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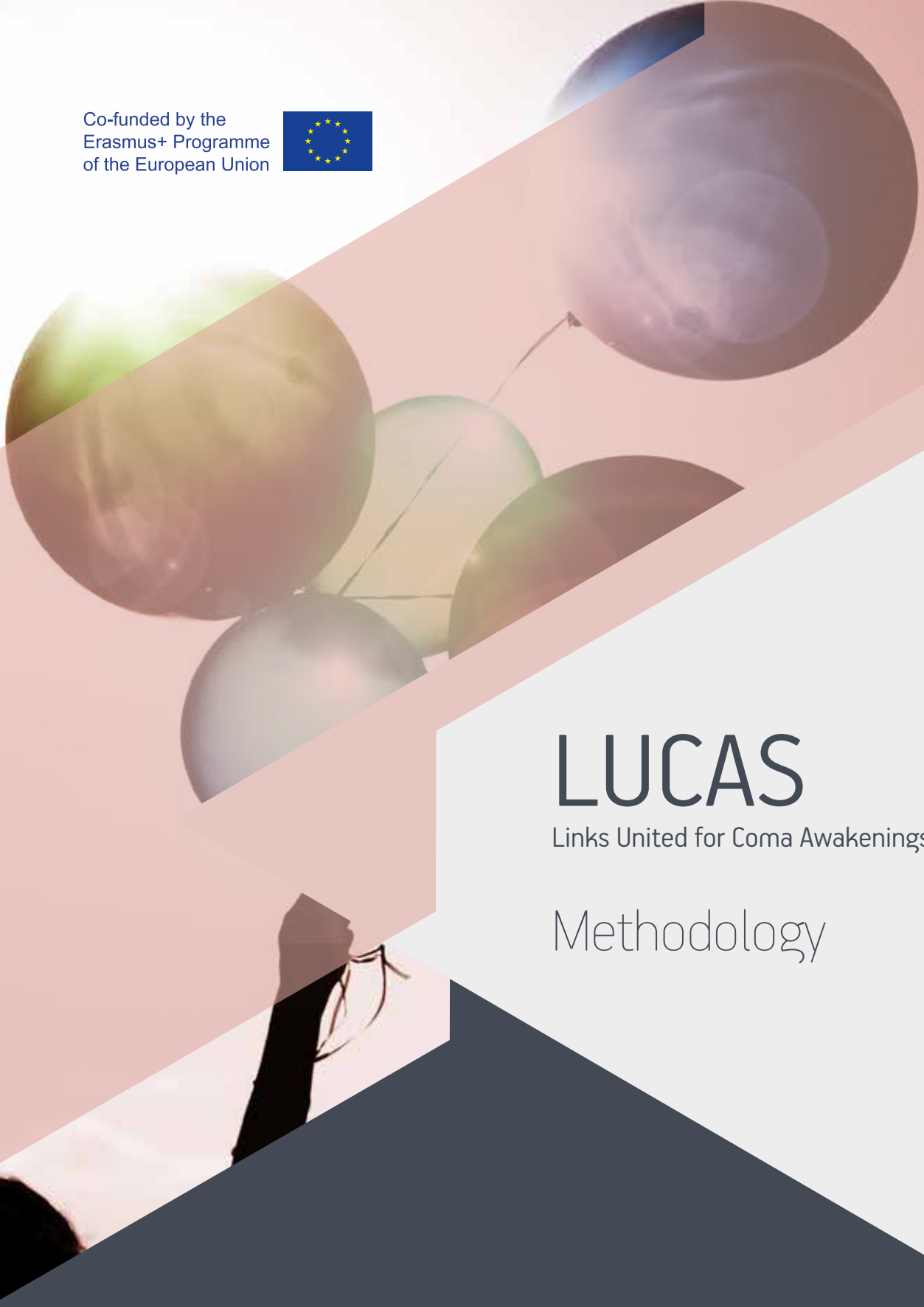

LUCAS

Links United for Coma Awakenings through Sport

Methodology

www.lucasproject.eu

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1. Introduction

There are many publications in the field of motor sciences and the promotion of health; many studies have been carried out to state both the value and the importance of motor activity, physical activity and sports on the psychophysical well-being of any individual. LUCAS project and methodology are based on general principles which could be found, among other relevant references in "Health 2020. A European policy framework and strategy for the 21st century", published by WHO Regional Office for Europe which provides the sanitary policy and strategy approved by the 53 countries of the European Region of the World Health Organization (WHO). It focuses on the improvement of health for all and the reduction of health inequalities through improved leadership and governance for health, and focuses on today's major health problems. In "Health 2020", as well as in our project LUCAS, becomes *"a common goal and a shared responsibility at all levels, if we work together in a innovative way, in terms of responses across all levels, focusing on a strong governance which invigorate the collaboration and the partnership between health and other society sectors."*

European policy action identifies four priority areas, two of which (1 and 4) refer to issues discussed in the LUCAS Project:

- ***Priority area 1***
  Investing in health through a life-course approach and empowering people
- ***Priority area 2***
  Tackling Europe's major health challenges: non communicable and communicable diseases
- ***Priority area 3***
  Strengthening people centred health systems, public health capacity and emergency preparedness, surveillance and response
- ***Priority area 4***
  Creating resilient communities and supportive environments[1]

Regarding LUCAS project target, we dealt with different contexts and needs of partner countries, with a variety of age groups (people with disability and caregivers) from children to seniors. Reference was made to WHO guidelines describing Recommendations on Physical Activity specific for each age group (following) and concepts and technical terminologies (see BOX 1).

1 WHO World Health Organization Regional Office of Europe (2012), "Health 2020" – 16-20

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5–17 years

For children and young people of this age group physical activity includes play, games, sports, transportation, recreation, physical education or planned exercise, in the context of family, school, and community activities.
In order to improve cardiorespiratory and muscular fitness, bone health, cardiovascular and metabolic health biomarkers and reduced symptoms of anxiety and depression, the following are recommended:

1. *Children and young people aged 5–17 years old should accumulate at least 60 minutes of moderate to vigorous-intensity physical activity daily.*
2. *Physical activity of amounts greater than 60 minutes daily will provide additional health benefits.*
3. *Most of daily physical activity should be aerobic. Vigorous-intensity activities should be incorporated, including those that strengthen muscle and bone, at least 3 times per week.*

18–64 years old

For adults of this age group, physical activity includes recreational or leisure-time physical activity, transportation (e.g walking or cycling), occupational (i.e. work), household chores, play, games, sports or planned exercise, in the context of daily, family, and community activities.
In order to improve cardiorespiratory and muscular fitness, bone health and to reduce the risk of NCDs and depression the following are recommended:

1. *Adults aged 18–64 years should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week, or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week, or an equivalent combination of moderate- and vigorous-intensity activity.*
2. *Aerobic activity should be performed in bouts of at least 10 minutes duration.*
3. *For additional health benefits, adults should increase their moderate-intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous-intensity aerobic physical activity per week, or an equivalent combination of moderate- and vigorous-intensity activity.*
4. *Muscle-strengthening activities should be done involving major muscle groups on 2 or more days a week.*

65 years old and above

For adults of this age group, physical activity includes recreational or leisure-time physical activity, transportation (e.g walking or cycling), occupational (if the person is still engaged in work), household chores, play, games, sports or planned exercise, in the context of daily, family, and community activities.

In order to improve cardiorespiratory and muscular fitness, bone and functional health, and reduce the risk of NCDs, depression and cognitive decline, the following are recommended:

1. *Adults aged 65 years and above should do at least 150 minutes of moderate-intensity aerobic physical activity throughout the week, or do at least 75 minutes of vigorous-intensity aerobic physical activity throughout the week, or an equivalent combination of moderate- and vigorous-intensity activity.*
2. *Aerobic activity should be performed in bouts of at least 10 minutes duration.*
3. *For additional health benefits, adults aged 65 years and above should increase their moderate intensity aerobic physical activity to 300 minutes per week, or engage in 150 minutes of vigorous intensity aerobic physical activity per week, or an equivalent combination of moderate- and vigorous intensity activity.*
4. *Adults of this age group with poor mobility should perform physical activity to enhance balance and prevent falls on 3 or more days per week.*
5. *Muscle-strengthening activities should be done involving major muscle groups, on 2 or more days a week.*
6. *When adults of this age group cannot do the recommended amounts of physical activity due to health conditions, they should be as physically active as their abilities and conditions allow. Overall, across all the age groups, the benefits of implementing the above recommendations, and of being physically active, outweigh the harms. At the recommended level of 150 minutes per week of moderate intensity activity, musculoskeletal injury rates appear to be uncommon. In a population-based approach, in order to decrease the risks of musculoskeletal injuries, it would be appropriate to encourage a moderate start with gradual progress to higher levels of physical activity.*

Overall, across all the age groups, the benefits of implementing the above recommendations, and of being physically active, outweigh the harms. At the recommended level of 150 minutes per week of moderate intensity activity, musculoskeletal injury rates appear to be uncommon. In a population-based approach, in order to decrease the risks of musculoskeletal injuries, it would be appropriate to encourage a moderate start with gradual progress to higher levels of physical activity. [2]

The recommendations also demonstrate that physical activity has health implications on beneficiaries (three age groups: 5-17 years old; 18-64 years old; and 65 years old and above):

- *Cardiorespiratory health (coronary heart disease, cardiovascular*
- *disease, stroke and hypertension).*
- *Metabolic health (diabetes and obesity).*
- *Musculoskeletal health (bone health, osteoporosis).*
- *Cancer (breast and colon cancer).*
- *Functional health and prevention of falls.*
- *Depression* [2]

During pilot actions implementation in partners' countries, we came in touch with all the issues listed above present in people with disability and caregivers, except for the cases of cancer.

2 World Health Organization (2010) "Global Recommendations on Physical Activity for Health" , 7-8 and c.4 – 16-33

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BOX 1

DEFINITIONS OF CONCEPTS USED IN THE RECOMMENDED LEVELS OF PHYSICAL ACTIVITY

Type of physical activity (What type). The mode of participation in physical activity. The type of physical activity can take many forms: aerobic, strength, flexibility, balance.

Duration (For how long). The length of time in which an activity or exercise is performed. Duration is generally expressed in minutes.

Frequency (How often). The number of times an exercise or activity is performed. Frequency is generally expressed in sessions, episodes, or bouts per week.

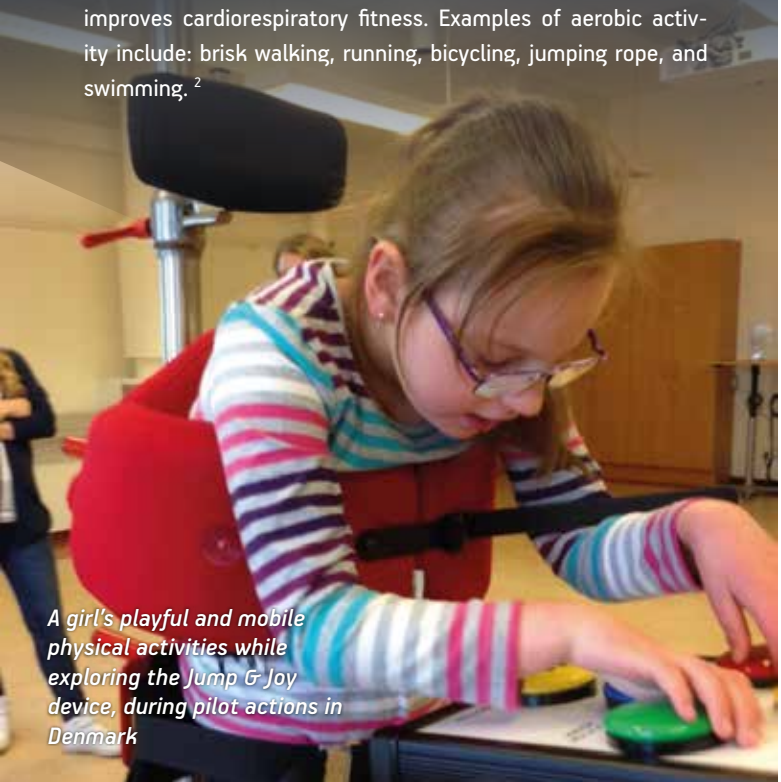
Intensity (How hard a person works to do the activity). Intensity refers to the rate at which the activity is being performed or the magnitude of the effort required to perform an activity or exercise.

Volume (How much in total). Aerobic exercise exposures can be characterized by an interaction between bout intensity, frequency, duration, and longevity of the programme. The product of these characteristics can be thought of as volume.

Moderate-intensity physical activity. On an absolute scale, moderate intensity refers to activity that is performed at 3.0–5.9 times the intensity of rest. On a scale relative to an individual's personal capacity, moderate-intensity physical activity is usually a 5 or 6 on a scale of 0–10.

Vigorous-intensity physical activity. On an absolute scale, vigorous intensity refers to activity that is performed at 6.0 or more times the intensity of rest for adults and typically 7.0 or more times for children and youth. On a scale relative to an individual's personal capacity, vigorous intensity physical activity is usually a 7 or 8 on a scale of 0–10.

Aerobic activity. Aerobic activity, also called endurance activity, improves cardiorespiratory fitness. Examples of aerobic activity include: brisk walking, running, bicycling, jumping rope, and swimming. [2]



A girl's playful and mobile physical activities while exploring the Jump & Joy device, during pilot actions in Denmark

In 2008 the U.S. Department Health and Human Services published the **Physical Activity Guidelines for Americans - Be Active, Healthy, and Happy!** *(www.health.gov/paguidelines) that provide achievable steps for youth, adults and seniors, as well as people with special conditions to live healthier and longer lives.* This document shows how the physical, motor and sport activity (not at middle-high agonistic level) is barely efficient and it affects the state of the form of the individual at world level. It should be practiced at least 2 times a week for a session of 1 hour (60 minutes) in order to be barely efficient and to affect the state of the individual shape.

We highlight in particular the following part drawn from the Guidelines mentioned above:

Key Guidelines for Adults With Disabilities

- *Adults with disabilities, who are able to, should get at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous-intensity aerobic activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.*
- *Adults with disabilities, who are able to, should also do muscle-strengthening activities of moderate or high intensity that involve all major muscle groups on 2 or more days a week, as these activities provide additional health benefits.*
- *When adults with disabilities are not able to meet the Guidelines, they should engage in regular physical activity according to their abilities and should avoid inactivity.*
- *Adults with disabilities should consult their health-care provider about the amounts and types of physical activity that are appropriate for their abilities.*

Key Guidelines for Children and Adolescents

- *Children and adolescents should do 60 minutes (1 hour) or more of physical activity daily.*
- *Aerobic: Most of the 60 or more minutes a day should be either moderate- or vigorous-intensity aerobic physical activity, and should include vigorous-intensity physical activity at least 3 days a week.*
- *Muscle-strengthening: As part of their 60 or more minutes of daily physical activity, children and adolescents should include muscle-strengthening physical activity on at least 3 days of the week.*
- *Bone-strengthening: As part of their 60 or more minutes of daily physical activity, children and adolescents should include bone-*

strengthening physical activity on at least 3 days of the week.

- *It is important to encourage young people to participate in physical activities that are appropriate for their age, that are enjoyable, and that offer variety.*

Key Guidelines for Adults

- *All adults should avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits.*
- *For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.*
- *For additional and more extensive health benefits, adults should increase their aerobic physical activity to 300 minutes (5 hours) a week of moderate-intensity, or 150 minutes a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount.*
- *Adults should also do muscle-strengthening activities that are moderate or high intensity and involve all major muscle groups on 2 or more days a week, as these activities provide additional health benefits.*

Key Guidelines for Older Adults

The Key Guidelines for Adults also apply to older adults. In addition, the following Guidelines are just for older adults:

- *When older adults cannot do 150 minutes of moderate-intensity aerobic activity a week because of chronic conditions, they should be as physically active as their abilities and conditions allow.*
- *Older adults should do exercises that maintain or improve balance if they are at risk of falling.*
- *Older adults should determine their level of effort for physical activity relative to their level of fitness.*
- *Older adults with chronic conditions should understand whether and how their conditions affect their ability to do regular physical activity safely."* [3]

3 U.S. Department Health and Human Services (2008) "Physical Activity Guidelines for Americans - Be Active, Healthy, and Happy!" - vi-viii

THERE ARE MANY BENEFITS OF PHYSICAL, MOTOR AND SPORT ACTIVITY

In addition, it is important to note that sport has an important social role, not only it helps to improve the physical and psychological recovery, but also it helps to develop social relationships regardless of the age, the social origin or the physical difficulties. It is a source of important values such as team spirit, solidarity, tolerance and fair play, contributing to personal development and fulfillment.
Sport is an important way of social integration by which the person (any and each one), improves relationships with the reality around, increasing social interchanges acting directly on the improvement of the personal self-esteem.
In conclusion, taking into consideration what mentioned before, there are many benefits of **physical, motor and sport activity,** holistically on the psycho-physical level, they are varied and include many life aspects of people with disability and caregiver.

What is the methodology

The LUCAS project had the aim of facilitating the pathway of cure and care of the person after coma and their caregiver through sport, a target not so much explored but rich in unexpressed potential.
The project reiterates the importance of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization, where the bio-psycho-social approach is important as opposed to the medical model. It defines health and disability in terms of an interaction between the psychic and the social components that characterize the functioning of the person. Therefore, the bio-psycho-social model of ICF represents an opportunity to introduce a comprehensive evaluation and classification of barriers and facilitators in the contexts of life so as to build a comprehensive intervention project.

The experience of the pathway of cure and care has been obtained in the project "INCARICO - social-health integration model in the pathway of cure and care of patients with disorders of consciousness" (CCM Ministry of Health from 2012 to 2014) created by the Istituto Besta in Milan coordinated by prof. Matilde Leonardi.
INCARICO project was attended by both the House of Awakenings Luca De Nigris as a public facility inside the National Health Sys-

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Pilot actions in Bologna - Italy, with fencing and dancesport

tem (Azienda USL di Bologna) and the association "Gli amici di Luca onlus" which is part of the Network of Italian associations.
In that case wide-ranging awareness involved Regions, rehabilitation facilities, health professionals, associations, caregivers and volunteers.
INCARICO project (aimed at people in a vegetative and minimally conscious state, INCARICO is a model of a process that can include also people affected by severe brain injuries) showed that, for the majority of persons with disabilities, the family was found to be a major facilitator with respect to social support.
It was also stressed how important is the role played by the family in the path "coma to community" in supporting patients in various issues: physical challenges, financial and psycho-social challenges related to caring for a sick family member.

Coma is a "family illness": it's not only the person involved who suffers the limitations of the surrounding environment, it is the whole family that has to face the complexity of practical and psychological issues, to solve and to deal with the sense of loneliness and abandonment, but also with the hardship, indifference and lack of understanding that the social context may hold.

The "LUCAS Methodology" introduces a new approach, a cultural change to enlarge the horizon on the pathway of cure and care of a person with acquired disability and caregivers, by proposing at the same time a work session for the person with disability and the caregivers. The latter are involved actively since a specific space is dedicated to them and activities with mixed groups caregivers – persons with disability are provided during the session/lesson/meeting (see chapter 3).
Based on twenty-year experience of the association "Gli amici di Luca" from which the "House of Awakenings Luca De Nigris" was born (example of an alliance between public health, private social and voluntary), it is understood that "in therapeutic alliance there is much more than is normally believed, and the dynamics between patient, family and professionals must be enhanced in all its complexity in order to unfold the maximum curative effectiveness in the care pathway.
In the debate on the states of reduced responsiveness or absence, after a serious acquired brain damage, the relationship, the family area of reference, the right treatment and care, the need of sharing a problem with such vast and dramatic repercussions in society are often lost."[4]
So what can communities do?
The *National Center for Chronic disease Prevention and Health Promotion USA* in its article dated 4/10/2015 suggests that the communities can participate in this theme in the following ways:

- Provide community based programs to meet the needs of persons with disabilities.
- Ensure that environments and facilities conducive to being physically active are available and accessible to people with disabilities, such as offering safe, accessible, and attractive trails for bicycling, walking, and wheelchair activities.
- Ensure that people with disabilities are involved at all stages of planning and implementing community physical activity programs.
- Provide quality, preferably daily, accessible physical education classes for children and youths with disabilities.
- Encourage health care providers to talk routinely to their patients with disabilities about incorporating physical activity into their lives.

The analysis of the context and of the good practices in partner countries (Belgium, Cyprus, Denmark, Italy, Lithuania, Spain,

4 R.Piperno - F.De Nigris, "Dal Coma alla Comunità – La Casa dei Risvegli Luca De Nigris" (2014) - 8-9

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Portugal) shows that existing practices do not combine physical/sport activity programmes for individuals with acquired disabilities and their caregivers working together at the same time. (See ***www.lucasproject.eu*** - "Analysis of the context and collection of good practices for rehabilitation through sport for people with disabilities acquired from traumatic brain injury and spinal cord injury (particularly as a result of a coma) and their families/caregivers" - Ferrando, M.T; Branchini, BGIbars, V.). Therefore, 'LUCAS Methodology' is an innovative approach to provide new opportunities and attention to people with acquired disability and their caregivers, each one according to their own peculiarities, to renovate and to strengthen the relationship between individuals (people with disability/caregiver), to give new social contexts to integrate themselves and to start life paths, to open new perspectives in.

The underlined needs engaged partners to focus on two key elements necessary for the elaboration of Methodology: specific target group and caregivers involvement.
The 'LUCAS Methodology' considers:

- Adapted sport activity **for persons with acquired disability**.
- (any adapted sport is considered, but specific technical basis competences should be provided).
- Physical and motor activity **for caregivers**.
- Motor, physical and sport activity for the **2 groups together**.

This methodology is an innovative approach focused on the rehabilitation of the brain- injured people through multidisciplinary sportive activities with the involvement of their families/caregivers in their reintegration process into the social life.
The final outcome of a person with disability with severe brain injury depends largely on having a collaborative and supportive family. For this reason the people with disability and their families take part in multidisciplinary activities.
The Methodology contains definitions, practical suggestions and examples of good practices for using this approach, in order to encourage organisations working on the field to apply it.

2. Objectives

By sharing the objectives of the White Paper on Sport[5] , the LUCAS methodology wants:

General objectives

- to promote voluntary activities in sport, together with social inclusion, equal opportunities and awareness of the importance of health-enhancing physical activity through increased participation in, and equal access to sport for all
- to enhance the role of sport in education and training. Through its role in formal and non-formal education, sport reinforces Europe's human capital. The values conveyed through sport helps to develop knowledge, motivation, skills and readiness for personal effort. Time spent in sport activities produces health and education benefits that need to be enhanced.
- to promote volunteer and active citizenship through sport. Participation in a team, principles such as fair-play, compliance with the rules of the game, respect for others, solidarity and discipline as well as the organisation of amateur sport based on non-profit clubs and volunteering reinforce active citizenship. Volunteering in sport organisations provides many occasions for non-formal education, that need to be recognised and enhanced.

Specific objectives

For the final beneficiaries (people with acquired disability and their families/caregivers) the specific objectives are:

- To facilitate physical rehabilitation through the improvement of motor aspect (improvement of the general physical state and acquisition of specific skills of the practiced sport/motor activity

5 European Commission (2007), "White paper on sport"

A session of Pilates developed in the gym of the Association of Acquired Brain Injury from the city of Malaga (Spain) - ADACEMA

Pilot actions in Cyprus, basketball session

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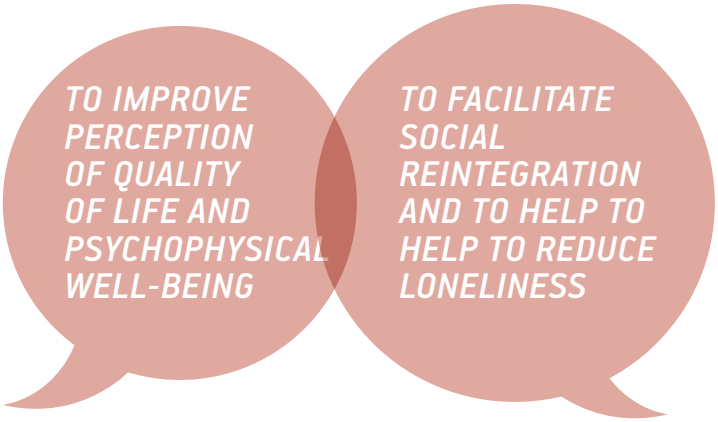
- To improve perception of quality of life and psychophysical well-being
- To facilitate social reintegration and to help to reduce loneliness
- To improve quality of relationship between person with acquired disability and his/her family / caregiver
- To improve awareness of the disability, both in the person with disability and in the caregiver
- To give the opportunity to the person with acquired disability to practice adapted sports

For the experts and staff involved in the process the specific objectives are:

- To provide new methods to approach and new skills for sport trainers who work with people with disability and/or caregivers.



3. Rehabilitation model

3.1 What

Persons with disability can practice any kind of adapted sport activity.

Expert technicians work on the residual abilities of each person in compliance with the specificity of the practiced discipline.

The *'LUCAS Methodology'* suggests to favour a multidisciplinary approach to allow people:

A. Who practiced sports before acquiring disability:

   to confront with known environments and situations and to measure the new modality of approach preserving the strength and motivation given by the passion for sport

B. In case they have not practised sport before acquiring disability:

   to access a universe of new possibilities where persons with disability are not prostrated by the confrontation with the past and the conquests achieved and to be achieved which are an incentive for the construction of a new life and of a new "myself".

Activities of postural re-education can be proposed to caregivers through a work aimed at reducing troubles and pains to body structure.

The importance of a work on the "hygiene" of the movement, e.g. how to use body levers ergonomically and functionally to assist the person with disability, strengthening and toning the body areas most involved by the efforts.

Part of each lesson is to be dedicated to relaxation and breathing. In a different environment, caregivers can test themselves within the same sport activities proposed to persons with disabilities. This moment is an important place for comparison and exchange of points of view.

The motor activity together (involving people with disability and caregivers together)

It is aimed at acquiring a new physical and psychical way to get in touch with each other, to relate.

At the same time, it is an occasion for families to compare with each other in order to acquire new tools to approach better with their own relatives.

It can be proposed with different modalities:

- 90 minute lesson with 60 minutes of activities with 2 separate groups, followed by 30 minutes of activities in joint groups
- 90 minute lesson with 15 minutes of welcoming and 15 minutes at the end of the activity with the whole group, while the 60 resting minutes individuals with ABI or SCI and caregivers are working separately.

3.2 Who

LUCAS Methodology **beneficiaries** are:

1. **People with acquired brain injury (ABI) with traumatic or vascular origines and people with spinal cord injury (SCI).** The group can be heterogeneous in terms of severity of disabilities, difficulties of the people in daily life, demands and expectations of them. In order to respect the need of the group, as well as the personality of the participants and to be efficient, the activity must present a relation technician/athlete to respect both physical and cognitive characteristics of persons with disabilities, the kind of sport proposed, and the spaces where the activity is carried out; therefore, a technician every 8 persons (ratio 1: 8)
2. **The families/caregivers.** It is recommended that the number of participants with disabilities would be the same

as the number of family members/caregivers. It would be even better but not necessary if the family member/caregiver would always be the same.

N.B. an open possibility should be given to more than one person who takes care of the person with disability (family members, caregivers, relatives, friends, anyone who takes care of the person with disability at any level constantly and who is part of their emotional world) to take part in the activity. Since not all the caregivers are able to attend all the lessons (for work problems, physical and/or other), it is possible to extend the participation of different caregivers for a person with disability, in order to grant continuity to the participants since one of the essential condition of 'LUCAS Methodology' is the participation of the couple.

EXCLUSION CRITERIA:

- Presence of Vegetative State, Minimally Conscious State or Locked In Syndrome
- Impossibility for the caregiver to participate in the activity
- Impossibility for the people with disability, for the caregiver or both to participate to both the activities
- Presence of medical complication that could be increased from the activity sporting proposal (for example, serious distonia).

Experts / trainers / coaches for LUCAS methodology are:

1. **FOR CONDUCTING ACTIVITIES**
   (they carry out the methodology)

Operators in the sport context:

- **Postural trainer:** he/she teaches postural gymnastics and their aim is to preserve and to strengthen the individual health, to improve the relation dynamics and to optimize the functions in daily activities.
- **Expert Technician** in adapted sports: he/she teaches a specific sport discipline to groups or individuals by adapting the rules and techniques of the discipline on the basis of the difficulties / disabilities of the person. He/she employs the techniques of all those adapted sports already codified and for which a specific description and well defined technical rules are shared. (v. wheelchair hockey, wheelchair basketball, tennis table and many others)
- **Graduate in motor sciences**: after attending courses at university, they own competences acquired in different fields: school, health, techniques, sports.

2. INVOLVED IN VARIOUS CAPACITIES.

They favour the participation of persons to methodology, they intervene in the management of possible difficulties, they ease re-socialization across a wide range of participants:

Other professionals
(Multidisciplinary Team): For example, they are represented by the following professionals:

- Psychologist
- Educator
- Physiatrist
- Social assistant
- Other

Volunteers

3.3 Where

The activities should be carried out in a suitable environment / sports facility (gym/movement hall/etc.), with adjacent rooms/ spaces, of which a bigger one to keep the two groups of participants reunited.

3.4 Stakeholders

- Local authorities
- Those in charge of the welfare
- Those in charge of health
- Private organizations
- NGO (Non-Governmental Organization)
- Associations of social promotion or voluntary associations
- Sport organizations
- Schools
- Trainers
- School teachers
- Pedagogues,
- Psychologists
- Psychotherapists
- All professionals related to the target groups (general therapists...)

FAMILIES ARE AT THE SAME TIME BENEFICIARIES AND STAKEHOLDERS.

3.5 How

We describe below the steps necessary to apply the methodology, as have been experienced during LUCAS project pilot actions in specific contexts. The preparatory phases in particular (phases 1 - 4), can be adapted to the specific field of application, but should always be taken into account as general guidelines,

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particularly with regard to the cooperation and communication between the various professionals involved.
It would be preferable, before starting the activity, to talk with the medical staff who took care or who continues to take care of the person with acquired disability.

PHASE 1

the organizer presents and describes the project to all the personnel involved in the rehabilitation and social reintegration path of people with acquired brain injury and spinal cord injury (physiatrists, psychologists and educators).
This phase is aimed to understand which persons (people with disability and caregivers) can be involved in the activities and to present the numerous positive implications of the participation in terms of resocialization and psychophysical well-being.

PHASE 2

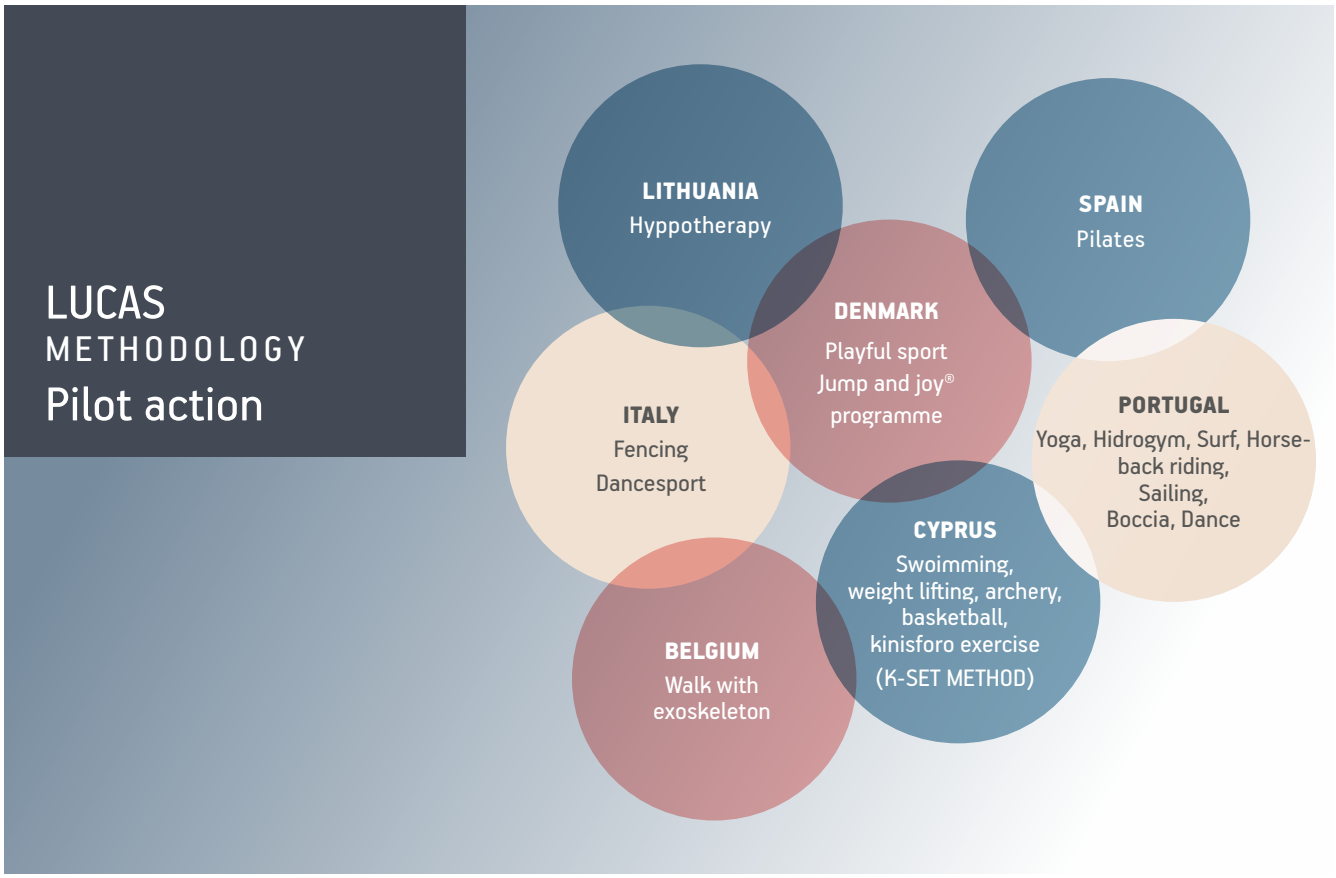
all the personnel involved in the rehabilitation and social reintegration path of the person with acquired disability and of the caregiver identify the most appropriate people and indicate them to the organizers.

PHASE 3

the organizer collects and brings together the information about the motor, cognitive, psycological state of the person with disability and his / her caregiver from those who have the situation in charge. In this way, it's possible to conduct sports activities in complete safety and to understand the psycho-motor and cognitive level of the person with disability and the caregiver.

PHASE 4

meeting with the operators in the sport context. They could meet the group (persons with disability and caregivers) and give them more information about the sport activities.



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PHASE 5

practical activities: according to 'LUCAS Methodology' the organization of the lesson has the following order:
the activities are proposed in 2 sessions of 1,5 hours per week **according to two possible modalities, A and B below:**

A **90 minute lesson with 60 min of activities with 2 separate groups, simultaneously, followed by 30 minutes of activities in joint groups**

60 minutes of adapted sport for people with disability:
Initial phase: global warming of all body areas, recovery of joint mobility and blood circulation

Central phase: preparatory exercises on the technique of the specific discipline

Cool-down phase: exercises designed to eliminate muscle fatigue, favouring a return to a situation of "calm" after the effort

60 minutes of gym for family members/caregivers:
Initial phase: brisk walking, light running, exercises for general mobilization. improving joint mobility and blood circulation

Central phase: slow and gradual movements that should be adjusted in order not to weigh on the joints, while allowing to maintain muscle expanse and to increase the physical resistance to the efforts. The aim of the activities proposed through simple exercises is to tone up muscles and to improve resistance.

Cool-down phase: stretching and relaxation exercises assisted by the proper breathing.

30 minutes of activities in joint:
exercises aimed at eliminating the fatigue of muscle groups involved in the previous activity. The exercises will be carried out in pairs and / or in a group, it will represent passive motion exercises, massage through the use of small tools (soft balls, wooden stick..) and socialization through motor playful games. Stretching.

B **90 minute lesson with the first 15 minutes of welcome activities in a joint group, 60 min of activities with 2 separate groups, followed by 15 minutes of activities in joint groups**

First 15 minutes of activities in joint:
Initial phase: global warming of all body areas, recovery of joint mobility and blood circulation. The exercises will be carried out in pairs and / or in a group.

60 minutes of adapted sport for people with disability:
Central phase: preparatory exercises on the technique of the specific discipline

Cool-down phase: exercises designed to eliminate muscle fatigue, favouring a return to a situation of "calm" after the effort

60 minutes of gym for family members/caregivers:

Central phase: slow and gradual movements that should be adjusted in order not to weigh on the joints, while allowing to maintain muscle expanse and to increase the physical resistance to the efforts. The aim of the activities proposed through simple exercises is to tone up muscles and to improve resistance.

Cool-down phase: stretching and relaxation exercises assisted by the proper breathing.

Last 15 minutes of activities in joint:
The exercises will be carried out in pairs and / or in a group, it will represent passive motion exercises, massage through the use of small tools (soft balls, wooden stick...) and through motor playful games. Stretching.

Another possibility that can be evaluated for the activities aimed at family members/caregivers is that they too will experience and practice the same sport practiced by people with disabilities.

The portuguese pilot actions focused in giving new and exciting experiences to the participants, promoting their well-being and social integration while doing different sports as horseback riding, yoga, outdoor fitness, sailing, adapted surf, hydro fitness, among others.

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4. Evaluation tools

The evaluation can preferably be pre- and post- the activity period. We used the indicators described below, but it's possible to define other and connected evaluation tools.

"LUCAS Methodology " includes activities that affect various and different fields of a person's life (physical, psychological, relational, emotional, environmental, well-being perception, social, etc.). For this reason we did not create a specific questionnaire, but we used a set of evaluation tools already validated to analyse some indicators of the activities proposed in the project.

INDICATORS FOR PEOPLE WITH DISABILITY:	VALIDATED QUESTIONNAIRES FOR PEOPLE WITH DISABILITY:
Disease awareness and functional abilities	Patient Competency Rating Scale (PCRS) Patient Form ("PCRS-patient")
	Activities of Daily Living Scale ("ADLscale")
Perception of quality of life and psychophysical well-being	Short Form Health Survey ("SF-36")
Perception of social integration	Community Integration Questionnaire ("CIQ")
INDICATORS FOR CAREGIVERS:	**VALIDATED QUESTIONNAIRES FOR CAREGIVERS:**
Disease awareness about his/her relative	Patient Competency Rating Scale (PCRS) Caregiver Form ("PCRS-caregiver")
Perception of quality of life	Short Form Health Survey ("SF-36")
Perception of social integration	Community Integration Questionnaire ("CIQ")
Caregivers' physical and emotional overhead of assistance	Experienced Pressure by Informal Caregiver ("EPIC")

5. Our results

87 participants (49 persons with ABI or SCI and 38 caregivers) completed a 24 week physical activity program consisting of 48 training sessions with separate and combined activities.

A comparative analysis of people with disability and caregiver characteristics across all partner countries indicated that an overall pre- versus post-intervention comparison was allowed. This means that the characteristics between persons with ABI or SCI and caregivers, but also between the partner countries were similar. Consequently, all data were pooled into one large dataset. As such, the effect of the 24 week physical activity programs was analysed for all participants. An additional analysis on the effect of the intervention on people with disability and caregivers separately was completed to provide a more complete understanding of the results.

Statistical analysis (Pearson χ^2 with significance level $p<0,05$) revealed the following findings:

Quality of Life (SF-36)

- Physical Functioning: No significant improvement
- Role Limitations due to Physical Health: Significant improvement for persons with ABI or SCI, not for caregivers
- Role Limitations due to Emotional Problems: Significant improvement for persons with ABI or SCI, not for caregivers
- Energy/Fatigue: Significant improvement for persons with ABI or SCI and caregivers
- Emotional Well-Being: Significant improvement for caregivers, not for persons with ABI or SCI
- Social Functioning: Significant improvement for persons with ABI or SCI, not for caregivers
- Pain: No significant improvement
- General Health: Significant improvement for persons with ABI or SCI, not for caregivers

Competency (PCRS)

- No significant improvement

Community Integration (CIQ)

- Home Integration: Significant improvement for persons with ABI or SCI and caregivers
- Social Integration: Significant improvement for persons with ABI or SCI and caregivers
- Integration into Productive Activities: No significant improvement

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Activities of Daily Living Scale (ADL) For participants only

- No significant improvement

Experienced Pressure by the Informal Caregiver (EPIC) – For caregivers only

- No significant improvement

The results of the study suggest that a 24 week physical activity program increases the general health and quality of life of persons with ABI or SCI, as well as their informal caregiver(s). The increased quality of life of people with disability (ABI or SCI) seems to be manifested in physical, psychological and social aspects of quality of life, whereas in caregivers, the improvements are mainly situated in psychological and social aspects (which can be expected given the physical consequences of brain injuries or spinal cord injuries versus the unchanged physical abilities of caregivers). Furthermore, the results also suggest a positive effect of physical activity on the social (re-)integration of people with disability and caregivers. On the other hand, no significant improvements could be demonstrated based on this study with respect to pain treatment, functioning in ADL, and experienced pressure by the caregiver(s).
In conclusion, physical activity improves the physical, psychological and social well-being of persons with ABI or SCI, as well as their informal caregiver(s). Further projects are now necessary to optimize the nature and content of the activities.

We also achieved unexpected results not evaluated through questionnaires, to be viewed in the pilot actions partners' reports at *www.lucasproject.eu*.

Pilot activities in Lithuania, hippotherapy sessions.

6. Implications and suggestions for future application

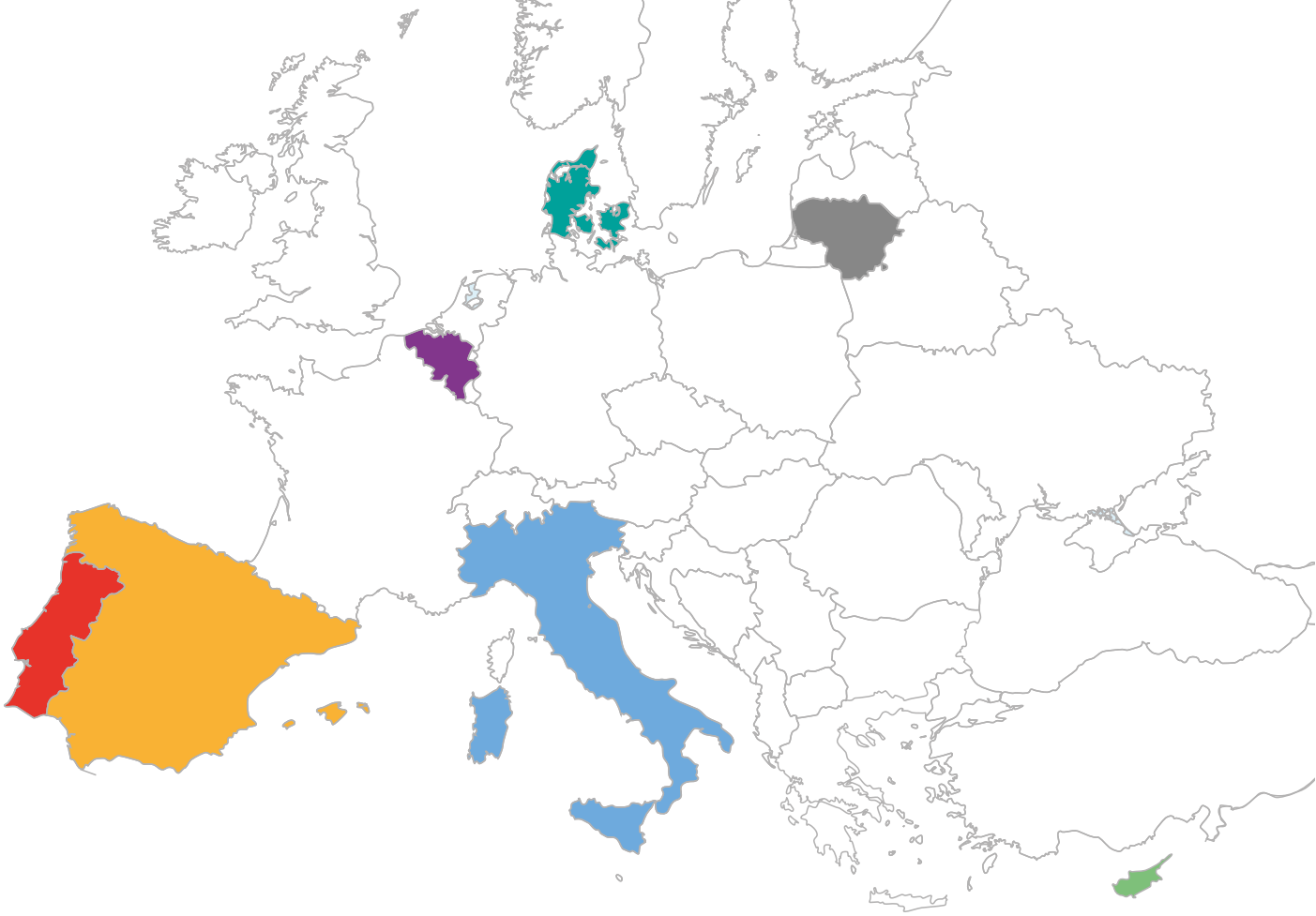
Experiences from LUCAS has resulted in an evolved flexible, open and all-encompassing methodology, that, whilst context and case dependent, innovates by being inclusive of caregiver\families alongside people with disability. Optimisation of engagement, fun, play and social interactions is targeted in method-based activities toward participants' benefits, thus advancing the field.
We encourage those who want to apply this methodology to be aware of the following points:

- Be flexible
- Context and case specific
- Pay attention to participants' needs (inclusive of caregivers/ family members)
- Optimize engagement fun and play (involvement)
- Promote a multidisciplinary approach
- Feel free to use any adapted sport and motor/physical activity

7. Insights

At the Lucas website (*www.lucasproject.eu*) you can find descriptive sheets of the pilot actions carried out in the seven partners' countries and the description of a case history for each country. You can also find a more detailed results analysis.

Robot-assisted Gait Training in the To Walk Again Post-rehabilitation Centre in Belgium.



Participating organisations:

IT	Futura Soc. Cons. r. l. (lead partner)
IT	CSI - Centro Sportivo Italiano
BE	MOBILAB - Multidisciplinary Expertise Centre of the Thomas More University College
CY	European Social Forum Cyprus
DK	Aalborg University
ES	Spanish Society of Social and Health Care (SEAS)
ES	Dependentias - Asociación Estatal Para El Desarrollo De Servicios Y Recursos
LT	Siauliau University
PT	PODES - Desenvolvimento Sustentável

In collaboration with:

IT	Associazione Gli Amici di Luca ONLUS

With the collaboration of:

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All pictures have been provided with the individuals consent

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