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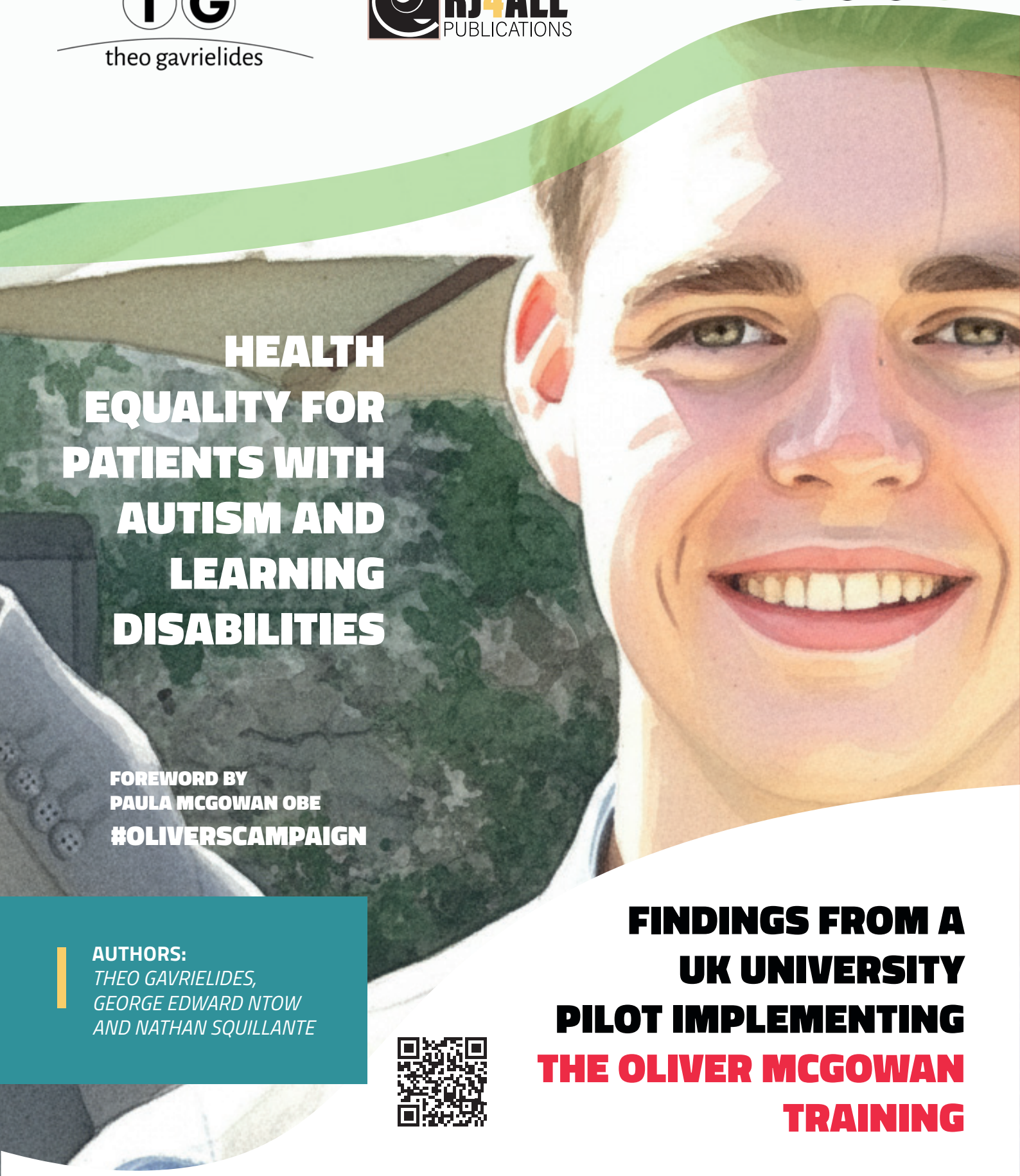

HEALTH EQUALITY FOR PATIENTS WITH AUTISM AND LEARNING DISABILITIES

FOREWORD BY PAULA MCGOWAN OBE

#OLIVERSCAMPAIGN

AUTHORS:
THEO GAVRIELIDES, GEORGE EDWARD NTOW AND NATHAN SQUILLANTE

FINDINGS FROM A UK UNIVERSITY PILOT IMPLEMENTING THE OLIVER MCGOWAN TRAINING

Buckinghamshire Health & Social Care Academy

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EXECUTIVE SUMMARY

BACKGROUND

In March 2023, Buckinghamshire New University (BNU) was commissioned from NHS England (NHSE) to pilot the integration of the Oliver McGowan Mandatory Training on Learning Disability and Autism (Oliver's training) into pre-registration nursing and midwifery education. As a result, a research project was carried out to understand the implications that this had on:

a) Trained BNU students as prospective nurses and midwives.

b) Trained BNU staff (academic and administrative).

c) BNU as a provider of Oliver's training.

The research project constructed an overall hypothesis that it tested through a mixed method investigation. This hypothesis was: *The integration of the Oliver McGowan Training into Nursing & Midwifery Council (NMC) approved pre-qualifying Curricula can better serve the aims of the Health and Care Act 2022, and help address health inequalities.* Ultimately, the research project aimed to find out whether Oliver's training should be integrated into pre-qualifying NMC approved Nursing and Midwifery curricula. **By the end of the pilot in September 2025, 59 BNU staff and 408 BNU student nurses and midwives received Oliver's training.**

The research was carried out between January – August 2025 and directly spoke to 238 individuals. To achieve its aims, the research looked beyond BNU by including the following sample groups: BNU students: 121(50.8%); BNU staff: 28(11.8%); experts or co-trainers with lived experience of autism and learning disabilities: 9(3.8%); HEIs: 8(3.4%); other training providers: 37(15.5%); lead BNU trainer: 1(0.4%); registered nurses and midwives and other healthcare providers: 23(9.7%); employers of healthcare providers: 5(2.1%); and the project management team: 6(2.5%).

The project was carried out in partnership with: Buckinghamshire Health and Social Care Academy (BHSCA), BNU and NHSE. The project was also in close contact with the Oliver's Campaign and Paula McGowan OBE.

This eBook reports on the final findings of the research project. The interim findings were published in June 2025 (Gavrielides, Ntow and Squillante, 2025).

FINDINGS

TRAINED BNU STUDENTS

- *Knowledge, skills and confidence:* Oliver's training significantly enhanced all three areas and especially students' confidence in caring for individuals with autism and learning disabilities. Based on the live evaluations, students demonstrated a better understanding of personalized care, improved communication and trust-building, and increased use of care plans. Their confidence in handling complex care scenarios grew, largely due to interactions with experts with lived experience.
- *Attitudinal shifts:* The training fostered a more respectful and person-centred view of individuals with autism and learning disabilities, encouraging students to see them as unique individuals rather than as patients with limitations. It also deepened their understanding of trust-building as essential to effective and individualised healthcare.
- *Reinforced professional development:* Oliver's training strengthened students' motivation and professional identity by promoting inclusive, person-centred care.
- *The role of the family:* The training helped students appreciate the crucial role of family involvement in healthcare particularly when it comes to patients with learning disabilities, autism or other communication needs. Their role as advocates and "experts" was acknowledged, something that was not originally considered as significant in caring for these patients.
- *Care plans*: It became clear how important it is that Care Plans for patients with learning disabilities and autism are reviewed regularly, and in partnership with the patient's carer.
- *Teaching and learning challenges*: The integration of the training did not feel as "organic" and was presented as an "add on" as opposed to being part of the regular curriculum. Students were expected to spend additional time for the training and the preparation, and it was not always made clear how this fitted with their existing undertakings and course expectations.
- *Research challenges*: It proved extremely hard for the fieldwork to collect data from students (both prior and post training). Additional resources had to be engaged. Integrating feedback or a test into the training to assess variables such as knowledge, skills and confidence will help overcome this hurdle.
- *Emotional risks*: By design, the training is meant to trigger emotions including empathy. The risks associated with this aim should not be underestimated. For example, there might be students with trauma or who may find the material or interactions with experts by lived experience triggering.

TRAINED BNU STAFF

- *Attitudinal changes:* The research showed a broader shift of staff towards better acceptance of the other, and inclusivity in both classroom and clinical settings. This broader impact of the training on academic and administrative staff was considered significant for building a stronger and more resilient human rights culture within university settings.
- *Understanding of autism and learning disabilities*: The research indicated a shift towards better recognizing the importance of (a) individualized, person-centred care (b) family involvement in care provision. Moreover, the need for tailored communication strategies was better acknowledged.
- *Delivery format:* There was an overall satisfaction with the blended delivery format (virtual pre-session and face-to-face) with lived experience experts. The implementation was seen as well-balanced and effective, combining theoretical background with practical insights.

- *Preparing for the course:* Pre-course awareness was not considered to be adequate. This could improve through webinars or forums that could increase uptake. However, it was acknowledged that this might have university cost implications while demanding further staff time commitments.
- *Emotional content:* Similarly to the students, there was acknowledgement of emotional triggers and risks, particularly during interactions with experts with lived experience.

EXPERTS WITH LIVED EXPERIENCE (BNU CO-TRAINERS)

- *Preparation:* The co-trainers commended the support that they had received prior to the training's delivery. This took the form of meetings in-person, rehearsing, arranging a call to talk about the session, receiving information on the delegates and venue, going through the slides and agreeing about roles.
- *Confidence levels:* Most co-trainers reported that their role improved their confidence in their ability to speak publicly. Overall, they enjoyed being part of the training sessions. Having a trusted relationship with the lead trainer and knowing that they were being supported improved their overall confidence.
- *Apprehension:* Most co-trainers shared that they were originally apprehensive to share their personal experience. However, gradually and with the right support they overcame this challenge without being judged or pressurised. This also helped in reducing the resources needed to support them.
- *Emotional and personal context:* There were some concerns about sharing their personal experience. They reported this to be a challenging experience for them and the trainees. This was particularly true when referring to cases of poor mental health and suicidal thoughts. Acknowledging this challenge and better preparing for its emotional impact can improve the training outcome.
- *Practical adaptations:* Some pointed out the need for better alignment of the training with their individual needs (e.g. adaptations to lighting, room temperature, being able to sit down during training sessions and positioning of tables). For example, some shared concerns over the size of the training groups as they tended to overwhelm them.

HIGHER EDUCATIONAL INSTITUTIONS AND OTHER TRAINING PROVIDERS

The research looked beyond BNU by including the views of other universities as well as private, charitable and statutory providers of Oliver's training.

HIGHER EDUCATIONAL INSTITUTIONS

Pre-requisites for delivering a successful training:

1. *Trainer recruitment*: Support in recruiting co-trainers with lived experience was considered critical. To effectively implement the training, it was suggested that universities could partner with NHS Trusts/ healthcare providers to identify and prepare Tier 2 trainers, cutting down costs and avoid replication of efforts. Financial support was also considered important for co-trainer's safety, particularly paying and transporting them from their preferred locations to the training rooms.
2. *Financial and administrative support*: They highlighted the need for funding to compensate co-trainers. Academic staff are often overburdened, and thus administrative support was recommended for tasks such as distributing materials, setting up classrooms, and rescheduling sessions.
3. *Support in creating accessible classroom space for co-trainers*: Given the needs of co-trainers, training spaces must be accessible. This includes the ability to control lighting and sound to reduce sensory

triggers during sessions.

4. *Curriculum integration and engagement time*: Co-trainers need time not only to prepare and deliver content, but also to build trust and relationships with participants. Universities must allocate time in their timetables to integrate the training while balancing other curricula demands.

Benefits for Higher Educational Institutions

1. Universities with courses that integrate Oliver's training are more appealing to future students, as they will be better equipped to take a job, cutting down future mandatory costs for the employer
2. Improved understanding among students and staff of the behaviour of individuals with autism and learning disabilities promoting a university-wide culture of tolerance.
3. Oliver's training builds confidence in communicating with people with autism and learning disabilities, helping students interact effectively, and thus better preparing them for practice.
4. By adopting Oliver's training, universities can gain recognition for producing care professionals who are workforce ready compared to graduates who weren't given the training at pre-qualification stage.
5. Oliver's training promotes empowerment and raises awareness of neurodiversity within the broader university community, an area that remains largely in the shadows of research, policy and practice.
6. Universities acknowledged that Oliver's training has a much wider impact than improving healthcare for individuals with autism and learning disabilities. It has the potential of helping to create a university-wide human rights culture of dignity and respect for each other's differences.

Barriers and other observations

1. *Resourcing challenges and staff workload:* Universities were concerned about the resource-intensive nature of delivering the training at scale. Key barriers included limited funding cycles, high logistical costs, and challenges in consistently paying co-trainers. However, it was acknowledged that as co-trainers gained confidence and experience in delivering the training, costs were coming down.
2. *Engagement difficulties of lived experience experts*: Difficulties included sustaining engagement with co-trainers, reliance on dual facilitation, and co-trainer burnout, particularly in large-scale delivery.
3. *Timing and scheduling challenges:* Universities reported challenges with integrating the training into diverse academic programmes with varying schedules and durations.
4. *Competition:* Alternative trainings and formats of providing similar content including the usage of online sources and e-courses were considered challenges in building a "business case".

OTHER TRAINING PROVIDERS

1. *Resource constraints* in the form of logistical costs and availability of persons with lived experience.
2. *Limited availability of trainers* with sufficient training on autism and learning disabilities
3. *Differences in institutional policies* between universities, NHS England, and civil society organisations can complicate collaboration.
4. *Growing competition and lack of regulation* of quality standards.

REGISTERED NURSES AND MIDWIVES

1. 87.0% of the sample believe that Oliver's training should have been provided to them at their pre-qualification stage.

2. 74.0% believe that Oliver's training can help better implement the Health and Care Act based on their practical experience and having received the training.
3. Key recommendations include: providing registered nurses and midwives with enhanced communication tools and greater access to specialist teams or co-trainers with lived experience to support learning and improve care for people with autism and learning disabilities.

EMPLOYERS

1. 100% of the sample believed Oliver's training should be integrated into pre-qualifying curricula for nurses and midwives, and that it would make a difference to them when recruiting.
2. Funding the training by the employer was not considered a good way forward. Therefore, graduates who had already taken the course were more employable that those who hadn't.
3. There were some major concerns around implementation barriers such as lack of qualified trainers (80%) and insufficient resources or funding for the training (60%).
4. 40% of the sample indicated that lack of time for scheduling the training into the curriculum can be a concern to its integration at the pre-qualification stage.
5. Overall, current employers of healthcare professionals believe that Oliver's training enhances improved patient care and outcomes. They also noted that it improved their workforce communication skills especially in relation to supporting patients with autism and learning disabilities (and their families).

REFLECTIONS AND RECOMMENDATIONS

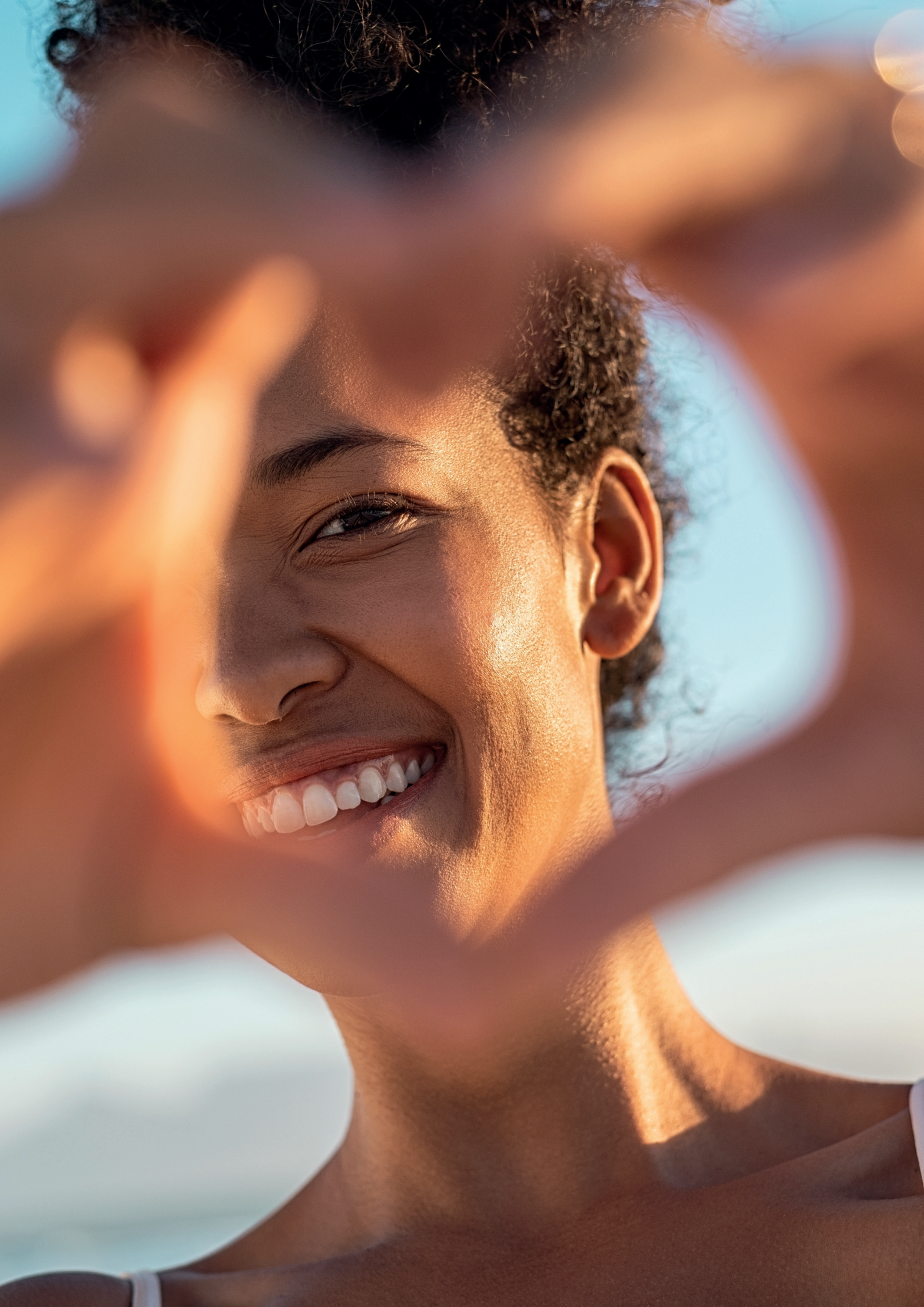
There is a clear value in introducing Oliver's training at the pre-qualification stage of nurses and midwives. There can be no doubt that by doing so, it can better serve the aims of the Health and Care Act 2022 and help address health inequalities. Notwithstanding, this must be balanced against several variables that are dependent on factors impacting: students, staff, universities, employers, other training providers.

The BNU pilot can be considered a success, based on the research findings. However, several caveats and weaknesses were highlighted. These could be addressed by considering the following recommendations that emerged from the fieldwork:

- √ **Inter-university collaboration** should be encouraged to help resource mobilisation (e.g. sharing of training space, co-trainers, know-how).
- √ **Year three of pre-qualification** was thought to be the best entry point for the training allowing for the learning to be better (a) integrated into existing student workload (b) embedded into practice.
- √ **Post-training compulsory assessment** can encourage trainees to approach their learning as part of their formal assessment, enhancing engagement, supporting reflection, and improving long-term retention.
- √ **Structured needs assessments and feedback mechanisms** by way of measuring trainee's understanding of the concepts taught and ability to apply the acquired knowledge-skills-confidence in real life situations. This should include in-built evaluation mechanisms (pre and post training).
- √ **Advance risk assessment** to identify potential triggers or related trauma that may harm participants

was highly recommended by all sample groups.

- √ **Sustainable funding model:** Currently there is lack of clarity as to how additional costs mentioned by the study would be covered. Clarity and a sustainable funding model will encourage university and other training providers and employers to introduce the training.
- √ **One size does not fit all**! The objectives of Oliver's training and achieving better health equality outcomes can be achieved or enhanced through various delivery models including:
    a. Use of technology such as e-courses integrated into current curricula
    b. Use of learning platforms for materials sharing, timetabling and for awareness creation to supplement or support the training
    c. Streamlining with existing curricula as opposed for the training to be sitting on top of them.
- √ **Where costs or other resource-related implications are preventing universities and employers to introduce Tier 2 of Oliver's training,** it is recommended that Tier 1 is adopted given that this is available for free online. Tier 1 could also be considered as essential in university curricula and Tier 2 as desirable.



FOREWORD

PAULA MCGOWAN OBE

“Oliver’s story stands as powerful evidence of why the human right to be involved in decision-making, and the need to truly listen to patients and their families, must never be underestimated. His experience revealed the devastating consequences when those rights are ignored. It also laid bare how far behind we remain, as a modern society, in recognising and treating autistic people and those with a learning disability with the dignity, respect, and equality they deserve, whether in healthcare, education, justice, or even in our day-to-day interactions.

Oliver’s Training is unique. From its inception, it has been co-designed and delivered by people with a learning disability and autistic people. Their lived experience and expertise are not an afterthought, but the foundation on which the training is built. This approach ensures that professionals are given the opportunity to learn directly from them rather than superficially about them. That distinction matters. It is the voices of people too often unheard that carry the most profound truths and the most urgent lessons.

Despite this, very little research has sought to explore the deep gaps that persist in healthcare provision, or to identify evidence-based solutions to address these injustices. That is why I warmly welcome the findings of this NHS-funded research project, under the leadership of Professor Gavrielides, and commend the pioneering work of Buckinghamshire New University in piloting this study. My hope is that this pilot will not only continue but will be replicated across the country.

It is only by embedding lived experience into research, policy, and practice that we can create a society where families like mine are no longer forced to fight for their loved ones to be treated with the basic dignity and respect that every human being deserves.”

October, 2025

PREFACE

THEO GAVRIELIDES

As I write this short note, yet again and with great shame, we are witnessing the revival of old debates of withdrawing from the European Convention of Human Rights, repeal the Human Rights Act and taking the country out of the Council of Europe. I would have hoped that the isolation and plethora of consequences that followed Brexit would have become lessons for a more humble and globalised vision of equality. But it seems that we have a long way to go before we hit rock bottom again.

Let's take a step back before I speak about what this e-book is about. I return to Eleonore Roosvelt's words in signing the Universal Declaration of Human Rights:

> *"Where, after all, do universal human rights begin? In small places, close to home, so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person: the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."*

After the shameful atrocities of two World Wars, we came together to say "never again", and signed a Declaration to acknowledge that every individual matters, and that the state must respect us not because we are its citizens or law abiding tax payers, but simply because of our humanity. Human rights are first and foremost for those who cannot speak for themselves. For our everyday realities that may lead to experiences and perceptions that defy our humanity. I would not want to live in a world where we chose who to protect, and where people are grouped into classes depending on their socio-economic value, gender, race, age abilities or disabilities.

It is not often that I agree to undertake work that I do not consider myself to be an expert on. Although human rights and restorative justice have been my areas of work, I have little knowledge about equality as this impacts on individuals with autism or learning disabilities. In fact, I was surprised when I was asked to lead on the research project that led to this ebook. Deep down I knew that the project was too important to pass. But there was also another selfish reason, I agreed to be involved. A neurodivergent individual myself as well as a dad of a teenager with ADHD, it felt personal. The superpowers that I always felt I had (and the same for my son), were not always seen as such especially by those who were meant to help us. I was fortunate to be able to articulate my thoughts and wishes from an early age and refused medication or treatments that just didn't feel right. As a (single) parent, I did the same for my son. We said no to medication and yes to nurturing the talents that feed into the superpower that a hyper brain charges our bodies and soul.

I am in great debt to parents, like Paula McGowan OBE, who can master the strength and take their child's tragedy and turn it into hope for others. The charitable sector would not have existed, and human rights movements would have been silent, if we did not have community leaders who can vision a better world. I truly hope that the research we conducted can make at least a small difference.

October, 2025

ACKNOWLEDGEMENTS

This ebook and the research that was conducted to inform its findings would not have been possible without the hard work of my two research assistants George Edward Ntow and Nathan Squillante. Despite of being in different parts of the world and time zones, somehow, we forged a strong team that was able to speak to an impressive 238 individuals directly impacted by Oliver's training. I am extremely proud of both of them and indeed grateful for putting up with my high expectations and tight timescales.

Special thanks go to Juliet Anderson (Director of Buckinghamshire Health and Social Care Academy) for entrusting me with this project as well as BNU. I am particularly grateful to BNU colleagues Dr Barry Hill, Dr Abbie Fordham Barnes, Prof. David Sines and Amsale Wamburu for their practical assistance. Nathan Green, lead BNU trainer and researcher for the fieldwork that we conducted with experts by lived experience must also be acknowledged. Similarly, huge gratitude to the NHS England team for their support and engagement with the project and pilot.

Finally, credit must be given to all those who agreed to take part in the fieldwork. They gave their time generously and voluntarily. This also includes individuals with autism or learning disabilities, and Paula McGowan OBE from whom I learned a lot.

Prof. Theo Gavrielides

October, 2025

ANNEX 1
ABOUT THE PROJECT TEAM

PROFESSOR THEO GAVRIELIDES, PHD

He is the Founder and Director of the RJ4All International Institute and the Founder of RJ4All Publications and RJ4All Sports. Pioneer of user-led research methods, and advisor to the European Commission, and governments. His most recent work involves working with the Buckinghamshire Health and Social Care Academy to collect primary and secondary data that would help develop a Framework for Social Care nurses. This resulted in the publication of three books, the latest one being Gavrielides, T. et al (2024). Developing a Framework for Social Care Nurses: Enhanced or Advanced Practice? A critical literature review, London: RJ4All Publications. He is a member of the UK Allied Health Professionals Leading Integrated Care Between Social Care and Health) Expert Reference Group.

Moreover, he worked with the BHSCA, NHS England and the University of Surrey to run (a) the Preparation for Practice Placements project which aims to pilot a resource for educators to prepare pre-registration healthcare learners for their first practice placement focusing on the non- clinical skill aspects of clinical practice (b) the Aspirant Educator Masterclasses project to guide healthcare practitioners towards educator roles and give them insight into the range of roles and required preparation.

Between 2009 - 2024, he acted as the Editor-in-Chief for The International Journal of Human Rights in Healthcare, Emerald, previously titled Ethnicity and Inequalities in Health and Social Care Journal. In 2009, he worked with the UK Department of Health to help them create a national delivery plan to support justice in healthcare. This resulted in Gavrielides, T. (2009) "Review by human rights specialist of Improving Health, Supporting Justice: A National Delivery Plan" in Department of Health Equality Impact Assessment of Improving Health, Supporting Justice, Department of Health: London.

In 2007, he was asked by the UK Parliament to give oral evidence to their public inquiry on the treatment of older people by healthcare public sector providers. This resulted in Gavrielides, T. (2007) The Human Rights of older people in healthcare, Parliamentary Joint Committee on Human Rights: London.

Finally, he worked with the UK Ministry of Justice (then Department for Constitutional Affairs) to introduce a Human Rights Strategy in health and social care services, resulting in:

- Gavrielides, T. (2006). Human Rights Insight Project Stage 1 Report:

Consumers: Reviewing the evidence on human rights awareness and experiences of consumers of public services: Building a human rights culture, Department for Constitutional Affairs: London.

- Gavrielides, T. (2006) Human Rights through the Education, Information and Advice Strategy, Department for Constitutional Affairs: London.
- Gavrielides, T. (2008) "Human rights and customer satisfaction with public services: a relationship discovered", Vol 12:2 International Journal of Human Rights, 187-202.

RESEARCH ASSISTANTS

GEORGE EDWARD NTOW

He is a young researcher with over seven years of experience in qualitative, quantitative, and mixed methods research across West Africa. He specializes in policy research and has long-term interests in community-based projects, infectious diseases, health systems, policies, and interventions aimed at protecting vulnerable groups in remote communities.

He has significant experience in stakeholder engagement, demonstrated through his three-and-a- half-year involvement with the West Africa Network of Emerging Leaders on Health Policies and Systems (WANEL) on an International Development Research Centre (IDRC) funded project on COVID-19. His project experience includes maternal and child health, UNICEF WASH in Ghana, tuberculosis prevention and control, and pandemic response. He is eager to collaborate on initiatives focused on equity, social justice, gender equality, and non-communicable diseases.

NATHAN SQUILLANTE

He has a BA in Sociology from the University of Cincinnati. He has experience in conducting quantitative and qualitative research from his education at the University of Cincinnati and his time with the Urban Appalachian Community Coalition (UACC) where he conducted health research on the issues facing 3rd, 4th, and 5th generation Urban Appalachians in the Cincinnati area.

Nathan has a small amount of experience with learning disabilities and autism, both from relationships in his personal life as well as through his experience as an Adaptive Gymnastics Volunteer where he assisted in teaching gymnastics to children with developmental disabilities including autism. Because of this, he is aware of some of the challenges people with learning disabilities and autism face.

This ebook reports on the findings of a research project that was carried out in England in 2025 to evaluate the impact of the Oliver McGowan Mandatory Training on Learning Disability and Autism. The project run within the context of a pilot that was carried out at Buckinghamshire New University (BNU), which received funding from NHS England to implement Oliver's training with students aspiring to become nurses and midwives. The research aimed to test whether 'the integration of Oliver's Training into approved pre-qualifying curricula can better serve the aims of the Health and Care Act 2022 and help address health inequalities. By the end of the project, 59 BNU staff and 408 BNU student nurses and midwives were trained.

The research directly spoke to 238 individuals: 121 BNU students; 28 BNU staff; 9 experts with lived experience of autism and learning disabilities; 9 Universities; 37 other training providers; 23 registered nurses and midwives; 5 employers of healthcare providers; and 6 NHS England staff.
Key findings include:

- There is a clear value in introducing Oliver's training at the pre-qualification stage of nurses and midwifes. There can be no doubt that by doing so, it can better serve the aims of the Health and Care Act 2022, and help address health inequalities.
- Notwithstanding, this must be balanced against several variables that are dependent on factors impacting: students, staff, universities, employers, other training providers.
- The BNU pilot can be considered a success. However, several caveats and weaknesses were highlighted by the research, and which could be addressed by considering its evidence.

"Health equality is a human right; and I have always argued that human rights are first and foremost for those whose dignity and respect is persistently violated by public services. People with autism and learning disabilities continue to be misunderstood by the very system that is meant to protect and promote their human right to health. I was honoured to lead on this groundbreaking research and work closely with inspirational individuals such as Oliver's mother, and experts by lived experience. I truly hope that our findings help to take the next step in advancing human rights for one of the most vulnerable groups of our society", Professor Theo Gavrielides, PhD.

"Oliver's story stands as powerful evidence of why the human right to be involved in decision-making, and the need to truly listen to patients and their families, must never be underestimated. His experience revealed the devastating consequences when those rights are ignored. It also laid bare how far behind we remain, as a modern society, in recognising and treating autistic people and those with a learning disability with the dignity, respect, and equality they deserve, whether in healthcare, education, justice, or even in our day-to-day interactions. Despite this, very little research has sought to explore the deep gaps that persist in healthcare provision, or to identify evidence-based solutions to address these injustices. That is why I warmly welcome the findings of this NHS-funded research project, under the leadership of Professor Gavrielides, and commend the pioneering work of Buckinghamshire New University in piloting this study. My hope is that this pilot will not only continue but will be replicated across the country. " Paula McGowan OBE.

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