

NEWS

Community Newsletter: Participatory research, burnout, sleep Kismet

BY CHELSEY B. COOMBS

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Hello, and welcome to this week's Community Newsletter! I'm your host, **Chelsey B. Coombs**, *Spectrum's* engagement editor.

We're starting this week with a study in *Autism* that looks at researchers' views on and experiences of **including autistic people** in study decision-making. **Laura Crane**, deputy director of the Centre for Research in Autism and Education at University College London in the United Kingdom, tweeted a thread summarizing the results.

New **#openaccess** paper out in **@journalautism**, by **@Hr_pickard @liz_pellicano @JacdenHouting** and me: Participatory autism research: Early career and established researchers' views and experiences. <https://t.co/bkeBH8WBp6>

— Laura Crane (@LauraMayCrane) **June 5, 2021**

One way that expectations around power can be managed is through open discussions. Yet, our participants highlighted challenges around communication, noting that differences in communication styles can often lead to misinterpretations – double empathy problem! 6/

— Laura Crane (@LauraMayCrane) **June 5, 2021**

Our researchers raised concerns regarding a perceived lack of diversity among the autistic people who contributed to research, as a ‘core group’ were consistently involved. We need to stop equating participatory involvement in research with research participation. 9/

— Laura Crane (@LauraMayCrane) **June 5, 2021**

“If you want to do it properly, you have to invest time and effort in working with these communities, and helping them, and doing things with them that simply isn’t of benefit to you in research terms, but actually builds a relationship and a rapport, and getting to know them better,” one established researcher said.

Sarah O’Brien, a research and policy officer at the U.K.’s national autism research charity Autistica, tweeted that it was a “great exploration of the tensions” of participatory research.

This study that really digs deep into what participatory research looks like within autism research from researchers perspectives. Laura breaks down some of the key points in the thread or have a read of the open access paper ????

A great exploration of the tensions of PAR <https://t.co/4fH6eOej1d>

— sarah o'brien (@Sarahmarieob) **June 7, 2021**

Another *Autism* study that received a lot of attention on social media this week **used participatory research** to better understand **autistic burnout**.

New co-produced study defines **#AutisticBurnout** through experts with lived experience of **#autistic** burnout syndrome. Research by **@JulianneHiggi16 @drsamarnold @liz_pellicano @JanelleWeise @3DN_UNSW. @AutismCRC, @NationalAutism @Autismhttps://t.co/UPLTAEIJJd**

A thread.

— Autism Journal (@journalautism) **June 8, 2021**

Meng-Chuan Lai, assistant professor of psychiatry at the University of Toronto in Canada, made note of the definition of autistic burnout used in the paper.

“Autistic burnout was defined as a highly debilitating condition characterised by exhaustion, withdrawal, executive function problems and generally reduced functioning, with increased manifestation of autistic traits – and distinct from depression”

<https://t.co/J7qwf1fYh1>

— Meng-Chuan Lai (@mengchuanlai) **June 6, 2021**

Though autistic people often mention burnout on social media, there are few studies on burnout in the literature, the researchers note. Burnout, they say, may often be the result of autistic people camouflaging their traits to fit in in an “unaccommodating neurotypical world.”

#AutisticBurnout is debilitating, onset linked to everyday stressors in an unaccommodating world. Research needs to validate definitions, important differences to **@dora_raymaker** et al (2020) findings. Clinicians need awareness, standard treatments may be inappropriate.

— Autism Journal (@journalautism) **June 8, 2021**

“Clinical understanding is key to accessing support not dismissal of concerns,” O’Brien tweeted.

“Further work is needed to differentiate autistic burnout from other conditions and to build clinician understanding of the accompanying complexity to be considered in treatment planning.”

Clinical understanding is key to accessing support not dismissal of concerns.

<https://t.co/7UjFrRBQP5>

— sarah o'brien (@Sarahmarieob) **June 6, 2021**

Finally, a new study in *Science Advances* looks at **sleep disturbances in autistic people** with mutations in CHD7 and CHD8 through the lens of a *Drosophila* model with mutations in an analogous fly gene called Kismet. **Annette Schenck**, professor of translational genomics of neurodevelopmental disorders at Radboud University in Nijmegen, the Netherlands, and paper co-author, tweeted about the research.

Our latest study is out in @ScienceAdvances! The CHD8/CHD7/Kismet family links blood-brain barrier glia and serotonin to ASD-associated sleep defects <https://t.co/o917qFLF8o>

— Annette Schenck (@annette_schenck) **June 8, 2021**

The researchers showed that Kismet mutations during development disrupt glial cells in the blood-brain barrier and lead to hyperserotonemia, or high levels of serotonin, and sleep disturbances in the flies. *Spectrum* covered the connection between **hyperserotonemia and autism** last week.

A version of a sleep-restriction therapy used in people can restore typical sleep patterns in the flies. “Time for a paradigm shift” when it comes to treating sleep issues in autistic people, Schenck writes.

Despite their developmental origin, Kismet’s sleep fragmentation can be completely reversed in adulthood by a behavioral regime resembling human sleep restriction therapy (SRT). In contrast to insomnia, SRT is hardly applied in NDDs - time for a paradigm shift!

— Annette Schenck (@annette_schenck) **June 8, 2021**

“Can’t wait for post covid invite to the Netherlands,” the lab of study co-author **Matthew Kayser**, assistant professor of psychiatry at the University of Pennsylvania in Philadelphia, joked.

Last of 3 related studies in [@ScienceAdvances](#) we are thrilled to be part of - congrats [@annette_schenck](#) lab on the amazing work! Can't wait for post covid invite to the Netherlands ????? [@naihuagong](#) you coming???? <https://t.co/eJOIJAk433>

— KayserLab (@KayserLab) **June 8, 2021**

Krishna Melnattur, incoming assistant professor of psychology and biology at Ashoka University in Sonipat, India, wrote that it was a “very nice story on sleep defects.”

A very nice story on sleep defects associated with Charge syndrome / autism spectrum assoc. genes CHD7/CHD8 (kismet in flies, a much nicer name). Sleep defects arise from dev dysregulation of serotonin and can be reversed by sleep restriction therapy in adults <https://t.co/JtkV8ACU3o>

— Krishna Melnattur (@melnattur) **June 9, 2021**

That's it for this week's *Spectrum* Community Newsletter! If you have any suggestions for interesting social posts you saw in the autism research sphere, feel free to send an email to me at chelsey@spectrumnews.org. See you next week!