 - ▶ Assess
 - ▶ Respond

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



Identification

- ▶ First you must identify the thoughts that cross your mind before your negative feelings. So, when you feel bad, ask yourself “what just crossed my mind?” Write down your negative thoughts- especially the thoughts you have about yourself. For example “I am very stupid”

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



Assessment

- ▶ Now see if the thought is correct. We are not perfect and often we tend to think in negative ways, especially when we are anxious or sad. Assess if the thought is correct by comparing it to some cognitive distortions listed in the next page. Also, ask yourself “is there proof that this isn’t true?” You might even consider what you would say to a friend how was having the same thought. Actually, you are “attacking” the negative thought and discussing with yourself why it is distorted.



Response

- ▶ Finally, when you have identified how the thought is distorted, incorrect, it's not supported by facts, or just not helpful- respond to the thought with a better thought- one that isn't distorted, is real, based on evidence or is more helpful.



WHEN AND HOW

- ▶ This technique is best learned if initially you write everything- your unhelpful thoughts, your assessment (including distortions) and the answers. Writing can be done on the spot, if this is possible, or later during the day or the week. The sooner you write it, the clearer you'll remember your thoughts, and the quicker you'll feel better. After you do this enough times in writing, you'll begin to do it in your mind. In time it will become an automatic process, and your thoughts will no longer lead you to sadness or anxiety.

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



COGNITIVE DISTORTIONS

- ▶ https://www.youtube.com/watch?v=VI3DgbZc7_o
- ▶ <https://www.healthline.com/health/cognitive-distortions>



COGNITIVE REFRAMING

AUTOMATIC THOUGHTS	DISTORTIONS	REASONABLE ANSWERS
Write all your negative thoughts	Recognize the distortions in each automatic thought	Replace each thought with a more positive and realistic thought
<p>Co-funded by the Erasmus+ Programme of the European Union</p> 		

CHALLENGING YOUR ANXIOUS THOUGHTS

- ▶ Are there reasons you're having this anxious thought?
- ▶ Evaluate the facts and evidence on which your thought is based
- ▶ Check your feelings and thoughts with other people who are in similar circumstances
- ▶ What's the worse that could happen? Are there facts that contradict this thought? Challenge what you think or are afraid that will happen
- ▶ Search for other ways to interpret the situation
- ▶ How can I approach and handle this situation?
- ▶ Are your expectations realistic?
- ▶ Οι προσδοκίες σου είναι ρεαλιστικές;
- ▶ Write down your realistic thoughts



Mindfulness

- ▶ https://www.youtube.com/watch?v=1kntcC9nICo&t=3s&has_verified=1



What do the siblings of special needs children feel?

- ▶ Your child may, at times, have trouble coping with being the sibling of a child with special needs. They may have many different and even conflicting feelings. For example, they may feel:
 - worried about their sibling
 - jealous of the attention their brother/sister receives
 - scared that they will lose their sibling
 - angry that no one pays attention to them
 - resentful of having to explain, support, and/or take care of their brother/sister
 - resentful that they are unable to do things or go places because of their sibling
 - embarrassed about their sibling's differences
 - pressure to be or do what their sibling cannot
 - guilty for negative feelings they have toward their sibling or guilty for not having the same problem

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



What do the siblings of disabled children need

- ▶ Caring for the needs of a typically developing child along with those of a child with special needs is definitely a challenge. Having some information to help handle this situation and the necessary sensitivity might help decrease the difficulties in the family

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



What do the siblings of disabled children need

▶ The right to their own life

- ▶ During their whole life the typical siblings play different roles in their special needs siblings life. Despite their support, parents must always remember they have a right to their own life. Parents must never decide about the responsibilities the typical siblings will assume without discussing it with them openly and honestly.

▶ Acknowledging the typical childrens concerns

- ▶ Just like parents, children also experience a range of often contradicting feelings, about the impact their special needs family have on them and all the family. These feelings are to be expected and should be validated by the childrens environment. Since most siblings will have the longest relationship with the disabled child, their concerns will change over time. It is important parents be aware of these issues so they can manage them in the best possible way.



What do the siblings of disabled children need

- **Expectations from the typical siblings**
 - ▶ Families must have high expectations of all their children. Some typical children react to their siblings disability and have non-realistically high standards for themselves. Some feel they need to make up for their special need siblings. Parents can help typically developing children by expressing clear expectations and providing unconditional support and acceptance..
- **Expect typical behavior for typical siblings**
 - ▶ Although it is hard for a parent to watch their children tease, fight or confront each other these are frequent and normal behaviors, even when one of the siblings has special needs. Although parents are often shocked by the harshness one sibling can show another, this tension might be a useful and normal stage of social development



What do the siblings of disabled children need

- **Expectations from family members**
- When families have high expectations of their children with special needs, everyone benefits. As adults, typical siblings play an important role in the life of their siblings. Parents can help the typical siblings by helping their special needs children develop skills that will allow them to be as autonomous as possible as adults. As much as possible, parents should have the same expectations of their child with special needs as of their typical children. In this way, not only is their development encouraged by the dissatisfaction expressed by siblings when there are other rules for different children in the house decreases
- **The right to a safe environment**
 - ▶ Some children live with siblings who have difficult behaviours. Others take on responsibilities which are beyond their age, and this puts them in a vulnerable state. Siblings deserve to have equal attention placed on their safety as is placed on those of children with special needs. It is important to assure the safety of all family members



What do the siblings of disabled children need

- **Possibility to meet peers in similar situations**
 - ▶ As it is important for parents to meet and communicate with other parents facing similar issues, so children can benefit from meeting other typical children who have siblings with special needs. It is important for the children, as it is for the adults, to know they are not the only ones with these special joys and concerns.
- **Access to information**
 - ▶ During their lifetime siblings need information about their siblings disability, treatments and outcomes. Parents should actively provide useful information to children. The conversations need to be repeated as the ability to understand and remember information increases and parents are the ones who should initiate these conversations. Often children do not express their concerns or complaints fearing they will upset their parents or because they feel shame for their emotions.



What do the siblings of disabled children need

- ▶ From a young age the siblings worry about the responsibilities they will have toward their disabled sibling in the future. Parents might reassure their typical children making plans for the future of their disabled child, listening to their suggestions while they are making these plans, think of alternative plans and realizing that the availability of their children might change in different phases of their life.
- ▶ Daughters are usually the family members who take care of their elderly parents. Similarly, adult daughters usually care for the disabled sibling when parents can no longer do so. It is important to explore equal sharing of responsibilities between siblings, regardless of their gender

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



What do the siblings of disabled children need

- **One on one time for typical children**
 - ▶ It's important for children to know from the words and actions of their parents that they care about them as individuals. When the parents find some time from their busy schedule to go for a walk or engage in small activity with their typical siblings, they convey the message that they will be there for them and create a very good opportunity for a communication experience regarding various issues which might concern the child.
- **Celebrate the successes of each child**
 - ▶ The needs of the disabled child shouldn't overshadow those of the typical children. It is important to have the necessary planning so all the family can participate and celebrate in the successes of its members



What do the siblings of disabled children need

- **The parents perception is often equally important as the disability itself**
 - ▶ It is important that parents remember the interpretation they give to the child's disability has a greater impact on the adjustment of the typical siblings, than the disability itself. When the parents seek out support, information and breaks for themselves they give a good example to their children of resiliency and healthy attitudes and behaviours towards they typical children, indirectly assisting the relationship between the children and their siblings

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



What do the siblings of disabled children gain

- ▶ Siblings of children with special needs have special needs themselves. Their sister or brother with special needs *will* get a bigger share of attention. While having a special needs sib presents challenges, it also comes with opportunities. Kids who grow up with a sibling with special health or developmental needs may have more of a chance to develop many good qualities, including:
 - patience
 - kindness and supportiveness
 - acceptance of differences
 - compassion and helpfulness
 - empathy for others and insight into coping with challenges
 - dependability and loyalty that may come from standing up for their brother or sister.



Self-care and family strategies

- ▶ REFERENCES
- ▶ **INDIVIDUAL STUDY MATERIAL**

“

Eliminating Social Exclusion EliSE Erasmus+

Nr. 2019-1-LV01-KA204-060427 ”

Scientist responsible for EliSe Erasmus+ in Greece

Andromachi Nanou, PhD

Chairwoman of Include

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

