

PROJECT "AFTER US"



ABOUT PARTING

“Parting is how much we know of heaven and how much we know of hell”
Emily Dickinson

In the natural history of the development of the human child, there is a silent but continuous and daily practice of breaking free from dependence on parents. None of these stories is without pain, without hindrances. And without failures. This is the story of becoming adults, autonomous and independent, and above all, continuers of the species. This is one way to interpret the biblical admonition “...for this reason man will leave his father and mother...” Gen.2-24



One of the most painful declinations of the story of ‘disabled’ humans consists in the eternalization of the need for parental dependence and care. From the earliest stages of the ‘disabled’ child’s life, the parent wields the ghost of his or her eternal need and the child’s fate when he or she is gone. There is no separation. There is no release.

Separations are always difficult and potentially painful, but in the case of ‘disabled’ people and their parents, separations, whether for a week or forever, are doubly problematic. Accompanying people with disabilities and their parents in processing this difficulty is an important task of the care professions.

To come into the world is an act of separation. To leave the world is to separate oneself. To live, on closer inspection, is to perpetually separate oneself from the previous moment that will never return. To separate forever is, inadvertently, an act so everyday and so ordinary that it is hard to understand why it is ultimately so tremendous, so solemn, so threatening to the human soul.

Proof of this lies in the fact that, as soon as they come into the world, the human child does nothing more than work hard to secure what the famous psychoanalyst John Bowlby (1907–1990), the father of attachment theory, called a secure base, i.e. the presence of an adult who is always present or at least available to make them safe. Safe from what? From being separated, which is both the great nightmare and one’s destiny. Let us reiterate: the story of the human child in their first 15–16 years, but on closer inspection the story of life as a whole, is a story about leaving, about separating, about taking leave.

The story of taking leave of parental figures is the premise for preparing oneself for all the separations that life proposes, from the most dreadful and atrocious, the mournful ones, to those of love, work, residential, up to the filial ones that are the replication experienced from the side of parents and not from that of children. The whole of life can thus be read as a continuous and incessant succession of an Easter triduum of death and resurrection, death and resurrection...

All the conditions that get in the way of this delicate journey of the first decades of life unfortunately promise a complication of this path and thus pain. Intellectual disability and all traumatic vicissitudes in general have the capacity to make this path full of pitfalls and hindrances. And this must be very clear and known to anyone applying for a life of caring for people with these characteristics.

Let us now try to retrace some stages of that path where one learns at one's own expense and on one's own body the pain of separation.

According to the thought of the Dutch anatomist Lodewijk Bolk (1866–1930), the birth of the human being would be a non-lethal abortive birth. How are we to understand the meaning of this alienating expression? We are helped by the Italian philosopher Enzo Melandri (1926–1993) who clarifies it as follows: “Man is born while still being a fetus. He would be incapable of survival without that substitute for the placenta which is the care society takes of him. (...) He must complete in the womb of civilisation that process of maturation which the lower species have largely already acquired as soon as they see the light’.

To put it another way: all animal species have an instinctual endowment that programs attachment and the early stages of life, the subsequent weaning and release in an automatic manner. A baby human being, on the other hand, while needing the presence, like other animals, of the secure base represented by maternal care, enters immediately into a linguistic dynamic for which it is necessary to learn to understand and be understood. So much for the instinct to automatically understand a dog and its puppy! The human's mother must not only feed but must interpret, understand and be understood. And above all, be there. This all-human complication will be decisive in explaining why what for a dog is so simple and natural, for a human can become a passage of immense pain. An immense pain that will be unique and typical for every human in the world with its own history and resources.



Initially, Bowlby's insights aroused a particularly hostile reaction precisely because he was accused of being 'too much of an ethologist', an accusation legitimized by the fact that his theories were based on the animal models of the Austrian ethologist Konrad Lorenz: Humans, like ducks, with their characteristic and slavish following of their mothers, have an innate predisposition in early life to remain attached to their secure base and not to separate from it. Initially, psychoanalysis was horrified by this wholly ethological, i.e. wholly animal and hardly psychological, insight into attachment, which seemed to contradict the research and discoveries of the founding master of psychoanalysis, Sigmund Freud.

On the subject of separations and reunions, one can read in Freud's writings a delightful and famous little story in which the founding father of psychoanalysis describes a game he had seen his grandson play. The grandson would accompany this practice by making two sounds in German: 'fort' and then 'da' whose translation is 'away' and 'here'. For Freud, this game allowed the grandchild to stage and in some way exorcise the absence of his mother and her subsequent return.

In short, it seems that the parental challenge consists precisely in the feat of alternating with wisdom, measure and timeliness, presence and absence, in the hope of cultivating in the filial generation an emotionality capable of help and presence and at the same time capable of separating and being on one's own, even if only by playing with a spool of string!

Some psychoanalysts have taken up Bowlby's insights and have studied and formalized the attachment styles of the human infant and the consequent ability to separate from reference figures. In concert with these studies, they have also studied the attachment profile of parental figures.

But there is a non-experimental and extremely common place where children separate from their parents on a daily basis: it is the hallways and entrances of kindergartens from 8 to 9 a.m. Here, endless repetitions of separations are staged daily, which obviously change as the relationship evolves.

These suggestions about separating and reuniting have allowed us to identify a focus on an emotional life set-up. It is important to emphasize that the separations that affect everyday life are only harmless replicas of the great separations: the first is that of coming into the world; the other is that which awaits us at the end of the lives of loved ones. Mourning.

It is said: "Mourning must be processed!" All civilizations, from the dawn of human history and under all the skies of the world, have equipped themselves with more or less complex rituals to accompany the surviving living person and his or her community to digest, to process the tremendous incomprehensibility of death and definitive absence. To process means to give oneself peace. As we all know, this is not an easy passage. How do we help, how do we facilitate, how do we train for this? This is the great challenge of life and, above all, of any parenting program.

We could say in a nutshell that the way in which this device, the processing of grief, comes into operation is made up of acts and words. Those who mourn need closeness, presence, rituals, stories and daily acts that force the suffering person to reformulate ties with the life that continues. There is nothing new in these words that are linear and familiar to humans but become painful when the experience of mourning occurs. When mourning and separation affect the world of intellectual disability, for more than one reason, it becomes complicated.

The first and most obvious is that the person with disabilities often cannot cope alone. A good definition of disability, after all, is precisely this: not being able to cope on one's own. It is evident that there is a gradient of severity of this incompetence, ranging from absolute dependence, in all areas of life, on human and technological aids, to only nuanced incompetence. But make no mistake: it is not necessarily the case that people with a greater impairment of autonomy have more difficulty with separation.

"It is not necessarily so" is the expression that best introduces and sets up the problem of managing and enabling the ability to separate of persons with intellectual disabilities and their relatives. "It is not said", as we shall see in a moment, means that there is no fixed rule.

The second complication is the fact that parents have always been accustomed to an omnipresent and substitutive bond that, in the face of separation, becomes fusion-like and desperate supported by the more or less clandestine idea that sounds like this: 'only I know and can...'. One can see how this style brings with it desperate and catastrophic experiences that make all separative practices more and more difficult.

A third complication is due to the fact that, however much study and knowledge on bereavement and separation has filled university libraries, the management of bereavement and separation in the world of intellectual disability always and inexorably presents only individual cases that are only the same. Family biographies are always very specific and, above all, the resources available in linguistic and affective terms for each person with an intellectual disability require continuous interpretative effort. All this is to say that, while there is a need to study the basic psychological elements for accompanying separation and bereavement, there is and always will be a lack of a real 'how-to'.

Families of people with disabilities need special support to deal with and manage the emotional, psychological and organizational aspects. Counseling is the word that defines, in the lexicon of rehabilitation facilities, the practices of meeting, planning support, and sharing that caregivers make available to families.

Counseling is a support over time and aims to accompany all age and clinical changes in the various seasons of life. The needs and challenges in the life of a child are very different from those of a young adult or an elderly person.

In our experience, the moment of counseling is an indeterminate one, both because of the themes that are always new at each meeting, even when they present themselves repetitively, and because of the situations and urgencies that each situation proposes. Despite the fact that the topics of counseling are literally infinite, as many as the challenges of life, we believe that when it comes to the topics of separation, counseling plays a decisive and irreplaceable accompanying role.



AN OPEN LETTER TO SERVICE USERS, THEIR FAMILY MEMBERS, AND SERVICE/SUPPORT PROVIDERS

One can separate for five minutes, for an hour, for a year or forever. When separation involves persons with intellectual disabilities, more careful and articulate reflection is needed. In the biography of these people always, sooner or later and for longer or shorter periods of time, there is a release from original and known places and relationships and a transition to new ones.

Whoever, in whatever capacity is involved needs accompaniment for the management of this emotional transition.

What follows is a contribution, in the form of an open and affectionate letter, to the three actors in this scene.



Dear M., dear F.,

This letter is for you and for all the people who, like you, for some reason and for some time, need to be placed in a living community or day center or are leaving for a summer holiday and are therefore about to separate from their habits, their family members, their home.

Perhaps you are separating for a fun reason such as summer holiday; perhaps because your schooling has come to an end and you therefore need to have a new commitment; perhaps because the person who has taken care of you until now has unfortunately become frail or ill or elderly or is no longer there.

We know that separating from dad, mom, brothers and sisters or from your own room and habits is not easy. We also know that it is not easy to create new relationships with people you do not know, be they companions or caregivers. There are many emotions you may feel.



You may be afraid of a situation you do not know. We know that it would be better for you to slowly get used to it but this is not always possible. You may miss the tastes and smells of your own kitchen, your own bed, your own habits; you may feel the fatigue of having to share with others attention, spaces and objects that are usually only yours. All this is normal. Fortunately, after a while you may find that things get better.

You will establish new, pleasant or even difficult relationships, you will have experiences and activities that can be fun or even complicated and boring, but you will realize that they will not be a big problem for you. You may make the pleasant discovery that even without your mom or dad or other family members, there are still other people who will take care of you and with whom you will share your days and new experiences. Patience and trust will help you with this.

Cellphones and computers will help you keep in touch and share your daily life with whoever you want, but be careful if you remain attached to your cellphone, as you risk not living your new experience to the full.

No one will take away your affections and memories and as far as possible the assistants will do everything possible to help you preserve them; they will also support you and help you and them to maintain your bond. We hope that these reflections will help you cope with this time of separation.

Dear assistant,

It is common to say that one must leave one's personal vicissitudes outside the workplace, but we know that this is never possible. It is not possible in simple manual jobs, let alone in jobs that involve a caring relationship and that involve you relationally, emotionally and affectively. When you walk through the gate of the community, the daycare center, or the outpatient clinic where you work, we know that you bring with you longings, desires, family, financial, health anxieties, and above all your personal history. Perhaps you remember your first day of kindergarten when your mother and father 'abandoned' you into the hands of the teacher. Do you remember the emotions you felt? It is possible that today a new guest makes his or her first entry into the place where you work and that teacher today is you: of a bond that is broken and one that is created, and of all the emotions that characterize this transition, let us try to talk now.

The big challenge at work is knowing how to deal with your own emotional issues and those of the other person waiting for your help. These are the big concerns: the uncertainty of the new bond you are going to make, the pain and emotions of the guest and the family member.

Who is this person? Will we understand each other? Will it be an easy relationship? Will I be able to be of help to them? This is the first and inevitable anxiety of any caring relationship. You know that time and cooperation with other practitioners will help you in this. If you are an experienced practitioner it may be easier for you but nothing is a given. Remembering that first day in kindergarten may come in handy and you will thus make your personal history a tool of empathy and knowledge. Now your task is to put yourself in the shoes of the family member and the guest and try to put them at ease. On closer inspection, you, the guest and the family have the same problem as the fox in Antoine de Saint-Exupéry's *The Little Prince*: taming each other. "What does taming mean? And the fox's answer again is something long forgotten. It means to create bonds. If you tame me, we will need each other."

To create a bond that tames, one must cultivate trust. It is necessary to be able to withstand the other's feelings and behavior: mistrust, judgment, testing, criticism. If you have learnt that the other's pain can come in infinite forms, you will know how to cope in your work.

If you have read the letters addressed to the family member and the guest, you will find a rough inventory of all the most urgent feelings they are experiencing at their first meeting with you. You have the task and the preparation to put yourself in their shoes; the reverse is not obvious.

It is known that the initial feelings of a separation and the creation of a new bond are the most critical and stormy, but usually subside with time. The work, however, does not end there. Those feelings require constant maintenance and there are two places to do that:

- the meetings with your team in which you question yourself and try not to feel alone;
- the periodic meetings, both formal and informal, with family members, which serve to welcome those feelings that in reality are never completely and never forever extinguished.

To conclude, time passes and you are now in a bond with these people. That person and those family members who were experiencing pain in separating from each other and the pain of bonding with you may now be experiencing pain in separating from you and you in separating from them. Remember the last day of kindergarten? Everyone cried that day: pupils, teachers and parents. The inexorable alternation of making bonds and tolerating separations makes for a strange game.

Dear family member,

First of all, the emotions and feelings you may experience when separating from a fragile person in your family may be very different depending on whether you are a mother, father, brother, sister or child.

In any case, whatever your family relationship, we know that separating is a delicate and painful transition. The following are some of the feelings and emotions you may experience during this time.

The most intense feeling may be worry;

Will they be able to cope without me? Will they manage to be with other people? Will they be able to cope in this or that situation? Will they eat? Will they sleep? These worries could turn upside down like a sinister game of mirrors and become: “Will they make it without me/us?”

You may encounter another feeling that has to do with guilt: “are we abandoning them for our own relief?”

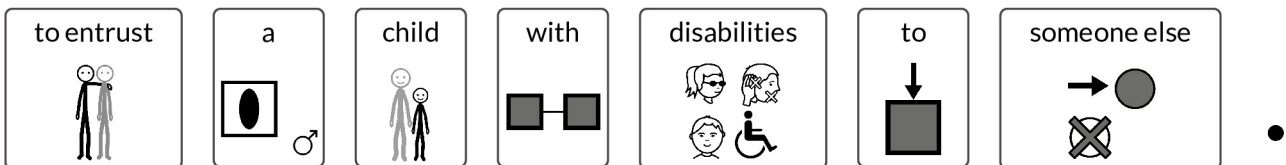
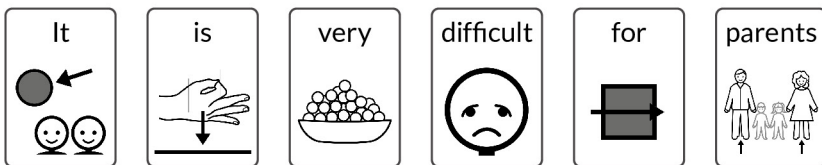
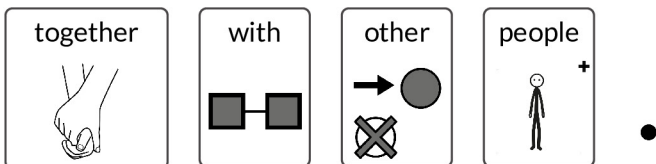
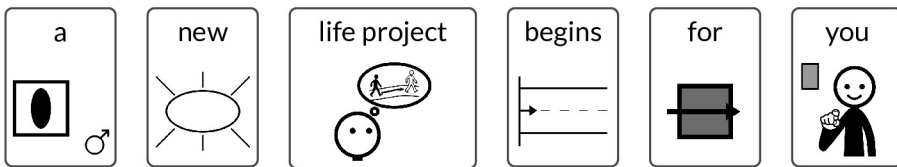
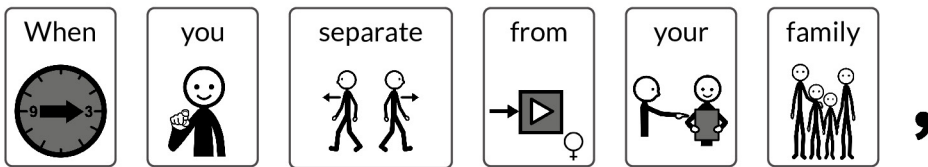
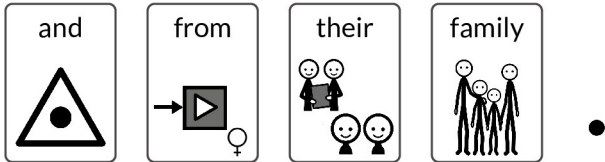
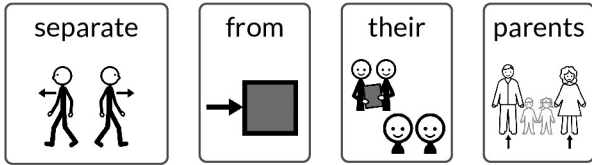
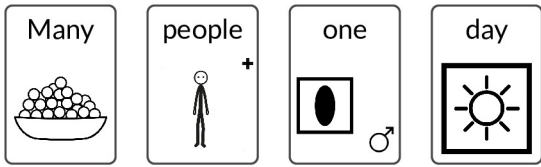
You may also feel mistrust and distrust towards people who are going to take care of your loved one: Will they be capable? Will they be trained? Will they be reliable? Will the number of carers be sufficient to guarantee the necessary attention to everyone?

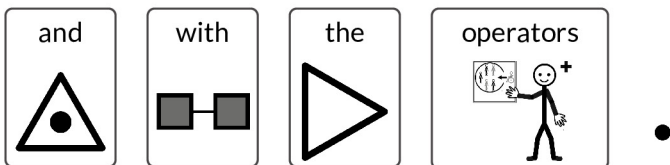
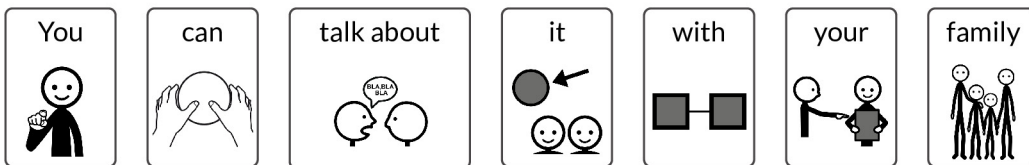
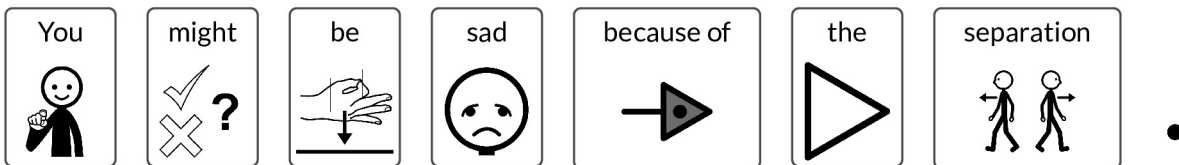
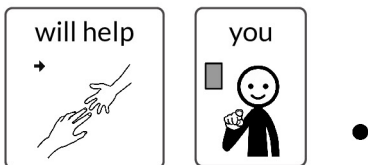
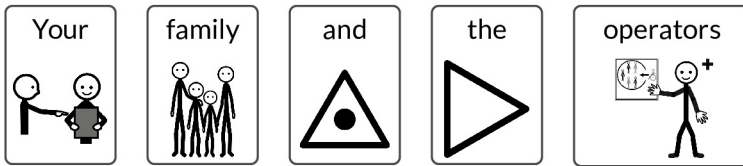
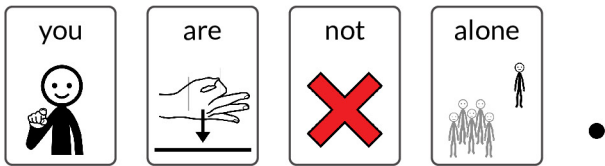
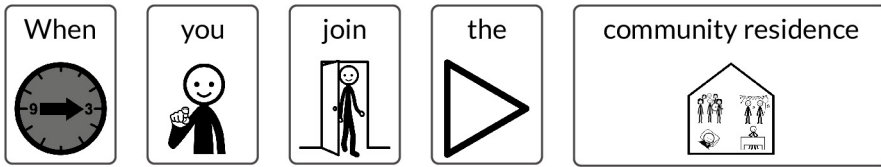
You may have the unfounded conviction that your loved one needs more attention than the others or that the severity of the others is out of proportion to the needs of your family member. Finally, you may encounter an unarticulated feeling that the caregiver has succeeded in relating to your loved one in a way that you never have.

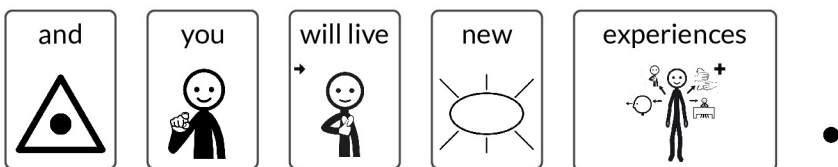
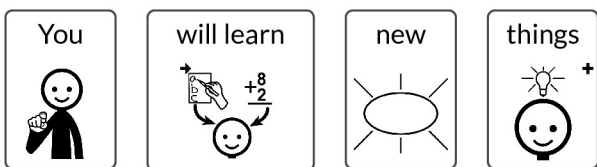
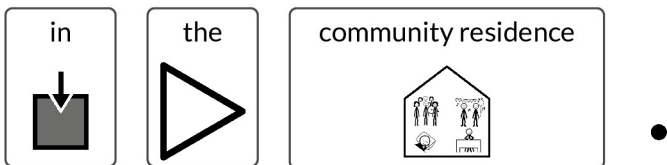
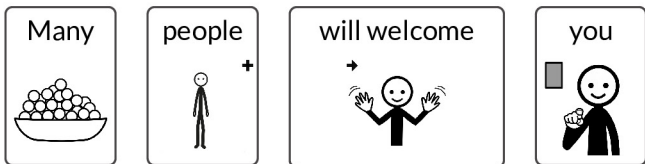
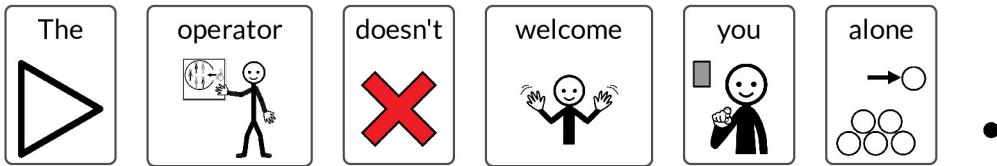
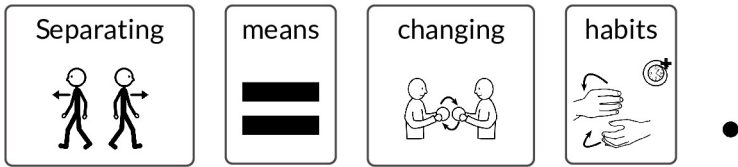
We are well aware that all these feelings are legitimate and well-founded and that they can sometimes even be confirmed by possible carelessness or shortcomings on the part of the assistants. Only time, cooperation and good, mutual communication will be able to extinguish or even soothe the intensity of these feelings and make you feel supported.

In conclusion, we would like to share a conviction that we hope will be of help to you: breaking free from the family unit, sooner or later in life, is a necessity for everyone. Even, to the extent possible, for a person with an intellectual disability. If you are willing to make this conviction your own, you will be more willing to separate from your frail family member.









KEY GUIDE LINES

- **To come into the world is to separate. To leave is to separate. To live is perpetual separating.**
- **To disengage from the upstream generation is everyone's destiny.**
- **No foster care placement is ever accomplished once and for all. It takes time, cooperation and good mutual communication.**
- **Disengagement from the family of a person with disabilities is always foster care.**
- **For a parent, entrusting their child to daycare can be a small problem in itself. Fostering a child with disabilities doubles the torment.**
- **Fostering a child is time-based. Fostering a person with disabilities is timeless.**
- **Those who are separating from a family member with disabilities must be accompanied and supported.**
- **In the helping relationship, foster care has three actors: the family, the person with disabilities, and the caregiver.**
- **The separation anxiety of a person with disabilities can be broken down, invisible, disguised. Never forget that.**
- **To separate is to change daily habits and horizons. To separate is to miss.**
- **In a story of fostering a person with disabilities, even the assistant must come to terms with his or her emotions of abandonment.**
- **Assistants, when you take in a person with disabilities remember your first day of daycare.**
- **Welcoming is never the work of an individual but of a plurality of arms of thoughts and emotions.**



L'Arche communities around the world present home, workplace and a space for socializing for people with and without intellectual disabilities. And while community living promotes independence, dignity, and community participation for people with intellectual disabilities, at the beginning, it involves a transit process of separation, which they and their families find practically and emotionally very challenging. A separation anxiety arises each time a person starts to spend time away from the family, regardless if it is a transition from the family setting to daily center activities only, or joining community living.

With this in mind, we created the project »The road to autonomy and wider inclusion for people with intellectual disabilities: Learning to cope with the separation from the family« (acronym AFTER US), which started in January 2024, and will last until December 2025. It has 3 objectives:

1. Increase the quality in the work and practices of the partners involved by providing learning opportunities to support families and adults with intellectual disabilities in the separation process that results from de-institutionalization
2. Support the inclusion of people with intellectual disabilities and their
3. Improve the cooperation among Europe-based organisations in addressing common needs and priorities related to ensuring independent and decent living for adult people with intellectual disabilities

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