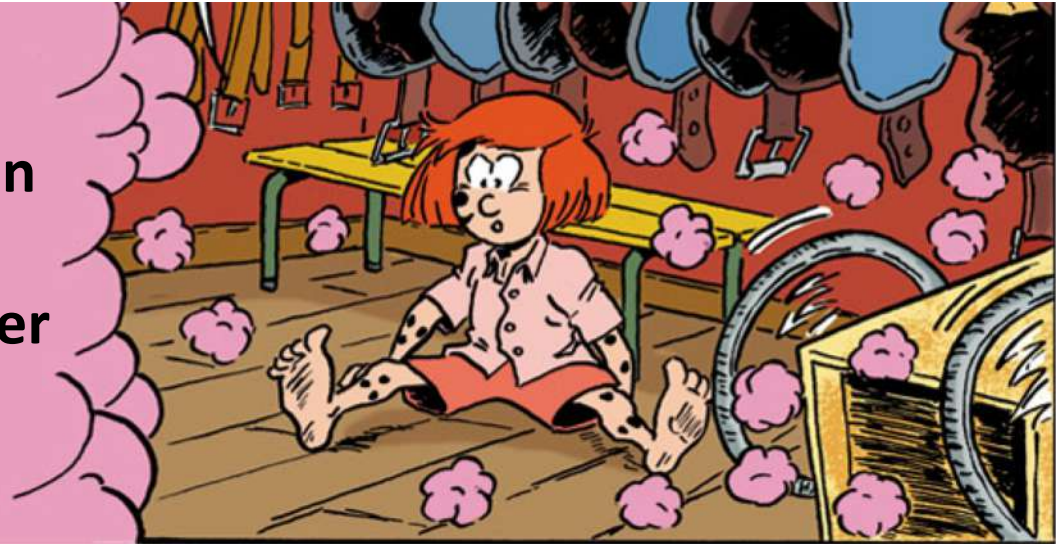


**Patient Therapeutic Education
Program.**

**"How to react to the way other
people look at you ?"**



**Dr Béatrice de Reviers
Leader of psychosocial team
Nævus International**



CMN is an Esthetic Vulnerability



Chronic dermatologic features are often associated with disability. This is the case for giant congenital melanocytic nevus.

WHO defines disability as “a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives”.

So far, the main activity in dermatology has been to address the features of individual bodies.

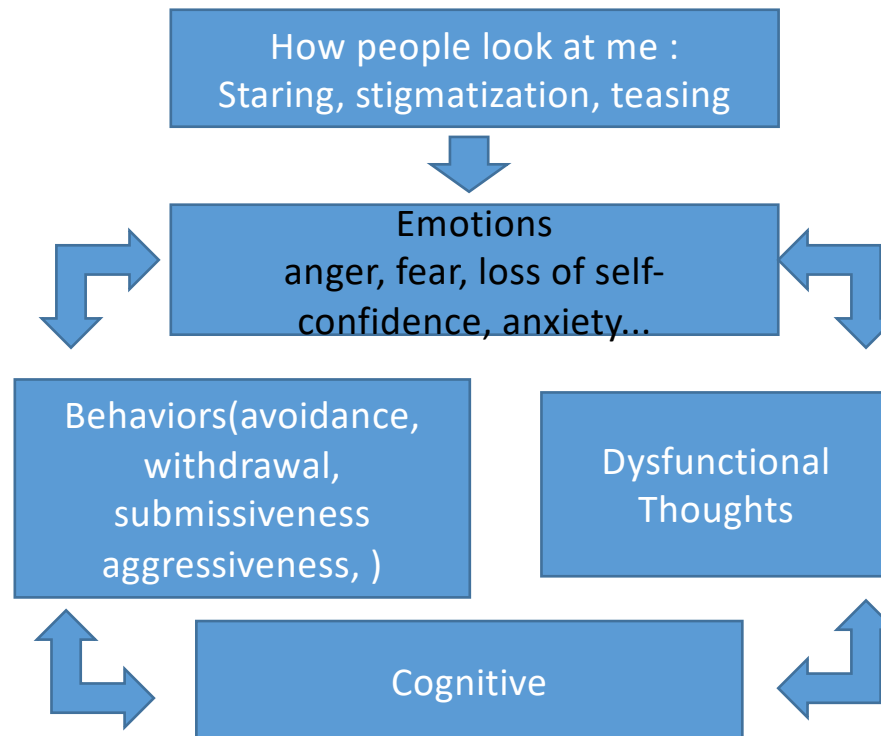
In contrast, the interaction related to the features of the society in which one lives remains poorly studied.

Yet such a birthmarks may have serious personal consequences in children and adults, as well as for the surrounding society, leading to esthetic vulnerability

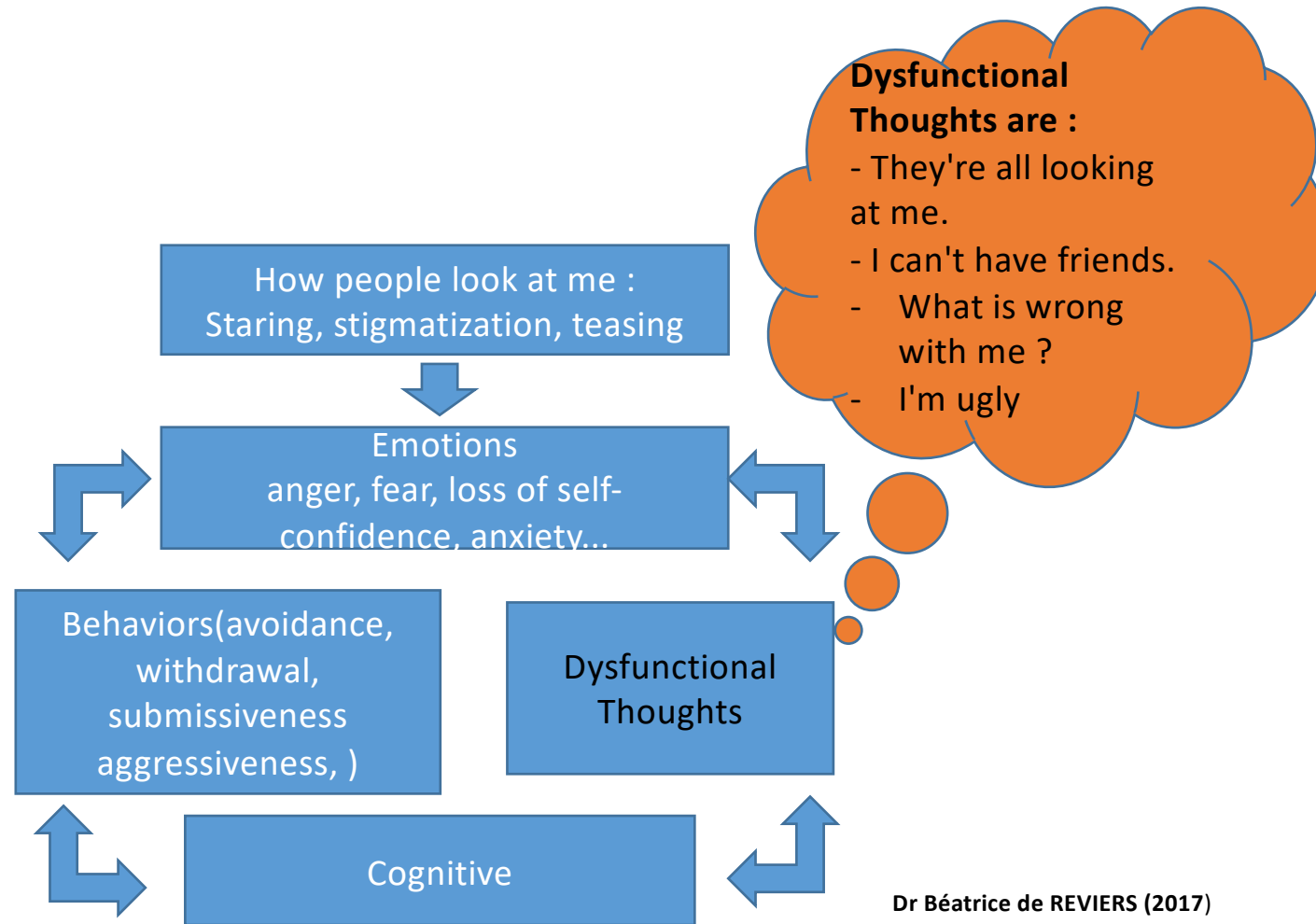
The vicious circle of an esthetic disability : SECCA mode

How people look at me :
Staring, stigmatization, teasing

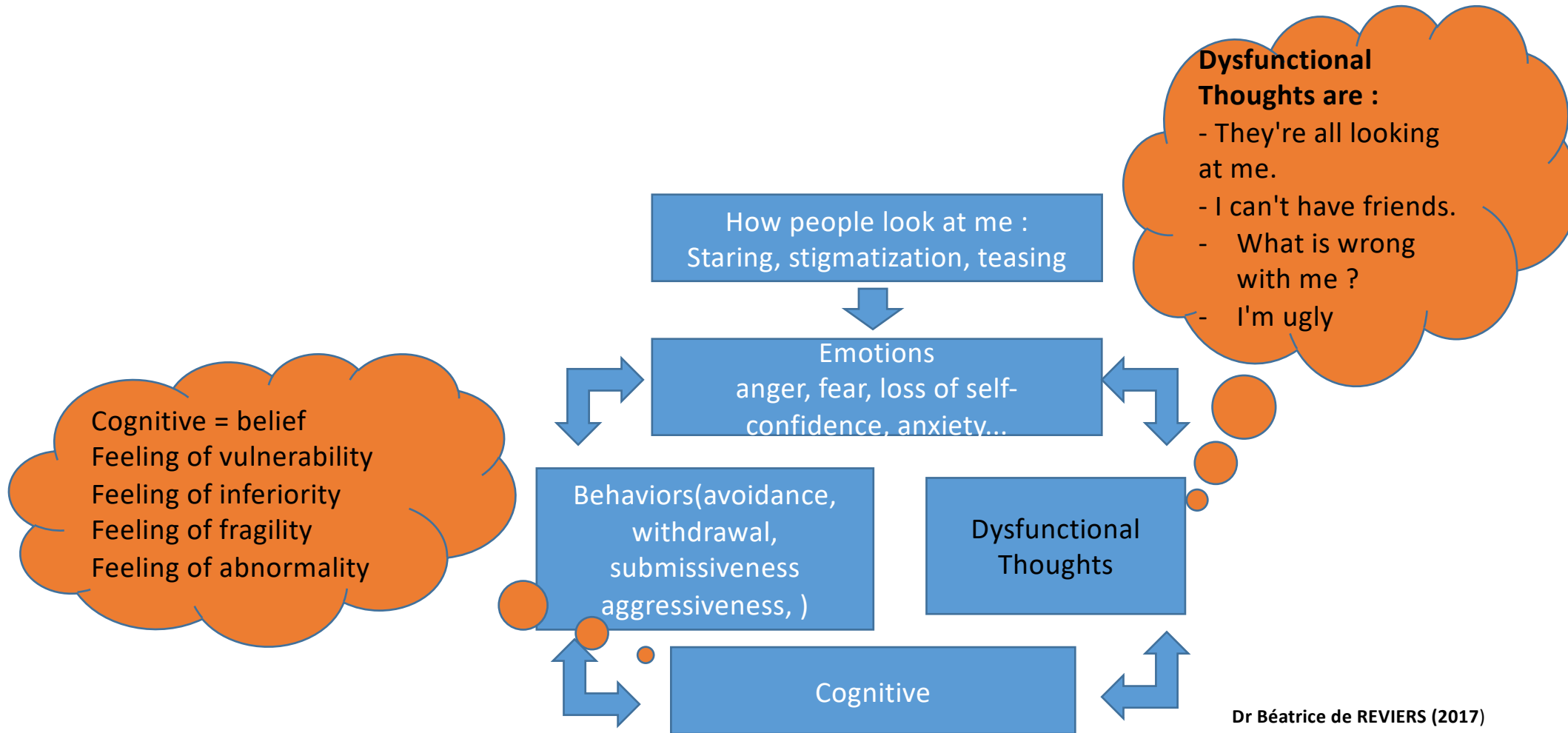
The vicious circle of an esthetic disability: SECCA mode



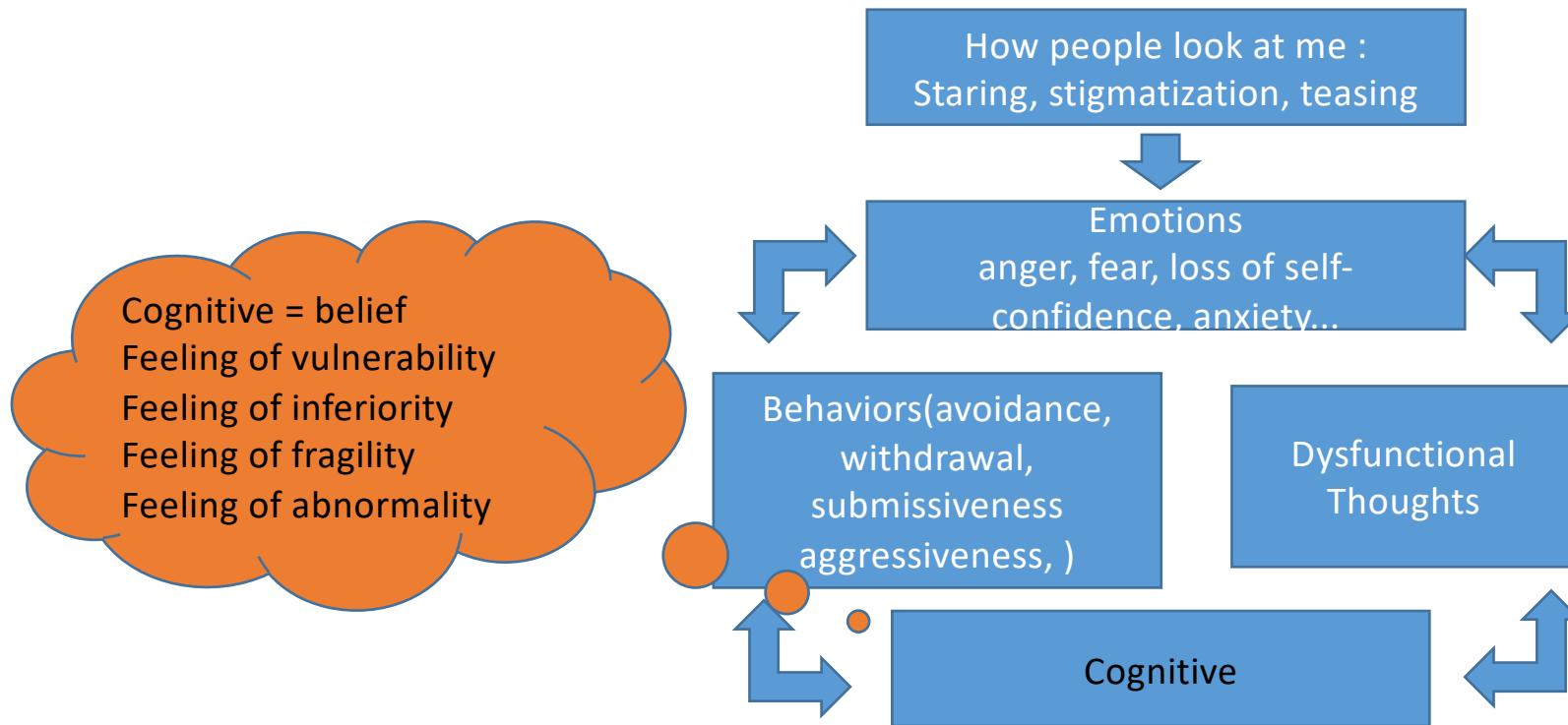
The vicious circle of an esthetic disability : SECCA mode



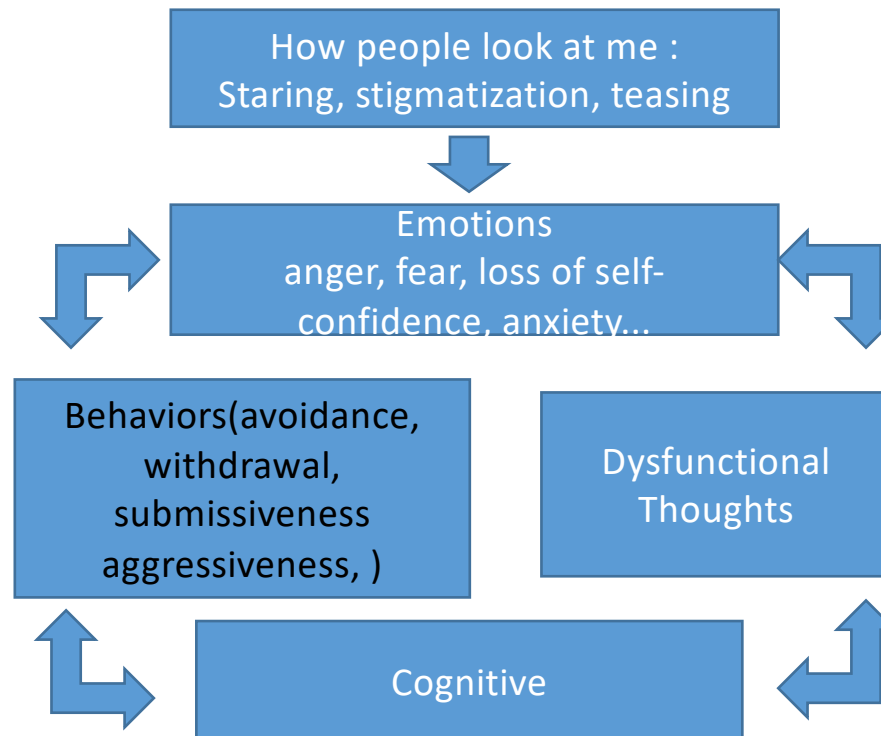
The vicious circle of an esthetic disability : SECCA mode



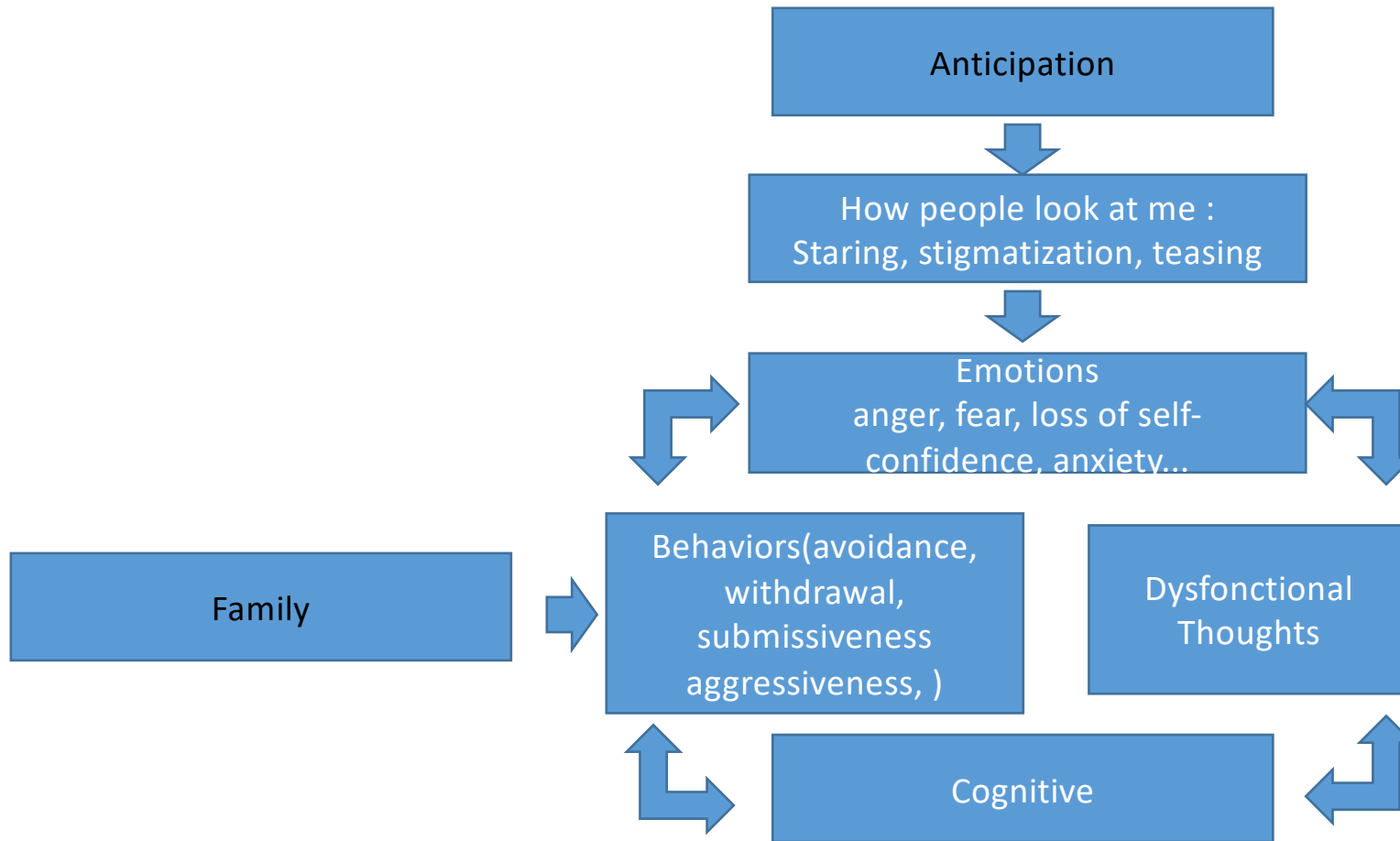
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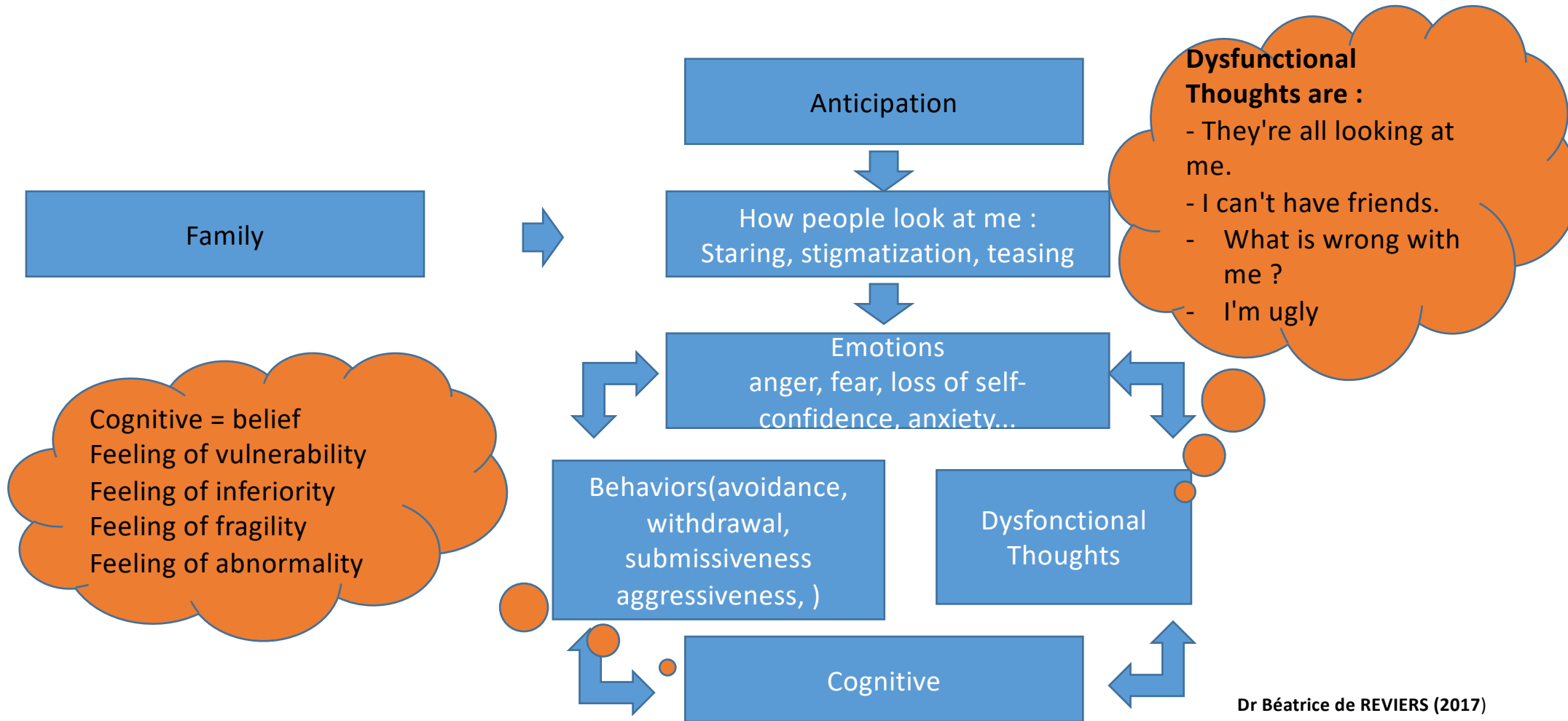
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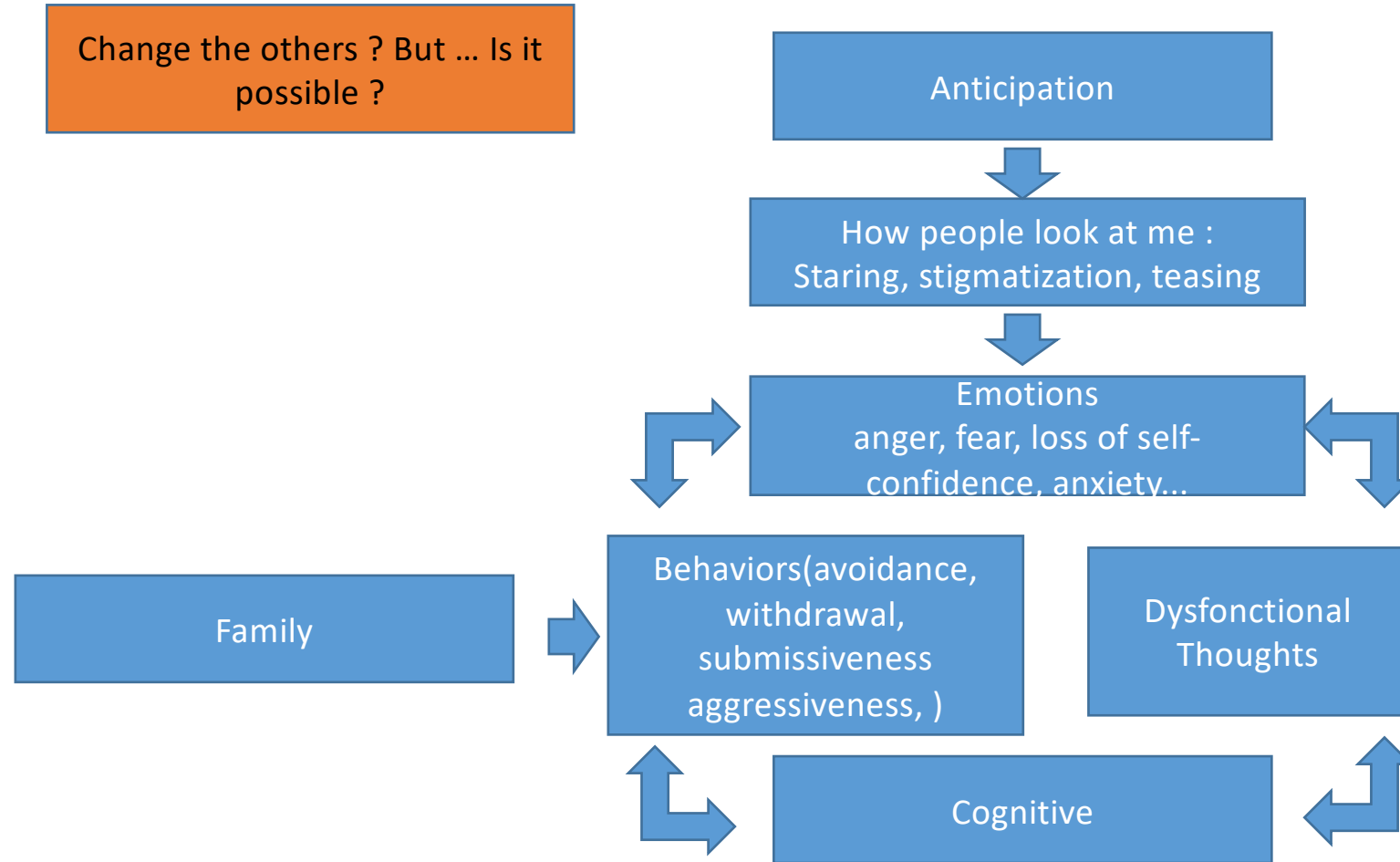
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The vicious circle of an esthetic disability : SECCA mode



The vicious circle of an esthetic disability : SECCA mode

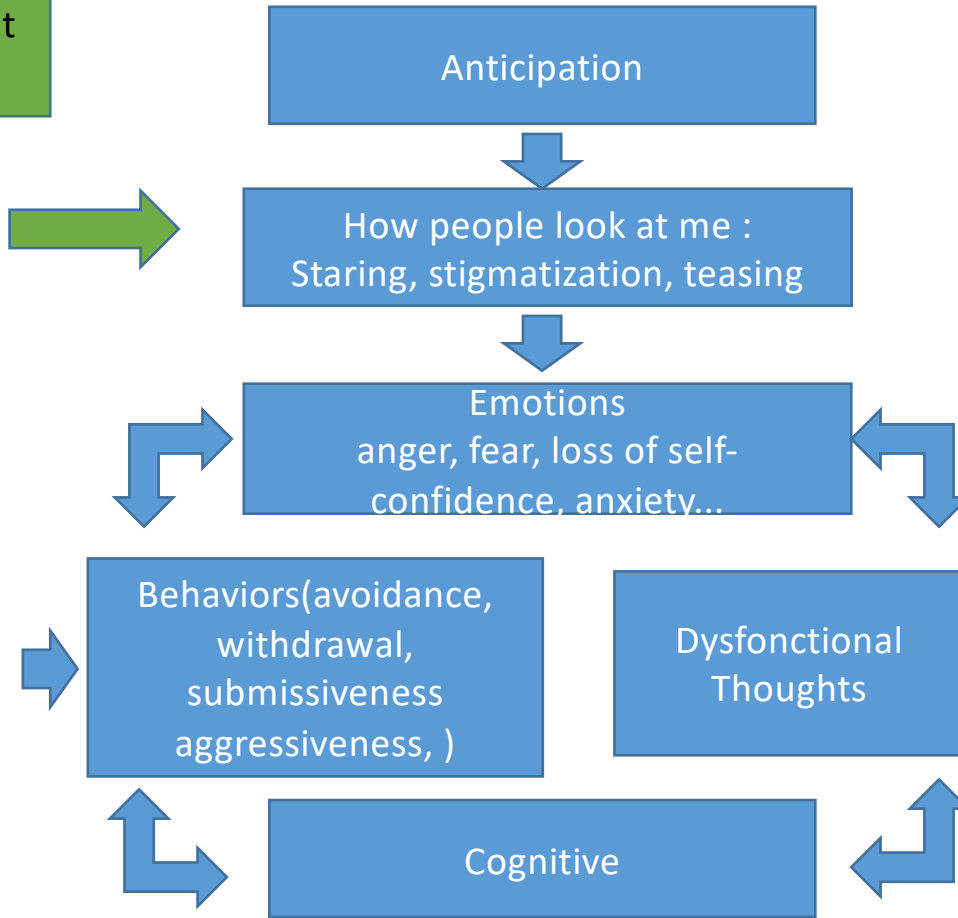


How to enter in virtuous circle (The green circle) ?

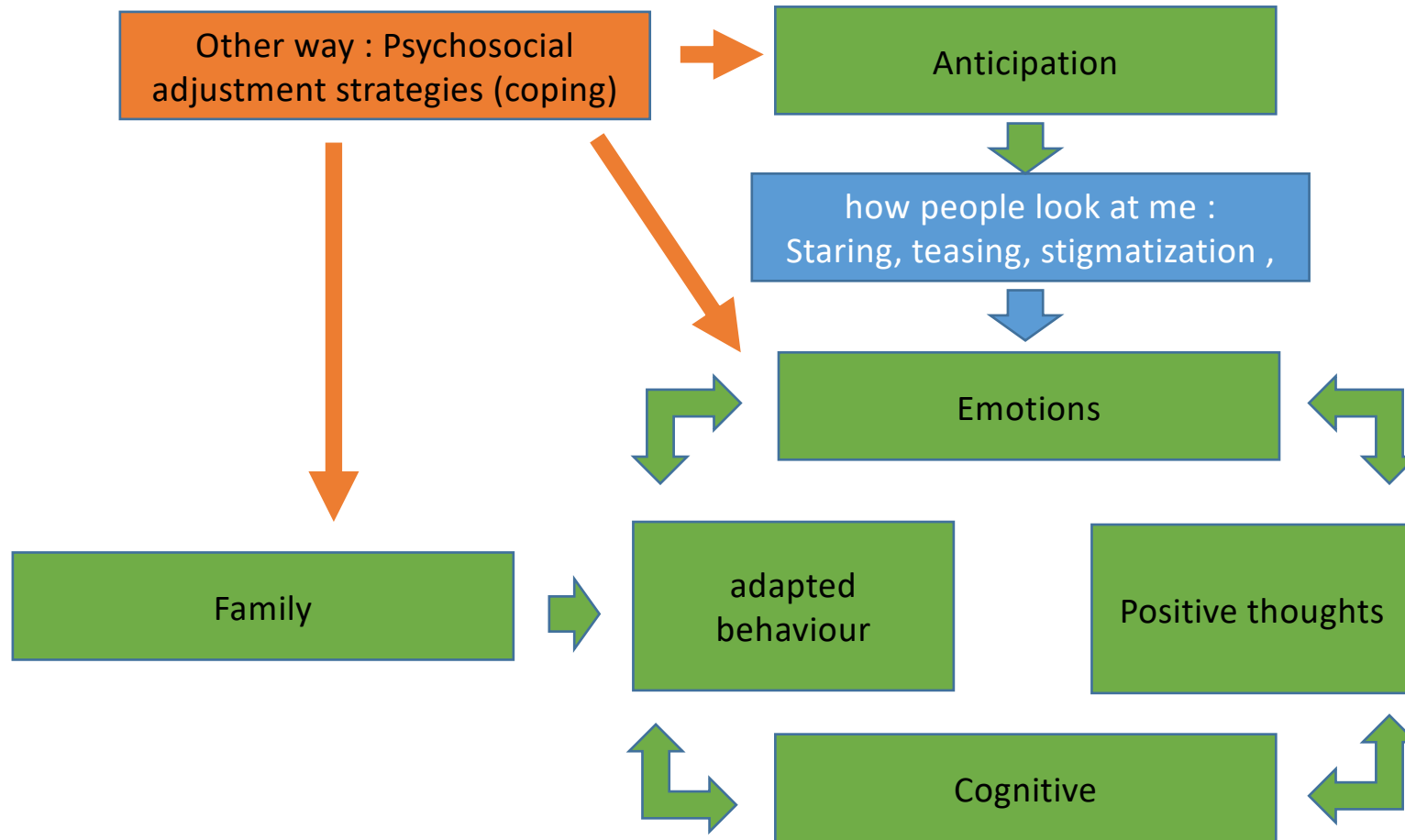
Change the others ? But ... Is it possible ?



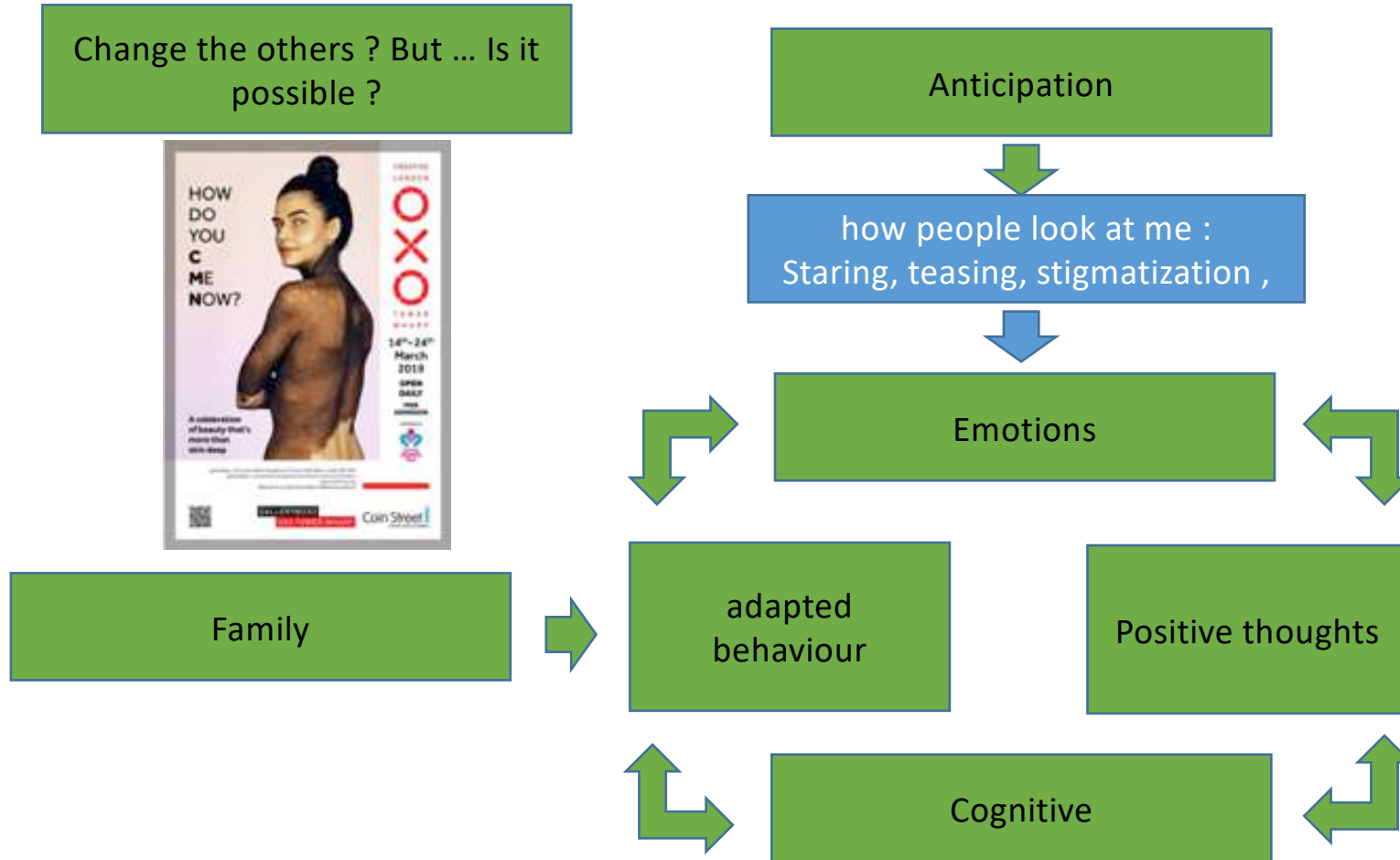
Family



How to enter in virtuous circle (The green circle) ?



How to enter in virtuous circle (The green circle) ?




Tools



1. **Self-Talk** — what we say to ourselves and believe
I love and accept myself the way I am and the way I am not.
I meet people easily and feel comfortable with them.
I Can Do It!
2. **Tone of Voice**
Friendly
Warm
Enthusiastic
3. **Eye Contact**
LOOK people in the eye—even if only for 3-4 seconds.
4. **Posture**
Head raised
Rib cage lifted
Shoulders back
5. **Smile**
Confident
Approachable

Imagine you are producing a TV commercial of yourself...use **STEPS** to produce the confident and comfortable image you want to project to your audience. **YOU** have total control over the image you choose for your audience to view.



Naevus Global

Guide pour les parents


Que dire, que faire face aux problèmes de la vie quotidienne ?



Naevus Global

Guide pour les enseignants

Que dire, que faire, face aux moqueries, taquineries et exclusions ?



Loïc Ballet Les amis d'Anna Patrick Ballet

TOUS EN PISTE
4 petites histoires de cirques




©Barbara Kammerer Quayle, M.A.

2



Contact us for more information: 1835 R W Berends Dr. SW, Grand Rapids, MI 49519-4953
(616) 458-2773 FAX (616) 458-2831 (800) 888-2876 www.phoenix-society.org

Strategy 1 : Steps



What should I do when someone stares at me ?





Explain – Reassure- Distract



COMMENT RÉPONDRE AUX QUESTIONS INDISCRÈTES D'INCONNUS

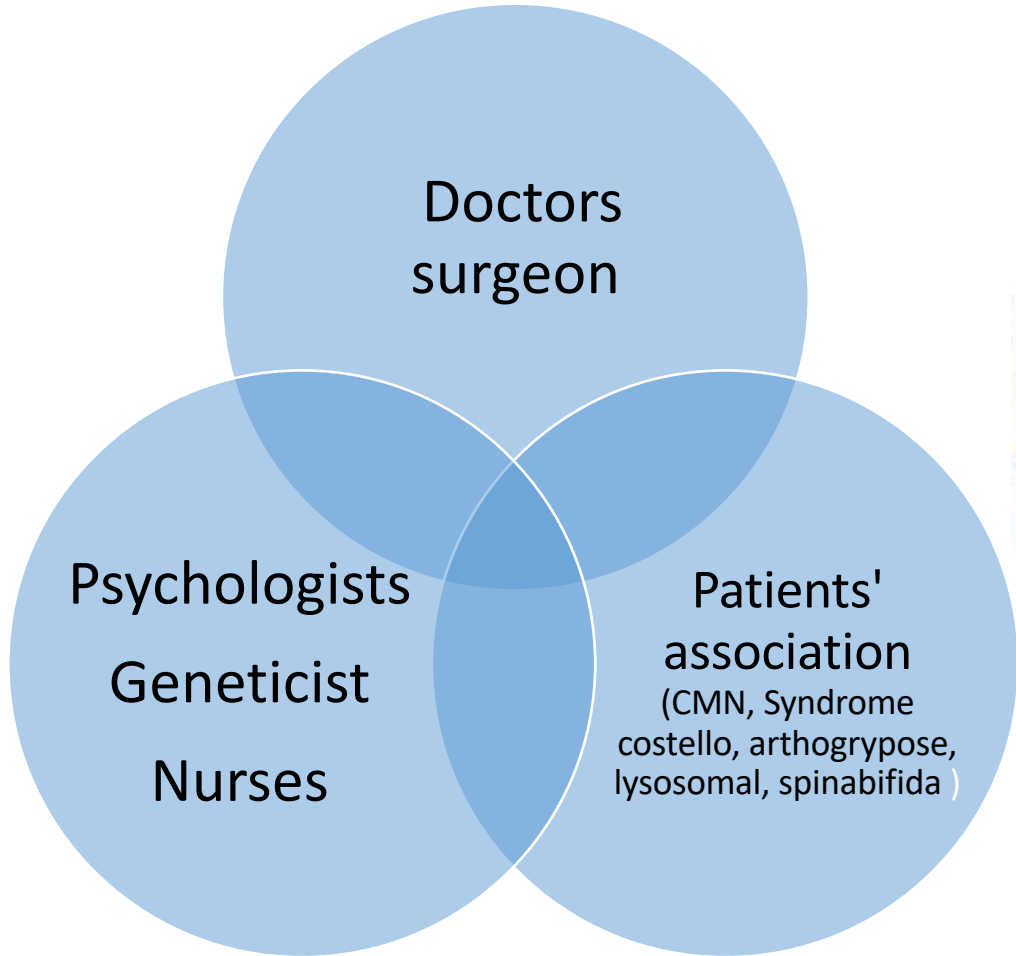


How to answer insensitive questions or remarks from strangers ?

Our Therapeutic Education Program



The French Team !



AnDDI-Rares



For whom?

what's the problem ?



How people look at us !



The programme is aimed at children aged 6-11 years old but by subgroup :
a group of 6-8 year olds and
a group of 9-11 year olds.
groups of 4 to 8 children

Each session is 3 hours long.
Either by homogeneous groups of pathologies, or mixed.

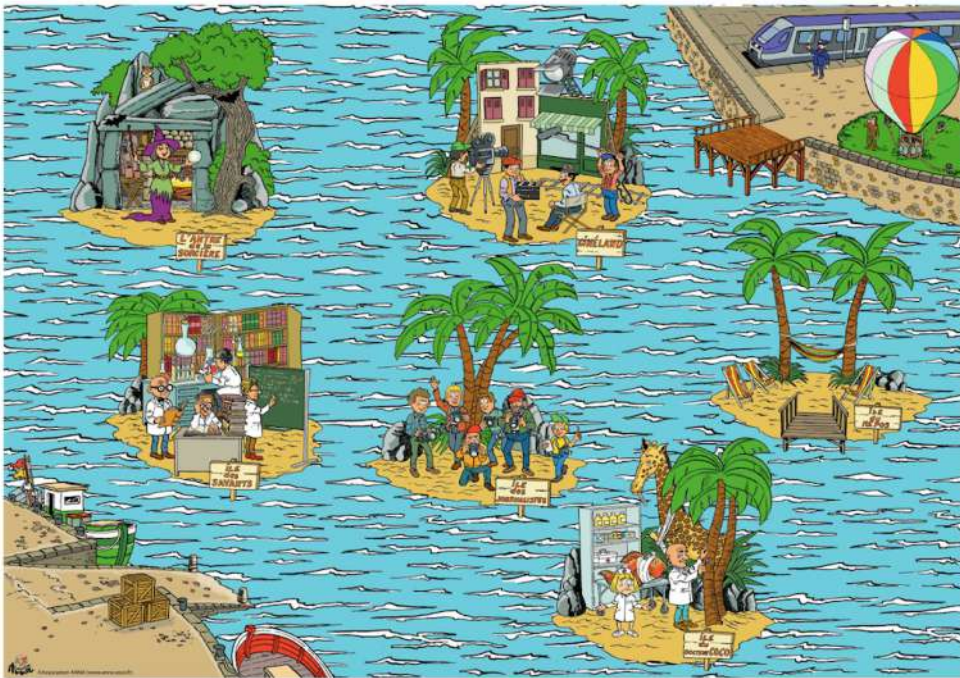


The program is based on childrens imagination and takes them on a hot air balloon trip, each stopover corresponding to a stage of the program.

We have created a case that contains all the tools necessary for the animation of these workshops (travel diary, flight plan, chek-list, situation cards, dominos-emotions...).

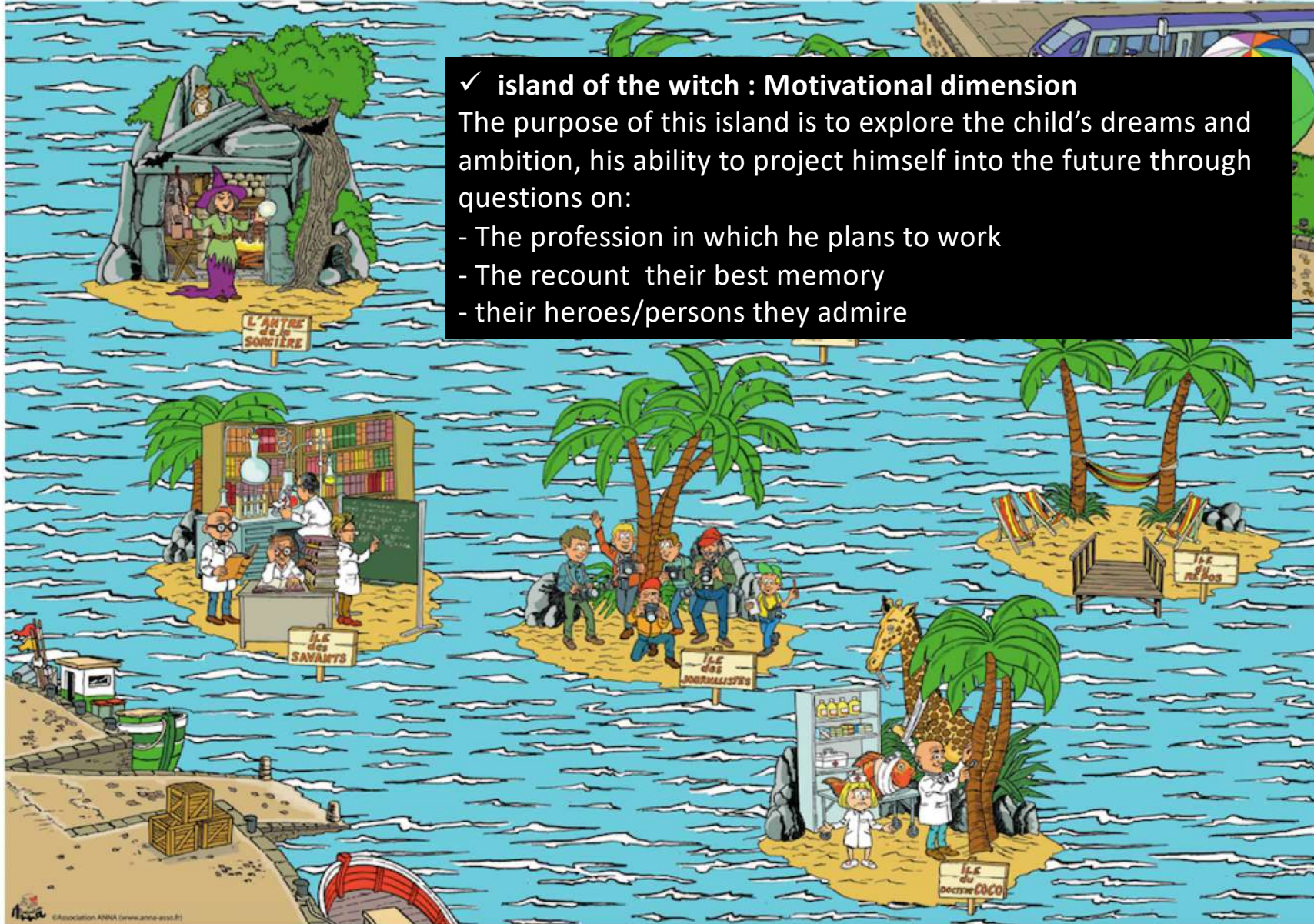
The child will be accompanied by the pilot of the hot air balloon who will play the role of the guide.

Before the program : The Educational Diagnosis



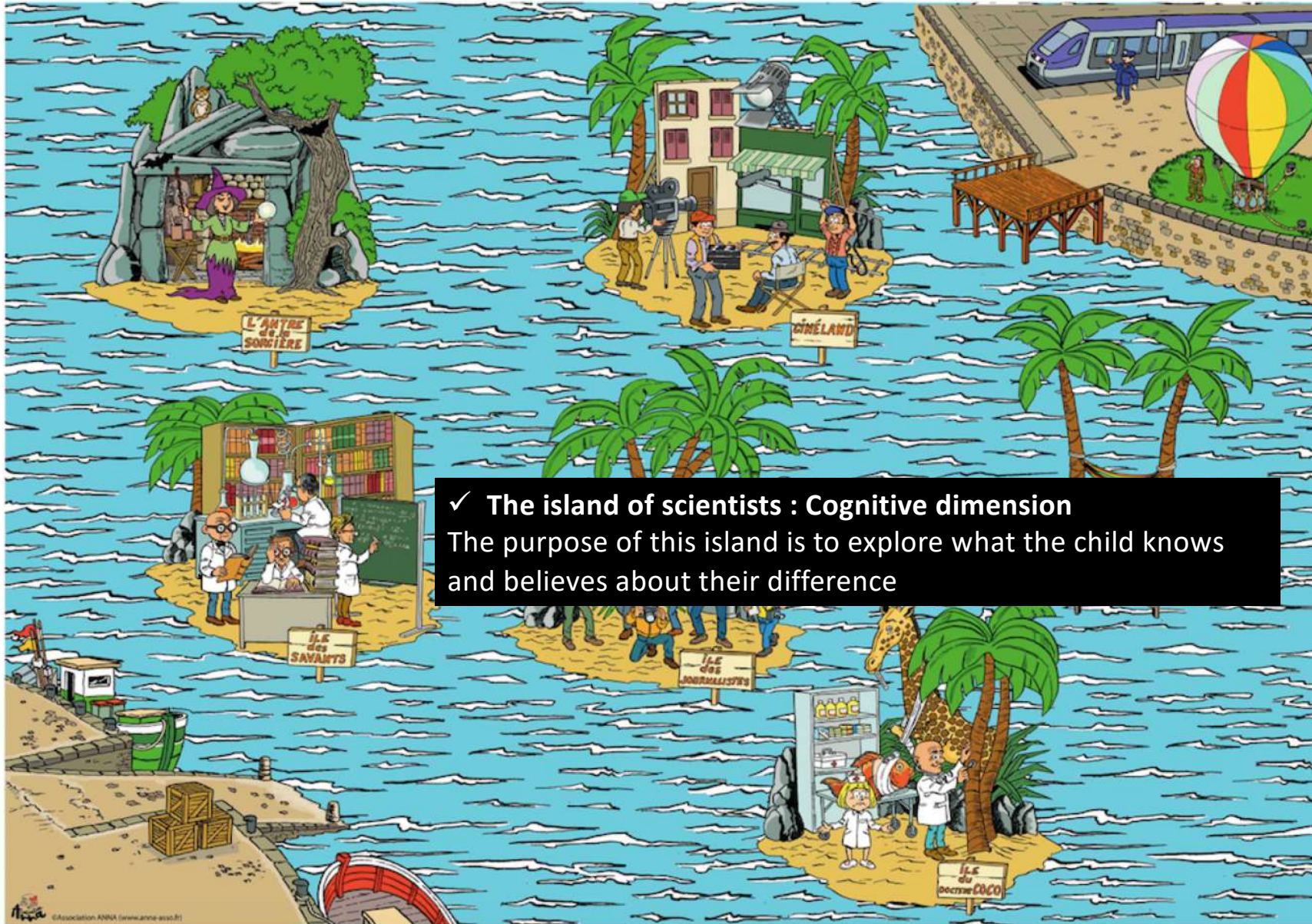
The educational diagnosis will aim to understand whether the child with a morphological difference experiences a problem or have they found their own personal resources to reach a form of resilience:

- If there is resilience, then it should be respected.
- Otherwise we need to determine the type of help the child needs
- We create a board game for this diagnosis.

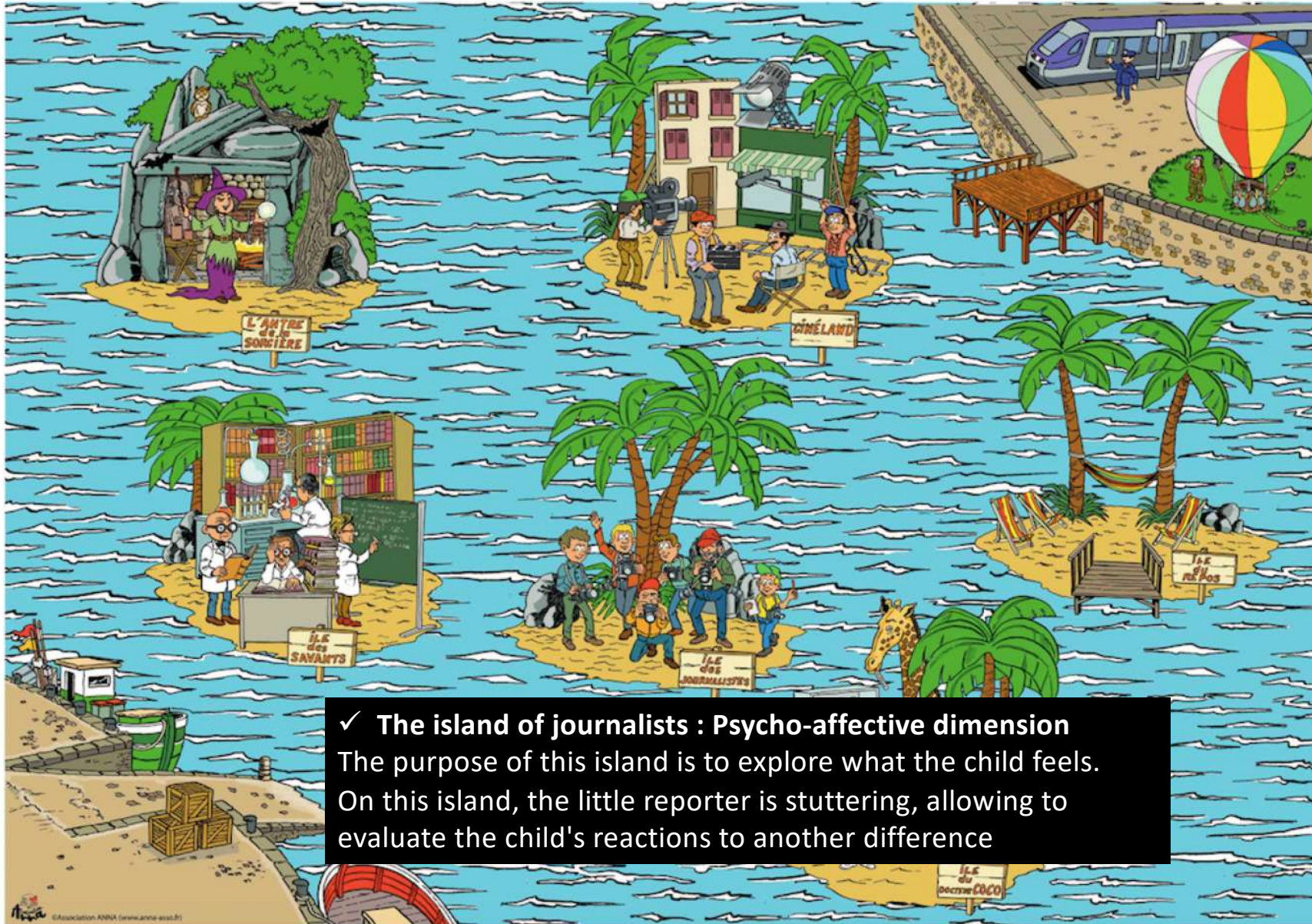


✓ **island of the witch : Motivational dimension**
The purpose of this island is to explore the child's dreams and ambition, his ability to project himself into the future through questions on:

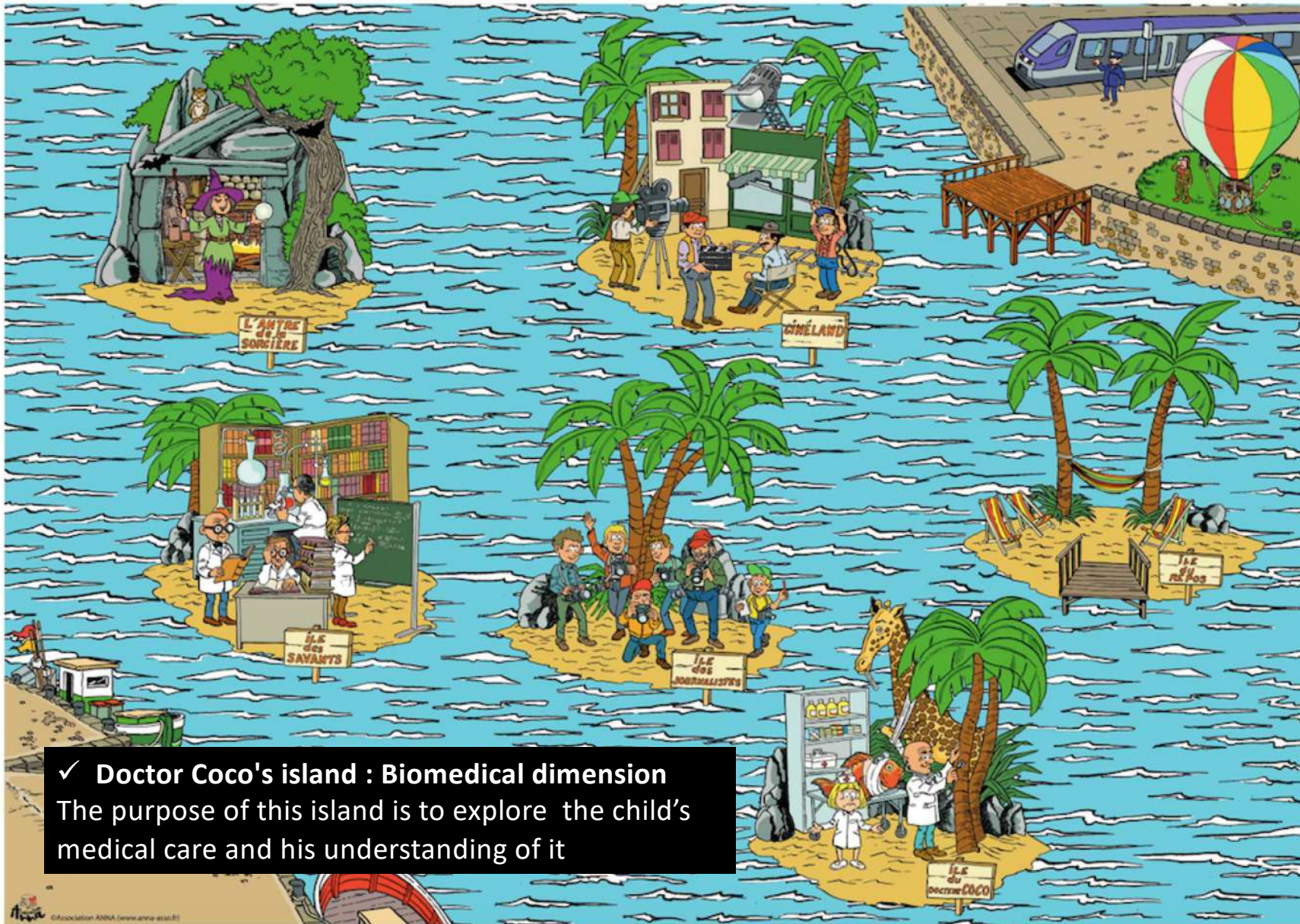
- The profession in which he plans to work
- The recount their best memory
- their heroes/persons they admire



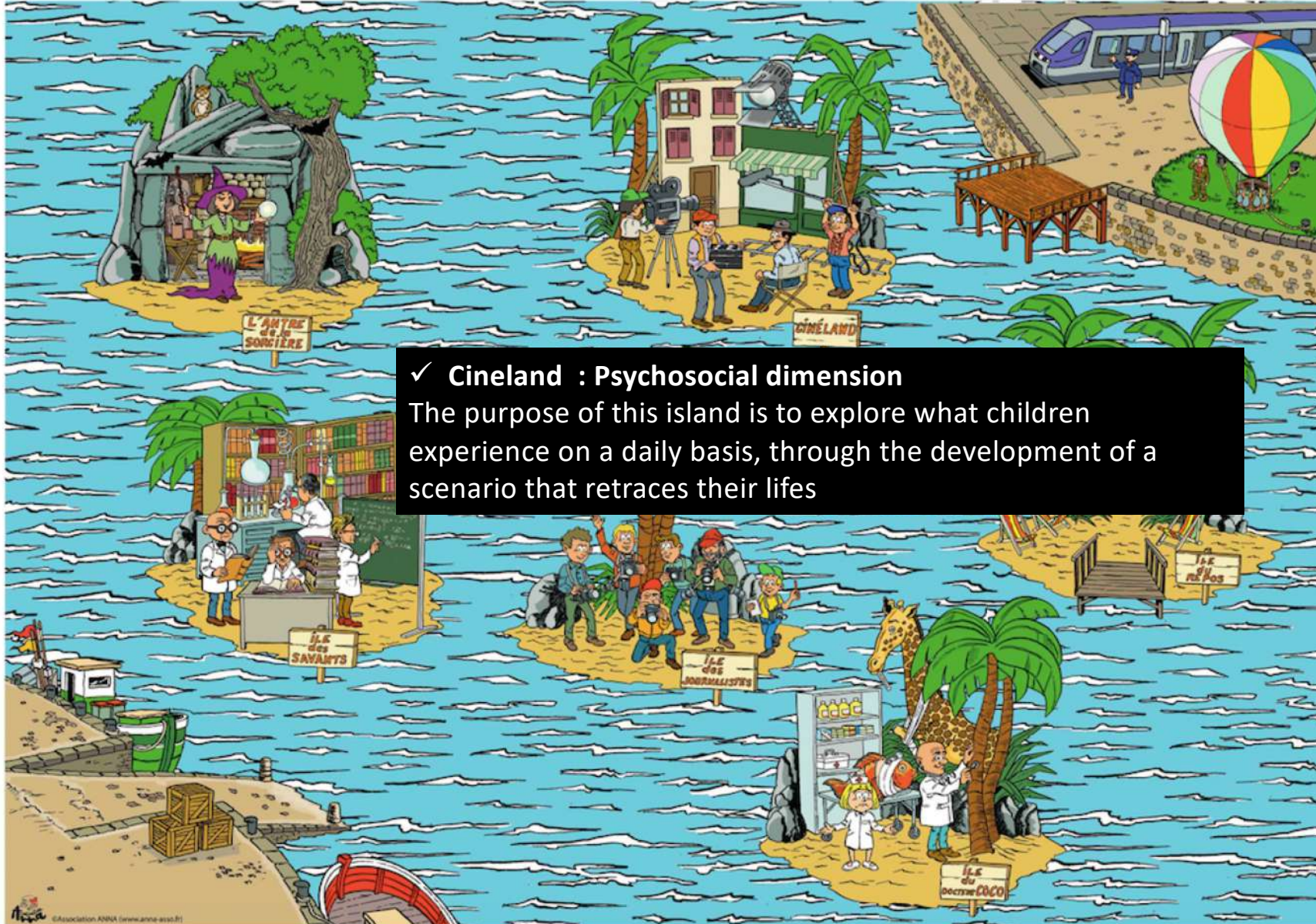
✓ **The island of scientists : Cognitive dimension**
The purpose of this island is to explore what the child knows and believes about their difference



✓ **The island of journalists : Psycho-affective dimension**
The purpose of this island is to explore what the child feels.
On this island, the little reporter is stuttering, allowing to evaluate the child's reactions to another difference



✓ **Doctor Coco's island : Biomedical dimension**
The purpose of this island is to explore the child's medical care and his understanding of it



✓ **Cineland : Psychosocial dimension**
The purpose of this island is to explore what children experience on a daily basis, through the development of a scenario that retraces their lives

Therapeutic Education Program

A hot air balloon trip with 4 stops and a final assessment

A travel diary will accompany the child throughout his journey to record their reactions, their discoveries, and to keep a record of they have learnt.



Workshop 1: Stopover 1

Important concepts to understand and work on



Understand the differences and similarities between all individuals,

- Understand difference between natural curiosity and negativ curiosity : To deal with natural curiosity in a positive manor.
- Review the medical knowledge they have acquired on the origin of their condition.



Coconut of knowledge



Hats game



Workshop 2: Stopover 2

Two psychosocial adjustment strategies (Coping)



Magic parchemin

EN PISTE (STEPS) and E-R-D

- How to introduce myself and prepare myself to face anxiety-provoking situations
- How to answer the curiosity about my physical particularity

This workshop aims to personalize each child's responses so that they can take ownership of them by experimentation.



Magic shield

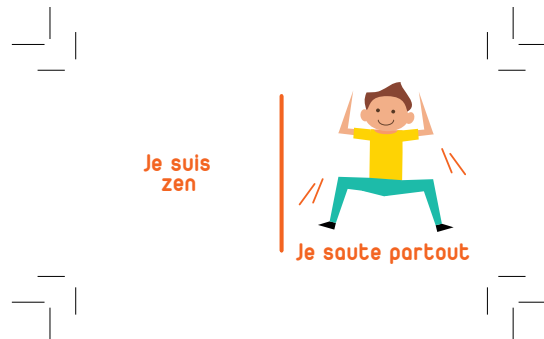
Workshop 3 : Stopover 3

Understanding emotions



- Understand their emotions and therefore the reactions they induce.
- Understand the emotions of others and their reactions

Domino game to understand that the same emotion can induce different behaviors and vice versa



Game « time's up » of emotions



Identify the emotions, and behaviour of the characters in the movie « Wonder »

Workshop 4 : Stopover 4

How to Deal with people and sensitive situations



On the strength of the three previous workshops, the child will be able to confront delicate situations that they have chosen to work in.

Tools :

- game cards situation
- simulation exercise with role play
- problem solving method (7 steps)

Situations :

Teasing, stigmatization, staring...



Final assessment



The travel diary



Stopover	Observation of flight conditions	Stamp and/or signature of the pilot



Thank you for your attention
and you to play now !

www.anna-asso.fr

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ou La Fnac