



*Report from Japan: the radically
integrated approach of Tōjisha-kenkyū*
Martijn Dekker

Online Autscape 2025
9th Feb 2025 10:30am GMT/UTC



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Martijn (rhymes with “design”) Dekker

Quick background

- ❖ 51 years old, autistic parent of three
- ❖ From the Netherlands; live in England
- ❖ Autscape vice chair and tech person
- ❖ September 2024:
 - ❖ Heta Pukki and I were invited to Japan to present on EUCAP and neurodiversity
 - ❖ We learned about a movement and method called “Tōjisha-kenkyū”...



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Tōjisha... (当事者)

- ❖ The Japanese word Tōjisha evolved from a legal term ("party involved in litigation") to a deliberately broad term that can refer to anyone disadvantaged and subject to discrimination
- ❖ Avoids disempowering connotations of words like "victim", "disadvantaged", "marginalised", etc.; reclaims agency
- ❖ Tōjisha is “a name for those without power who are willing to organise and fight for their place in society, and for a right to determine their own future” (Ayaya & Kitanaka, 2023)
- ❖ It's untranslatable!
 - ❖ Inadequate translations include: Party, Party concerned, Party involved, Person concerned, Person involved, Interested party, Stakeholder, Person with hardship



...kenkyū (研究)

- ❖ Kenkyū simply means research
- ❖ **Tōjisha-kenkyū** (当事者研究): people with disabilities and/or mental illness learn to study their own experiences
- ❖ It emerged at Bethel House, in the Japanese fishing town of Urakawa in southern Hokkaido in the early 2000s, from a radical peer support group for people diagnosed with psychiatric disorders. (Ayaya & Kitanaka, 2023)
- ❖ The tōjisha experience is isolating: no collective sharing and problem-solving; there are *no words or concepts* for your experiences. Tōjisha have sometimes invented new words or concepts while researching themselves.
- ❖ 2015: creation of the Tojisha-kenkyu Kumagaya Laboratory at the University of Tokyo, led by Shin-ichiro Kumagaya and Satsuki Ayaya, academics but also tōjisha themselves.
- ❖ The lab *directly interfaces tōjisha-kenkyū with mainstream* science. This makes it possible to confirm and validate hypotheses that tōjisha participants came up with during their process of collective self-discovery. (Kumagaya, 2016)
- ❖ Disabled people are firmly in charge of this process!



12th–13th Sept Arrival







14th Sept Interview



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IFI staff
May 2022



...problem in Europe and in the west in general still very much exists it has not been eliminated.



Many organisations in the west Now use the correct words to make it seem as if they are very enlightened about neurodiversity.

14:43



They might even hire an autistic person so that they can claim that autistic people are involved in the decisions.



But all too often that is a rather agreeable autistic person without too many opinions of their own.

▼ 英語(英国) (English(UK))



ヨーロッパや西洋は依然として存在



西洋の多くの組織発されているかの



彼らは、自閉症の...
するために、自閉



しかし、多くの場
たない、も

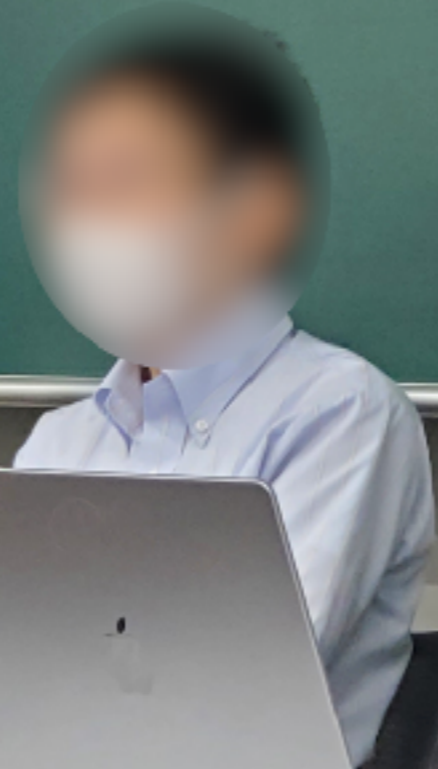
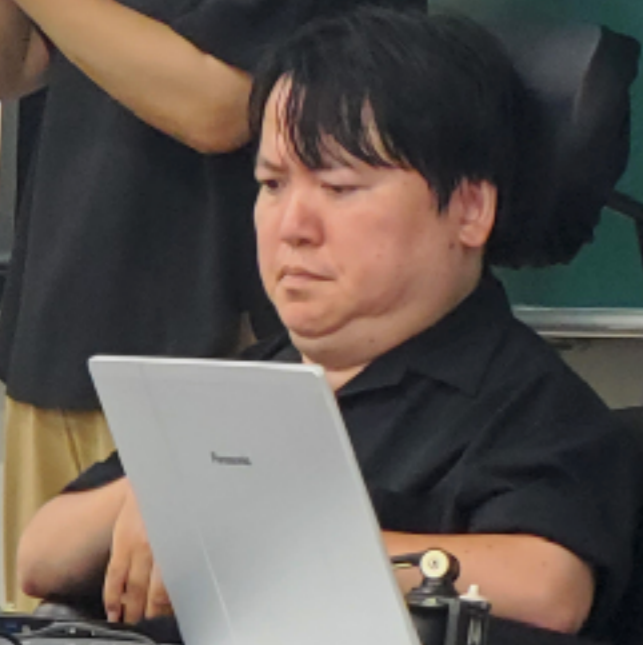
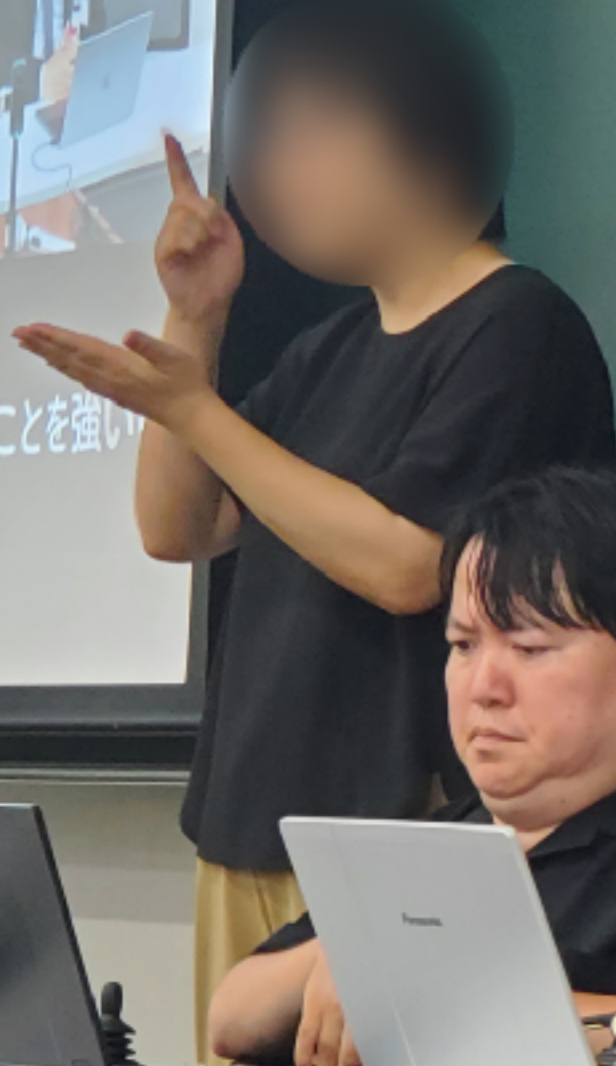
▼ 日本語(日本語)

SHARP

15th Sept
Symposium of the Japan Society for
Disability Studies







ニューロダイバーシティ

- ❖ InLvコミュニティから生まれた概念 (用語)
- ❖ 神経学的な違いは広範囲にわたるという現実を認識。他の特性と同様に、神経学的にも異なる

- ❖ 生物多様性の一面
(Dekker, 2020)

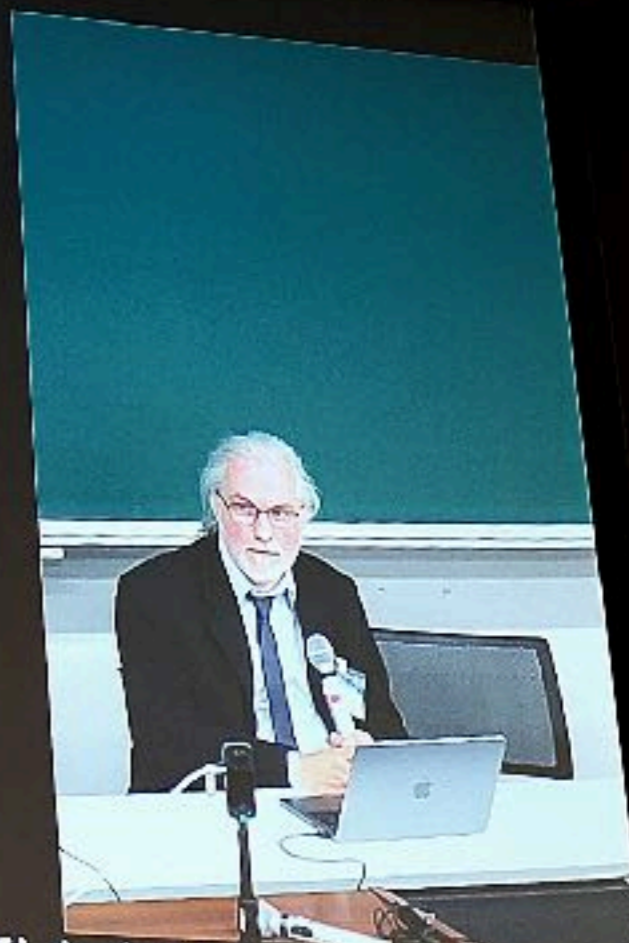
Date: 29 Oct 96 09:41:38 +1900
From: Tony Langdon <tlang@freeway.apana.org.au>
To: Multiple recipients of <brain@inlv.down.ni>
Subject: Re: Oliver Sacks

[From the Brain InLv forum, Topic: (dys)functions of the brain.]

I also believe that this is a lot closer to the real picture than what most psychologists think. My own experience is that while I have noticeable deficits in social function, and some "everyday" aspects of life, I also have a lot of real, practical abilities. For example, being in a technical support field, it looks, from my perspective that most NT people range from plain 'stupid', to positively 'disabled', when it comes to dealing with any hi-tech gizmo. In a sense, this is a special situation where the rules of common-sense are turned around in a way that favours me. I'm becoming more sure that what allows the human race to progress socially and technologically is the neurological diversity of people. I.e. the atypical, and a society provide the different perspectives needed to generate new ideas and advances, whether they be technological, cultural, artistic or otherwise.



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論理上、これはニューロダイバーシティにも適用できると私たちは考えました。これは、1996年10月にInLvに投稿されたメールで、ニューロダイバーシティに触れています。フロッピーディスクのバックアップから何とか取り出しました。

16th Sept
International Symposium
The Origins and Development of Neurodiversity





Origify

Origify

人と会う時間を減らし、途中で仮眠をとること、クロストークではなく、一人ずつ順番に話すコミュニケーションルールを用いることも、私に適したコミュニケーションデザインとなっています。私の身体的な特徴は変わらなくても、こういったデザインを用いることで、

私に適したコミュニケーションデザイン Communication design suitable for me



面談時間を短くする
Spend less time with others



1人ずつ順番に話す
Speak one person at a time,
in turn



仮眠をとる
Take a nap

私の特徴は変わらなくても、私の身体に無理のない動きを選べるようになる
Even if my characteristics do not change, I will be able to choose actions that are not too much for my body.
→著しい疲労・状態の悪化を回避できる/ Avoid significant fatigue and deterioration of my condition.

Satsuki Ayaya
綾屋 紗月

17th Sept Meeting at Kita-Senju









18th Sept
Tōjisha-kenkyū meeting





① Parental authoritarianism

When I was a child, undiagnosed autistic, my father was often angry with me. Everything I could think to say would only make him angrier, which then made me unable to speak out of fear, which made him angrier, too.

② Bullying

When children called me bad names in school, I felt very bad. I never spoke back to my bullies because I had learned that they would only use my words against me.

③ Stress

In extremely stressful situations it can become hard to speak. For example, when everything has gone wrong and I'm about to miss an important deadline, I start stuttering, repeating the same word a lot, or the words will fail to come out altogether.

① Parental authoritarianism

Find a trusted adult to share your problems with and get support.

However, this is risky. If the abusive parent finds out, the abuse may get worse.

② Bullying

There is not much that victims of bullying can do. "Just ignore them" does not work.

Campaigning and advocacy to change teacher attitudes in school so they will control bullying more effectively.

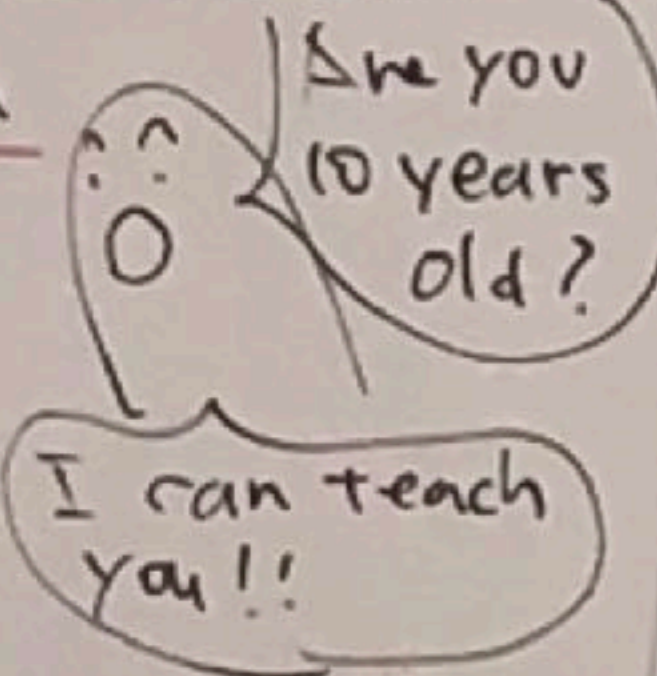
③ Stress

Good planning in advance.
Gathering all information that is needed.

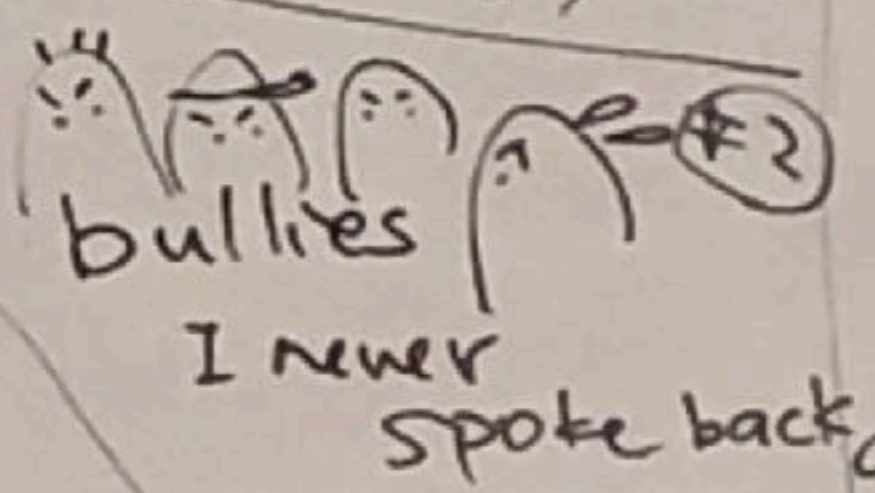
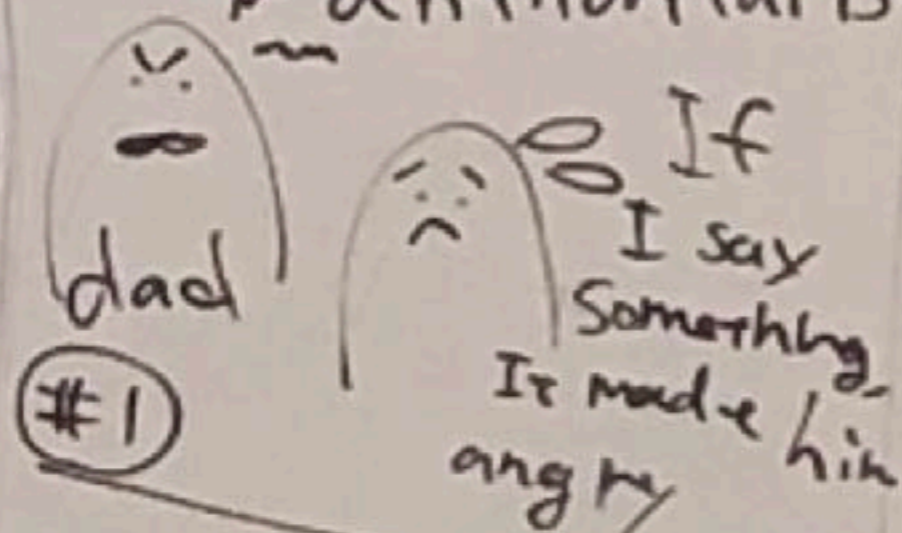
Getting support workers to help me organise my time.

experience where you were made
were unable to speak in public

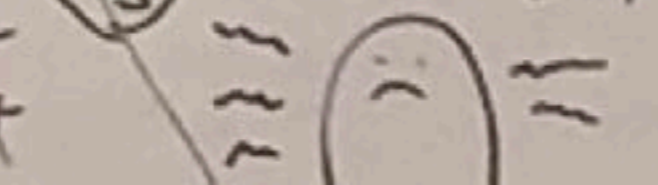
ied abroad



Maintain parental
authoritarianism (ex))

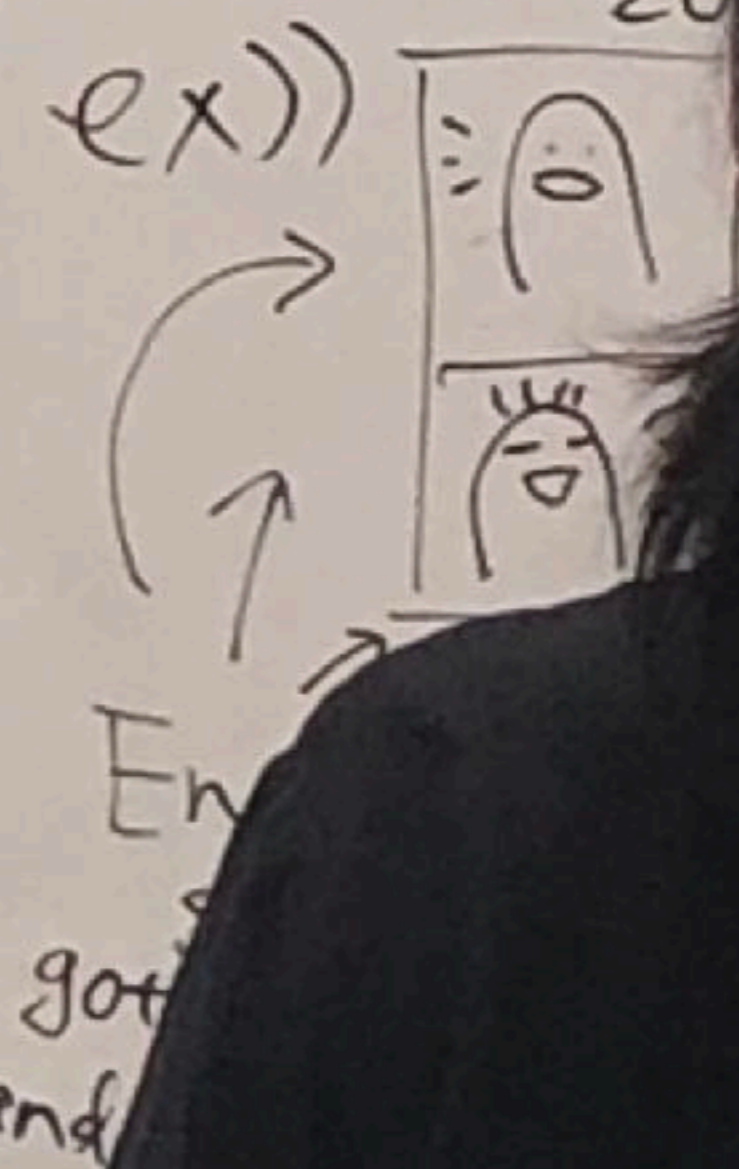
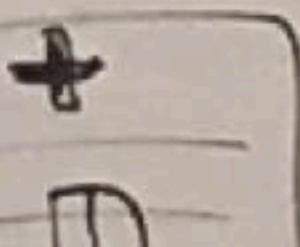


Stressful
Situation



received
very rude
treatment

hard to
get my voice
started



20



田学 英語

子ども? 10才?

教えてあげよう!

言せたい ありがとう!

Heta 先生

あなたは 二どわてる

難しい問題だけ 手を上げ

Heta

打ちに 伝言

店は 混雑あり

Martain

大きな声

X 自分から「おもしろい話」

O 聞か? おもしろいリアクション

頭にあるけど 言葉にならない...

そんた自分でOK

夫. そんたわたの話を 最後まで聞かしてくれ

Pancho

あなたは 自閉症

でも あなたは 心理学者

そのふかにあてて

台本作やく 心理学用語

ジョークも準備

英語力 おちるな! 若者よ!

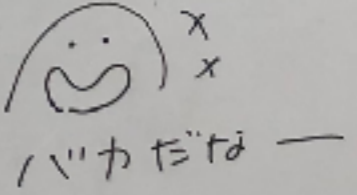
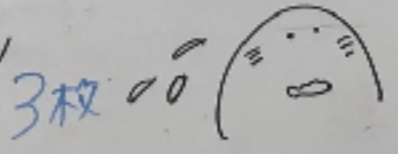
うらやま

声

さかのぼる

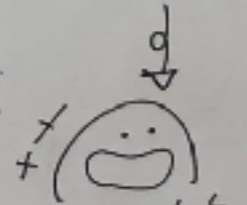
要点は? と聞く

① 言せたい時. バカにされた!



② その時. どのように自分を助けた?

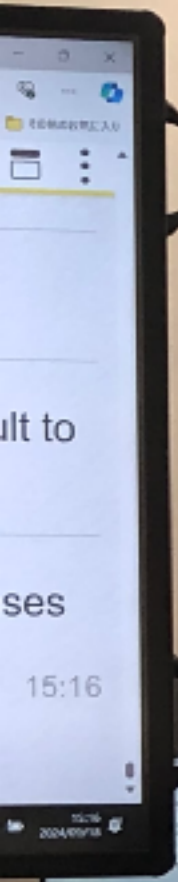
3枚



例)

② そうならたように工夫したこと

笑ってごまかした



Shoko
 2 could ask Q&A
 He treated me like a kid
 @ meeting
 I felt like I don't belong here

Pancho #1
 When I think about them, I felt uncomfortable
 @ conference

Leader said #2
 "you are unclear you need to think more"

#3
 I don't know what to say when someone said "you should not use your authentic symptoms"

Kano #1
 Eng WS about dialogue
 @ felt sick
 Young Japanese and comfort out of Eng ability

Asako
 available, the convo

Yui
 me during class

Kane
 Utilize nonverbal communication
 Swing my body

Asako
 Utilize text information
 Ask the speaker about the point
 Start a new topic

Yabu
 something (just)

Yui
 Escape!
 Drawing
 Develop a "funny" idea

...nce where you
 ...nable to speak

when
 I couldn't speak

Maintain parental authority
 If I say something to make him angry

Successful Situation

when
 International conference
 He didn't seem to understand
 New good at telling funny stories
 friends
 Discussion
 int conference
 and Jpn
 got nervous
 had to put them

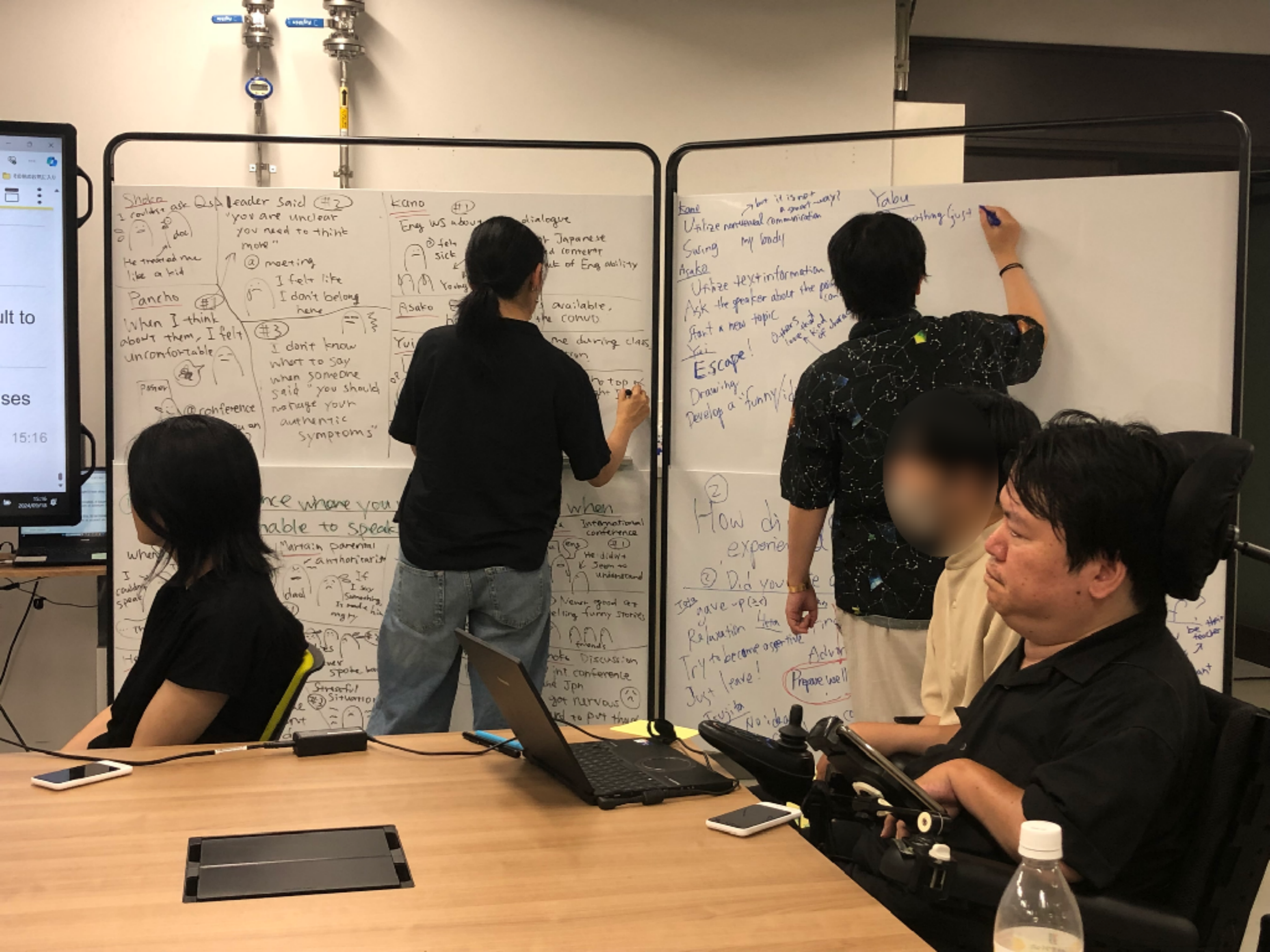
#2
 How did you experience
 #2 Did you
 Relaxation
 Try to become assertive
 Just leave!
 Prepare well

15:16

lt to
ses

I
could
speak

be the
teacher



Conclusion

- ❖ The *tōjisha* notion avoids dividing disadvantaged people into silos. By being deliberately broad, it is inclusive and promotes collaboration and exchange between various disability, mental health, and other marginalised communities.
- ❖ Tōjisha-kenkyu is self-help, peer support, empowerment, self-advocacy, auto-ethnography, participatory research – all rolled into one, with an optional interface to peer-reviewed mainstream science! It’s a radically integrated approach.
- ❖ Though powerful, it is not a magical fix-all. If it’s not led or executed correctly, intersectional power dynamics may end up harming participants. A support system, based on a solid awareness of the history and philosophy of the tōjisha-kenkyu movement, is needed for long-term safety (Ayaya et al, 2020).
- ❖ I believe we in the West should learn from this movement and method, perhaps even create our own version of it — but we should do this carefully and with respect for the culture, history and philosophy of the original movement.



Epilogue: “Double empathy problem” *avant la lettre*

- ❖ Ayaya & Kumagaya: “Tōjisha-kenkyū on Asperger syndrome” (アスペルガー症候群の当事者研究), Japanese Society for Disability Studies, **2007**
- ❖ “Re-describe autism from the tōjisha’s internal sense, without assuming ‘social disorder’”
- ❖ Autistics have “sociality of order”: based on sharing values (ways of thinking, rules and manners)
NTs have “sociality of connections”: based on sharing emotions and desires
- ❖ Neither way is broken, but they’re incompatible
- ❖ **Disorders of communication (and empathy) exist *between* people**, not in any individual(s)
- ❖ That’s the “double empathy problem”, explained in terms that make more sense than that, five years before Milton.
- ❖ Why have so few in the West heard of Satsuki Ayaya?

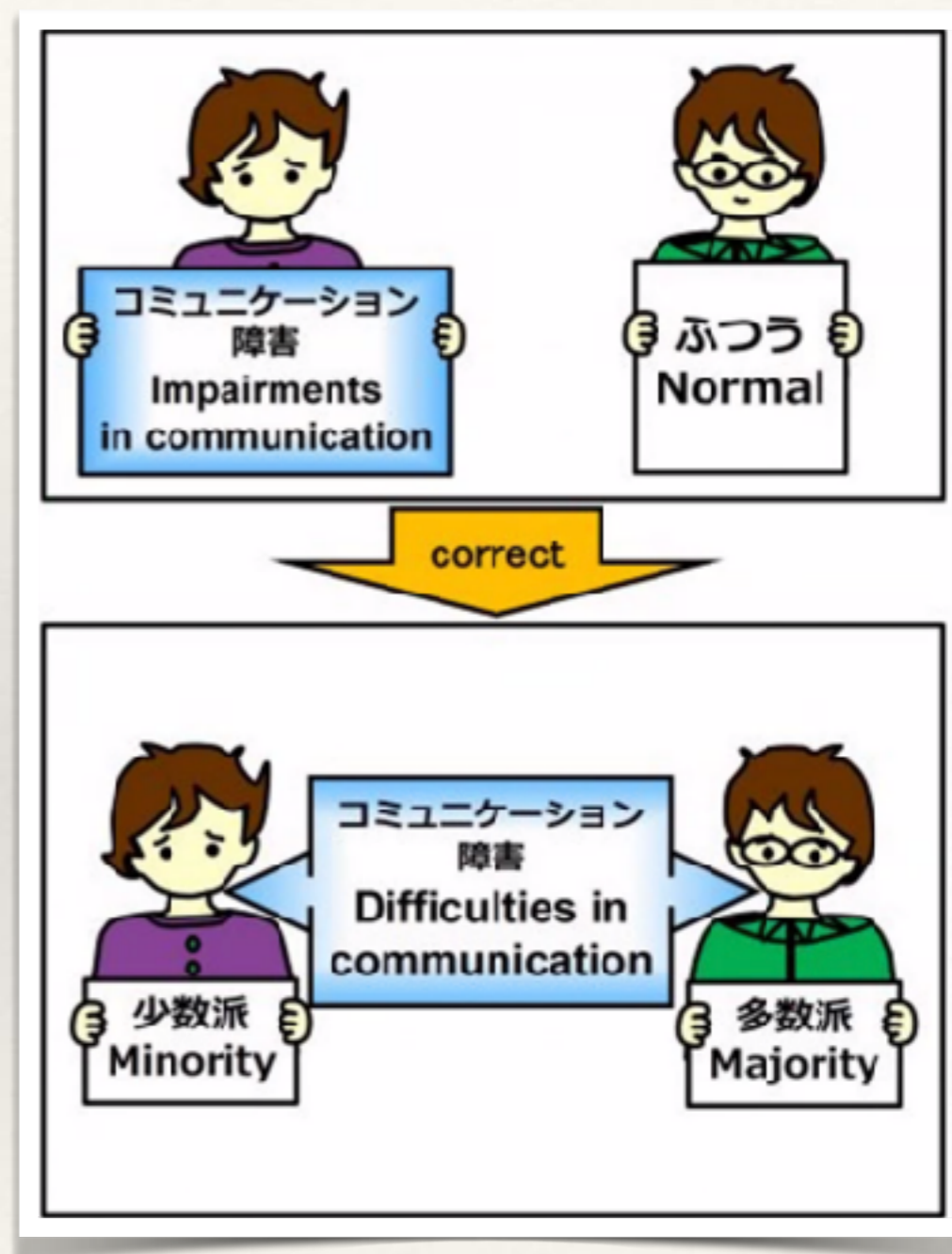


Illustration: Ayaya & Kumagaya



References & further reading

Underlined links are clickable.
Translated links use Google Translate;
note that it consistently mistranslates “Tōjisha-kenkyū”!

- ❖ Ayaya, Satsuki & Kumagaya, Shin-ichiro (2007): [Tōjisha-kenkyū on Asperger syndrome](#) (アスペルガー症候群の当事者研究). Japanese Society for Disability Studies.
- ❖ Kumagaya, Shinichiro (2016): [An Invitation to Tojisha-Kenkyu: A New Science Focusing on Oneself](#). Tansei, the University of Tokyo Magazine, issue 33.
- ❖ Ayaya, Satsuki et al (2020): [Creating a support system to enable diverse peers to safely conduct tōjisha-kenkyū](#) (多様な仲間が安全に当事者研究できるための応援体制づくり). Tōjisha-kenkyū Network (当事者研究ネットワーク).
- ❖ Ayaya, Satsuki & Kitanaka, Junko (2023): [Tōjisha-kenkyū: this radical movement makes space for people with mental health and other challenges to study \(and celebrate\) themselves](#). Aeon.



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