Autism in Context

Scottish autism
CELEBRATING
50 YEARS

From neurodiversity to neuroharmony.
Plea for a smaller but stronger autism

Medical and social model of disability

Medical model

- The cause of the disability is one or more deficits in the person
- Try to find the deficits, e.g.:
    - Genes
    - Toxic substances
    - Vaccines
    - Lack of social skills and Theory of Mind
- And then treat it:
    - All kind of therapies

Social model

- The cause of the disability is society and it's lack of opportunities for autistic people and other neurodiverse people to fit in
- Try to find the shortcomings of society, e.g. the discrimination, inequality, exclusion etc.
- And then do something about it through political action, awareness campaigns, etc.

What's wrong with the (extreme) medical and social model?

- They are linear: cause $\rightarrow$ effect
- They involve some kind of blaming
- They are polarizing: us vs. them

What's wrong with the (extreme) medical and social model?

- They have some unwanted side effects:
  - Medical model: trying to 'normalize' autistic people reduces their authenticity
  - Social model: can lead to pampering and 'learned helplessness'
- Autism can never be an alibi nor an excuse
  - For the environment to make no efforts to become more autism friendly and make adaptations and adjustments
  - For the autistic person not to try to fit in and learn to adapt to the environment as much as possible

Autism is never an excuse

Temple Grandin

"Mother just knew how hard to push me"

"My mother had high expectations for my behaviour"

Ros Blackburn

"I need high expectations and high levels of support"

"Give me moments of disappointment and frustration, so I can learn to deal with it"

Autism friendly environment

Is not the same as avoiding challenges and obstacles

It is about helping autistic people to face the challenges and overcome the obstacles

Happiness is not the absence of problems; but the ability to deal with them.

Don't avoid challenges, but make them autism friendly

Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity

Adam Helles[1,2], I Carina Gillberg[1], Christopher Gillberg[1] and Eva Billstedt[1]

Despite difficulties with functioning in everyday life, many seem to be able to deal with adversity and cope well with challenges

What's wrong with the (extreme) medical and social model?

- It's too black and white
- The question is not: is autism a disability or not?
- The question is: when and where does autism lead to a disability?
- Disability is not a characteristic of the person, nor of the environment: disability is the consequence of the combination person-environment
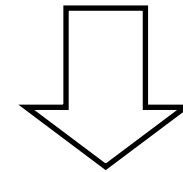
Double track approach

Society	Autistic person
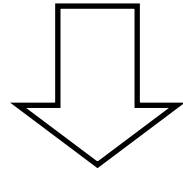
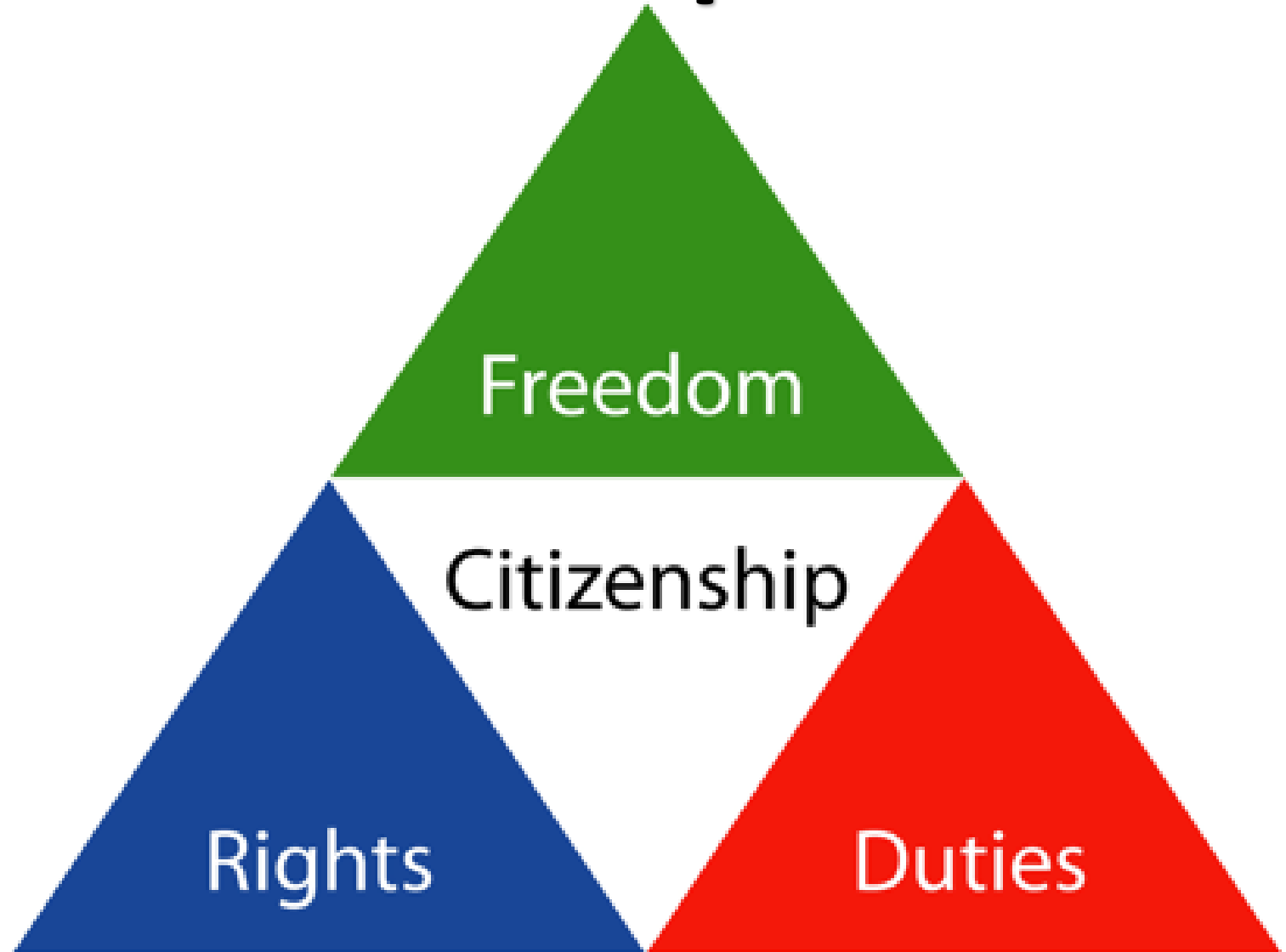| Changing the environment	Changing the person
adapting	teaching

Citizenship model

The alternative for the medical and the social model:

Time to make a U-turn

What can society offer to autistic people?

What can autistic people offer to society?

Every autistic person has something to offer.
So, therefore society can expect them to contribute to society.
We all need each other!

What's wrong with the (extreme) medical and social model?

- It starts from differences

- Differences should be acknowledged, but not inflated to the cost of ignoring all the similarities

- It is time to start focussing also on the similarities, not only the differences

Autistic people are not that different

In terms of
- Behaviour
- Cognition
- Needs

There is no such category as "autistic behaviours," only "human behaviours".
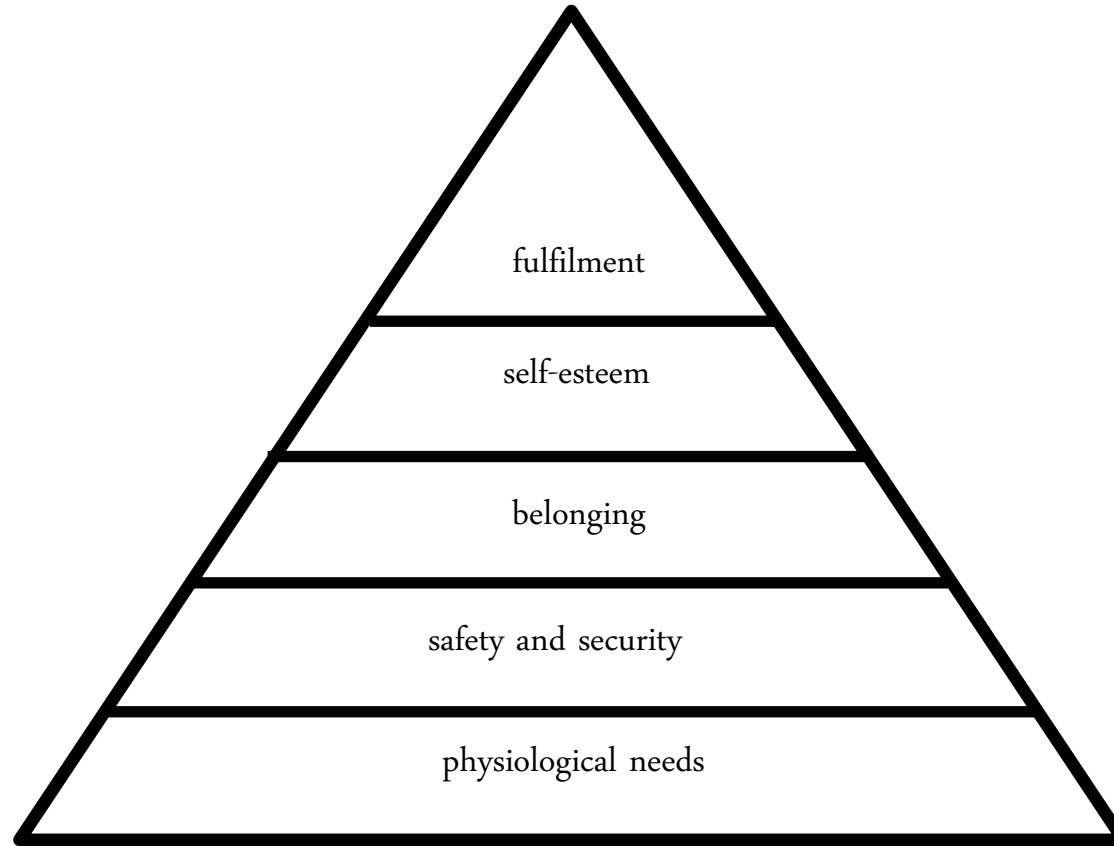
Let's start from a shared human experience.

Barry Prizant

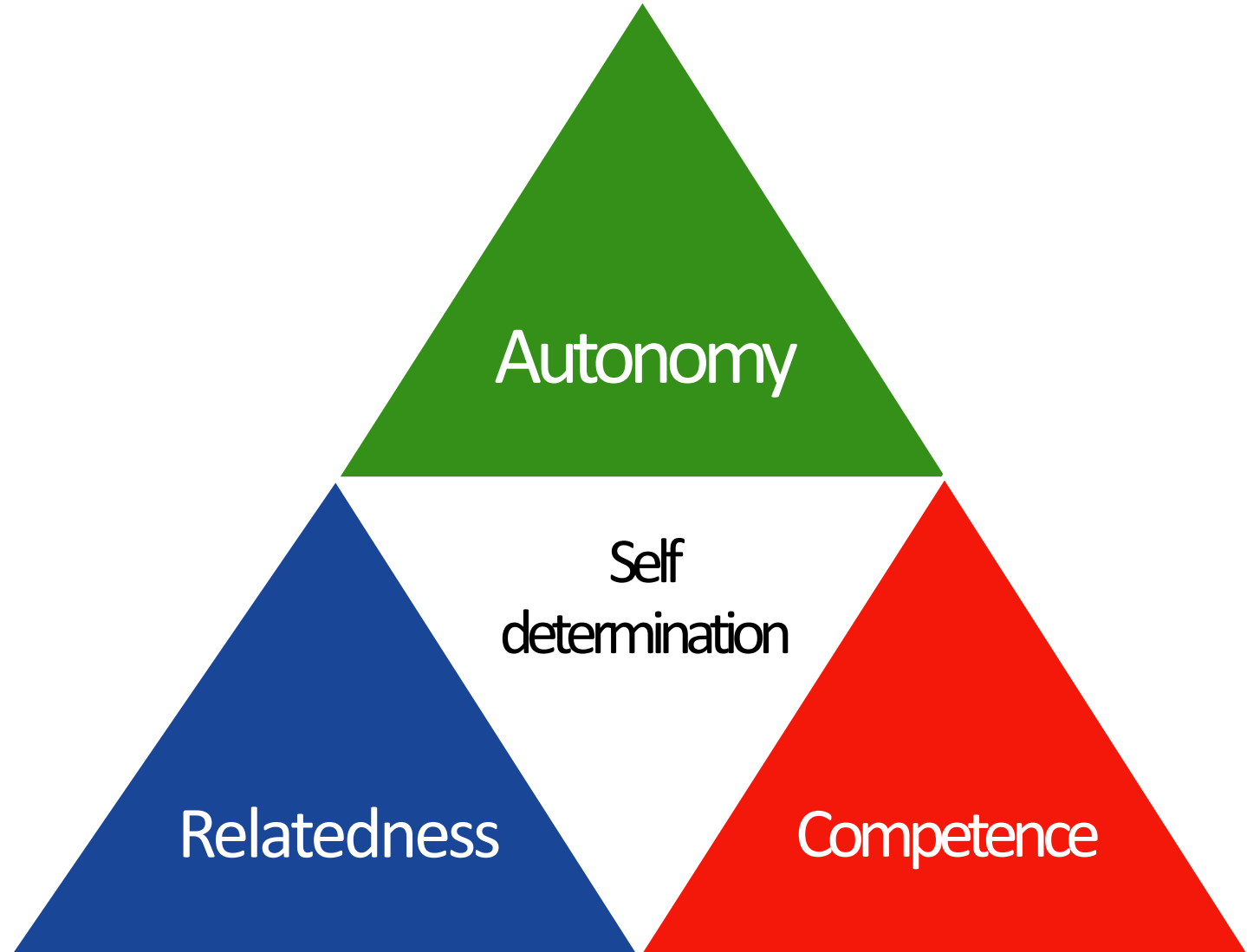There is more in the autistic brain than autistic thinking.
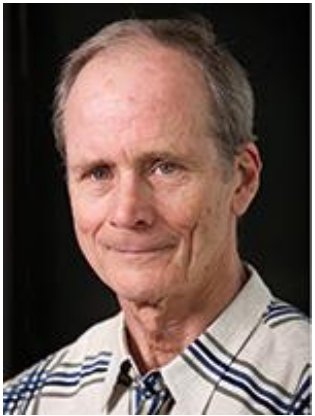
A guy from Belgium

Universal needs: Maslow's hierarchy

Abraham Maslow

fulfilment

self-esteem

belonging

safety and security

physiological needs

Universal needs: self-determination theory

Edward Deci & Richard Ryan

Redefining the outcomes in autism

employment   relations / friends   health

cognitive functioning   living situation   autism symptoms

+

Objective criteria
societal norms

Subjective criteria:
wellbeing

Too little attention for wellbeing

Evidence-Based
Practices for
Children, Youth,
and Young Adults
with
Autism Spectrum Disorder

Connie Wong, Samuel L. Odom,
Kara Hume, Ann W. Cox, Angel Fettig,
Suzanne Kucharczyk, Matthew E. Brock,
Joshua B. Plavnick, Veronica P. Fleury, and Tia R. Schultz

Autism Evidence-Based Practice Review Group
Frank Porter Graham Child Development Institute
University of North Carolina at Chapel Hill

Outcomes related to	Studies (N = 456)
Communication	182 (39,9%)
Social skills	165 (36,2%)
Challenging/Interfering Behaviors	158 (34,6%)
Play	77 (16,9%)
School Readiness Skills	67 (14,7%)
Pre-Academic/Academic	58 (12,7%)
Adaptive/Self-Help	57 (12,5%)
Joint Attention	39 (8,6%)
Motor skills	18 (3,9%)
Cognitive skills	15 (3,3%)
Vocational skills	12 (2,6%)
Mental Health and Emotional Well-being	1 (0,2%)

Challenge for the future: increasing the eudaimonic aspects of well-being

Pleasant life

Positive feelings

Joy - Pleasure

Absence of pain

Safety

Activities you like

Meaningful life

Contentment

Purpose in life

Personal growth

Serving others

Life satisfaction

Diagnostic overshadowing

Makes invisible:

- Talents
- Needs
- Interest
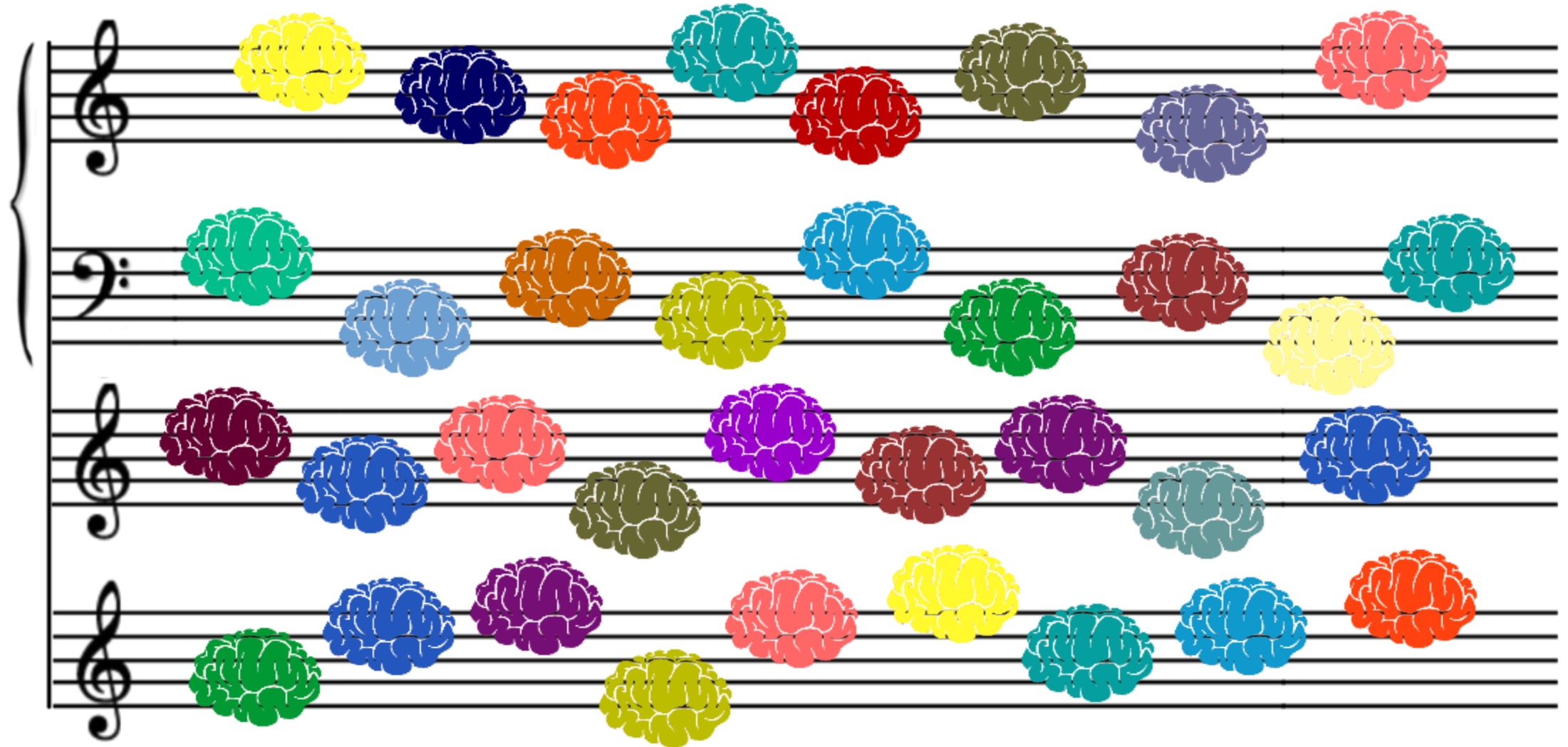- And all the other characteristics of a person

Autism is being used as a catch-all explanation

People with autism being forced into stereotyped one-liners about autism

Neuroharmony

Ways to neuroharmony

- Moving from the traditional models of disability (medical model and social model) to a citizenship model of disability
- Seeing the similarities, not only the differences
- Starting from (individual) needs, not from diagnoses or labels
- Not using autism as an explanation for everything (both positive and negative things)
- Making autism smaller again