LUBELSKI ROCZNIK PEDAGOGICZNY T. XLIV, z. 1 - 2025

DOI: 10.17951/lrp.2025.44.1.153-170

JESSICA E. CARR

The Open University ORCID - 0000-0002-6357-3610

JANE SEALE

The Open University ORCID - 0000-0002-4279-7463

HOW CAN PEOPLE WITH INTELLECTUAL DISABILITIES BE SUPPORTED TO ENGAGE IN CITIZEN SCIENCE?*

Introduction: In the scientific community, there is growing interest in citizen science as an approach to involving non-experts in scientific research. However, currently there are very few examples of citizen science projects that involve people with disabilities, particularly those with intellectual disabilities. There is a need therefore to explore whether and how citizen science projects can become more inclusive.

Research Aim: This commentary paper draws on literature and research examples to explore whether inclusive research methods and processes have a role to play in increasing the participation of people with intellectual disabilities in citizen science projects.

Evidence-based Facts: In order to develop a case for the potential role that inclusive research methods and processes might play in enhancing the inclusivity of citizen science, this paper: 1) provides an overview of the characteristics, methods and principles of citizen science; 2) compares citizen science to inclusive research and 3) provides an example drawn from a small pilot study of how inclusive research methods and approaches were employed to support people with intellectual disabilities to engage in a citizen science project.

Summary: The authors conclude that it is possible to use inclusive methods and processes to engage people with intellectual disabilities in citizen science projects, but that professional scientists will need to be willing to be more flexible in their understanding of what citizen science is. The adoption or adaptation of inclusive research methods and processes offers citizen science an opportunity to expand engagement and create more inclusive research environments for people with intellectual disabilities.

Keywords: inclusive research, citizen science, intellectual disabilities

^{*} Suggested citation: Carr, J.E., Seale, J. (2025). How Can People with Intellectual Disabilities be Supported to Engage in Citizen Science? Lubelski Rocznik Pedagogiczny, 44(1), 153-170. http://dx. doi.org/10.17951/lrp.2025.44.1.153-170



INTRODUCTION

In the scientific community, there is a growing interest in citizen science as an approach to including non-experts (citizens) in scientific research. However, citizen science does not have a strong or long record of involving marginalised people such as those with disabilities. As a result, there is a growing call for a more inclusive and accessible approach to citizen science (Dawson, 2018; Dibner & Pandya, 2018). Whilst some attention is being paid to developing more inclusive approaches to involving people with disabilities in citizen science (e.g. Krüger et al., 2023), very little of this has focused on including people with intellectual disabilities. This is a gap in knowledge that needs to be addressed.

Unlike citizen science, there is a strong tradition of using inclusive research methods to engage people with intellectual disabilities in research. A key intended outcome of inclusive research is increased opportunities for people with intellectual disabilities to have a say in the nature and quality of support that they receive from local authorities, by, for example influencing decision-making connected to where people with intellectual disabilities live and how they spend their time. As a result, inclusive research is argued to be an important way to promote the citizenship of people with intellectual disabilities (Chalachanová et al., 2021; Nind & Strnadová, 2020). This perceived link between inclusive research and citizenship suggests that it could be useful to explore in more detail the relationship between inclusive research and citizen science.

RESEARCH AIM AND QUESTION

The overarching aim of this paper is to explore whether inclusive research methods and processes have a role to play in increasing the engagement of marginalised groups such as those with intellectual disabilities in citizen science. Our related research questions are:

How does inclusive research compare to citizen science?

Can inclusive research methods and processes be used to build capacity of people with intellectual disabilities to engage in citizen science?

Should inclusive research methods and processes be used to support people with intellectual disabilities to engage in citizen science?

In order to address these questions and develop a case for the potential role that inclusive research methods and processes might play in enhancing the inclusivity of citizen science in this paper we will:

- provide an overview of the characteristics, methods and principles of citizen science;
- compare citizen science to inclusive research and consider what inclusive research methods and processes can offer citizen science;

 draw on examples from a pilot study to illustrate and discuss the potential use of inclusive research methods and approaches in supporting people with intellectual disabilities to engage in a citizen science project.

EVIDENCE-BASED REVIEW

Currently, citizen science is defined as the involvement of the public in scientific research. A key outcome of the involvement of the public in such "organized research efforts" (Dickinson et al., 2012, p. 1) is the advancement of "knowledge in a wide range of scientific disciplines" (Havens & Henderson, 2013, p. 378). Like inclusive research, citizen science has a long history, but it is not always well understood. It is important to understand this history in order to understand why, despite certain similarities, citizen science might currently be viewed as distinct from inclusive research and why inclusive research might be positioned as having something to offer citizen science. In this section we will provide an overview of the key characteristics, methods, and principles of citizen science. This overview will provide the foundation for our exploration of whether and how inclusive research methods and processes have a role to play in increasing the engagement of marginalised groups such as those with intellectual disabilities in citizen science.

Key characteristics and methods of citizen science

Citizen science is essentially a collaboration between professional and amateur scientists. The collaborative nature of citizen science pushes scientists to reconsider what constitutes effective science practices. This disrupting of traditional practices is argued by some to create opportunities for innovation, such as advances in open data and open access publication (Robinson et al., 2018). The challenge for professional scientists is to embrace such disruptive potential whilst still maintaining the perceived rigour of scientific processes and outcomes.

A common motivation for professional scientists to involve amateurs or citizens in their research is that it can enable them to gather more data (Bonney et al., 2009). One of the most common motivations for amateurs to initiate and sustain participation is the opportunity to contribute to science (Curtis, 2015). Such volunteering is undertaken for the good of the wider community or to make a difference to the world in general. Studies have also identified how people are also motivated to engage with citizen science projects due to a pre-existing interest in science. This is often accompanied by some knowledge and understanding of the topic (Jones et al., 2018; Land-Zastra et al., 2016).

A broad range of approaches fall under the umbrella of citizen science. Some citizen projects are local or community-driven, others address issues that are of more global concern or relevance. Some citizen science projects use digital technologies

to engage citizens and/or capture data, some do not. Participation in citizen science also varies in the extent to which citizens are afforded opportunities to engage in each stage of the scientific process from problem definition through to data collection and analysis. Haklay (2013) proposed four different levels of participation: crowdsourcing; distributed intelligence, participatory science, and extreme citizen science. In "crowdsourcing" type citizen science projects, volunteers participate solely in collecting data or sourcing information. For example, for the Sci-Starter "Stream Selfie" project, citizen scientists were asked to take a "selfie" of themselves next to a stream and provide basic information relating to the content of the photograph (https:// scistarter.org/stream-selfie). Distributed Intelligence projects engage citizen scientists in interpreting sets of data. For example, in 2007, astrophysics researchers used an online platform called Zooniverse to launch a citizen science project called Galaxy Zoo, where volunteers were asked to help sort and classify millions of images of galaxies (https://www.ox.ac.uk/research/research-impact/zooniverse-and-beyond). In participatory science, citizens participate in problem definition and data collection. Extreme citizen science projects are collaborative in that citizens participate in problem definition, data collection and data analysis. One example is the "EXCiteS" project in which professional environmental scientists supported indigenous groups in the Congo basin to formulate research questions, collect and analyse the data they needed to tackle illegal logging in their territory and improve environmental management (https://www.ucl.ac.uk/geography/research/research-centres/extreme-citizen-science-excites/projects/extreme-citizen-science-analysis).

Key principles of citizen science

Whilst definitions help us to understand what a field of research is, principles help to guide researchers' practice in the field. For inclusive research, there are a number of published and highly cited set of principles (see, e.g. Nind & Vinha, 2012; Walmsley & Johnson, 2003; Walmsley et al., 2018). There are, however, very few published principles for conducting citizen science. One exception is the European Citizen Science Association (ECSA, 2015), which produced ten principles for good practice when conducting citizen science:

1. Citizen science projects actively involve citizens in scientific endeavour that generates new knowledge or understanding.

- 2. Citizen science projects have a genuine science outcome.
- 3. Both the professional scientists and the citizen scientists benefit from taking part.
- 4. Citizen scientists may, participate in multiple stages of the scientific process.
- 5. Citizen scientists receive feedback from the project.

6. Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for.

7. Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format.



8. Citizen scientists are acknowledged in project results and publications.

9. Citizen science programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact.

10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities.

Robinson et al. (2018) argue for more description and testing of these principles in practice in order to further understanding of the value and challenges of engaging in citizen science. This is likely to be particularly important with regard to informing judgments about the extent to which citizen science can contribute to increasing the engagement of people with intellectual disabilities in research.

How does inclusive research compare to citizen science?

"Inclusive research" is as an umbrella term for a family of methods (e.g. emancipatory research; participatory research and participatory action research) that moves away from involving people as subjects of research and instead aims to involve them as "instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Walmsley & Johnson, 2003, p. 10). A key objective of inclusive research methods is democratization, empowering people with intellectual disabilities to shape and influence all aspects of research about their lives and the factors that influence their ability to live good lives (Nind, 2014; Woelders, 2015). In considering what inclusive research methods and processes can offer citizen science it is important to evaluate the similarities and differences between the two. Such an evaluation will help to address two key issues. Firstly, to identify what the recognized weaknesses of citizen science are and whether inclusive research has strengths that might help to mitigate these weaknesses. Secondly, to establish whether there are sufficient similarities between inclusive research and citizen science to mean that the adoption or adaptation of inclusive research methods and processes by citizen science projects will not unduly distort their intended objectives and outcomes.

Differences between inclusive research and citizen science

There are three main differences between citizen science and inclusive research.

Firstly, each take different positions regarding what characterises "good" scientific research. For citizen science, the emphasis is placed on 1) managing legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities and 2) controlling for limitations and biases (see principles 6 to 10, ECSA, 2015). In contrast, Nind and Vinha (2012) proposed that

good social science meets good inclusive practice when:

1. The research answers questions the authors could not otherwise answer but are important.

2. The research reaches participants, communities, and knowledge in ways that the authors could not otherwise access.

3. The research involves reflecting upon the insider cultural knowledge of people with learning disabilities.

4. The research is authentic (recognized by the people involved).

5. The research makes impact on the lives of people with learning disabilities. (p. 44)

In essence, whilst both approaches aim to promote good quality research through participation; the principles of citizen science appear to place greater emphasis on the process of science, whilst the principles of inclusive research appear to place greater emphasis on the nature and extent of participation. This is probably due in large part to the fact that, in contrast to citizen science, the focus of inclusive research is the lives and experiences of people with intellectual disabilities.

A second difference is that, compared to inclusive research, citizen science does not have a strong record of involving marginalised people, particularly people with intellectual disabilities. This is despite the fact that many proponents of citizen science such as Silvertown (2009) argue that citizen science has the potential to be "for all" publics rather than for the scientific elite. The reality is, however, that those who engage in citizen science tend not to be the most marginalised in society. Dawson (2018) argues that the descriptions of "publics" contained within citizen science are vague and although they do not specifically exclude under-represented communities, neither do they explicitly include them. In effect, the barriers to participation, are invisible. In a review of citizen science literature Dibner and Pandya (2018) identified "that members of communities historically under-represented in science, [are] people with less formal education, and people of colour" (p. 44). It is interesting to note that the categories of diversity that Dibner and Pandya used to interrogate citizen science literature did not include disability or intellectual disability.

The citizen science community is beginning to recognise the need for more inclusivity. For example, part of the reason why, in May 2023, the Citizen Science Association changed its name to the Association for Advancing Participatory Sciences was a recognition that using the name "citizen science" excludes those marginalised by discrimination based on citizenship status (https://participatorysciences.org/). In debating the merits of such a name change, Cooper et al. (2021) argued that "it is clear that citizen science is typically not truly an egalitarian variant of science, open and available to all members of society, particularly those underrepresented in the scientific enterprise" (p. 1386). Some researchers are also beginning to explore how disabled people can be involved in citizen science projects. For example, Chapman et al. (2022) suggest that extreme citizen science is an effective way of involving people with disabilities in health-related research. Krüger



et al. (2023) report on a project called "IncluScience" which used a crowd-sourcing approach whereby wheelchair users uploaded information about the accessibility of local streets onto a free online street map called "Wheelmap"(https://wheelm-ap.org/). The citizens themselves decided which types of places were particularly relevant and were involved in developing and selecting those. Our review of the citizen science literature identified just two citizen science projects that specifically aimed to include people with intellectual disabilities and address how barriers to their inclusion in citizen science could be addressed (Carr, 2021; Howlett et al., 2021). Currently, therefore, people with intellectual disabilities are routinely excluded from citizen science.

In both citizen science and inclusive research, one particular barrier that limits the inclusion of citizens, particularly those with intellectual disabilities, in citizen science relates to lack of knowledge of how science works (Durant, 1994). Scientific literacy is often seen to be a key component to initiating participation in citizen science. Irwin (1995) argued that a lack of scientific literacy can exclude people from citizen science and therefore deprive them of opportunities to engage. In a study focused on people with intellectual disabilities understanding of citizen science, Carr (2018) identified that negative school-based experiences of science meant that some participants were less likely to want to engage in scientific inquiry. This has the potential to significantly hinder their ability to see any value in gaining "scientific citizenship". Carr (2018, 2021) drew on these findings to argue that if the scientific community does not work to build confidence and self-efficacy among citizens and groups who may already feel excluded, it would be difficult to fulfil the potential for citizen science to be "for all".

Compared to citizen science, inclusive research has paid more attention to the need to build the capacity of participants to meaningfully participate in research (Nind et al., 2016). For example, Strnadová et al. (2014) describe how they incorporated research training into an inclusive research project focusing on understanding how older women with intellectual disabilities live. Their evaluation of this experience concluded that there were four main areas where researchers with intellectual disabilities need training and support: (1) understanding the concept of research, (2) determining what important questions the team want answers to, (3) accessing and producing written materials and (4) time management and remaining on task. In contrast, in much of the citizen science literature, there is an implicit suggestion, through reference to participant motivation, that responsibility for engagement, or indeed disengagement, lies with the participant, not the researcher (see, e.g. Jones et al., 2018; Land-Zastra et al., 2016). In contrast, the literature surrounding the implementation of capacity building tools within inclusive research offers several suggestions for how the engagement of co-researchers with intellectual disabilities can be developed and supported. For example, Inglis and Cook (2011) facilitated a study in which they engaged co-researchers with intellec-



tual disabilities in drama-based workshops to promote discussions and "engage in learning and knowledge building" (p. 99). Furthermore, these workshops engaged the co-researchers in "developing understandings and finding the confidence to articulate and critique thoughts and ideas". Inglis and Cook (2011) highlighted how in these workshops complex ideas were broken down into smaller, simpler ideas which was key to the co-researchers understanding of research.

Similarities between inclusive research and citizen science

There are three main similarities between inclusive research and citizen science. Firstly, both involve a collaboration between experts (professional scientists or researchers) and non-experts. For inclusive research, collaboration entails involving people with intellectual disabilities in the process of accessing and representing their views and experiences (Walmsley & Johnson, 2003) as well as "standing with" those whose issues are being explored or investigated (Walmsley et al., 2018). Like aspects of inclusive research, the participatory approach of citizen science is argued to break down at least some of the barriers between "experts" and "non-experts" by opening up interactions between scientists and members of the public.

Secondly, both inclusive research and citizen science intend to empower non-experts. For Walmsley and Johnson (2003), inclusive research is empowering if it goes beyond accessing the voices of marginalized groups and involves people from marginalised groups taking control of the action. Advocates of citizen science also emphasize its "empowering" possibilities. It is claimed that citizen scientists benefit by creating and reframing their experience of science through engaging with professional scientists (Toerpe, 2013). Havens and Henderson (2013) argue that citizen science "empowers people from all walks of life to participate in the scientific process" (p. 378). It is important to acknowledge however, that despite the intention of both citizen science and inclusive research to empower non-experts, both fields of research face challenges surrounding the extent to which the inherent power differences between expert and non-expert prevent genuine empowerment for the non-expert (Groot & Abma, 2022; Rix et al., 2020).

Finally, like citizen science (see Haklay, 2013), it is also recognised that there are different levels of participation in inclusive research. For example, in a review of inclusive research studies, Bigby et al. (2014) distinguished between three approaches to inclusive research: advisory, leading and controlling, and collaborative. An advisory approach involves participation in setting research priorities or decisions about funding. A leading and controlling approach aims to give control to people with intellectual disability to initiate, lead and execute their own research about issues that are important to them. In a collaborative approach and distinct purposes which are given similar attention and make contributions that

are equally valued. In a more recent review of inclusive health and social care research with people with intellectual disabilities Hewitt et al. (2023) noted that some studies involved researchers with intellectual disabilities in nearly every aspect of the research process, whereas others engaged them in discrete aspects of the research.

It is our contention that there are sufficient differences between inclusive research and citizen science to mean that it makes little sense to treat them as one and the same approach. Equally, there are sufficient similarities between the two to mean that it is not inappropriate to explore the value of one approach adopting or adapting the methods and processes of another. If citizen science is routinely excluding people with intellectual disabilities and does not have a strong tradition of building the capacity of citizens to engage in citizen science projects, then there may be merit in exploring the extent to which adopting inclusive research approaches and methods might support people with intellectual disabilities to engage in citizen science.

Can inclusive research methods and processes be used to build the capacity of people with intellectual disabilities to engage in citizien science?

In this section we provide examples from the doctoral research of the first author which drew on the creative and capacity-building tradition of inclusive research to explore potential methods for supporting people with intellectual disabilities to engage in citizen science (see Carr 2021 for a fuller description of methods). The first author worked with eleven members of a self-advocacy group called "My Life My Choice", based in Oxfordshire, (the United Kingdom) to explore the support that people with intellectual disabilities needed to engage with citizen science. The sampling method was one of convenience in that the first author had prior experience of working with the group and therefore approached the group to find out if they would be interested in taking part in this pilot study. The first author attended a meeting with the group to verbally explain the study, answer questions, distribute accessible information sheets and consent forms. Research ethics approval for the project was provided by The Open University's Human Research Ethics Committee (HREC/2958/Carr) and all participants gave informed consent. Ten of these participants had mild to moderate intellectual disabilities. One of the participants was a member of the support staff. Prior to their involvement in this project, most of the group had been involved in research in some way, but mostly as research respondents rather than co-researchers. As this project asked them to be involved in the design and execution of citizen science research, it was important to identify their research capabilities and build these where necessary. The whole project took place over twelve monthly sessions, with each session lasting approximately three hours. Phase one of the project focused on using creative methods to build capacity for the participants to engage in a citizen science pro-



ject. Phase two focused on supporting the participants to plan and conduct their own citizen science project and phase three focused on evaluating the project and disseminating the results. All three phases were underpinned by principles and methods of inclusive research. During phase one and two, the first author audio-recorded each meeting and kept a detailed field diary of their observations and reflections. In phase three, the first author conducted online interviews with the participants. Reflexive thematic analysis was employed to analyse data from these three sources.

The use of creative methods to build capacity to engage in citizen science projects

In the field of inclusive research with people with intellectual disabilities there is a growing tradition of employing creative tools or methods such as photographs, theatre, body-mapping, murals, or visual presentations to increase the accessibility of the research and enhance opportunities to engage (Dew et al., 2019; Kim et al., 2021). Rojas-Pernia and Haya-Salmón (2022) argue that using visual and creative methods facilitates curiosity and the exchange of experiences and interests. The first author therefore drew on this knowledge to use a range of creative methods to build capacity to engage in citizen science.

One creative method that was used to help co-researchers identify what a citizen scientist is and create a shared understanding of the term, was an adapted form of the "Draw-A-Scientist" activity (Chambers, 1983). Each co-researcher was asked to draw the type of scientist they think they are or could be and then to share their drawing with the first author (professional researcher). The group were then shown a video of a citizen science project. Following this they were asked to draw a picture of what they believed a citizen scientist is. This prompted a discussion in which both sets of drawings were compared. Through these discussions co-researchers were supported to develop their personal understandings of citizen science.

Another creative activity applied in this project was the creation of an "identity box". Co-researchers were asked to create an "identity box" using an empty shoebox and a selection of craft materials. The particular identity they were asked to convey through their "identity boxes" was themselves as a citizen. On completion, each participant shared and described their identity as a citizen with the rest of the group. This method was adapted from the method used by Brown (2018) who was researching with people with fibromyalgia. Her "identity boxes" were created as a form of narrative account to help her participants to represent who they were in relation to this condition. Brown described this method as an expressive and artistic experience that allows for communication beyond language, which is why it was believed to be suitable for the multiple levels of communication within the group of co-researchers.

The professional researcher observed how all of the participants used their identity boxes to define their core identity as one that was not linked to having an intellectual disability (see Figure 1 for an example).



Figure 1. An example of an "identity box"

Source: (Carr, 2021).

The identity box in Figure 1 conveys different potential components of the participants identity:

Gender: The reference to "girls just want to have fun" suggests the participant is identifying their gender but also an aspect of their wishes in life through popular culture.

Abilities or qualities: The references to "confidence is a superpower", "strength" and "positive" suggest a belief in their abilities.

Likes and hobbies: The references to "tennis", "pink", "France" and "baking" serve to identify things they enjoy doing or that they like.

We are not arguing that it is necessary for people with intellectual disabilities to ignore or deny their identity as a person with a disability in order to successfully engage with citizen science projects. Rather we are suggesting that using a range of



inclusive creative methods can encourage connections with identity as both connected to and separate from disability – and this can enable people with intellectual disabilities to discuss potential citizen science projects that are of interest to both them and to others.

Supporting the participants to plan and conduct their own citizen science project

A collaborative approach was adopted to support the co-researchers to plan and conduct their own citizen science project. Such an approach is well recognized in inclusive research with people with intellectual disabilities (Strnadová et al., 2016) and it is akin to the "leading or controlling approach" identified by Bigby et al. (2014). The professional researcher planned the structure and activities in each session. As part of this planning and structuring they introduced co-researchers to the citizen science online platform called nQuire (https://nquire.org.uk/) and the citizen science projects that were currently being run on the platform. The professional researcher also facilitated discussions about potential citizen science topics and a democratic voting process to support the group coming to decisions about what kind of citizen science investigation they wanted to conduct. This is similar to the approach used by Howlett et al. (2021) where professional researchers (undergraduate students) collected a range of examples of existing citizen science projects in the local area and shared these with the co-researchers with intellectual disabilities in order to help them make decisions and their own citizen science project.

The professional researcher also spent a lot of their time prompting the participants to focus and bringing the group's attention back to the task they were completing at the time:

JC - Ok and why does that mean research to you?

- P3 I don't know.
- JC Is it something personal?
- P3 Yeah personal.

JC – And is it something you want to research into, is it something that you're just interested in?

P3 – Yeah hmm. (Transcription_Session_1_P3)

JC – You should see mine, umm, so P4, what, what question, what is our big question for the cats and vets one?

- P4 Vets and cats.
- JC But that's not a question.

P4 – Oh question oh.

JC – We need to come up with a question P4 – got to come up with a question, umm, how do we look after them? (Transcription_Session_5)

The result of such prompting supported the focus of their citizen science project, the co-researchers focused not only on topics with a relevance to their community, but topics which also affected other communities such as bullying, knife crime, animal cruelty and hospitals. Ultimately, the group decided they wanted to identify best practice regarding looking after domestic pets such as cats and dogs. Together, the professional researcher and co-researchers designed a questionnaire that they circulated around their local veterinary practices; analysed the returned questionnaires and produced an accessible easy-read leaflet that presented a summary of the results.

SUMMARY

Should inclusive research methods and processes be used to support people with intellectual disabilities to engage in citizen science?

When we have shared the outcomes of the exploratory study outlined in the previous section with the citizen science community, some professional researchers have argued that the project is not a valid citizen science project. They point to the fact that a leaflet summarising the results of a local survey on how best to look after cats and dogs is not a genuine science outcome that generates valuable new knowledge (see ECSA, 2015, principles 1 and 2). The topic is perceived to have limited appeal or interest to the wider community and therefore will not lead to a scientific research paper. If this argument is accepted, then one reasonable conclusion is that inclusive research methods and approaches should not be used to try and support people with intellectual disabilities to engage in citizen science because they change the project into something that is not recognized as citizen science. We would argue, however, that a scientific project does not always need to produce new knowledge. Instead, it can reproduce knowledge which is new to either the researchers themselves or the targeted audience. Furthermore, we would argue that the citizen science project conducted by the people with intellectual disabilities in the exploratory study is a valid type of citizen science as it meets the definition of extreme citizen science as defined by Haklay (2013) in that the people with intellectual disabilities defined the problem or topic, designed, and implemented the data collection method, analysed and presented the data. Alternatively, it could be recognised as "citizen inquiry" as defined by Herodotou et al. (2018) in that the professional researcher acted as an advisor to the participants with intellectual disabilities who defined their own research agenda which produced learning benefits for them and others. Furthermore, we argue that to include those that are currently excluded, citizen science needs to understand what these communities are interested in research-



ing. Citizen science needs to be more flexible on what science may mean to different communities

CONCLUSION

Citizen science has potential to engage people with intellectual disabilities and create spaces for them to investigate topics of interest that are unrelated to their disability. However, currently little consideration has been given to making citizen science accessible to this group. This paper has made a key contribution to knowledge by developing an argument that people with intellectual disabilities can engage in citizen science if effort is taken to support them to develop the skills and capacity to engage. The adoption or adaptation of inclusive research methods and processes offers citizen science an opportunity to expand engagement and create more inclusive research environments. We call for more research in this area so that professional scientists have more examples and experiences to draw upon when considering how to increase the inclusivity of their citizen science projects.

REFERENCES

- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. Journal of Applied Research in Intellectual Disabilities, 27(1), 3-12. https://doi.org/10.1111/jar.12083
- Bonney, R., Cooper, C.B., Dickinson, J., Kelling, S., Phillips, T., Rosenberg, K., & Shirk, J. (2009). Citizen science: A developing tool for expanding science knowledge and scientific literacy. BioScience, 59(11), 977-984. https://doi.org/10.1525/ bio.2009.59.11.9
- Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection methods. Cogent Social Sciences, 4(1). https://doi.org/10.1080/2331188 6.2018.1447759
- Carr, J.E (2018). How do People with Learning Disabilities Understand Citizen Inquiry? Masters in Research Thesis. The Open University. http://oro.open.ac.uk/53815/
- Carr, J.E. (2021). Can an Inclusive Approach Meaningfully Engage People with Learning Disabilities? Exploring Capacity Building for Citizen Science. PhD Thesis. The Open University. https://oro.open.ac.uk/79450/
- Chalachanová, A., Lid, I., & Gjermestad, A. (2021). Citizenship of persons with intellectual disabilities within the frame of inclusive research: A scoping review of studies to inform future research. Alter, 15(2), 139–152. https://doi.org/10.1016/j. alter.2020.09.001
- Chambers, D.W. (1983). Stereotypic images of the scientist: The draw a scientist test. Science Education, 67(2), 255-265. https://doi.org/10.1002/sce.3730670213



- Chapman, K., Dixon, A., Cocks, K., Ehrlich, C., & Kendall, E. (2022). The Dignity Project Framework: An extreme citizen science framework in occupational therapy and rehabilitation research. *Australian Occupational Therapy Journal*, 69(6), 742–752. https://doi.org/10.1111/1440-1630.12847
- Cooper, C.B., Hawn, C.L., Larson, L.R., Parrish, J.K., Bowser, G., Cavalier, D., Dunn, R.R., Haklay, M., Gupta, K.K., ... & Wilson, S. (2021). Inclusion in citizen science: The conundrum of rebranding. *Science*, 372(6549), 1386–1388. https://doi. org/10.1126/science.abi6487
- Curtis, V. (2015). Online citizen science projects: An exploration of motivation, contribution and participation. PhD Thesis. The Open University. http://oro.open. ac.uk/42239/
- Dawson, E. (2018). Reimagining publics and (non)participation: Exploring exclusion from science communication through the experiences of low-income, minority ethnic groups. *Public Understanding of Science*, 27(7), 772–786. https://doi. org/10.1177/096366251775007
- Dew, A., Collings, S., Dillon Savage, I., Gentle, E., & Dowse, L. (2019). "Living the life I want": A framework for planning engagement with people with intellectual disability and complex support needs. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 401–12. https://doi.org/10.1111/jar.12538
- Dibner, K.A., & Pandya, R. (2018). *Learning Through Citizen Science: Enhancing Opportunities by Design*. The National Academies Press.
- Dickinson, J.L., Bonney, R., Louv, R., & Fitzpatrick, W.J. (2012). *Citizen Science: Public Participation in Environmental Research*. Cornell University Press and Comstock Publishing Associates.
- European Citizen Science Association. (2015). *Ten principles of citizen science*. https://ecsa.citizenscience.net/sites/default/files/ecsa_ten_principles_of_citizen_ science.pdf
- Durant, J. (1994). What is scientific literacy? *European Review*, *2*(1), 83–89. https://doi. org/10.1017/S1062798700000922
- Groot, B., & Abma, T. (2022). Ethics framework for citizen science and public and patient participation in research. *BMC Med Ethics*, 23, Article 23. https://doi.org/10.1186/s12910-022-00761-4
- Haklay, M. (2013). Citizen science and volunteered geographic information: Overview and typology of participation. In D. Sui, S. Elwood, & M. Goodchild (Eds.), *Crowdsourcing geographic knowledge: Volunteered geographic information (VGI) in Theory and Practice* (pp. 105–122). Springer.
- Havens, K., & Henderson, S. (2013). Citizen Science takes root. *American Scientist*, *101*(5), 378–385. https://doi.org/10.1511/2013.104.378
- Herodotou, C., Sharples, M., & Scanlon, E. (2018). Introducing citizen inquiry. In C. Herodotou, M. Sharples, & E. Scanlon (Eds.), *Citizen Inquiry: Synthesising Science and Inquiry Learning* (pp. 1–6). Routledge.



- Hewitt, O., Langdon, P.E., Tapp, K., & Larkin, M. (2023). A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences? Journal of Applied Research in Intellectual Disabilities, 36(4), 681-701. https://doi.org/10.1111/jar.13100
- Howlett, R., Sitbon, L., Hoogstrate, M., & Balasuriya. S.S. (2021). Accessible Citizen Science, by people with intellectual disability. In Proceedings of the 23rd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '21). Association for Computing Machinery, New York, NY, USA, Article 48, 1-3. https://doi.org/10.1145/3441852.3476558
- Inglis, P., & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability in research. Journal of Learning Disabilities and Offending Behaviour, 2(2), 98-104. https://doi.org/10.1108/20420921111152441
- Irwin, A. (1995). Citizen Science: A Study of People, Expertise, and Sustainable Development. Routledge.
- Jones, M.G., Childers, G., Andre, J., Corin, N.E., & Hite, P. (2018). Citizen scientists and non-citizen scientist hobbyist: Motivation, benefits and influences. International Journal of Science Education, Part B, 8(4), 287-306. https://doi.org/10.1080/21 548455.2018.1475780
- Kim, M.A., Yi, J., Bradbury, L., Han, K.M., Yang, J., & Lee. J. (2021). A photovoice study: The life experiences of middle-aged adults with intellectual disabilities in Korea. Journal of Applied Research in Intellectual Disabilities, 34(3), 852-865. https:// doi.org/10.1111/jar.12870
- Krüger, D., Krümpelmann, S., Pelka, B., & Schulz, A.C. (2023). Inclusiveness of citizen science. How people with disabilities can participate in citizen science approaches. In M. Antona & C. Stephanidis (Eds.), Universal Access in Human-Computer Interaction. HCII 2023. Lecture Notes in Computer Science (Vol. 14020, pp. 88-98). Springer. https://doi-org.libezproxy.open.ac.uk/10.1007/978-3-031-35681-0_6
- Land-Zastra, A.M., Devilee, J.L.A., Snik, F., Buurmeyer, F., & Vander Broek, J.M. (2016). Citizen science on a smartphone: Participants motivations and learning. Public Understanding of Science, 25(1), 45-60. https://doi.org/10.1177/0963662515602406
- Nind, M., & Vinha, H. (2012). Doing Research Inclusively: Doing Research Well? Rehttps://www.southampton.ac.uk/assets/imported/transforms/ search *Report.* content-block/UsefulDownloads_Download/97706C004C4F4E68A8B54DB90E-E0977D/full_report_doing_research.pdf
- Nind, M. (2014). What Is Inclusive Research? Bloomsbury Academic.
- Nind, M., Chapman, R., Seale, J., & Tilley, L. (2016). The conundrum of training and capacity building for people with learning disabilities doing research. Journal of Applied Research in Intellectual Disabilities, 29(6), 542-551. https://doi.org/10.1111/ jar.12213
- Nind, M., & Strnadová, I. (2020). Belonging for People with Profound and Multiple Learning Disabilities: Pushing the Boundaries of Inclusion. Routledge.



- Rix, J., Garcia Carrizosa, H., Seale, J., Sheehy, K., & Hayhoe, S. (2020). The while of participation: A systematic review of participatory research involving people with sensory impairments and/or intellectual impairments. Disability and Society, 35(7), 1031-1057. https://doi.org/10.1080/09687599.2019.1669431
- Robinson, L.D., Cawthray, J.L., West, S.E., Bonn, A., & Ansine, J. (2018). Ten principles of Citizen Science. In S. Hecker, M. Haklay, A. Bowser, Z. Makuch, J. Vogel, & A. Bonn (Eds.), Citizen Science: Innovation in Open Science, Society and Policy (pp. 1-23). UCL Press.
- Rojas-Pernia, S., & Haya-Salmón, I. (2022). Inclusive research and the use of visual, creative and narrative strategies in Spain. Social Sciences, 11(4), 154. https://doi. org/10.3390/socsci11040154
- Silvertown, J. (2009). A new dawn for Citizen Science. Trends in Ecology & Evolution, 24(9), 467-471. https://doi.org/10.1016/j.tree.2009.03.017
- Strnadová, I., Cumming T.M., Knox, M., Parmenter, T., & Welcome to Our Class Research Group. (2014). Building an inclusive research team: The importance of team building and skills training. Journal of Applied Research in Intellectual Disability, 27(1), 13-22. https://doi.org/10.1111/jar.12076
- Strnadová, I., Walmsley, J., Johnson, K., & Cumming, T.M. (2016). Diverse faces of inclusive research: Reflecting on three research studies. Scandinavian Journal of Disability Research, 18(1), 52-64. https://doi.org/10.1080/15017419.2014.964766
- Toerpe, K. (2013). The rise of Citizen Science. The Futurist, 47(4), 25-30.
- Walmsley, J., & Johnson, K. (2003). Inclusive Research with People with Learning Disabilities: Past, Present and Futures. Jessica Kingsley.
- Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. Journal of Applied Research in Intellectual Disabilities, 31(5), 751-59. https:// doi.org/10.1111/jar.12431
- Woelders, S., Abma, T., Visser, T., & Schipper, K. (2015). The power of difference in inclusive research. Disability and Society, 30(4), 528-542. https://doi.org/10.1080/ 09687599.2015.1031880

W JAKI SPOSÓB MOŻNA WSPIERAĆ OSOBY Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ W ANGAŻOWANIU SIĘ W NAUKĘ OBYWATELSKĄ?

Wprowadzenie: W społeczności naukowej rośnie zainteresowanie nauką obywatelską jako podejściem do angażowania osób niebędących ekspertami w badania naukowe. Jednak obecnie istnieje bardzo niewiele przykładów projektów nauki obywatelskiej, w które zaangażowane są osoby niepełnosprawne, w szczególności te z niepełnosprawnością intelektualną. Istnieje zatem potrzeba zbadania, czy i w jaki sposób projekty nauki obywatelskiej mogą stać się bardziej inkluzywne. Cel badań: Niniejszy dokument komentarzowy opiera się na literaturze i przykładach badań, aby zbadać, czy inkluzywne metody i procesy badawcze odgrywają rolę w zwiększaniu udziału osób z niepełnosprawnością intelektualną w projektach nauki obywatelskiej.

Stan wiedzy: Aby opracować przypadek potencjalnej roli, jaką inkluzywne metody i procesy badawcze mogą odegrać w zwiększaniu inkluzywności nauki obywatelskiej, niniejszy doku-



ment: 1) przedstawia przegląd cech, metod i zasad nauki obywatelskiej; 2) porównuje naukę obywatelską z badaniami inkluzywnymi i 3) przedstawia przykład zaczerpnięty z małego badania pilotażowego dotyczącego tego, w jaki sposób inkluzywne metody i podejścia badawcze były stosowane w celu wspierania osób z niepełnosprawnościa intelektualną w angażowaniu się w projekt nauki obywatelskiej.

Podsumowanie: Autorzy dochodzą do wniosku, że możliwe jest wykorzystanie inkluzywnych metod i procesów w celu zaangażowania osób z niepełnosprawnością intelektualną w projekty nauki obywatelskiej, ale zawodowi naukowcy będą musieli być gotowi na większą elastyczność w rozumieniu tego, czym jest nauka obywatelska. Przyjęcie lub adaptacja inkluzywnych metod i procesów badawczych daje nauce obywatelskiej możliwość rozszerzenia zaangażowania i stworzenia bardziej inkluzywnych środowisk badawczych dla osób z niepełnosprawnością intelektualną.

Słowa kluczowe: badania włączające, nauka obywatelska, niepełnosprawność intelektualna

