

SUPPORTING A RELATIVE WITH A DISABILITY

Guidance & resources to better understand, take action and empower

KINDLING A BETTER WORLD

Disability FAMILIES EUROPE

L.I.N.K.

EDUCATIONAL GUIDE

Co-created by COFACE Families Europe and KMOP

L.I.N.K. **L**earning and **I**nnovating through **N**ew **K**nowledge

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FOREWORD

Supporting a relative with a disability is a commitment. Whether it's a daily or one-off task, it always requires time, energy, skills and a great deal of adaptability. But it's like getting on a train without knowing where it's going.

Many people, like you, find themselves in this role without having been prepared for it. This guide is here to help you better understand this journey: how you end up on this train, what it involves, what it changes, and what you can make of it.

To begin with, it is worth noting that perceptions of disability have a very long history. For centuries, disability was seen as a sign – sometimes a curse – linked to birth, an accident or an illness. Without always realising it, families today still inherit this way of thinking. The onset of a disability can therefore feel like a sudden shift into a 'different world'. Gaining a better understanding of these perceptions and learning about the different approaches to disability today is a first step towards regaining some control over what is happening to you. It means putting your experience into words and starting to write your own story.

You will also realise that, over time, as you support your relative, you develop valuable skills. These skills, gained through experience, are often invisible to others – and sometimes even to yourself. Yet they are real, legitimate, and deserve to be recognised.

You will also discover why it is essential to assess the impact of the support you provide and to look after your own health, as you are there for your relative in all circumstances, sometimes at the expense of your own wellbeing. Yet it is vital to look after yourself.

Finally, please bear in mind that whilst your role is vital in your relative's life, it must never replace the responsibilities of the public authorities. They have a duty to ensure accessible, appropriate and high-quality services, and to respect your rights.

You can add to this guide, share it... It belongs to you.



Chantal Bruno
Co-Chair, COFACE Disability

Supporting a family member with a disability is a journey that can profoundly transform the lives of both the person with a disability and those who care for them. It is a journey that requires time, adaptability, knowledge and skills, but also recognition, support and empowerment.

We considered it important to begin this guide by exploring the different meanings that disability can take for different people. This is more than a starting point: it is a fundamental precondition for understanding disability and for deciding how to act as a carer. By recognising the person beyond their disability, carers can better prioritise their actions and focus on what truly empowers the person with a disability, - their autonomy, dignity, participation and right to make choices about their own life.

Carers are then invited to look at their own role and recognise the many skills they develop through experience. Every action, word, effort and gesture matters. The attitudes we express, the way we communicate, our body language and the many "unseen qualities" we develop over time, can influence how persons with disabilities see themselves, how carers grasp their own role in relation to the care they offer, the atmosphere created around them, and ultimately how communities and societies perceive and respond to disability.

The European Charter for Family Carers provides an important framework for recognising carers as rights-holders and for understanding both the value of their contribution and the challenges they face. The guide also encourages carers to turn their attention to themselves: to acknowledge their feelings, recognise their own needs and take steps towards protecting their well-being.

Finally, it explores the importance of connection with peers, professionals, services and the wider community, reminding carers that they do not have to face this journey alone.

Last but not least, I would like warmly to thank all the member organisations of COFACE Disability whose expertise, experience and commitment contributed significantly to the development of this guide.

Antonia Torrens
President, COFACE Families Europe



INTRODUCTION



Supporting someone with a disability can be deeply meaningful but also very demanding. Many people take on this role without having received any training or preparation. And while family carers play a crucial role in ensuring the well-being, inclusion and daily support of persons with disabilities, they remain largely invisible.

Target audience of the guide

This guide is meant for people who support a family member, partner, or close friend with a disability. Some people wholly identify as family carers, while others prefer to see themselves as helping someone they care about, out of love or duty. We want to stress that both experiences are valid. The guide is meant for you, either way.

It is intended for people who provide occasional or daily support to children, adults, or older persons with disabilities. Whether you are new to this role or if you have been on a caregiving journey for many years, the information and reflections in this guide may be useful to you.

People who support someone with a disability come from many different backgrounds. They may be parents, including single, adoptive or foster parents and parents in blended families, children, siblings, grandparents, other relatives such as aunts, uncles or cousins, or close friends. They may be younger or older, working full-time, part-time, not working, or retired. Some live close to the person they support,

while others provide help from a distance. They can also be providing care to more than one family member.

This guide may also be useful for disability, community, or health professionals who support family carers and wish to share clear and practical information with the people they work with.

Purpose of the guide

Based on a review of best practices and existing national and international resources, this guide aims to provide you with simple information, practical reflections and key tips to support you in your daily life and strengthen your capacity to empower yourself and your relative. It is not intended to tell you how to do things but rather to help you better understand your situation and reflect on what may support you best.

The guide has been co-created with family carers and professional carers of the COFACE Disability platform for the rights of persons with disabilities and their families.[1]

Contents of the guide

This guide includes four short self-paced modules:

1. Understanding disability;
2. Recognising your roles and skills in supporting someone with a disability;
3. Navigating personal challenges and practicing self-care;
4. Engaging with the community.

How to use the guide

Please bear in mind that this guide is not meant to be read from start to finish in one go: you can read the modules in any order, return to them or skip parts that do not feel relevant right now. Additionally, the activities are short reflections designed to help you connect the information you read to your own experience. However, they are optional and you can skip them if you prefer.

While you navigate through this guide, keep in mind that there is no single "right way" to care for someone: your experience matters and is valid.

We hope you find ideas and encouragement along the way. Most of all, we hope you feel acknowledged and seen throughout this guide!

Disclaimer: While this guide provides information and practical tips, it cannot replace professional medical or psychological support. If you have concerns about your own or someone else's health, please seek advice from a qualified professional.

1 COFACE Disability was founded in 1998 to improve the representativeness of persons with disabilities and their families. It brings together over 20 national associations, all members of COFACE. It aims at helping persons with disabilities enjoy their rights throughout the life cycle, and in particular within their family context. COFACE Disability advocates for a central place for families in disability-related policy making.

MODULE 1:

UNDERSTANDING DISABILITY



1. Description of the module

This module introduces you to inclusive, rights-based ways of understanding disability. It highlights how disability is shaped by individual differences but also by social, physical and attitudinal environments. It also emphasizes how inclusive practices can promote participation, dignity and access to rights of persons with disabilities.

After reading this module, you may be better able to:

- Summarise the main approaches to disability;
- Build an inclusive understanding of how disability interacts with the environment;
- Increase your awareness of societal barriers that may limit participation or access.

Reading this module and completing the activity may take about 30 minutes. You can focus on the sections you find the most relevant and return to others later if you are more comfortable with that.

→ You do not need to become an expert but just grow more familiar to have a clearer understanding.

2. Key information on disability and rights

The approach to disability influences how one experiences and interacts with the world. There are different approaches to disability which are evolving through time and progress. Here, we will mostly focus on three of them.

The Medical model of disability

Approach



Medical Model

Focus

The focus is put on the **person's impairment**, which is considered the source of inequality.

Implications

In this model, disability is considered **the problem of the individual**. There is an emphasis on **"fixing" the person**, and thus on healthcare and medical specialists as solutions.

To better understand what the medical model stands for and what it means, you can look at this image:



Figure 1 Medical model of disability

The person with a disability is thus seen as a passive receiver of care, needing a cure and depending on others. This model has also faced criticism from key organisations in the disability rights movement, for perpetuating stigma, framing persons with disabilities as unequal rights holders, and promoting a charitable rather than human-rights-based perspective, and posing a higher risk of segregation.

The Social model of disability

Approach



Social Model

Focus

The focus is put on the **environment** of the person. Here, disability is considered the consequence of the interaction of the individual with an environment that **does not accommodate the individual's differences.**

Implications

In this model, disability is seen as **created by society**. In that case, solutions and measures place an emphasis on:

- Accessibility
- Inclusion
- Social change

To better understand what the social model stands for and what it means, you can look at this image:

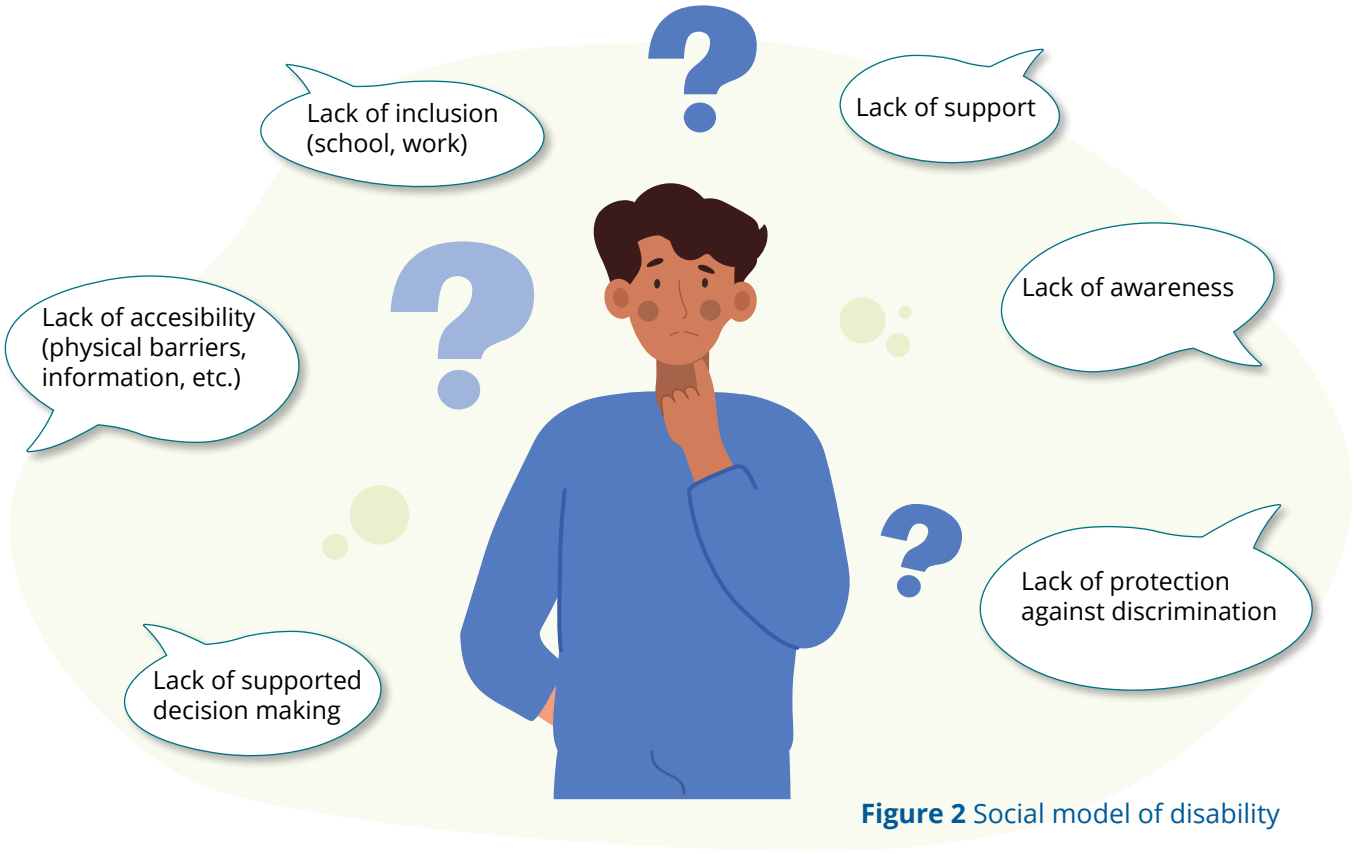


Figure 2 Social model of disability

We can observe a clear shift in mindset from the medical model to the social model: from "how to fix the person?" to "how to change the environment?".

The Human rights model of disability

Approach



Human rights Model

Focus

This approach builds on the social model by acknowledging persons with disabilities as **subjects of rights**. The state and other institutions have responsibilities to respect these persons and their rights.

Implications

In this model, disability is seen as a **human rights issue**.

It means that rights-based laws, participation and accountability of the state are part of the solution.

Why is it important for you to know?

Understanding the different models of disability helps you see how society can either create barriers or support the inclusion of persons with disabilities.

This is essential when you consider your environment - school, work, services, etc. – in order to assess whether they empower the person you support or create barriers.

The next step is now to look at some policy frameworks that guide inclusive practices and protect the rights of persons with disabilities.

Starting with the United Nation Convention for the Rights of Persons with Disabilities (UNCRPD):

UNCRPD - United Nations Convention Of The Rights Of Persons With Disabilities

What it is

- An international human rights treaty adopted by the United Nations in 2006.
- It recognises the rights of persons with disabilities.

Its purpose

- Protect and promote the full and equal enjoyment of all human rights by persons with disabilities.

How it works

- It is signed by countries across the world. Most countries have signed it.
- It has been signed by all European Union (EU) countries as well as all EU neighbouring countries.
- Countries that have signed the UNCRPD are required to:
  - Respect the autonomy and dignity of persons with disabilities
  - Eliminate discrimination on the basis of disability
  - Ensure accessibility (buildings, transport, information, digital spaces)
  - Guarantee inclusion in education, work, family life and community life
  - Provide support that enables independent living

The UNCRPD is based on a combination of the social and human rights models of disability so it believes that:

- Disability is not a medical problem
- Disability is not to be addressed through charity or welfare-based protection
- Disability is a matter of human rights and equality.

Why is it important for you to know?

Better understanding what the person you support is entitled to may help you feel better equipped to identify and ask for inclusive practices, whether at school, in the workplace or in services.

It also gives you a framework if you want to advocate for inclusion and rights, but that is optional.

In addition to the UNCRPD, there are several European policies and strategies that shape how countries support persons with disabilities and their family carers. You can find a summary in the table below:

Policy framework	Why it matters
Employment Equality Directive (2000)	It protects persons with disabilities from discrimination at work. Some working carers (e.g. parents) may also benefit from reasonable workplace accommodations.
Work-Life Balance Directive (2019)	It supports workers with caring responsibilities through carers' leave (minimum 5 working days per year) and flexible working arrangements.
European Care Strategy (2022)	It encourages EU countries to improve support for family carers and strengthen professional care services, making them more affordable and accessible.
Recommendation on Long-Term Care (2022)	It promotes better support for family carers, including respite, psychological and financial support.

As you read this, you may realise how important it is to be well informed and aware of your rights and those of the person you are caring for.

3. Case study: the UNCRPD in practice

In Spain, FIAPAS – the Spanish Confederation of Families of Deaf Persons – organises regular training sessions for families of deaf children and for professionals working in local family associations. These trainings provide a space for participants to meet, share experiences, and learn about topics related to family life and disability.

One training focused on the rights of children with disabilities. It introduced families to:

- the United Nations Convention on the Rights of Persons with Disabilities
- the United Nations Convention on the Rights of the Child

The training explained how these frameworks protect the rights of children with hearing impairments and families learned about possible complaint procedures when rights are not respected.

FIAPAS adopts a dual approach for the family support programme, combining professional support with peer support among families. Beyond providing access to information, counselling and capacity-building opportunities, FIAPAS also ensures that families can use peer exchange, as one of the ways to connect with one another, and better understand and exercise their rights and those of their relatives with hearing loss.

Access to training opportunities such as this one can help family carers better understand the rights of the person they support and how to advocate for them. By organising such yearly sessions, FIAPAS contributes to raising awareness of disability rights among deaf persons, their families and the professionals supporting them.

Reflecting on this case study

This case study shows how knowledge of the UNCRPD (and other national and international frameworks) can be shared with both family carers and professionals to raise awareness of rights and improve support. **You might take inspiration from this best practice by seeking out further guidance or resources in your own community that help you better understand the rights of the person your support, as well as your own rights**.

Awareness of rights is often the first step toward ensuring that they are respected!



4. Activity: Seeing disability differently

We now invite you to dive into a short, optional self-reflection activity.

Goal of the activity:

Reflect on how different models of disability shape your attitudes, language and expectations.

a **Start by thinking about a situation** – at home, at school, in the workplace, in the community, in a service environment – where the person you help receives support or faces challenges.

b **Ask yourself how people in that environment responded to disability**:

- Do they focus mainly on your relative's limitations or medical conditions (medical model)?
- Or do they try to find ways to remove barriers and make the environment more accessible (social model)?

c **Reflect:**

- How do others treat your relative in this situation? What approach do they seem to have?
- If they have a medical approach, what might be different if the focus was on removing barriers and supporting inclusion?

A better understanding of the approach used by others (for instance, extended family, professionals and support services) helping your relative may eventually lead you to advocate on their behalf for a better quality of life.

5. Take action

To end this module, here are a few tips that can help guide your next steps:

- ✓ You may want to connect with an organisation in your country and ask about informative sessions, webinars or workshops and find out more about the rights of the person you support;
- ✓ You can ask the person you care for or other family members if they know about the different approaches to disability and you can explain it to them;
- ✓ You may want to take information one step at a time: it is normal to feel overwhelmed and you can try to focus on what is most useful for you right now.

6. Explore more

If you would like to find out more about this topic:

- More about the family dimension of the UNCRPD: in English and in French, a position paper drafted by COFACE Disability (2012);
- A series of videos developed by *Mental Health Europe* to explain the UNCRPD and some of its articles: https://www.youtube.com/playlist?list=PL-8jKPBGeZeKQjms6lQ7XpOYu1GTvRVAB;
- A family guide (developed by the organisation *Disability Belongs* in the USA) to help children and families learn and talk about disability and inclusion: Talk and Take Action: A Family Guide to Disability Inclusion.

All references mentioned in this module can be found in the bibliography, at the end of the guide.

MODULE 2:

RECOGNISING YOUR ROLE AND SKILLS IN SUPPORTING SOMEONE WITH A DISABILITY



1. Description of the module

This module was designed to help you recognise and value the skills, knowledge and strengths developed through supporting a family member with a disability. It encourages reflection on family care through lived experience while also focusing on self-awareness and self-identification. Through this module, you will improve your capacity to acknowledge and value the competences you have acquired through family care and start recognising some of your needs.

After reading this module, you may be better able to:

- Understand the various roles you are playing;
- Recognise some of the key competences and skills you have developed through providing support;
- Apply this knowledge to reflect on your own experiences and advocate for the value of the family care you provide.

Reading this module and completing the activity may take about 30 minutes. You can focus on the sections you find the most relevant and return to others later if you are more comfortable with that.

→ This module is meant to help you recognise your abilities. Every day you do things to support a family member with a disability (whether it small or big things) which give you abilities that are important to recognise whether you label yourself as a family carer or not.



2. Key information on your caregiving strengths

The *European Charter for Family Carers*, developed by COFACE Disability in 2005 and revised in 2024, recognises the important role of persons who provide unpaid care to a relative or close ones. It highlights carers' rights and challenges, as well as stresses that caring should always be a personal choice.


EUROPEAN CHARTER FOR FAMILY CARERS

Updated!

EUROPEAN CHARTER FOR FAMILY CARERS

What is the European Charter for Family carers?

It is a rights-based tool developed by family carers to recognise and support carers across Europe.

By COFACE Disability, in 2005 (updated in 2024).

Key points to know about the Charter:

Who it covers

People providing unpaid care to relatives or close ones due to disability, illness, ageing or other long-term needs.

Objective of the Charter

Formally ensure recognition of family carers in all their diversity and acknowledge the challenges they face.

Challenges highlighted

Physical, mental, economic and social burdens, including care-related isolation, interrupted careers, poverty risk and health strain.

Rights and measures to be put in place for family carers

Social protection, income support, pension rights, access to health and long-term care services, legal recognition in national systems.

Important principle

Recognition should not trap someone in a carer role.



"Family carers should always have the opportunity to decide whether to fulfil caring duties or not, full-time or part-time, and to reconcile with their work and personal life. Such choices for both the caregivers and care receivers must be free, informed, and open to reassessment". European Charter for Family Carers, Article 2 'Choice of family carer'.

You may find that, sometimes, in certain national or European policy documents, family carers can be referred to as:

- 'Informal carers' (as stated in the European Union's Care Strategy adopted in 2022);
- 'Unpaid family carers' (as stated in the International Labour Organisation's 2024 Resolution on decent work).

Why is it important for you to know?

- Family carers should be seen as right holders, not invisible or purely private actors in care.
- While some people become family carers because, for a variety of reasons, there is no other option available to them or their family, taking on caring responsibilities should, wherever possible, be a choice made by the individuals themselves. Recognition as a family carer should not trap someone in the caring role or define them by it.

Recognising your role as a family carer matters

Supporting someone with a disability means wearing many 'hats'.

In Belgium, *Ouders voor Inclusie*, an organisation run by and for parents of children with disabilities, organises an annual Inclusion Day for parents. For 2026, they chose the theme of the 'Millipede' to show all the roles parents play when supporting their child with a disability.

> ***"It shows how many roles we are playing and it helps us recognise everything we do as parents. You take care of finances, attend meetings, defend your child's needs, and you also become the taxi driver. You do so many things. You have to realise how much you're actually doing".*** Mother of a child with a disability (Belgium).

But why does it matter to acknowledge your roles and competences as a family carer?

Understanding the many hats you wear and the skills you develop can help you:

- Be aware of your strengths:
  You are building valuable competences such as organisation, problem-solving, communication, advocacy, etc.
- Access support and resources:
  Some European countries provide specific rights, services and support programmes for family carers, as do certain NGOs and national associations. Do you know any of them in your country?
- Take care of yourself:
  Being aware of your responsibilities helps you balance support for others with your own wellbeing.
- Build confidence and opportunities:
  Recognising your skills can improve self-confidence, relieve some stress and also open opportunities – a lot of the skills you are already using can be used in different sectors such as: education, work, volunteering – either building on the skills you already have for a specific action or sharing your knowledge with others.
- Communicate your role:
  Having a clear understanding of what you achieve through family care gives you the words to explain it to others, namely extended family, professionals or teachers.

Can you think of the different hats you wear as a family carer? Maybe you help with daily tasks (e.g. helping the person you care for eat or dress), you give emotional support, you plan and coordinate care and appointments, you drive your family member to various services, etc.

Why does acknowledging your role and competences matter?

Recognition affirms your rights and your place in society:

- You maintain your original relationship: it means that you remain a parent, spouse, sibling, child, friend, not only a carer;
- You stay connected to society: your identity is not reduced to your caregiving role. Consider other skills you have been developing as a family carer that can be useful to you in other settings.

3. Case study: thinking about competences in practice

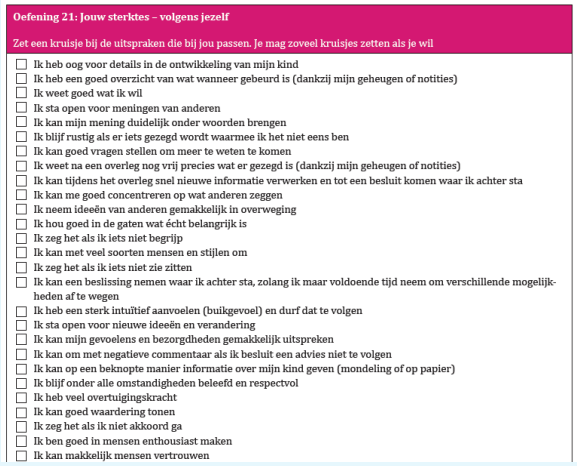
In Flanders (Belgium), *Magenta* is a project run by and for parents of children with additional support needs. It offers workshops to support parents of children and young people with disabilities aged 0 to 25.

A key feature of these workshops is that they are facilitated by experienced parents. Their lived experience helps them share practical advice and encouragement.

During workshops, *Magenta* uses simple tools such as checklists and reflection exercises to help parents:

- Identify some key competences they have developed;
- Reflect on what works well in their caring role;
- Recognise where they might need additional support and what might block them from asking for support.

This kind of reflection helps parents realise the valuable competences they already use in their daily lives. Besides, the group atmosphere can help learn from other peers and share practical, personal experiences.



Oefening 21: Jouw sterktes – volgens jezelf

Zet een kruisje bij de uitspraken die bij jou passen. Je mag zoveel kruisjes zetten als je wil

- ☐ Ik heb oog voor details in de ontwikkeling van mijn kind
- ☐ Ik heb een goed overzicht van wat wanneer gebeurd is (dankzij mijn geheugen of notities)
- ☐ Ik weet goed wat ik wil
- ☐ Ik sta open voor meningen van anderen
- ☐ Ik kan mijn mening duidelijk onder woorden brengen
- ☐ Ik blijf rustig als er iets gezegd wordt waarmee ik het niet eens ben
- ☐ Ik kan goed vragen stellen om meer te weten te komen
- ☐ Ik weet na een overleg nog vrij precies wat er gezegd is (dankzij mijn geheugen of notities)
- ☐ Ik kan tijdens het overleg snel nieuwe informatie verwerken en tot een besluit komen waar ik achter sta
- ☐ Ik kan me goed concentreren op wat anderen zeggen
- ☐ Ik neem ideeën van anderen gemakkelijk in overweging
- ☐ Ik hou goed in de gaten wat écht belangrijk is
- ☐ Ik zeg het als ik iets niet begrijp
- ☐ Ik kan met veel soorten mensen en stijlen om
- ☐ Ik zeg het als ik iets niet zie zitten
- ☐ Ik kan een beslissing nemen waar ik achter sta, zolang ik maar voldoende tijd neem om verschillende mogelijkheden af te wegen
- ☐ Ik heb een sterk intuïtief aanvoelen (buikgevoel) en durf dat te volgen
- ☐ Ik sta open voor nieuwe ideeën en verandering
- ☐ Ik kan mijn gevoelens en bezorgdheden gemakkelijk uitspreken
- ☐ Ik kan om met negatieve commentaar als ik besluit een advies niet te volgen
- ☐ Ik kan op een beknopte manier informatie over mijn kind geven (mondeling of op papier)
- ☐ Ik blijf onder alle omstandigheden beleefd en respectvol
- ☐ Ik heb veel overtuigingskracht
- ☐ Ik kan goed waardering tonen
- ☐ Ik zeg het als ik niet akkoord ga
- ☐ Ik ben goed in mensen enthousiast maken
- ☐ Ik kan makkelijk mensen vertrouwen

You can click here to see one of these exercises which invites parents to go through a checklist of strengths, selecting the skills that apply to them and discussing them with other parents.

Reflecting on this case study

Taking time to reflect on everyday experiences can help reveal some of the many skills and competences you have been developing through supporting a relative with a disability.

4. Activity: looking at your competences

We now invite you to dive into a short, optional self-reflection activity.

Goal of the activity:

Reflect on the competences you develop and use through your family caring role.

Examples of skills you develop and put into practice in your role as a family carer.

Action taken	Skill	What I learned
I had to explain my family member's situation to professionals.	Communication.	Ability to explain complex situations and advocate for my relative.
I manage and coordinate my family member's appointments and schedules.	Multi-stakeholder organisation and coordination.	Ability to coordinate people, services and information.
I support my relative during a difficult emotional time.	Listening and emotional support.	Empathy and relational skills.
I went through some very stressful times but I kept a cool head.	Stress management.	Resilience and problem-solving.
I support my relative with their meals and washing themselves.	Care, hygiene, emotional support.	Ability to provide practical help while maintaining dignity and building relational skills.
I support my relative with first aid and taking medication.	Rigour, knowledge of protocol, technical skills.	Responsibility and attention to detail.

Your turn now! What skills in other situations might you be developing without even realising it?

To go further:

Think about how you might use some of these skills in other situations: at work, at school, in your community. For example, you could:

- Rethink the balance between your work and your family life: make time for your own needs and wellbeing;
- Remain active with the labour market: through work, volunteering or part-time opportunities;
- Further develop your competences: explore training, certification or learn something new;
- Create a project at your own rhythm: apply your organisational and problem-solving skills in flexible ways.

5. Take action

To end this module, here are a few tips that can help guide your next steps:

- ✓ You are not defined by your role as a carer: you are a person with competences and rights;
- ✓ You have a wide range of competences acquired through family care and these are great strengths you can use;
- ✓ You can transfer your abilities to another context: they are useful in many areas of life!

6. Explore more

If you would like to find out more about this topic:

- *European Charter for Family Carers* in English and in French, and in English Easy-to-Read language, developed by COFACE Disability (2024 revised version);
- Online resources on balancing care, work and life developed by *Magenta*, in Dutch;
- E-learning resource "A capable carer" developed by *Association Française des Aidants* on the competences developed as a family carer and what you can do with them in other settings. It is available in French.

All references mentioned in this module can be found in the bibliography, at the end of the guide.

MODULE 3:

NAVIGATING PERSONAL CHALLENGES AND PRACTICING SELF-CARE



1. Description of the module

While in the previous module you focused on recognising your role and competences as a family carer, we invite you, in this module, to acknowledge your own needs. It is essential to reconnect with yourself, and we hope this module will gently help you do so. For parents, it is especially important to be aware of your own state and to face your situation when, for any reason (such as divorce or bereavement), you find yourself alone as a parent or a caregiver.

This module explores everyday challenges faced by family carers and introduces some practical self-care strategies. You will be encouraged to reflect on your needs and see self-care as an essential part of your caregiving journey. It covers topics without taboos, including difficult or unspoken emotions.

After reading this module, you may be better able to:

- Acknowledge that your emotions and thoughts are valid and not a sign of weakness;
- Set boundaries to protect your physical and mental health;
- Feel empowered to care for yourself while also taking care of your relative.

Reading this module and completing the activity may take about 30 minutes. You can focus on the sections you find the most relevant and return to others later if you are more comfortable with that.

→ A gentle warning: this module may cover emotionally challenging topics. You can choose to skip parts of or the entire module if you do not feel ready. Please keep in mind that the content of this module does not replace professional psychological support.



2. Key information on wellbeing and self-care

Some family carers can derive positive elements from the care they provide to a person with a disability. Perhaps you may recognise some of these positive experiences:

- A sense of making a difference in someone's life;
- Satisfaction in knowing your relative is receiving good care;
- A stronger bond and connection with the person you support.

If you experience any of these positive experiences, you may find that it helps you cope with stressful situations.

> ***"Today the guilt is a bit less because I know that I have tried my best and I am still trying my best to ensure my son has everything he is entitled to and deserves."*** Mother of an adult with a disability (Malta).

The challenges and risks of caregiving

Caring for a family member or a close relative can be deeply meaningful but it can also bring significant challenges. A lot of family carers provide support with limited assistance from services or professionals which can then lead to stress and exhaustion. It is still the case in many European countries that family carers and their relatives with a disability lack access to support services.

The impact of caring can be physical, emotional and social. For example, you may have already experienced one or several of the following:

- Physical strain such as lack of sleep, chronic fatigue or muscle pain;
- Emotional stress, including anxiety, feeling overwhelmed and depression;
- Social isolation when caregiving tasks leave little time for connections with friends, work, or personal hobbies.

In addition to these, you may have noticed that you carry a heavy mental load, trying to juggle with the everyday tasks of a family carer: organising appointments, managing administrative procedures, coordinating with professionals and planning daily care. These responsibilities can gradually become overwhelming, especially in the absence of adequate professional support.

Managing care alone, especially after the loss or separation from a co-parent, can add a significant emotional burden. In these situations, seeking professional support is also important.

Naming the unspoken

You may sometimes notice that you experience thoughts and emotions that you feel you should not have. And you do not voice them because they feel taboo. These feelings are often kept silent but they are more common than a lot of people realise.

You may have already felt:

- Grief, for the life you once imagined for your family member, for your family, for yourself;
- Fear or anxiety about the future of your family member: worrying about what it will look like for them, or if they will receive the support they need when you are no longer there;
- Loneliness, especially when you feel that others (perhaps your extended family, colleagues or friends) do not fully understand your situation;
- Feeling overwhelmed: you feel like you can't take it anymore, that you can't stand this situation any longer;
- Frustration or anger toward systems and professionals that do not provide enough support. Perhaps you have also felt frustration toward the person you support because you feel they do not realise or appreciate everything you do for them;
- Jealousy or resentment when you compare your situation with others.

Does any part of this description feel familiar to you? These thoughts and feelings are totally understandable and common to a lot of family carers of persons with disabilities.

You may also experience conflicting emotions at the same time: for example, love and exhaustion, devotion and frustration. One does not exclude the other.

Why is it important for you to know?

Having these thoughts does not mean that you care less about the person you are supporting. It means that you bear great responsibility.

"You have a cocktail of emotions. I think we need to normalise. That's how you feel and you're not alone. Other people feel the same." Mother of a child with a disability (Belgium).

When your own needs become invisible

Reflecting upon your thoughts and feelings may make you realise you have become invisible to yourself. Over time, a lot of family carers become so focused on supporting their relative that their own needs seem to fade.

When you enter a 'survival mode' where the priority is always on others, it can be hard to pause and ask yourself: "What do I need right now?". The question can even start to feel distant.

Now let's look at ways to support yourself.

Rediscovering self-care

Self-care does not mean you are adding more tasks, it means trying to notice yourself in small ways.

Self-care can look like this:

- You take a few minutes to have a coffee or tea and not do anything else at the same time.
- You pause to notice how you feel: it could be an emotion, a thought or noticing something in your body.

It is about where you are right now, rather than where you think you should be.

That said, keep in mind that self-care looks different for everyone: it can vary depending on culture, traditions and habits. It can also be community care where you ask for help, you share responsibilities and you connect with supportive people.

"It can often be difficult to say to yourself, 'No, I can't do anything else, I don't have any more time, I'm a single mother and I have my children full-time, etc.' In fact, by going through something like this where you break things down, you realise that even small things are within your reach."

Family carer for several family members with disabilities (France).



How you can reconnect with your needs

When you focus on someone else's needs, recognising your own needs can feel hard. You can start with small steps:

1. Check in with your body: are you tired, hungry, thirsty, tense? What could help right now in the next few minutes?
2. Notice signals: if you feel withdrawn or emotional, it can indicate that some of your needs are unmet.

Do not worry about solving everything at once, you can just pay attention to one small need at a time.

Why is it important for you to know?

Caring for yourself does not take away from the person you support.

Think about the oxygen mask on the plane: when it drops in the cabin, you are instructed to first put it on yourself so you can then help others, right? Why not try and do the same with self-care? Caring for yourself first means you will be able to better support others.

3. Case study: Self-assessment scale



Unapei, a French, parent-led network advocating for the rights and support of persons with intellectual disabilities and their families, has designed a self-assessment tool to support family carers reflect upon their wellbeing. It is meant as an awareness and prevention instrument.

This tool, which takes the form of a scale, can help you reflect on how your caring responsibilities affect your life and wellbeing.

I still have time for myself. Helping my loved one(s) is not really a burden because …	• I can be away (for a few hours, a few days) • I can see my friends and family • I know that my relative can be independent at times • I can do activities outside my home • I can share activities with the person I care for
I'm beginning to feel overwhelmed. There are risks for my physical and mental health when …	• I help my relative but it is becoming a real burden • I feel guilty when I'm not around the person I care for • I'm not sure whether to invite people at home • I need to adjust my schedule (work, leisure, etc.) • I lfeel overwhelmed
I need to actively seek help I put myself in danger when …	• I can no longer take care of myself • I no longer dare to leave my relative alone • I absolutely need support • I no longer have a social life • I can't cope anymore

Figure 3 Translated version of Unapei's Aidantomètre

Do not worry about solving everything at once, you can just pay attention to one small need at a time.

You find yourself in the green zone and notice that you feel balanced, still having some time for yourself.

Key tip: that is great and we can only encourage you to keep maintaining this balance and focus on what works well.

You find yourself in the orange zone and realise that you start feeling overwhelmed.

Key tip: perhaps you can start exploring respite services and support options in your community.

You place yourself in the red zone because you are struggling and you feel a high caregiving burden.

Key tip: here it is important to ask for professional support and actively protect your health.

Reflecting on this case study:

This scale is not a test, and there are no right or wrong answers. It is simply meant to help you notice how your caregiving responsibilities affect your life and wellbeing. Small awareness is already a key step toward caring for yourself.

4. Activity: taking small steps for yourself

We now invite you to dive into a short, optional self-reflection activity.

Goal of the activity:

Reflect on your needs, dreams and practical ways to care for yourself.
You can use these 5 questions to guide your reflection:

1. **What would you dream of doing if there were no limits or constraints?**
   - Don't be afraid to dream big, this is where you don't have to be realistic.
   For instance: *"I would like to go away for the weekend, just by myself".*

2. **What would you like to do that would be more realistic?**
   - Here something smaller, an achievable step that you could perhaps take toward that dream.
   For instance: *"I could start with a short half a day trip somewhere nearby"*.

3. **What are you going to do?**
   - You can plan a small action and think about what you will do in the next days or week, to make it more realistic.
   For instance: *"I will plan a two-hour outing next Sunday morning"*.

4. **Identify two things that would prevent you from doing it.**
   - This is to help you anticipate potential challenges.
   For instance: *"I might feel guilty for leaving my relative."*

5. **How will you react if these things happen?**
   - Think about how you could respond and adapt if these challenges happened.
   For instance: *"I can ask a friend or a family member to help for a few hours"*.

Here again there are no right or wrong answers, it is for you only, to help you reconnect with your needs and what you want for yourself.

This exercise, used by the French organisation *Parentraide*, helps parents of children with disabilities reflect on themselves, recognise their needs and wishes, and see that caring for themselves is possible.

"So, doing this little exercise in your head gives you little nuggets of wisdom for everyday life, allowing you to take time for yourself and stop feeling guilty about it." Family carer for several family members with disabilities (France).

5. Take action

To end this module, here are a few tips that can help guide your next steps:

- ✓ Acknowledge your feelings: feeling tired, overwhelmed is normal and it does not mean you care less;
- ✓ Take small, consistent steps: you do not have to start with big things, even brief moments of self-care, like a walk in the park, or enjoying a warm cup of tea or coffee;
- ✓ Reach out for support: you can connect with family, friends, professionals or community resources. You don't have to do everything alone: sharing the care is also beneficial for the person you support.

6. Explore more

If you would like to find out more about this topic:

- *SupportCare*, an EU-funded project, has developed several resources for family carers: Results – SupportCARE;
- Short media resources on self-care and wellbeing by the *University of Edinburgh*, in English;
- Short e-learning course available for free on carers' health prevention, by *La Compagnie des Aidants*, in French.

All references mentioned in this module can be found in the bibliography, at the end of the guide.

MODULE 4:

ENGAGING WITH THE COMMUNITY



1. Description of the module

While self-care helps you reconnect with yourself, community connections can help you feel supported and less lonely. This module encourages family carers to reflect on the importance of maintaining and building relationships within their wider community, including family, friends, peers and support networks. It explores how social connections can provide emotional support, shared understanding and practical help, while also acknowledging some of the barriers family carers face in staying connected.

You will be invited to reflect on the relationships that already support you, explore opportunities to connect with others and think about ways to strengthen your sense of belonging.

After reading this module, you may be better able to:

- Recognise the value of peer support and community networks for family carers;
- Identify opportunities to connect with others and access local or online resources;
- Reflect on how sharing experiences with others can strengthen wellbeing and caregiving skills.

Reading this module and completing the activity may take about 30 minutes. You can focus on the sections you find the most relevant and return to others later if you are more comfortable with that.

2. Key information on peer support and community

Peer support can occur before, after, or alongside professional support. It is neither mandatory nor a solution to everything, but it can be seen as a shared human space where new connections are made.

Why connecting with others matters

Family carers often need different types of support, such as training, counselling, information, financial help or access to respite services. Peer support is sometimes overlooked yet very valuable. Indeed, connecting with others who understand your experience can help you feel supported, less lonely in your caregiving.

> ***"Also the physical meeting with peers, with people who understand, it's also something that gives a boost of energy".***
> Professional working with family carers (Belgium).

Is there a type of support that makes you feel less alone?

Did you know?

American studies and research have shown that family carers who connect with others in similar situations can:

- Feel less alone and better understood;
- Gain practical ideas for coping and caring;
- Build confidence in their caregiving skills.

Peer support works because peers who have experienced the same can offer greater understanding and encouragement that is hard to find somewhere else.

What peer support looks like in practice

Peer support can take many forms. It does not necessarily take place within a formal support group.

It can happen in your everyday life, for example:

- During brief conversations at the supermarket, at the school gates, in a park or in the waiting room of an appointment;
- In online chats or social media groups for parents, family carers, etc.;
- In community meetings or workshops;
- Or in organised support groups led by/ for other family carers.

Would you see yourself talking with other family carers in online chats or social media groups? In Flanders (Belgium), for example, *Zorgtvooronsmoeder vzw* has set up a system of temporary chat where you can connect online and chat with a group of 5 other family carers you do not know, for a month. And, every month, you can connect with a new small group of family carers. It is designed as a safe place for parents and siblings of children with disabilities to get to know each other and share experiences.

You can check more information here in Dutch (or use automatic translation to access it in your preferred language): #ZV♡MCHAT - Zorgtvooronsmoeder vzw



Why peer support helps

Peer support does not solely consist in talking about feelings, it helps you connect, learn and share. Here is what you can expect from it:

- A safe, non-judgmental space to share your thoughts and feelings;
- Some practical advice and tips on caregiving and navigating services (for instance school, workplace, support services, medical services, etc.);
- A place to also support others: maybe you have tips and experiences that can contribute to other family carers' journey and wellbeing. This ultimately also strengthens your own confidence;
- Opportunities to build meaningful friendships.

Reading this, can you think of any other carers you could connect with?

> ***"We can understand each other and we don't need to go into all those details. We don't have to feel as though we need to make people pity us to understand us."*** Mother of an adult with a disability (Malta).

About support groups

The most important feature of support groups is that they allow you to focus on yourself rather than on the person you support. It is a place designed for you and welcoming you, putting your needs first.

Do you remember the allusion to the oxygen mask on the plane in module 3? It is the same philosophy here: when the oxygen mask drops in an airplane cabin, you always put on your own mask first before helping those who might need you.



Reaching out is not always easy

Wanting support from others and connection is natural, but family carers may face barriers in doing so. Stigma, fear of judgement, lack of information, limited time, low confidence or logistic challenges like transport or internet access can make it hard to ask for help.

Yet, there is support available in many ways, and finding the right connections can bring relief. Who in your life or community can you reach out to for support?

In reality

Sometimes family is not a source of support: some family members may distance themselves from the person you are supporting. When this happens, the family circle becomes a source of stress rather than comfort. Know that this is understandably painful and unfair

If you are confronted with this situation, you could consider the following approaches:

- You can try to raise awareness on disability and convince them to be inclusive;
- You can stop trying to convince them and instead take a step back from unsupportive family members, to protect yourself and your relative;
- You can turn to a "chosen family", building your own support circle made of friends, peers, other family carers or professionals who respect and support both you and the person you care for.

"Because sometimes even family doesn't understand. So, when you have friends who understand and support you, or other peers you can talk to and connect with, it helps. Even if you are talking with other parents you do not know personally through a WhatsApp network group, it is a place where we can just talk and find understanding, advice and inspiration." Mother of a child with a disability (Belgium).



3. Case study: parents becoming peer supporters and experts

APF France Handicap, one of the largest French organisations representing and advocating for the rights of persons with disabilities and their families, has developed a peer support programme called RePairs Aidants. It runs awareness-raising and training sessions, both online and in-person, and open to everyone: parents, spouses, siblings, etc.

It enables family carers to be trained to provide peer support to other carers.

All training sessions are co-facilitated by a qualified professional and a family carer who has received prior training. This is a great example of peer support.

The topics covered in the sessions vary greatly:

- Carer wellbeing, rights and self-care;
- Balancing family, social & professional life;
- Collaborating with support professionals;
- Practical care skills;
- Emotional support, grief & end-of-life care.

This is an example of peer support that works in various ways:

- You can join as a family carer to share your experiences if you want to, or simply benefit from the experiences, knowledge and tips of others;
- Or you can decide to take an extra step and upscale the knowledge and competences you have developed as a family carer and share it with peers as a co-facilitator.

Reflecting on this case study:

Looking at this example, can you think of similar spaces close to you? Would you consider joining one of them? Or even would you consider becoming a peer support expert and co-facilitating such a session?

4. Activity: Find one door

We now invite you to dive into a short, optional self-reflection activity.

Goal of the activity:

Reflect on your needs, dreams and practical ways to care for yourself.

Support often begins by asking the first person or the first place you already trust. Can you already think of someone?

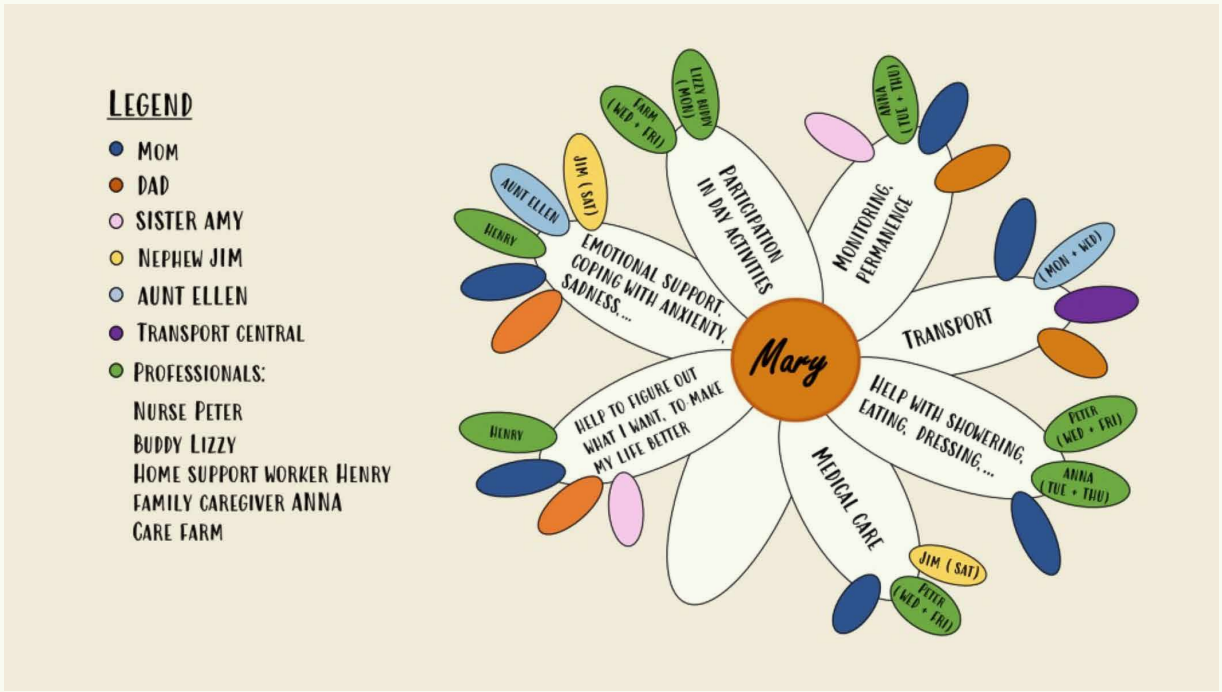
To help you, read the list below and pick one place that feels easiest or most familiar. Don't worry, you don't have to contact them today:

- A local disability organisation or association
- A health or social worker you already know
- A school, health centre or community centre
- A faith-based or cultural group
- An online group of family carers

Then complete this sentence with your own words: "One place I could ask about carer support is: _____".

This is meant to help you identify one safe entry point to peer support that you could start with when you are ready. You can simply start by asking for information and then let yourself be guided

Alternatively, if you would like to put it down on paper, you can use this template to map your community, where you know you can already seek support.



See here the example designed by Magenta, a Belgian organisation. Here is how we suggest you use the template:

- In the large petals, you can write down the type of support you receive and/or your family member receives.
- In the small petals, you can write down the names of people or groups that provide this support.

This is meant to help you recognise existing support and see that you are not starting from zero.

5. Take action

To end this module, here are a few tips that can help guide your next steps:

- ✓ Start with the connections you already have: you do not have to dive straight into formal peer support groups, you can start with a conversation with another carer, an online group, it can already make a difference;
- ✓ Take one simple step at a time: asking for information, joining an online discussion or attending a local event can be a first step towards building more supportive connections;
- ✓ Remember that sharing helps everyone: when you connect with others, it can bring understanding and practical ideas for yourself but also for the others. You are not alone.

6. Explore more

If you would like to find out more about this topic:

- The *National Parents Society of Persons with Disability* in Malta are a community of parents where members are both beneficiaries and active contributors in sustaining peer support. They launched in 2026 psychosocial support groups specifically for couples as disability is not experienced in isolation;
- *Genitori Tosti,* an Italian association of families with children with disabilities, advocating for the rights of family carers in Italy. Some of the parents have become engaged activists and advocates;
- The Hungarian organisation *Single Parents Centre*, in Budapest, provides support to single parents of children with disabilities. Its development centre, "StarLight Hub", provides both special education for children and support for parents.

All references mentioned in this module can be found in the bibliography, at the end of the guide.

LOOKING AHEAD

Being a family carer is a unique and personal journey. Through this guide you have explored different aspects of that journey.

Keep in mind that there is no single way to be a family carer: your experience and your feelings are your own. Remember that your role is essential, that your wellbeing matters and that support comes from many places.

A final reflection: if you had a nugget of wisdom to share?

Before we send you off, we invite you to take one more minute to reflect.

You have gained knowledge through your experiences, and your insights can help others who are on a similar journey.

- Think about one thing you have learned as a family carer that might help someone;
- Keep it to yourself, share it with another carer or post it in an online group when you feel ready.

We hope this guide has helped you inform yourself, celebrate your strengths, honour your needs and surround yourself with supportive people and communities.

Most of all, you are not alone. You are seen and valued.



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L.I.N.K. (**L**earning and **I**nnovating through **N**ew **K**nowledge) is an education and training programme for lifelong learning on social rights from a whole-family perspective. It offers educational tools and resources based on values of human rights, non-discrimination, gender equality, social inclusion, diversity, empowerment and intergenerational solidarity. The tools and resources are designed for contributing to addressing important challenges that modern families face.

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Access to a free interactive version



https://education-hub.kmop.org/courses/supporting-a-relative-with-a-disability/

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KINDLING A BETTER WORLD

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