



AUTISM in CONTEXT

from neurodiversity to neuroharmony

H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

What is H.A.P.P.Y.?

Autistic individuals may have a brain that works differently from the brains of non-autistic people, leading to a different and unique experience of the world. But they are not different from any other human being on this planet in their basic needs. People on the autism spectrum have the same needs as everyone and the ultimate need of all human beings is to be happy.

Research has shown that quality of life and well-being is – on average – lower in the autistic population, but there is a huge variability on the individual level. There are autistic individuals who are very unhappy. And based on what research tells us, a significant number of autistic people have mental health issues and suffer from stress, depression or anxiety issues. But there are also autistic people who are very happy. So, there is evidence that it is possible to lead a happy and fulfilling life if you have autism. And there are examples. For instance, case number 1 in the pioneer article on autism written by Leo Kanner in 1943, a boy named Donald T., has led a safe, happy and fulfilling life. At the time of this writing, Donald is 87 years old. He is retired, but still plays golf, drives around with his car and travels abroad. If you got an autism diagnosis in the 30's of the 20th century, it was certainly not because the so-called 'symptoms' or behaviours indicative of autism were very mild and subtle. So, Donald's story proves that the so-called severity or degree of autism (terms I actually hate, but I use them because they are commonly used) is unrelated to quality of life. Therefore, I am convinced that happiness is within the reach of all people with autism, regardless of the nature and profile of their autism, their intellectual abilities and their age.

There is an abundance of books, websites, and programmes for happiness. There are innumerable happiness gurus out there all offering their recipe for happiness. But not



all not all of that advice is substantiated by solid scientific research. At Autism in Context we have always valued research and evidence based strategies. We are convinced that autistic people have the right to receive information and suggestions that are underpinned by decent scientific research.

Well-being research has revealed several strategies that increase the happiness and wellbeing of people. However, I am convinced that these evidence based wellbeing strategies cannot be applied to autistic people without taking into account their unique profile of perceiving and understanding the world.

One small example. Learning to relax and being mindful is one of the many evidence based strategies for feeling better and coping with stress. Research by Annelies Spek in The Netherlands has shown that mindfulness has the potential to help people on the autism spectrum reaching a more peaceful mind but also that 'regular' mindfulness interventions are too 'vague' for autistic individuals (see: <https://www.autismandmindfulness.org/articles/>). So, in order to be effective, mindfulness activities and instructions need to be made 'autism friendly'.

On top of that, although the quest for happiness is universal, the pathways towards happiness are unique. There is scientific evidence that kindness and gratitude increase our wellbeing, but the concrete gratitude activities that work for one person do not necessarily work for other people. And this applies also to autistic people. There is this famous quote by Dr. Stephen Shore, world-renowned autism advocate: "If you've met one person with autism, you've met one person with autism." With this quote, Stephen wanted to emphasize that there is great diversity within the autism spectrum. Like all people, people with autism are unique. So, any wellbeing strategy or intervention needs to be tailor made and personalized.

To summarize, these are the postulates of the H.A.P.P.Y.-programme:

- happiness is within reach of all people with autism, regardless of the nature and profile of their autism, their intellectual abilities and their age
- a programme for happiness and wellbeing should be underpinned by scientific findings
- a programme for happiness and wellbeing for autistic people should make the regular evidence based wellbeing interventions autism friendly
- a programme for happiness and wellbeing for autistic people should be individualized

In addition, we strongly believe that such a programme should involve as much as possible the active participation of the individual with autism: a programme that is 'made together' as much as possible.

This is what H.A.P.P.Y. is all about: **developing evidence based, personalized and autism friendly strategies that aim at increasing an autistic persons wellbeing.**

H.A.P.P.Y. is a flexible programme

H.A.P.P.Y. is a programme that results in a **personalized workbook** for a *young* person on the autism spectrum with suggestions for activities that are concretisations of 10 evidence based wellbeing strategies.

With 'young' we mean every person between 0 and 99. Trying to stay and feel young is a part of every happiness plan....

There are two basic versions:

- one for **autistic children**: here the workbook is made with and for the parents and/or the professionals working with the child
- one for **autistic (young) adults**: here the workbook is made with and for the autistic individual

H.A.P.P.Y. is a flexible programme:

- with youngsters or young adults, the workbook can also be developed with them **and** their parent(s) or another person or professional of their choice;
- making the workbook together can be done on an **individual basis**, but also in **group** (a group of parents making a personalized plan for their children or a group of adults making a plan for themselves);
- the workbook with the suggestions can be written by a qualified and licensed H.A.P.P.Y.-coach and when completed discussed with the parents / professionals / autistic adult, but the workbook can also be gradually developed and discussed in different stages; there is **no predefined procedure, nor a predefined number of 'sessions'**. It is up to the H.A.P.P.Y.-coach to decide (preferably in agreement with the user) what is the best procedure to develop and discuss the workbook;
- discussing the different sections of the workbook can be done in **live** meetings but also in **online** meetings;
- the programme can end with a discussion of the personalized workbook, but it is also possible to organize one or more **follow-up sessions**. Actually, it is highly recommended to have follow-up sessions, knowing that is far from easy to translate suggestions into concrete actions. The H.A.P.P.Y.-programme could also be used at the beginning of a counselling process or other clinical and/or psycho-educational work.

How does H.A.P.P.Y. work?

To start with, the parents (child version) or the autistic individual (adult version) fills in a **questionnaire** to inform the H.A.P.P.Y.-consultant about the current well-being, the unique living situation and the wishes for a happy life.

Attached to this questionnaire is the **Personal Wellbeing Index (PWI)**, a validated scale measuring satisfaction in eight life domains, developed by the Australian Centre on Quality of Life of Deakin University. This measure can be used for measuring the effect of the H.A.P.P.Y.-programme, in addition to other and more informal ways of evaluating the programme.

Based on the information given in the questionnaire, the H.A.P.P.Y.-coach develops a **unique and personalized workbook** with ideas to increase the well-being of the autistic person. These suggestions and recommendations are grouped into 10 categories, covering the different evidence based strategies:

1. Accepting and loving yourself
2. Good Feeling toolbox
3. Flow activities
4. Physical exercise
5. Problem focused coping strategies
6. Emotion focused coping strategies
7. Positive thinking
8. Gratitude
9. Kindness
10. Personal projects: learning something new

Each section starts with a general explanation of the strategy, followed by concrete suggestions made by the H.A.P.P.Y.-coach. The workbook offers the opportunity to add suggestions that cannot be placed in one of the 10 categories.

On average a completed workbook contains between 30 and 40 pages.

Prior to the suggestions there is some **psycho-education on happiness**: a chapter about happiness, what it is but also what happiness is not. This chapter also clarifies what can and what cannot be expected from the workbook.

Once the H.A.P.P.Y workbook is completed and discussed with the autistic person and/or the parents and professionals, they then start working with the suggestions written in the workbook. The workbook is a kind of to-do list for practicing activities that can enhance the well-being of the person.

Depending on how the workbook is being used, **follow-up sessions** can be organized to discuss how the implementation of the suggested activities goes.

After 3 or 6 months, an **informal evaluation** is done and the autistic person and/or the parents and professionals are asked to fill in the **Personal Wellbeing Index** again, with the purpose of some more formal assessment of the effects of the H.A.P.P.Y.-programme.

What are the requirements to work with H.A.P.P.Y.?

The qualities of a competent H.A.P.P.Y.-coach are:

- **profound knowledge of the autistic cognitive style** (including knowledge about a.o. episodic memory, self-reflection, absolute thinking, interoception and emotion regulation, predictive processing in autism) beyond theoretical knowledge, i.e. being able to translate the knowledge into concrete actions;
- **autism friendly in interaction and communication** (e.g. skilled in concrete communication, sensitive to information processing difficulties)
- **flexible**: willing to adapt the programme to the person rather than adhering to the structure of the programme in a strict way
- focused on **collaboration** and **empowerment**
- **creative**, especially in terms of generating individualized, concrete and practical tips

The H.A.P.P.Y.-programme can only be used after **training**.

This training will be available live and online and contains the following:

- an introduction to 'autism and well-being'
- a lesson describing the evidence based happiness strategies
- a lesson on the autistic cognitive style and how it can affect the happiness strategies
- a lesson describing the different formats of the H.A.P.P.Y.-programme
- a lesson with the guidelines for working with the H.A.P.P.Y.-programme
- supervision and intervision session(s) where the trainees present their work with the H.A.P.P.Y.-programme and get feedback on that work

After following this basic training, the trainee receives a **certificate**.

That certificate allows the trainee to use the H.A.P.P.Y. materials but does not allow using the term 'certified H.A.P.P.Y.-coach'.

To qualify for the use of the term 'certified H.A.P.P.Y.-coach', a **license** is required. To obtain a H.A.P.P.Y.-coach license, the following is required:

- an engagement to use the H.A.P.P.Y. programme with at least 5 people every year
- attending one supervision session per year where the trainee shows competence in using the H.A.P.P.Y.-programme
- sending in the Personal Wellbeing Index forms used at the beginning and at the follow-up of the H.A.P.P.Y.-programme for research purposes

Licensed H.A.P.P.Y.-coaches will be informed about updates of the H.A.P.P.Y.-programme.