

Coping with uncertainty

Peter Vermeulen, PhD
Autism in Context

MAR
11
2021

**Autism and Mental Health
Conference 2021**



www.petervermeulen.be



How can we play tennis?



The brain is a
prediction organ

And it doesn't like
uncertainty!



VUCA

VOLATILE

UNCERTAIN

COMPLEX

AMBIGUOUS

WORLD

Precise Minds in Uncertain Worlds: Predictive Coding in Autism

Sander Van de Cruys, Kris Evers, Ruth Van der Hallen, Lien Van Eylen,
Bart Boets, Lee de-Wit, and Johan Wagemans
KU Leuven



Autism as a disorder of prediction

Pawan Sinha^{a,1}, Margaret M. Kjelgaard^{a,b}, Tapan K. Gandhi^{a,c}, Kleovoulos Tsourides^a, Annie L. Cardinaux^a,
Dimitrios Pantazis^a, Sidney P. Diamond^a, and Richard M. Held^{a,1}

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Contributed by Richard M. Held, September 5, 2014 (sent for review November 13, 2013; reviewed by Leonard Rappaport, Stephen M. Camarata, and Nouchine Hadjikhani)

The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis

Autism
2020, Vol. 24(8) 1933–1944
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DOI: 10.1177/1362361320932437
journals.sagepub.com/home/aut



Richard Jenkinson¹ , Elizabeth Milne¹ and Andrew Thompson² 

Abstract

The association between intolerance of uncertainty and anxiety has proved robust in neurotypical populations and has led to effective interventions targeting intolerance of uncertainty. The aim of this systematic review and meta-analysis was to investigate this association in autistic people, given the high prevalence of anxiety in this population and the limited effectiveness of therapies used currently to treat anxiety in autism. A protocol was published on the Prospero database (CRD42019125315), and electronic databases were searched using terms related to intolerance of uncertainty, anxiety and autism. Included in the systematic review were 12 studies, of which 10 were included in a meta-analysis. Results showed that anxiety and intolerance of uncertainty were consistently elevated in autistic participants. Examining the correlation between these two constructs, the meta-analysis revealed a large sample-weighted effect size, $r=0.62$, 95% confidence interval = [0.52, 0.71], $p < 0.001$. The strength of this association was comparable to meta-analyses conducted on neurotypical populations, and therefore, it was concluded intolerance of uncertainty may be an appropriate target for intervention for autistic individuals. However, conclusions were limited due to the small number of relevant studies that were available and due to issues with methodological quality.



VUCA

VOLATILE

UNCERTAIN

COMPLEX

AMBIGUOUS

WORLD

more than ever now

Living in uncertain times

Left stranded: our new report into the impact of coronavirus

Published on 07 September 2020



- 9 in 10 autistic people worried about their mental health during lockdown
- 85% said their anxiety levels got worse



The impact of the COVID-19 pandemic on autistic adults

Research group EXPLORA (Ghent University) has set up an online survey to investigate the effects of the current COVID-19 pandemic on the mental health and daily lives of adults on the autism spectrum. The tremendous impact of the pandemic has affected society as a whole, but this study aims to better understand how the current pandemic affects autistic adults specifically, so that tailored support and advice can be given to this group. Here we present the most societally relevant preliminary results of our ongoing study, in the hope that this will benefit the autistic community and their broader support network at this time.

The preliminary results are based on a sample of 839 participants (mean age = 38, range: 18-81; 573 female), of which 473 reported that they have a formal clinical diagnosis of autism spectrum disorder (ASD)^[1]. To respect the wishes of autistic individuals, we use the term 'autistic', a term endorsed by many individuals with ASD (Kenny et al., 2016). All participants were residents of either Belgium ($N = 467$), the Netherlands ($N = 220$), or the United Kingdom ($N = 152$). For the current report, we combined data from these three countries, but note that results were similar when analysing data for residents of the three countries separately.



Coping with anxiety

angst en autisme



Angst en Autisme

25 abonnees

KANAAL AANPASSEN

VIDEO'S BEHEREN

HOME

VIDEO'S

PLAYLISTS

KANALEN

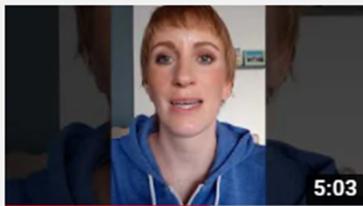
DISCUSSIE

OVER



Uploads

▶ ALLES AFspeLEN



Sanne vertelt hoe ze omgaat met de Coronacrisis

92 weergaven •
5 maanden geleden



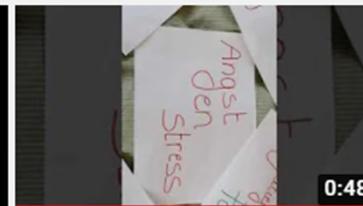
David getuigt hoe hij omgaat met angst en onzekerheid

171 weergaven •
5 maanden geleden



Minne vertelt over angst en onzekerheid

110 weergaven •
6 maanden geleden



Loes vertelt wat angst en onzekerheid met haar doet...

101 weergaven •
6 maanden geleden



Jari over onzekerheid en angst

113 weergaven •
6 maanden geleden



AUTISM in CONTEXT

from neurodiversity to neuroharmony



Uncertainty is not new to us.
We have coped with uncertainty before.

*“You have power over your mind, not outside events.
Realize this and you will find strength.”*

Marcus Aurelius



UNCERTAINTY



WORRYING



ANXIETY / STRESS



Managing your worries

- Plan your worry-time
- Limit the amount of uncertain input
- Contextualize to counterbalance





Will I get infected?

What about the
restrictions?

When will this be over?

There will always be more healthy
people than sick people

We will always be allowed to
watch TV/play games

Every crisis has a beginning
and an ending



What do we NOT know?

If we will be allowed to travel for our summer vacation

When restaurants will re-open

When we will all be protected against the virus

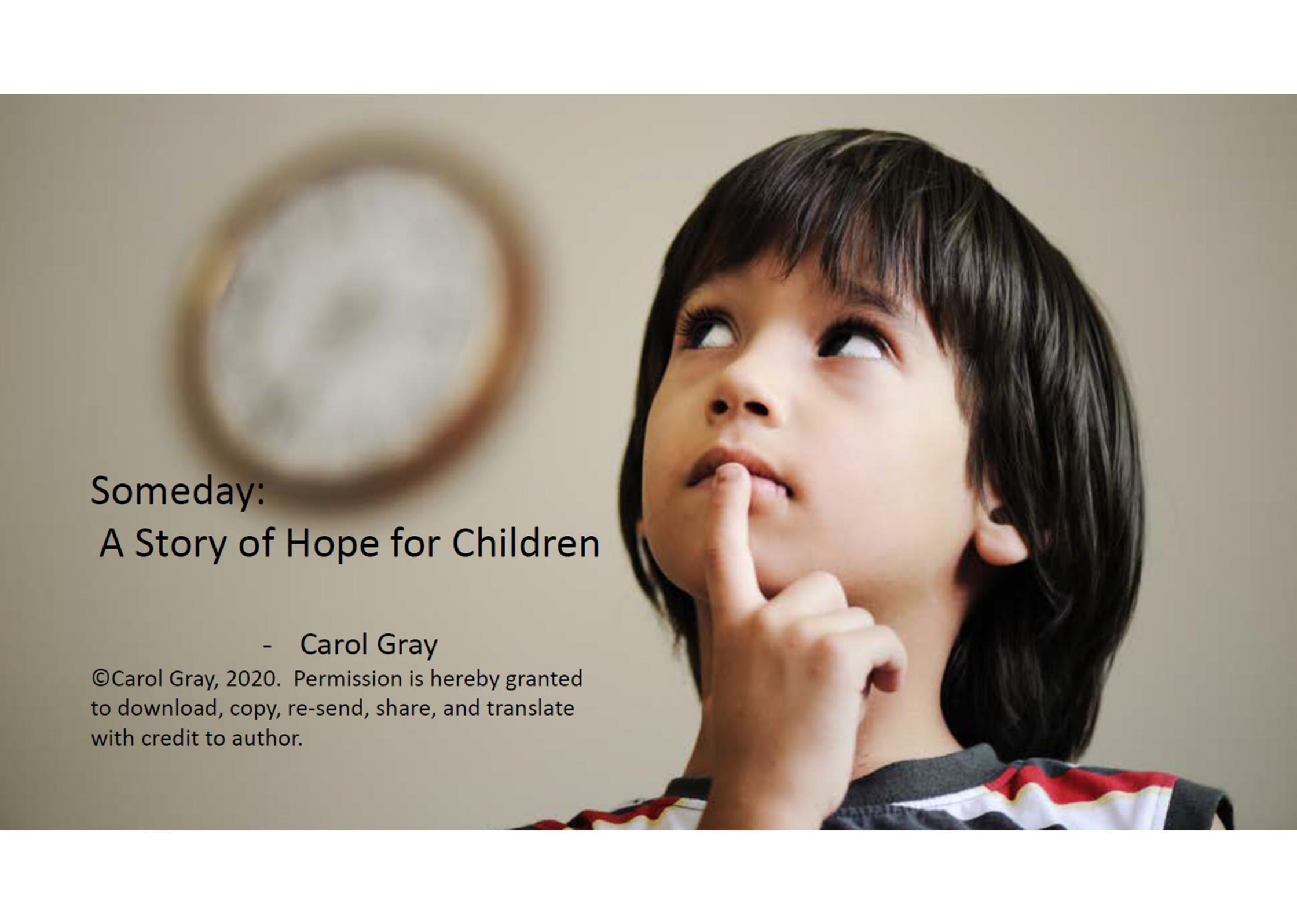
What DO we know?

That we're going to do nice things in our summer vacation

That we can have nice meals at home too

That we can already do things to protect ourselves





Someday:
A Story of Hope for Children

- Carol Gray

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THINK

- True?
- Helpful?
- Inspiring?
- Necessary?
- Kind?



T **IS IT TRUE?**
Is this fact or is it really an opinion or feeling?
Know & be clear before you speak.

H **IS IT HELPFUL?**
Does it help you, them or the situation?

I **IS IT INSPIRING?**
Also, does it IMPROVE on the silence?

N **IS IT NECESSARY?**
Would this be better left unsaid?

K **IS IT KIND?**
What is your motivation for communicating?

The infographic features a light blue background. On the right side, there is a cartoon illustration of two women in business attire. One woman is pointing upwards, and the other is looking at her. Above them are several thought bubbles, suggesting a process of thinking or communication.



H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

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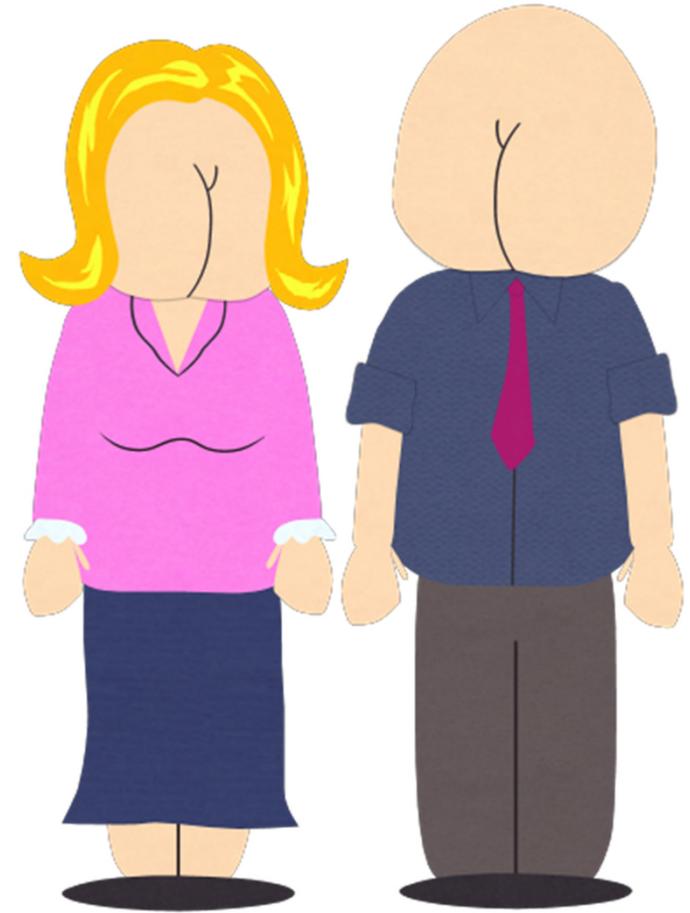


Positive diary
Pride diary

But person

But....

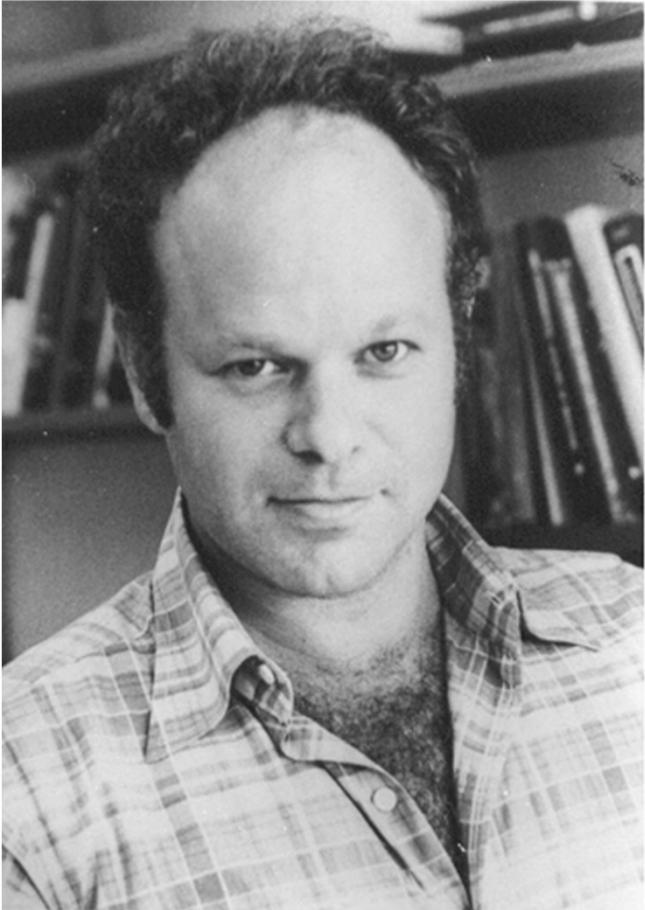
We don't know
when we will
be allowed to...



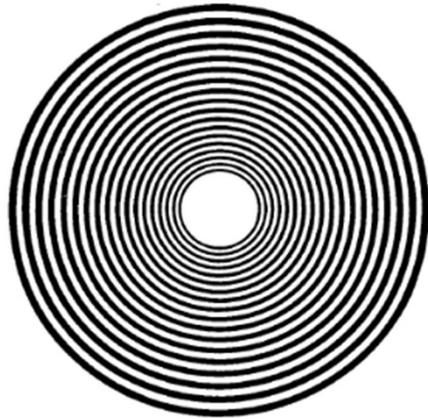


Uncertainty, stress and control

Martin Seligman



Importance of control in stress



URBAN STRESS

Experiments on Noise and Social Stressors

DAVID C. GLASS / JEROME E. SINGER

*New York University
and
Russell Sage Foundation
New York, New York*

*State University of
New York at Stony Brook
Stony Brook, New York*



ACADEMIC PRESS
New York San Francisco London 1972
A Subsidiary of Harcourt Brace Jovanovich, Publishers



David Glass & Jerome Singer



Create islands of control in the ocean of uncertainty



A top-down view of a wooden desk. On the left, a silver laptop is partially visible, showing the keyboard with keys for 'S', 'D', 'Z', 'X', 'C', 'V', 'option', and 'command', and the trackpad. On the right, a green succulent with thick, rounded leaves is partially visible. In the center, a yellow sticky note is placed on the desk, featuring the text 'Your Daily Routine Matters' written in a blue, cursive font.

Your Daily
Routine
Matters

Routines are good for the mental health of children

Published in final edited form as:

J Abnorm Child Psychol. 2011 January ; 39(1): 83–94. doi:10.1007/s10802-010-9447-5.

Family Routine Moderates the Relation Between Child Impulsivity and Oppositional Defiant Disorder Symptoms

H. Isabella Lanza and

Department of Psychology, Temple University, Philadelphia, PA, USA; Integrated Substance Abuse Programs, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, 1640 S. Sepulveda Blvd., Ste. 200, Los Angeles, CA 90025, USA

Deborah A. G. Drabick

Department of Psychology, Temple University, Philadelphia, PA, USA

Feature Articles

Why Routines Matter: The Nature and Meaning of Family Routines in the Context of Adolescent Mental Illness

Femke Koome MHS, Clare Hocking PhD & Daniel Sutton PhD 

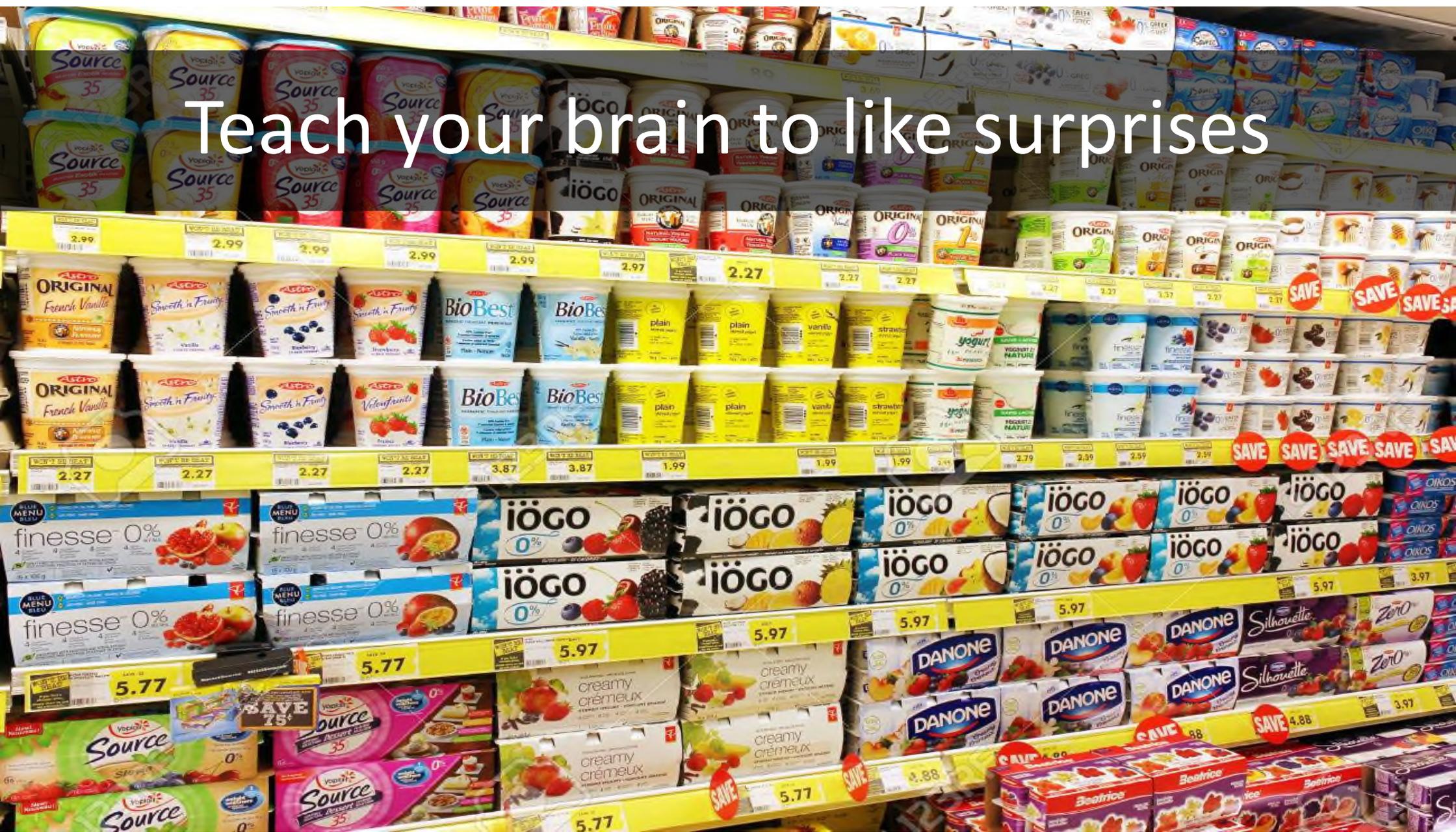
Pages 312-325 | Published online: 19 Sep 2012

 Download citation  <https://doi.org/10.1080/14427591.2012.718245>

Controlled and
predictable small
variations in
routines



Teach your brain to like surprises



Don't try to control the uncontrollable

control



My control chart

Things I cannot control

- The virus
- The measures
- Availability of food
- Time line exit
- The weather
- My personality
- Mr. Donald Trump

Things I can control

- What I eat
- How often I watch the news
- When I do my chores
- When I go to bed

Things I can control with support

- My anxiety
- My thoughts
- My free time
- My screen time
- My children
- My partner



H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

What-if script

I don't know
when my cat
will die.

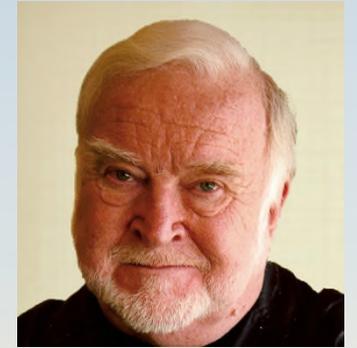


I don't know if I will be
able to cope with the loss.

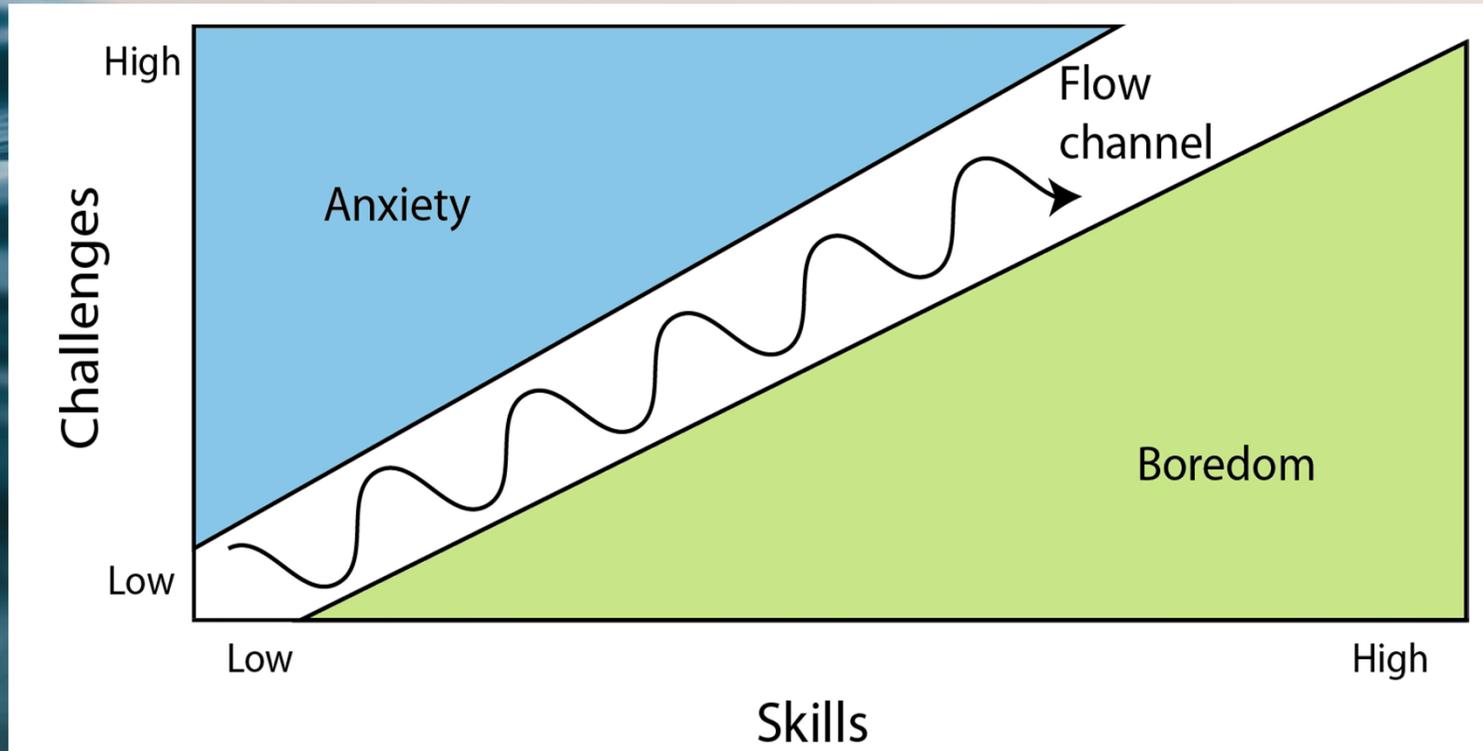
If my cat dies...

...my mum will help me to
cope with my
sadness.

Distraction: flow activities



Mihaly Csikszentmihalyi



Distraction: flow activities



- Catch your attention
- Match your interests
- Stretch your skills a bit
- Have a goal that you have chosen
- You enjoy the journey, not the end



Motivation follows action

Plan the well-being activities



Plan everything!

- The positive thinking
- The physical exercise
- The flow activities
- The worry time
- The relaxation activity
- When you listen to/watch the news

DAY PLANNER

___/___/___



To Do List:

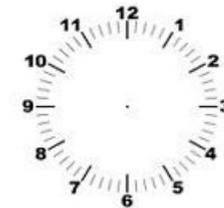
A vertical list of 18 horizontal lines for writing a to-do list.

today I am grateful for

A rectangular box for writing a gratitude note.

daily goals

A rectangular box for writing daily goals.



appointments

A vertical list of five horizontal lines for writing appointment details.

breakfast

A rectangular box for writing breakfast plans.

lunch

A rectangular box for writing lunch plans.

dinner

A rectangular box for writing dinner plans.

water: Eight blue water drop icons arranged in a horizontal row.

snacks

A rectangular box for writing snack plans.

fitness

A rectangular box for writing fitness plans.

mood

A rectangular box for writing mood notes.

Learn to embrace
uncertainty

Fight the insecurity



This is certain:

Uncertainty is the key to
unlocking opportunity





AUTISM in CONTEXT

from neurodiversity to neuroharmony

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[PETER IN CONTEXT](#) ▼

[YOUR CONTEXT](#)

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THANK YOU FOR YOUR ATTENTION

