

Call for urgent improvements after new study reveals flaws in Autism Health Passport project

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Researchers are calling for new approaches to reduce health care inequalities for Autistic people when they need medical treatment after

identifying serious flaws in NICE-recommended health passports.

Autistic people die between 16 and 30 years before their non-Autistic peers and inaccessible [health](#) care may be a contributory factor. [Health passports](#), such as that designed by the [National Autistic Society](#), were developed to help Autistic people communicate their needs to doctors, nurses and other health care professionals.

Recommended by NICE guidance, these passports allow people to list their [personal details](#) and medical history as well as information about their communication and sensory needs.

Similar tools—such as the [asthma self-management plans](#)- have been found to help reduce mortality when used properly.

Researchers based at Swansea University's Faculty of Medicine, Health and Life Science wanted to find out how effective Autism Health Passports actually are and if the infrastructure surrounding them is fit for purpose.

For their study, the team analyzed previous research relating to health passports that had been published in scientific journals around the world. [Their findings](#) have just been published by online journal *PLOS ONE* and include:

- Evaluation of health care settings that were using the passports revealed a lack of staff knowledge and training in Autism;
- how staff lack of awareness of Autistic communication styles and how to amend their communication were often a barrier to providing equitable care;
- how Autism Health Passports varied not only in terms of their contents, but also in the infrastructure around them such as staff training and reminders to use them; and,

- although many papers stated that the health passports improved care, for example by saying that they increased trust or improved communication, it was not clear how this was supposed to happen, and it was rare that anything was measured to assess if health care quality or satisfaction had improved, because of this, we cannot currently say that Autism Health Passports are effective.

Dr. Aimee Grant, senior lecturer in [public health](#) at Swansea University stated, "NICE guidance and UK policy recommend that Autism Health Passports are used, with the aim of reducing known health inequalities for Autistic people."

"However, at its most basic a health passport is a piece of paper, and unless the environment is carefully crafted to give that piece of paper status—like the status granted to an actual [passport](#) that allows people to cross borders between countries—that piece of paper can achieve nothing."

The researchers say there is an urgent need for new interventions to improve health care accessibility and quality for Autistic people to reduce early death and increase quality of life.

They are calling for interventions that are specifically designed to remove the many barriers they identified, including lack of staff time and knowledge of Autism, including Autistic communication.

Lead researcher on the project, Dr. Rebecca Ellis, public health research assistant at Swansea University, added, "All new interventions to reduce health inequalities for Autistic people should be evidence based, and co-produced both with the Autistic and wider neurodivergent community, and with health professionals who will be responsible for implementing them."

"It is also essential that they are adequately funded, to avoid the tokenism seen with Autism health passports, and to create meaningful change."

For their study the research team worked with Autistic UK. The organization's research director Kathryn Williams added, "Autistic adults often ask for our advice about how to receive better health care and for links to Autism Health Passports recommended by other organizations."

"We were not convinced of their efficacy, yet we had no access to evidence to either support or refute their helpfulness as stated in NICE guidelines. This research provides much-needed evidence and will hopefully enable organizations supporting Autistic people to provide improved guidance and signposting."

More information: Rebecca Ellis et al, A realist review of health passports for Autistic adults, *PLOS ONE* (2023). [DOI: 10.1371/journal.pone.0279214](https://doi.org/10.1371/journal.pone.0279214)

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