



BISHOP
GROSSETESTE
UNIVERSITY

[BG Research Online](#)

Lawrence, C. (2022) *Our autism resources community hub: a celebration*. Journal of Inclusive Practice in Further and Higher Education. ISSN 2398-5976

This is a manuscript accepted for publication in Journal of Inclusive Practice in Further and Higher Education.

This version may differ slightly from the final published version.

Copyright is retained by the author/s and/or other copyright holders.

End users generally may reproduce, display or distribute single copies of content held within BG Research Online, in any format or medium, for personal research & study or for educational or other not-for-profit purposes provided that:

- The full bibliographic details and a hyperlink to (or the URL of) the item's record in BG Research Online are clearly displayed;
- No part of the content or metadata is further copied, reproduced, distributed, displayed or published, in any format or medium;
- The content and/or metadata is not used for commercial purposes;
- The content is not altered or adapted without written permission from the rights owner/s, unless expressly permitted by licence.

For enquiries about BG Research Online email bgro@bishopg.ac.uk.

Our Autism Resources Community Hub: a celebration

Dr Clare Lawrence clare.lawrence@bishopg.ac.uk

Orcid: 0000-0003-0563-6385

Word count: 3,365 + references

Acknowledgement: With grateful thanks to all ARCH members who are co-creators of this article.

Abstract

This paper reports on, describes and celebrates ARCH: Bishop Grosseteste's Autism Resources Community Hub. ARCH is a new initiative, started in the last 12 months by autistic undergraduate students and supported in its development by the wider autism community of the university – autistic postgraduates, autistic academics and other staff, family members, allies, alumni and advocates. The paper emerges from the student voice of the community and articulates the value and importance that ARCH holds for this cohort. It employs a 'nested' approach where the methods employed to create the report reflect the ethos of what is under scrutiny. As participatory research, autistic voices are central to every aspect under discussion - inception, creation, analysis, evaluation and dissemination. The paper concludes that the symbiotic relationships that are at the heart of ARCH that are its strength. ARCH interweaves information, support, social activities, participatory research and marketing/recruitment in a rhizomic mesh that embeds autistic awareness and understanding as central to all aspects of the university. What emerges is a confident autistic identity that draws strength from the interconnectivity involved. Implications for autism support at other institutions is considered.

Key words: autism, community, participatory, student-led

Our Autism Resources Community Hub: a celebration

Introduction

This paper outlines the value that our Autistic Resources Community Hub (ARCH) holds for members of the autism community at Bishop Grossetete University in Lincoln, UK.

Members of the autism community have been central to this paper at every stage – in its inception, in its creation, in analysis of the data gathered, through evaluation of the resulting documents and in dissemination of the findings. This involvement in the paper reflects the ethos of the hub under discussion. ARCH is owned by the autism community, and the sharing of it through this paper seeks to both celebrate it for the university and to look to the future and consider how it might continue to grow and develop.

Research background

Recent research (e.g. Lei and Russell, 2021; Davis et al., 2021, Gurbus et al., 2019) suggests that more autistic students are continuing their education to degree level or postgraduate study than ever before. Although, in percentage terms, numbers remain low (Lambe et al., 2019), and although attrition rates for autistic students remain high (Dijkhuis et al., 2020), there is growing interest from universities in more effectively providing for their autistic cohorts.

Much of this interest focusses on identifying the challenges that autistic students face (for example Bolourian et al., 2018; Nuske et al., 2019; Dijkhuis et al., 2020), with some focus apparent on potential solutions (for example Kuder and Accardo, 2018; Sarrett, 2018). The most recent research does investigate through interrogation of autistic experiences, report of autistic perspectives and relay of narratives from autistic students, so that ‘autistic voice’ is, in this way, represented. Yet truly participatory methods of exploring the autistic student experience remain rare, a position that may lead to epistemological as well as moral challenges (Chown et al., 2017). Inclusion of autistic people as full and equal members of the autistic research community should more effectively articulate autistic perspectives, not least through addressing potential issues regarding differing cognitive approaches (Chown et al., 2017). The ‘double empathy’ problem (Milton, 2012; Mitchel et al., 2021) that suggests that researchers from the predominant neurotype (PNT) community may fail to intuitively understand autistic communication, may lead to epistemological weakness in autism research that does not fully include autistic people at every level.

As important, remediation to meet autistic students’ needs at university has traditionally focussed on various types of support either for the autistic students themselves, or for staff (and sometimes for PNT students) through training aimed to facilitate understanding and reduce stigma. Gillespie-Lynch et al. (2021) have argued for the case of involving autistic students as core to these remediations, arguing that their studies ‘provide empirical support for the oft-cited, but rarely directly tested, benefits of involving autistic people in research about autism’ (Gillespie-Lynch et al., 2021 p. 10). However, ownership of this remediation is not always given to autistic students. Autistic students may be consulted, and may have input

into training, but the remediation nonetheless remains something that is frequently provided *by* the university *for* the autistic community, rather than *by* the autistic community *for* itself. However kindly meant, this approach continues to position autistic students as 'other' and does not integrate the voice of autistic staff or the wider autism community of family members, friends and allies into a shared and empowered collective.

The institutional context of the ARCH project

Our university, Bishop Grosseteste (BGU), is a small, publicly funded university based in Lincoln, UK. The university has, for some years, strived to be more inclusive for its autistic students. In 2016 it instigated an 'Autism Friendly Campus' project to seek to more effectively meet autistic students' needs through a study managed through staff interview of autistic student volunteers. This did result in some institutional changes (for example, the provision of 'quiet spaces' around campus, the availability of 1:1 tours of student accommodation at quieter times during Open Days etc.), and soon afterwards a regular 'Autism Café' was started, supporting the regular meeting of those interested in autism both internally and from the community. However, neither of these projects was initiated by the autistic student population, and – although autistic members of the university were involved in each – the projects remained under 'ownership' of the university and had, therefore, less impact on autistic students than was desired.

Towards the end of the 2020-2021 academic year, a single autistic student had the initiative to flag up the continuing need for autism network support at the university and worked with the student outreach team regarding the potential to create an autism 'blog'. This initial spark of student-initiated interest was welcomed by university staff keen to build on the earlier projects who were in a position both to go back to the university to secure further support, and to encourage and facilitate the on-going and growing involvement of the autistic student body.

In the academic year since its inception the resulting Autism Resources Community Hub (ARCH) has grown into an autistic-led and autistic focussed community resource for the university. The ARCH Student Council - the student group - meets weekly to discuss suggestions and developments and these insights feed into the monthly meetings of the wider Working Party group for discussion and implementation. The Working Party consists of autistic staff members together with members of the wider autism community including autism family members, friends, advocates and allies, endorsed and assisted by the university's designated student support teams. Together, the Council and the Working Party identify and instigate changes determined as important by ARCH's autistic members. Recent examples are the introduction of a designated Quiet Time in the library, where overhead lights are dimmed and movement is minimised, the inclusion of plain sandwiches (without mayonnaise, mustard or salad) in the Refectory, a named meeting room with streamlined booking system where ARCH members can come together for social activities such as Book Group and *Dungeon ad Dragons* games etc. as well as hold their meetings, and increased clarity regarding communication preferences for Learning Support access. ARCH is built up and by autistic people - students both undergraduate and postgraduate, academic staff and support staff - and in addition to facilitating reasonable adjustments it features community and social inclusion information, various social activities and a thriving (and growing) participatory autism research community of postgraduates and academics. In

the summer, for example, as part of the annual Learning and Teaching Conference it will host an exhibition of artefacts, images and recordings exploring autistic identity.

The case study

ARCH is autistic student generated, supported by the wider autism community of staff both professional and academic, and it is this symbiosis that has made it a truly university-wide community. In its inception ARCH embraces the affirmative model of disability, a model that is 'borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity (Swain and French, 2000, p.578). Important to the affirmative model is that the members who form ARCH are through their membership affirming a positive identity as autistic. We believe that ARCH is worth celebrating; capture of ARCH as an example of inclusivity in Higher Education was suggested by the Corresponding Author (CA), with the Student Council fully embracing the idea.

Method

It was key from the beginning that this case study would feature the voice of the students as central to its design throughout. As such, it is a 'nested' project, where the methods used to gather, analyse and disseminate data reflect the ethos of the case under scrutiny. It is an autistic-student-led project, facilitated by the CA who is Head of Participatory Autism Research at the university and who is an 'insider researcher', being herself a member of the wider autism community.

The method for the project was predicated on two core principles: that the content is created by the autistic students at the core of ARCH, and that the work burden of the study would be carried by the CA and not make undue demands on the students, especially in the high-pressure context of exams and assessments. Given that the voice is that of people who are autistic, it is also imperative that all elements and stages reflect understanding of and respect for preferred forms of communication by members of the autistic community.

Inception

Before the case study was started the ARCH Student Council confirmed enthusiasm in principle for the project. It validated the two core precepts (that the 'voice' of the case study should be that of the autistic students and that the collection of this 'voice' must not make undue demands on these students). These precepts defined the case study and formed the basis by which university Ethics Committee clearance was sought.

Creation

We were keen that methods of data gathering conformed to the principles of 'inclusion but low demand' as indicated in the precepts of the case study, and that they were also accessible by, and respectful of, autistic preferred forms of communication. The council suggested the following criteria:

- *Big groups or focus groups are not ideal*
- *1-1 is preferred, but any interviews should not be longer than half an hour (15-30 minutes would be the maximum)*
- *Questionnaires/written data gathering should also be kept short.*
- *A small item for discussion brought to Council meetings each week is the most manageable way forward*

After consideration of these, the following method was proposed:

'What five words?'

What five words would you use to describe ARCH/why ARCH is important to you?

If you have time, please can you explain each choice in just one or two sentences?

The following articulated the potential thematic analysis of the data:

We will see if there are consistencies in the words that people choose, or the sentiments that they express, and gather these together into themes. The data gathering approach is quick (if people are really short of time, they need only give five words) and will give a starting point to begin to understand what ARCH means to its members.

This approach was approved in principle by the council and taken to the university Ethics Committee, clearance to proceed being given on March 10th, 2022. Data was subsequently collected from those student members of ARCH who wished to take part during the remainder of March 2022.

Analysis

The words collected through the survey were used to (automatically) generate a Word Cloud. This simple 'analysis' makes words (or word groups) that are given more frequently larger and therefore more prominent. The rationale for this approach is that it is a quick and visual way for data to be organised, in line with requirements to limit time demands on the students involved, and that it also limits the CA as an influence on what 'themes' emerge, thereby facilitating continued autistic student ownership of the project.

Evaluation

The council members discussed the more prominent words to emerge from this process during scheduled council meetings in April, and considered if they felt that they fairly and accurately reflect their perception of ARCH. They also discussed the connections that had been made to the wider research literature. A member of BGU staff who regularly attends these meetings made anonymised notes during these discussions. These notes were fed back to the CA to be collated into this report, together with the elaborations that had been given during the 'What 5 words' process.

Initial summary documents were returned to the student council for evaluation and comment throughout the creation of this report, and changes and clarifications were requested and made. This process was repeated until the council members were happy that the document fairly and fully reflects ARCH's collective 'voice'.

Dissemination

A summary of findings agreed by the student council, together with the Word Cloud, will be shared by the council with the wider community via the ARCH pages on the BGU website and will in addition form an element at the university's annual Learning and Teaching Conference in June. Lessons learned from the case study will be carried into next year's student council cohort and will be available to inform the future development of the community hub.

The Council has further agreed the wider sharing of findings through the potential publication of this paper in the *Journal of Inclusive Practice in Further and Higher Education*. Should it be accepted for consideration, the published deadline for resubmission of updated papers falls outside term time. However, provision is in place to ensure that autistic student members of ARCH will remain fully involved in any rewriting or editing decisions as requested by the journal.

Findings

The suggested words resulted in the following Word Cloud:



This gives the following 'themes' to have emerged:

Primary themes: Friendly, Community

Secondary themes: Support, Welcoming, Acceptance, Aware, Fun.

Discussion

The most powerful element to emerge from this study is that ARCH is a **friendly community** for its members. Words such as 'helpful', 'together' and 'share' all echo a feeling that this is a community of people who work together, support each other and understand each other.

Members are pleased that these words were emphasised: as one articulates, ‘ARCH isn’t what it does, it’s the members’. Other words used to express something of this element are ‘kindness’ and ‘loyalty’; it is understood as important that ARCH is about ‘students helping each other’, although the importance and value of allies is also noted.

Identification of ARCH as ‘**friendly**’ expresses something of the importance of acceptance, of being in a group that shares feelings of connection, of similar norms and values (Hickey et al., 2018). Crompton et al. (2020) suggest that autistic people may feel more comfortable expressing their feelings with other autistic people, and it may be that autistic people create a feeling of community by sharing their experiences of autism within their shared group (Jones et al., 2013; Jones et al., 2021). As well as friendship and friendliness this sense of being a ‘**community**’ is worth recognising. The neurodiversity movement (Singer, 2017) and the affirmative model (Swain and French, 2000) support understanding of autism as a culture and as a group of people who share an identity. As such, this understanding embraces autism in much the same way as the Gay Pride movement has embraced (and de-medicalised) homosexuality (Dyke and Russell, 2020). The platform for autistic people coming together to self-support began through use of the internet (for example, Davidson, 2008), with the forming of in-person autistic communities such as ARCH a relatively recent phenomenon (Dyck and Russell, 2020).

An impression emerges of **support** both given and received, where the shared lived experience of autism is valued and respected. This is seen as important and pleasing; one member expresses that ARCH is where ‘students [are] coming together with common issues’. ARCH is recognised as an active force – a community that is approachable and which is ‘there when help is needed’. It is understood as being there to ‘help with needs for many students who are on the autistic spectrum’, and as having authority: it can ‘approach issues firmly’. The **welcoming** element of ARCH is particularly strongly reported and recognised as important, as is the feeling that this is a community where autistic people are **accepted**. This is celebrated as empowering and may be particularly important to a cohort who throughout their education may have been at increased risk of rejection and bullying (for example, DeNigris et al., 2018) and for whom loneliness has been identified as a significant negative factor (Umagami et al., 2022; Quadt et al., 2021).

The autistic **awareness** that is an intrinsic element of the ARCH community emerges as important to its members, both as a community that is aware of its members’ needs and one that spreads greater awareness of autism throughout the wider university. The fact that ARCH is accessible and that its approach is flexible and adaptable are identified as of value. One member highlights the importance that individual autistic communication preferences are ‘not just recognised but are celebrated’, and that because of this, all members of the autistic community have ‘a voice’. This voice is an essential element of self-advocacy and self-determination (Lei and Russell, 2021).

Interestingly, the value of the community to support learning about autism within its members is identified in a number of responses. It seems that ARCH increases awareness of autism both within and outside the autistic community. Members indicate that ARCH supports them in ‘understanding more about autism’, and that they ‘learn more about what it means to be autistic every day’. Indeed, one member goes so far as to suggest that ARCH is a ‘great support system in creating an identity’. Recent research suggests that understanding oneself as autistic and ‘not as a broken neurotypical’ can ‘empower people to explore and nourish ... self-identities’ (Botha and Gillespie-Lynch, 2022 n.p.).

As well as more serious issues, ARCH's role as something that is enjoyable shines through the responses. Members report it as such, which pleased the council who identify that the use of the word 'fun' slightly surprises them. They feel that they have not been able to arrange as many social activities as they might have liked, but celebrate that members find the meetings and the general chat fun and clearly enjoyable. Feedback also recognises the importance of ARCH as being 'calm' and 'relaxed'. The power of ARCH to give autistic students time to be themselves comes across powerfully, as does that it is a place to 'explore creative outlooks', with 'activities and tasks that are easy and fun for students with autism'. Sharing time, experience and ideas is identified as both 'important and beneficial', as is the time to 'talk and hear different perspectives and experiences of autism'. Members report that meetings are 'exciting' and that they bring 'a whole range of autistic students, staff and allies together'. One student simply reports, 'ARCH makes me happy!'.

An awareness of the value of ARCH, and a pride in its creation, also emerge. Students are aware that, although as of yet a small element within the university, it is a 'platform to have a say on things' and to 'contribute to change'. They see it as 'constantly pushing to spread the word ... and gain more resources', recognising it as 'an important part of Uni as it gives people the ability to form connections'. One member describes how ARCH 'feels alive', and a number of respondents articulate the perceived vibrancy of the community. However, the responsibility of 'ownership' of ARCH as an autistic community, and the consequent pressures of care, is also identified as an element by its founding member. This student indicates that they 'care for everyone in the group and when one admin task is not done, I feel guilty'. They add that it can feel 'quite stressful when something goes wrong', highlighting an element of challenge caused by the insider nature of the group. This is countered, though, by considerable report of feelings of pride at the way the community has grown in just 12 months and is continuing to grow. Whilst the inherent demands and potential stress of self-determination must be acknowledged, autistic autonomy is a powerful force. 'The last decade has witnessed the emergence of a powerful call from autistic people to have real input into the decisions that shape their lives (Poulsen et al., 2022 n.p.), and ARCH can be celebrated as an example of just such an input.

Conclusions

ARCH is an important example of autism university support provision because it is 'autistic owned'. This does bring pressures as well as considerable benefits, and these need to be acknowledged. That said, the wider autism membership of the group – that as well as autistic undergraduates it includes autistic alumni, postgraduates and staff members, autism family members, friends and allies – suggests that it has access to a depth of understanding that is not always evident through provision by external support services. Additionally, it empowers the autistic community through visibility. The simple (but seldom recognised) fact that autistic people are a part of every element of the university is itself a counter to the potential 'othering' of some disability rhetoric. It is a model that might well be considered by other institutions moving forward. It supports the affirmative model (Swain and French, 2000) for institutions, facilitating autistic inclusion practices to be positive, generative and a source of pride.

References:

- Bolourian, Y., Zeedyk, S.M. and Blacher, J., 2018. Autism and the university experience: Narratives from students with neurodevelopmental disorders. *Journal of Autism and Developmental Disorders*, 48(10), pp.3330-3343.
- Botha, M. and Gillespie-Lynch, K., 2022. Come As You Are: Examining Autistic Identity Development and the Neurodiversity Movement through an Intersectional Lens. *Human Development*.
- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L. and MacGregor, D., 2017. Improving research about us, with us: A draft framework for inclusive autism research. *Disability & society*, 32(5), pp.720-734.
- Crompton, C.J., Hallett, S., Ropar, D., Flynn, E. and Fletcher-Watson, S., 2020. 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24(6), pp.1438-1448.
- Davidson, J., 2008. Autistic culture online: virtual communication and cultural expression on the spectrum. *Social & cultural geography*, 9(7), pp.791-806.
- Davis, M.T., Watts, G.W. and López, E.J., 2021. A systematic review of firsthand experiences and supports for students with autism spectrum disorder in higher education. *Research in Autism Spectrum Disorders*, 84, p.101769.
- DeNigris, D., Brooks, P.J., Obeid, R., Alarcon, M., Shane-Simpson, C. and Gillespie-Lynch, K., 2018. Bullying and identity development: Insights from autistic and non-autistic college students. *Journal of autism and developmental disorders*, 48(3), pp.666-678.
- Dijkhuis, R., de Sonnevile, L., Ziermans, T., Staal, W. and Swaab, H., 2020. Autism symptoms, executive functioning and academic progress in higher education students. *Journal of autism and developmental disorders*, 50(4), pp.1353-1363.
- Dyck, E. and Russell, G., 2020. Challenging psychiatric classification: healthy autistic diversity and the neurodiversity movement. In *Healthy minds in the twentieth century* (pp. 167-187). Palgrave Macmillan, Cham.
- Gillespie-Lynch, K., Bisson, J.B., Saade, S., Obeid, R., Kofner, B., Harrison, A.J., Daou, N., Tricarico, N., Delos Santos, J., Pinkava, W. and Jordan, A., 2021. If you want to develop an effective autism training, ask autistic students to help you. *Autism*, p.13623613211041006.
- Hickey, A., Crabtree, J. and Stott, J., 2018. 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, 22(3), pp.357-367.
- Jackson, S.L., Hart, L. and Volkmar, F.R., 2018. Preface: Special issue—College experiences for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), pp.639-642.
- Jones, R.S., Huws, J.C. and Beck, G., 2013. 'I'm not the only person out there': Insider and outsider understandings of autism. *International Journal of Developmental Disabilities*, 59(2), pp.134-144.

- Jones, D.R., DeBrabander, K.M. and Sasson, N.J., 2021. Effects of autism acceptance training on explicit and implicit biases toward autism. *Autism*, 25(5), pp.1246-1261.)
- Kuder, S.J. and Accardo, A., 2018. What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), pp.722-731.
- Lambe, S., Russell, A., Butler, C., Fletcher, S., Ashwin, C. and Brosnan, M., 2019. Autism and the transition to university from the student perspective. *Autism*, 23(6), pp.1531-1541.
- Lei, J. and Russell, A., 2021. Understanding the role of self-determination in shaping university experiences for autistic and typically developing students in the United Kingdom. *Autism*, 25(5), pp.1262-1278.
- Milton, D.E., 2012. On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, 27(6), pp.883-887.
- Mitchell, P., Sheppard, E. and Cassidy, S., 2021. Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*, 39(1), pp.1-18.
- Nuske, A., Rillotta, F., Bellon, M. and Richdale, A., 2019. Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*, 12(3), p.280.
- Poulsen, R., Brownlow, C., Lawson, W. and Pellicano, E., 2022. Meaningful research for autistic people? Ask autistics!. *Autism*, 26(1), pp.3-5.
- Quadt, L., Williams, G., Mulcahy, J.S., Silva, M., Larsson, D., Arnold, A., Critchley, H. and Garfinkel, S., 2021. "I'm trying to reach out, I'm trying to find my people": Loneliness and loneliness distress in autistic adults.
- Sarrett, J.C., 2018. Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders*, 48(3), pp.679-693.
- Singer, J., 2017. *Neurodiversity: The birth of an idea*.
- Swain, J. and French, S., 2000. Towards an affirmation model of disability. *Disability & society*, 15(4), pp.569-582.
- Umagami, K., Remington, A., Lloyd-Evans, B., Davies, J. and Crane, L., 2022. Loneliness in autistic adults: A systematic review. *Autism*, p.13623613221077721.