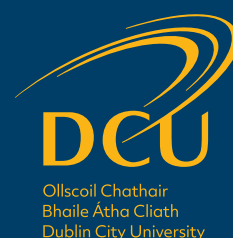


Living with Autism as a University Student at Dublin City University: Developing an Autism Friendly University

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Background

Autism is a developmental disability that affects how one relates to, and communicates with other people. A number of definitions for autism exist but there is general agreement that the following characteristics are common amongst those on this spectrum - difficulties with communication, socialising, repetitive behaviours and a heightened sensory perception.

Last year, Dublin City University (DCU) announced its intention to make the University more autism friendly www.dcu.ie/news/2016/jan/s0116j.shtml. The project report presented here marks the end of an 18-month programme of research undertaken to identify how DCU can become an Autism Friendly University. The goal is to allow students with Autism to take part more fully in University life and also to enhance their opportunity to gain employment after their studies are completed.

Researchers at the School of Nursing and Human Sciences at DCU, in collaboration with AsIAm (asiam.ie) undertook a multi-arm study that explored the experiences of those living with Autism as a DCU student.

Aims and Methods

The study aimed to identify and explore current services for DCU students with Autism, to explore their adequacy and to identify any gaps that could be addressed to

improve life on campus. A whole campus approach to the study was taken, involving students, academics and support staff from across the multi-site university.

By reviewing what is currently known about the challenges faced by students with Autism in higher education and by identifying the specific concerns/difficulties of DCU students with Autism, the research team set out to make a series of recommendations to the University to further meet the needs of students while on campus. In making these recommendations, it is hoped that they will, in turn, lead to an improved college experience for DCU students with Autism. As an integral part of this project, a literature review of peer reviewed studies was undertaken to explore what other Higher Education Institutes (HEIs) have been doing in this space. A comprehensive search and review of HEI websites across Europe and the United States of America was also undertaken. Both of these reviews then informed the methods and materials for four separate, but linked, studies described below.

Study 1

An online anonymous survey was administered, via the Qualtrics software platform, to DCU students with Autism who have attended DCU for at least one semester. This survey was advertised to students through the DCU Disability & Learning Support Service (DLSS) but was also advertised via a call for participants issued by the

Principal Investigator to the general student mailing list as we wanted it to be accessible to all students with Autism, including those who have not disclosed their diagnosis to the DLSS. The purpose of the survey was to explore the experiences of students with Autism attending DCU, to examine what services and parts of the university experience were and were not working well for them and to explore how these might be improved. Forty-five students with Autism began the online anonymous survey, but just 17 completed all aspects of it.

Study 2

An online anonymous survey of the entire student body in DCU was administered, via Qualtrics, to explore the attitudes of the general student body to their peers with Autism and also to examine their levels of knowledge about Autism. This survey took the format of a short vignette and a range of questions about the vignette character (who has Autism). Participants in the study were asked to read a short vignette and to respond to a series of eight statements about the central character, using a 5-point Likert scale, where responses ranged from Strongly Disagree to Strongly Agree. In total, 227 students completed the general student body survey.

Study 3

Focus groups and semi-structured interviews were conducted with academic and support staff of the University to explore the services and

supports currently available on campus for students with Autism, to examine the issues arising for staff in engaging with students with Autism and to explore how they could be supported to engage more effectively with this student group.

One focus group was conducted with academic staff (n=9) representing Chemical Sciences, Mathematical Sciences, Physical Sciences, the Institute of Education, Nursing and Human Sciences, Biotechnology, Engineering, Computing and Special Education. Another focus group was conducted with staff (n=4) from the DLSS, Student Services, Accommodation Services and INTRA Services. To augment these focus groups, five one-to-one interviews were conducted with staff from the DLSS, the Centre for Talented Youth in Ireland (CTYI), the Library and the Catering services. A further one-to-one interview was also conducted with a member of the Student's Union team.

Study 4

A sensory audit of both the DCU Glasnevin and DCU St Patrick's Campus was conducted by four students with Autism accompanied by two members of the research team to explore the issues that might arise for students in navigating the physical environment. An audit tool was developed and used and photographic records were taken. The goal of this audit was to look at the physical environment primarily from the perspective of noise, smells, lighting and signage.



Key Findings

Literature review/HEI websites scoping exercise:

The literature review revealed that there are pockets of activity in relation to creating an Autism Friendly environment within many HEIs in the USA and the UK. Within the Irish context, there is evidence that HEIs are now placing a greater emphasis on ensuring that students with Autism are catered for in terms of general and specific student support services. Importantly, there is an increased recognition that students with Autism might need and benefit from supports that extend beyond and complement the support services that are typically provided to all students.

Study 1: Survey of Students with Autism

The majority of students with Autism felt that they had the academic skills to attend DCU, but only around half of the sample felt that they had the social skills needed to succeed at University.

Many reported that they feel stigmatised by their diagnosis of Autism and are reluctant to disclose it, even to the DLSS. In total, 54% of students had not disclosed their diagnosis to the DLSS and even fewer (27%) had disclosed their diagnosis to academic staff. Because of this reluctance to disclose, many had not linked in with the DLSS, which could have provided valuable resources and supports. The reported reasons for non-disclosure included stigma, fear of discrimination, embarrassment, shame and adverse experiences in the past when having disclosed to somebody.

Half of those surveyed reported that they felt lonely in DCU and that they do not cope effectively with stress or anxiety. A majority of students reported that they feel isolated or generally depressed and reported that they eat alone in the cafeteria or preferred to spend spare time alone in quiet places on campus. The majority indicated that they have considered dropping out. Most commonly cited difficulties related to socialising were - difficulties in talking to people, not knowing what to expect, difficulties in meeting people with similar interests and difficulties in being part of a group. As reported, heightened sensory awareness of noise, bustling environments, smells and lighting often

exacerbates isolation of students with Autism, with restaurants, student bars, and social events being reported as difficult.

While some students felt that there was little else that DCU could do to support them in their social experience, other students had clear ideas about what they need to do to improve their opportunities for socialising on campus. Among the suggestions made was the education of class representatives regarding the problems faced by students with Autism socially, reduction in the academic workload, and the setting up of a society specifically for students with Autism. Another suggestion was the hosting of smaller events and workshops by the Student's Union.

The majority of the students reported that they did not find group work easy and just over half the sample felt they did not have a good routine established around their study and assignments. Just over half of the students indicated that it was not easy to ask questions and seek guidance from lecturers, and just over one third reported that it was not easy to get support and information from the DCU support services. The majority of the students reported that they found attending lectures stressful and almost one in three reported that it is not easy to keep up with lectures. Over half the sample indicated that they did not manage their time effectively. Around half the sample did not find academic or support staff knowledgeable about Autism and many felt that academic staff are often



unaware of students with Autism in their lecture theatre or are unsure of how to engage with them.

The majority (65%) of students indicated that the range of supports available at DCU were adequate to meet their needs while 35% said they were not adequate. When asked what else would support them, some felt that the university did enough already but others made concrete suggestions about what they considered would be beneficial. Among the suggestions for improvements made were the creation of a society for students with Autism, to help them make friends and socialise and have a more involved role in DCU extra-curricular life, greater involvement with the disability office, more information, conversations and awareness of the needs of persons with Autism on campus, tackling the sensory issues on campus that impact negatively on students with autism, more overt offers of support (without having to go looking for them), support with exams, assignments, planning and organisation, quiet spaces to sit and eat at break times - as the canteens can be daunting and noisy and lead to social isolation at break times - as well as more information on the supports available. Other suggestions included - the provision of guidelines to staff around students with Autism, greater range of teaching and learning methods, greater variety

of assessments, better spread of workload across the semester and greater flexibility with re-sit opportunities.

Additional suggestions for improvements related to addressing over-crowding and noise in lectures and laboratories, reducing time pressure in labs, increasing the number of posts on Loop (DCU's Virtual Learning Environment (VLE)), and better explanations of assignments.

The role of the Student's Union, student ambassadors, class representatives and Clubs and Societies was highlighted as a means to increasing awareness, promoting inclusion and improving life on campus for students with Autism.

Just over a third of final year students felt that they get enough support in preparing their Curriculum Vitae in preparation for employment and around one fifth of students felt they were adequately supported from the careers service to transition to employment.

When asked what they liked about DCU, students identified the campus and its location, the fact that the DCU community was friendly and accepting, the friendliness of the DLSS office, the number of Clubs and Societies, very good lectures, the Library, the Student's Union, fellow students and the campus accommodation.

Among the greatest needs identified were: the need to establish a society for students with Autism, which welcomes students with Autism, their friends and their allies; the need to address sensory issues on campus; the provision of quiet spaces; the need for quiet times at busy events such as Orientation, signing up for Clubs and Societies etc; the need for more visible information on the DCU website for students with difficulties; the need to reduce stigma, making DCU an environment where students feel they can reveal their diagnosis without any fear of adverse effects; the need for specific Autism training for staff across all sectors, appropriate to their level of engagement with students; the need for better communication across the different offices; the need for improved signage, ensuring that it is clear, un-ambiguous and at the correct height (e.g. eye level); the need for additional library support (e.g. in filtering information) and the need for additional support in navigating on-campus catering services (e.g. pre-orientation visit/tour and introduction of a prepay card system in order to avoid long, noisy queues).

Study 2: Student-body Survey

Whilst it is recognised that the survey may not have captured fully respondents' views, attitudes and beliefs, student responses to the series of questions related to the short vignette about an individual with Autism generally reflected positive rather than negative attitudes and beliefs about their peers with Autism.



Study 3: Focus groups and semi-structured interviews with academic and support staff

There was a clear openness among participants in all focus groups and interviews to the concept of DCU becoming an Autism Friendly Campus.

Participants were keen to support students with Autism and they offered a range of suggestions about how this could be approached in a way that would utilise existing forums and structures to embed the necessary principles and practices into a busy, growing university.

Lack of knowledge about Autism and the tools and techniques to provide appropriate support to students with Autism were an issue for staff. While participants' professional and personal knowledge and experience varied widely, there was a clear willingness to engage with others to address this knowledge gap. The student's right to non-disclosure was acknowledged but focus group and interview participants identified that students who do not disclose may miss out on benefits that those who disclose receive. It was acknowledged that stigma is still an issue. Resources are also an issue within classes and labs.

Improved or shared communications between the various university offices, with appropriate staff, along with a clear referral pathway to the DLSS was identified as a potential means to provide solutions to many of the difficulties currently experienced. Greater awareness across all services and offices in the University, in addition to sharing of expertise from the CTYI (eg. Prepay and Buddy systems) were identified as potentially useful.

Staff training was highlighted as a gap - guidance, information and Autism specific training on how to better support students with Autism was identified as needed. This could, for example, take the format of videos or presentations at staff meetings.

An increased role for the DCU Office of Student Life, which includes the Student's Union, Clubs and Societies, student ambassadors and class representatives was identified as a potential route to explore. An expanded role of and increased visibility of DLSS was also identified as potentially important as was timing of information to all students. Among the suggestions made was provision of information at Orientation by the President, which may improve reach but also work to reduce the stigma associated with Autism.

Provision of quiet times at typically busy events and provision of quiet spaces were also identified as very important. Furthermore, it was suggested that parental involvement should be considered where a student agrees or requests this. The notion of a designated Autism service in the University was also put forward as this would demonstrate that the University is serious about the term "Autism Friendly Campus".

Study 4: Sensory Audit

From the sensory audit, it was apparent that some aspects of the physical environment on campus was working well for the students who took part in the audit while other aspects could be a source of potential difficulty, particularly for those with heightened sensory awareness to smells (e.g. cooking smells and cigarette smoke), bright colours (e.g. red on walls), fluorescent lighting and noise (e.g. a bustling noisy space, such as the restaurants at peak times). Queuing systems in on campus eateries created significant difficulties for some of the participants of the audit. Other less obvious things such as hard seating surfaces, dimly lit spaces, noise from photocopiers in the library and unused or stacked cluttered furniture in classrooms were all identified as making life more difficult for these students. Other aspects of the campus environment that could potentially cause difficulties included missing, busy or ambiguous signage or signage not at eye level. A low humming noise from a projector left on in one of the lecture theatres was also highlighted as a potential sensory irritant as it could be detected by some as a high-pitched sound.



Conclusion

This whole campus project provides important information about the experiences of third level students with Autism. Whilst DCU is already providing a wide variety of supports to students with Autism, we have, through this project, identified that additional supports (policy, practice and practical) would help enhance the experiences of students with Autism and would help empower these students to flourish socially and academically. This will, we believe, be particularly important as more students with Autism transition from secondary education to third level in the future.

In conclusion, based on the findings from the separate but linked aspects of this project, it is apparent that there are many things that DCU is currently doing well in terms of meeting the needs of students with Autism. There are, however, many students with Autism who are struggling with the everyday navigation of academic and social life and there is much we could do to support them further. In this research, we have, in line with international literature, identified that the needs of students with Autism are not fully being met with the traditional services offered by Disability and Learning Support units and that additional Autism-specific supports should be put in place to complement the standard services offered. Additional support services to benefit students with Autism should include complementary academic and social supports as well as supports in the realm of communication, information processing, life skills, navigation of the physical campus and securing internships and employment. These student-centered supports

should be augmented by increased Autism-specific training and awareness elements amongst academic and support staff across the whole campus.

Arising out of this project, we outline a series of principles that are grounded in the findings of this research and we have now begun the process of translating these principles into DCU-specific actions that will be implemented within a three-year timeframe. To achieve this, we have begun the process of identifying the DCU offices and services that are best placed, in terms of their expertise, to support the implementation of these actions. This will constitute Phase Two of this larger project.

The President of DCU, Prof. Brian McCraith, has committed to adopting the eight Principles of an Autism Friendly University outlined below and to delivering on the proposed DCU-specific proposed actions to embed the principles of the Autism Friendly University over the next three years. Given this commitment, AslAm and Specialisterne Ireland now recognise DCU as an Autism Friendly University and will award DCU Provisional Accreditation as an Accessible, Welcoming and Empowering (AWE) University.

Ultimately, it is hoped that the principles identified here could be adopted by other HEIs that, like DCU, wishes to be recognised as an Autism Friendly University.



Principles of an Autism Friendly University

- 1 Encourage and enable students with Autism to transition into and participate in university programmes.
- 2 Support and build capacity to equip students with Autism to meet the academic challenges of everyday university life.
- 3 Support and build capacity to equip students with Autism to meet the social challenges of everyday university life.
- 4 Seek to establish an Autism friendly operational environment.
- 5 Seek to combat the stigma around Autism and recognise the diverse experiences of those with the condition.
- 6 Develop understanding and relevant knowledge and skills within the University community.
- 7 Establish channels so that students with Autism can have a voice in various aspects of university life.
- 8 Increase employability of graduates with Autism, through a range of initiatives that will help develop their soft skills to support their transition beyond University.



DCU-specific proposed actions to embed the principles of the Autism Friendly University

These actions will, where appropriate, be supported by AslAm.

1. Encourage and enable students with Autism to transition into and participate in university programmes.
 - a. DCU Communications and Marketing team will lead a campaign about DCU's commitment to Autism Friendly University status at both internal and external information and promotional events.
 - b. DCU will ensure greater visibility of information provided to students at orientation events about the suite of Autism-specific resources available at DCU to complement routinely-provided student support services.
 - c. Students with Autism will be invited to submit a profile of their Autism-specific needs to the DCU DLSS prior to commencing their studies at DCU.
 - d. DCU Head of Access will add an Autism-specific element to the current DCU Outreach Access Programme to complement the information currently provided.
 - e. DCU will promote increased awareness of the existing DCU model that permits students to designate an advocate (e.g. parent/guardian) to support them during the course of their studies.
 - f. DCU will continue to promote its programmes to prospective students with Autism who attend, for example, the Centre for Talented Youth, Ireland (CTYI) and the Coderdojo programmes.



2. Support and build capacity to equip students with Autism to meet the academic challenges of everyday university life

- a. DCU Library Service will add an Autism-specific element to their orientation programme to support students with Autism who have difficulty filtering material.
- b. DCU will put in place a peer mentoring model (buddy system) to support students with Autism to transition to university life.

In line with international best practice, this peer mentoring will take the format of a buddy system provided by appropriately trained graduate students (e.g. from health and allied disciplines).

- c. DCU will, where required, add an Autism-specific element to complement the recently launched 'Discover DCU' suite of resources: www.dcu.ie/studentlearning/online-tutorials.shtml

The 'Discover DCU' resources were developed to support students in the areas of balanced lifestyle, developing a community, learning and study skills, organisational skills, assignment writing and exam success.

- d. DCU will develop guidelines for academic staff to empower them to support students with Autism to reach their full potential academically.
- e. DCU will develop tools to help students with Autism to improve their Executive Functioning skills.

3. Support and build capacity to equip students with Autism to meet the social challenges of university life

- a. DCU Student Support and Development will run Autism-specific courses and/or workshops to support students in managing anxiety.
- b. DCU Estates Office will ensure that DCU Student Accommodation is suitable for students with Autism (minimum 20 beds if required).
- c. DCU will offer workshops on independent living skills for students with Autism who are living away from home.
- d. DCU will develop guidelines for the general student body on promoting the social engagement of their peers with Autism.

4. Seek to establish an Autism friendly operational environment

- a. DCU will provide designated quiet spaces in a number of locations across the University.
- b. DCU will be mindful of the sensory issues arising for students with Autism when infrastructure is being updated.
- c. DCU will develop sensory guidelines for major Students' Union events.
- d. DCU DLSS will scope potential for development of support tools such as 'DisabledGo' to improve Autism accessibility.
- e. DCU Communications and Marketing team will provide information on the DCU website about known issues that might present difficulties for students with sensory processing difficulties (e.g. notification of fire alarm drills).
- f. DCU researchers will develop a DCU Campus Map App, to help students navigate their way around the University.
- g. DCU staff will continue to improve local signage and other communication strategies to help students identify staff, office locations etc.
- h. DCU will work to improve further its communications with students by ensuring that all student information and policy documents are available in plain English following the National Adult Literacy Agency's Guidelines for Plain English.

5. Seek to combat the stigma around Autism and recognise the diverse experiences of those with the condition.

- a. DCU will hold an Annual Autism Inclusion Day/s in DCU.
- b. DCU's Office of Student Life will aim to ensure that the needs of students with Autism are considered routinely as part of routine activity planning.
- c. DCU will develop a network of "Student Champions" to support the Autism Friendly University initiative.
- d. DCU will provide specific supports for students who receive their Autism diagnosis in late teens/early adulthood.
- e. In order to continuously improve service provision, DCU DLSS will review the current processes and procedures in place for students wishing to disclose and formally register their diagnosis of Autism.

6. Develop understanding and relevant knowledge and skills within the University community (staff and service providers)

- a. DCU DLSS will expand and promote the resources available to support academics in their teaching of students with Autism.
- b. DCU will aim to ensure that all staff know where information on how to support students with Autism can be found.
- c. DCU will aim to ensure that all DCU Schools, Units, Services and on-campus businesses receive a short training programme on Autism Awareness from the DLSS at the start of each academic year.
- d. DCU will implement a pilot Autism training scheme for a sample of academic staff, with support of DCU Training & Development, the DCU Teaching Enhancement Unit and the Middletown Centre for Autism, with a view to extending the training to all academic staff in DCU.
- e. DCU will expand the Autism section / resources available on the University's DLSS webpages – in order to improve access to and visibility of relevant information.
- f. Given its role in education, DCU will capitalise on its potential to increase Autism awareness and knowledge amongst educators at all levels (primary, secondary and third level) through development and provision of a Module on Autism-specific Teaching and Learning issues.

7. Establish channels so that students with Autism can have a voice in various aspects of University life.

- a. DCU Clubs and Societies will run Autism friendly events.
- b. DCU will support the establishment of an Autism Society to provide a safe space for students with Autism and their friends.
- c. DCU will aim to ensure adequate representation of students with Autism on the Autism Friendly University implementation group.

8. Seek to increase future employability of DCU students with Autism

These actions will be facilitated and supported by the DCU Intra and DLSS offices and, where appropriate, will be supported by Specialisterne.

- a. DCU will complement current supports designed to build the social skills and other personal attributes of students, with an Autism-specific element.
- b. DCU will complement current student supports designed to develop Curriculum Vitae, interview skills and internship opportunities, with an Autism-specific element.
- c. DCU students will be advised of the additional specialist training offered and provided by Specialisterne which has been designed to enhance opportunities to secure and retain employment. This includes access to assessment workshops and advice on career opportunities.
- d. DCU students will be advised that all of the services detailed above are available to them and they will be given reminders about these services at a number of key transitory points / stages.
- e. DCU will continue to identify and to grow the number of companies prepared to offer internship and employment opportunities for students with Autism.
- f. DCU will continue to disseminate information to all students about companies that are interested in taking students with Autism on to internship programmes or into employment.





Autism Spectrum
Information Advice
and Meeting Point



Comhshaol, Pobal agus Rialtas Áitiúil
Environment, Community and Local Government



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