DARREN BRITTEN: Hi everyone, and thanks for joining me for this ADCET podcast. In this episode, you'll hear PhD candidate Alison Nuske discuss research into the experience of students with Autism as they transition to higher education. The research draws on the voices of students and family members. This podcast is adapted from a webinar Alison presented with ADCET and it's a great resource for disability practitioners to learn about current evidence and to use it to inform their day-to-day work. Over to you Alison.

ALISON NUSKE: I just want to acknowledge the traditional custodians of the Adelaide region, the Kaurna people, and acknowledge that their cultural and heritage beliefs are still as important to the living Kaurna people today and would like to pay our respects to Elders, past, present and emerging.

As Darlene mentioned, I'm currently a PhD candidate at Flinders University, I've been working at Flinders University for the past year or so as well as an associate lecturer, but prior to that, I was disability adviser at the University of South Australia for seven years and part of my role as a disability adviser was supporting the development and the implementation of their transition program to support students on the spectrum and other students with anxiety or needs in transitioning to university.

Prior to working at Uni SA, I also worked for our State-based autism association, which is Autism SA, in their school program and I worked as a developmental educator there and a consultant as well. I have lived experience of autism spectrum disorder and so, this has been part of my life for quite some time and has led to me undertaking this PhD study at this time.

I don't profess to have all the answers. Part of the reason why I'm doing this research is trying to get the opportunity to find out that information from people on the spectrum themselves. I will try my best to give you some ideas and strategies, but I don't profess to know the solutions to every issue that we come across in our role.

What I am hoping to do today is provide a little bit of a summary of a systematic review that myself and my supervisors went through and we published early last year and the process we went through was very interesting to find support for some of the issues, anecdotally, I definitely had experienced. I think it's a luxury in a way to be able to go through that process and identify all of the literature and explore it in great detail and so, I'm hoping that I can share some of that which might support some of the decisions and things that you need to look at in the future.

In that, I would like to acknowledge that this publication was not done just by myself and acknowledge that my supervisory team, who are fantastic, have supported me through this process as well. That's Dr Fiona Rillotta, Associate Professor Michelle Bellon and Professor Amanda Richdale.

I've included the reference there just in case anyone wants to go and have a look for the paper as well if they want more detail about anything we talk about today, because I'm sure we won't be able to get through everything that's in there.

I just want to make a mention about terminology and language before we look in more detail about the study or the systematic review we conducted. This presentation will use the term “on the autism spectrum”. I know that for some students, they prefer the term “autistic” and I respect that. We've chosen the term “on the autism spectrum” to be as inclusive as possible, but we also acknowledge that there are references to person-first language in this presentation and that reflects the language that was used to accurately reflect what we included in our systematic literature review on publication. At the time of publication, the APA required person-first language which was “students with autism” and we have replicated that here where necessary, however, since publishing, the APA have actually relaxed those requirements and so, we hope in the future we can use alternative language that might be more appropriate.

So, we looked at — when I started this research, I was interested in looking at this from my own professional background. As a practitioner and working as a disability adviser, I had a lot of experiences supporting students with ASD at university and was interested in exploring that in a lot more detail.

We found the research showed there was an increase in prevalence in autism spectrum disorder diagnosis, but also an increasing number of students on the autism spectrum that were enrolling in higher education settings. And anecdotally, we were seeing the same thing in practice.

What we found as well was that we acknowledge that transition to university specifically, and higher education, is a complex process. So, students are moving into a higher education environment which has an adult learning focus, requires students to self-disclose and to advocate for themselves and sometimes, this is the first time students have had an opportunity to do this or the first time they've needed to do this in order to access support.

We also acknowledge that first year of university involves an increased risk for students either to not pass courses, not pass topics or for student attrition as well and this is part of why we looked at focussing specifically on transition in our review.

When we started the process of doing this review, we found that there was other research already out there about the accommodations and supports and strategies students on the spectrum needed when they were at university, but what we found was there wasn't a lot of research around the transition specifically and that first year experience, and if we can't support students to transition to university effectively, we have difficulties in then implementing some of those further accommodations down the track because students often will withdraw, leave, may not continue on to their second and third year and so on.

So, after scoping some of this information, the question that we wanted to explore was what the experiences are of individuals with autism and/or their family members regarding the transition to higher education. And we specifically included family members' experiences as well because a lot of the research and a lot of my experience, anecdotally, have involved support from family members in that process. So, in transition and disclosure, etc. So, one of the key focuses that my research project and this review focused on was making sure that it's the experiences of students themselves that we're highlighting. There was other research that looked at what may be best practice suggested, but what we wanted to see were what the experiences of students were that were being recorded in the literature.

So, really briefly, these were the databases that we explored. Medline, CINAHL, ProQuest, PsycINFO, Scopus and Informit. We also had other education based databases which were housed within some of those databases as well. We were looking for not just — we didn't want to just focus on health, but health psychology, education, as much of that broad area as possible.

And these were some of the key words, definitely not all of the key words that we used, but we were trying to give scope to the fact that there was changing diagnostic terminology during the last 20 years and different terminology that different countries might use to represent higher education, further education as well. So, we were trying to be as broad as possible and really scope what was available.

We only found 11 articles that we could include for our review, which was probably not surprising, given that we were focussing specifically on transition and for the articles to be included, they had to have a qualitative focus for at least 10% of the paper. So, as I was saying before, we wanted to make sure that what we were exploring involved the perspectives of students themselves. So, it had to have a component of that.

The articles also had to have at least 10% of the individuals were on the autism spectrum so we could look at those experiences specifically and that was how we identified the articles that we were looking for.

Interestingly, we only found one article that met our requirements that was an Australian study. All of the other studies were from the US, Sweden, United Kingdom, Belgium, and the Republic of Ireland. So, there was very, very limited research around the transition experiences, particularly from the perspectives of students on the autism spectrum.

I'm not going to go through all of these. What I wanted to do was provide you with the references that we're talking about. As I go through, I will try — where possible, I've tried to link in the reference that the information relates to and then if you want to go back and find out a bit more information about those particular studies, then you can do so by accessing these references as well.

So, in the study that we were looking at, one of the things that I'm really keen about is exploring the experiences of students and recognising that students have these experiences within a network of policies, procedures, supports, etc, and to do that, we use this bioecological theory model where we explored different elements of the research to see whether they had examined the impacts of some of these systems on the student.

So, at the individual level, we wanted to see what the individual characteristics were that students were experiencing, that may have had impacts on their transition, but we also wanted to know more broadly what the impacts of family or what sort of family support was experienced or support from professionals or staff, what the policy impacts were and in this example that I've provided here, we've used some of the Australian examples of the policy that we might consider. And then, we wanted to see whether there was any discussion around, more broadly, what the cultural beliefs around disability or inclusion may have impacted on support experiences that students had in their transition.

So, we started by looking at the individual characteristics of students themselves and we found a lot of things that probably we recognise in practice and see every day and part of those experiences were some of the challenges that students reported. So, students did report social communication difficulties and sensory processing difficulties. They reported difficulties in the change in routine and structure that's involved with moving into higher education and difficulties with executive functioning skills like time management, planning, organisation and those sorts of things.

Independent living skills was something noted more in international research, not in the Australian research specifically, but definitely, you know, perhaps moving into residential college situations did pose some challenges for some students as well.

What was significant is a number of these studies actually talked about the importance of how individual these characteristics can be and individual the experiences are for students as well. One study that we were exploring asked students about things like group work and group skills and typically, we often make assumptions that group work and group skills are going to be difficult for students on the autism spectrum and yet, the reports they had conflicted, so some students had difficulties in these situations, but some people found that group work was a strength because it enabled them to meet people or connect with other students. It highlighted, for me, the importance of making sure we're being individualised in how we address some of these things and not jumping to conclusions that some of these characteristics, or all of these characteristics will affect all students on the spectrum and just making sure that our support is individualised and I think that's a really key element that we need to make sure we're doing.

The strengths were really good. I was a bit disappointed to find out that only one study really looked at the strengths that students reported they brought to their transition experience. Moving into university, the students in this study identified that they had strong memory which assisted them to study in their particular area. A dedication and an interest in their area and strong focus and also, attention to detail and those strengths were reported by students about their transition, but it was interesting, and somewhat disappointing for me to see that that was only in one of the studies that we found, which was the Van Hees and colleagues article.

One of the really big challenges that was evident in a number of studies was self-awareness and self-disclosure. Self-awareness, they found, in a lot of studies, varied and some students didn't identify they needed support or didn't wish to seek support when they transitioned to higher education. I've definitely seen this in practice in my experience - students that I meet, maybe in their second year or third year, that have decided to disclose for some reason. And the delay in disclosing or seeking assistance in these studies tended to relate to doubts about disclosure, about whether it's a good idea to disclose, about what the consequence of disclosing might be, about who to disclose to and how to do that and students reporting that they wanted to fit in. So, starting at a new environment, they wanted to fit in and not be seen as different to other students, so, avoiding disclosure either to staff that they were working with or more broadly, you know, to access supports by disclosing to disability services, for example.

And difficulties in self-determination skills were also evident in some of these studies as well, with students not having experience at disclosing or advocating for supports or identifying the supports that would help them the most, especially being if higher education is a completely new setting, then we can imagine the needs of students would change in that setting from what they've experienced before and maybe plying the supports they've had in the past to their new setting was a bit of a challenge as well.

We also found many studies did report, not surprisingly, increases in stress and anxiety for students during this transition period. What they did find was if timely support was provided and if planning was in place and students were prepared, then that anxiety can be significantly reduced. So, where supports were put in place early, that anxiety could be reduced.

The other element that we wanted to look at was the support element. So, this idea of either professional or family support most often was reported, supporting students to make that contact and make that disclosure in most cases. We found that all studies, in some way, discussed family support. So, family support was a really big factor that was addressed in every study.

In most cases, the sort of supports that were provided were things like emotional and psychosocial support, but often taking on some sort of role in relation to disclosure and initiating access to support services and this is particularly important to recognise because it was, you know, so clearly identified in each study and it did mean that students, in some way, were using support from family in particular.

What was particularly interesting to notice in the studies that explored this is that in most cases, and in no cases was this support not wanted, so, students didn't report not wishing to have this support, and in most cases, it was reported that family support was, in fact, valued by the individuals themselves as well, which was interesting to note.

Most often, the family support was from parents that was reported in the studies, although one study did talk to, I think there was one sibling. So, it would be really interesting to see if there are other family networks that are actually providing support that haven't been explored before.

The other support that students had access to was professional supports. This seemed to be usually in the process of preparation for transition. Helping in planning, providing information, and what students reported is that they wanted support from people who were honest and reliable, who had knowledge and understanding of autism spectrum disorder, and could provide them with timely information in a really clear and concise way. So, the information had to be really clear, easy to follow, and relevant to what they needed as well.

The next consideration that we had was around a couple of different areas, partly around the interactions between some of these support networks, but also around the, I guess, impact of some of the policy and legislation that might create some barriers. So, we did identify, in many of the studies, that transition should be a collaborative effort. It should involve the student, their support networks, other stakeholders, family where appropriate, and that pre-planning should start taking place early and in the school years and some of the research shows around the age of 14 is when some of this transition planning should really start to take place to give students enough time to work towards that transition.

We found, though, that there were challenges to that collaboration and I've definitely experienced these in practice, so this wasn't overly surprising to find evidence for, but I felt really validated in finding evidence in the literature to show that this was the case as well. In some cases, the support networks, particularly family support, may not have been aware of the rights and responsibilities under the legislation, so they may not have been aware of how to go about supporting the person in their particular country based on their relevant legislation. And much of that legislation does come down to privacy issues where the student is now an adult and that really impacts on that need to disclose individually and for themselves and the privacy legislation was a really significant barrier where support — parents, in particular, were trying to provide supports.

Because they're moving into an adult learning environment as well, students were expected to be able to, firstly, to be able to disclose for themselves and secondly, there were barriers to them actually having support to do that in many cases in these studies as well.

What we didn't find in any of the studies was any discussion about the broader, so, cultural society beliefs, about disability or inclusion and how that might have affected students transitioned experience and we also didn't find experiences in relation to changes in policy or things over time where that might have impacted as well. So, the studies that we found, we particularly selected studies that had occurred after the introduction of the UN convention on the rights of people with disabilities and that underpins much of the relevant legislation in most places that we were looking at. But there wasn't really a discussion of the much broader societal impacts and beliefs.

So, as a result, some of the important considerations that this highlighted for us was the significant importance of early access to services and accommodations, not just so that students have successful transition, but this early access to supports also had an impact on students' anxiety. So, I think supporting student wellbeing and mental health really was a significant factor of those individual characteristics. So, supporting access to services early and that's part of — and I'll talk shortly about what we're looking to explore, but that's part of the reason why, I think, exploring this area is really important.

We did find evidence that there was a delay in disclosure or disclosing to support services in particular and then, knowing how and when to disclose beyond that, say, to peers or to academic staff, for example, and most commonly, it was reported that these sorts of things happened after crisis. So, we did find that would have a significant impact for students as well.

It really highlighted the role of family and that then impacted how we went about or how we're going about conducting the research we're doing and kind of validated those concerns around the impact of privacy legislation and adult learning environments and expectations. And as a result of that, I think has, you know… would suggest that we need to look at ways of supporting and being aware of the need for students sometimes to have support that otherwise may not meet some of those requirements and how can we do that effectively and support students to access services with assistance from family, if needed.

It's really important that staff have a knowledge and understanding of autism spectrum disorders and ability to put that into practice. So, having experience working with students on the autism spectrum and learning from them and really understanding their own experiences and being really careful not to apply a kind of one-size-fits-all approach to any of that is particularly important.

Again, that individualised planning was really highlighted, looking at the complexity and the way that a lot of these factors interact and impact on the students' transition.

So, we went through the process of trying to find the reasons why there may have been challenges or where the strengths were. I think, predominantly, the research showed lots and lots of challenges and we weren't able to find a huge amount of research around some of the strengths which would be interesting, definitely, to explore further.

Our current study is hoping to answer some of those questions and the main focus that I really want to see come from this research is that we give an opportunity for students on the spectrum to tell us what has and hasn't worked for them during their transition to university and to see what we can keep. So, what we can continue to do that's working well and what sort of things we might be able to change to make that more effective as well.

So, we're really hoping that we can find out and give an evidence base to decisions. I know the transition, there's lots of talk about peer mentoring programs and the sorts of research in that area, so I'm hoping this supports a lot of the transition literature that we can build to support decision-making in practice and our requests for resources and strategies and similar as well.

Through this current study, we do hope that we will be able to understand a bit more about the experiences of students on the autism spectrum and their family members. This is kind of significant for us to understand what those experiences are and what is and isn't working. We also want to look at the experiences and understanding and knowledge of university staff as well. So, we're hoping to find what's working really, really well, what sort of experiences staff have had, what they feel they need in order to make this a successful time for students. And so, therefore, we're hoping that this will give us evidence base for best practice and to inform some recommendations for training and staff development down the track as well. So, we're hoping that will be one of the outcomes for this study.

I wanted to make a special note of how we have kind of got to this point and some of the support that I've had in this process. We started off with a really informal advisory group, based on the guidelines from Autism CRC's inclusive research practice which is a really, really fantastic resource, if anyone is looking at conducting a research to support students on the autism spectrum, I highly recommend accessing this resource as well. It gives some really great ideas, right down to, you know, preplanning for interviews and making sure that you've thought about how to familiarise someone with locations and those sorts of things as well.

One of the key things that's really, really important in the CRC's guidelines is including people on the autism spectrum during the research process and we definitely, from very early in this study, I was a big push in this area to make sure that I wasn't researching for other people, that I was, you know, really trying to give a voice to people to support further knowledge in this area.

So, we started off with quite an informal group, some students on the autism spectrum and family members to give us feedback on — particularly on research tools. So, we explained what we were looking at doing, we had support from this group of students, then we talked about the tool we were using which, for the first phase of our study, is an online survey, and we ask them for some feedback on question clarity, question relevance, the way that questions were proposed and whether, perhaps, we'd missed any really important factors that they think students might want to contribute information on.

So, that started off quite informal in our first, probably six months or so of this study. Students, initially, were asked to provide feedback on the questions in the survey and what we realised was that without formalising that input, it's really difficult to explain how that's working and what support that's providing for your study. So, we identified the need to formalise that, partly to recognise the efforts that the students were contributing and other family members and some research staff as well on the autism spectrum. And also, to, I guess, make people feel more comfortable about the fact that this research was being done in connection with people on the spectrum and that we weren't ignoring that part of the process.

So, we decided to formalise the role as an advisory group and we contacted the students that we had been, you know, contacting informally and a couple of other researchers on the spectrum who had indicated interest to us in the past and had been part of the process of developing this study to where it is, and we asked them if they would like to be part of an advisory group. They were asked if they would be willing to provide feedback on things like interview questions, planned methodology. We actually have another component to our study we're about to roll out and this advisory group was asked to provide feedback on whether they felt that was appropriate and suitable and also, on terminology usage and how we can work with that as well.

Any changes — we have needed to make changes to the direction of the study, particularly at the moment, this group was asked to provide feedback on that as well.

We outlined to them that the expected involvement of this group is actually quite ad hoc. It's maximum of maybe one to two hours per month on an ad hoc basis, but it could be email, phone, face-to-face, we're quite flexible with how that works. To date, we've contacted participants in that advisory group or individuals in that advisory group, provided them with information and requested that if they're interested, they can provide feedback through either of these methods.

It's entirely voluntary for these individuals to be part of this group and the input would be acknowledged in the final thesis and we're hoping that once we have some data to analyse, we can consider some opportunities to do some peer review journal articles together.

We emailed all the people who we had some feedback from and they were actually very keen to be a part of this advisory group. So, we now have three university students on the autism spectrum, we have two autistic researchers as part of this advisory group and a family member as well of a student on the autism spectrum to give us some feedback. I think, one of the best things that we've done is formalising this process and I think I had tried to make it informal to try not to be too inconvenient to people. I didn't want to bother people, but I think formalising it is one of the best decisions we've made in the last few months to really recognise the support these people have provided to our study as well.

So, I would really highly encourage people to consider how they can incorporate this really early on.

As I said, we did, but we didn't formalise it in a way that really helped to clarify and I think it's particularly relevant to make sure that expectations are clear. And I'm really… so far, we have had feedback from participants or from individuals in this group who have been just invaluable. I cannot tell you how invaluable that support has been from the group as well.

So, I want to acknowledge their input and highly encourage people to consider doing similar in future.

So, part of the study that we're conducting at the moment, we have one phase which is an online survey and we've got some case studies we're about to start. We were going to do some face-to-face case studies here in South Australia, but unfortunately, with the current COVID-19 situation, we're having to look at some online options, which has, in some ways, I say unfortunate, it's just meant a change of ethics applications, but in other ways, it's actually great because we can open that up to a much broader audience and participant group as well. So, we're hoping that that will be an opportunity for people to engage in that way.

So, at the end of this year, we want to look at what we've collected from our first phase of the study, the information that we've gathered and then we really want to, I guess, narrow down on what that means for students. So, we're planning to hold some focus groups online and if we're able to, face-to-face, just with students on the autism spectrum because we want to get their perspective on all of the information that we've collected from family, from students, from staff, and really identify what's important for them and what they see as being valuable for that transition process.

So, I just wanted to give an explanation of what our online study involves, so if you are interested in supporting the study or want to contribute to this area of research, you know what we're looking for.

So, we're actually exploring — we have three surveys going at the moment. They've been going for a bit of time online and the first survey is for students on the autism spectrum who have done at least six months of undergraduate study in an Australian university. We've tried to make it broad in terms of when they studied, so it could have been at any period in time. They do have to have a diagnosis now, but it doesn't necessarily mean they needed to have a diagnosis when they were studying. We know often, that's not the case. But if they are aware they are autistic, they have done at least six months of study at an undergraduate level, we'd be really keen to hear what their experiences were like.

We also have another study to kind of parallel that which we're asking family members of any students who similarly have completed six months of undergraduate study at an Australian university, where that family member may feel they've provided some support to that student. We'd be really keen to hear about those experiences, too, so that we can kind of understand what that is like for family members and that could be any family member, you know, aunt, uncle, parent, sibling, anyone who has been in that support role.

And we'd also be really keen to hear from university staff as well and that's professional, academic staff, anybody at a university who feels that they've, you know, they may have had interactions with someone on the autism spectrum or someone they believe to be on the autism spectrum. Just an opportunity to talk about what their experiences are supporting students as well.

That's, I guess, trying to give us those broad elements of all of these different layers that impact on students' transition so that we can then take that to these focus groups and really ask students what they think about these different factors and ideas.

So, in addition to that, at the moment, we're actually about to start recruiting for some case studies and we're hoping to explore similar sort of characteristics. So, we're hoping to understand what the student's experience was when they transitioned to university, we're hoping to understand a bit more about what the role that, perhaps, their disability liaison officer or disability adviser provided during that transition. We would like to look at the policies that are in place that support transition and support students to access support and then, you know, try to collate that information so that we can get some really in-depth detail about student experiences that we can also then take to our focus groups and explore from that perspective.

So, we are hoping that we will be able to get a number of students who are interested and if you know any students who might be interested in supporting that research and letting us, you know, find out from them, this is a really great opportunity for us to look at giving a voice to the student themselves. It's significantly focused on the student's experience of that transition process and we are looking for students who transitioned in the last couple of years, if possible, but we are happy to explore where that might work.

So, if anyone knows any students who are really interested in contributing to the understanding of that transition support, I know a lot of students have had good and bad experiences, who may want to share those and we’d be really keen to hear from anyone who is interested.

So, there is links to our survey information on the ADCET news page. I'd like to say thanks to Jane for helping me to organise all of that and for sharing that resource. So, if anyone is interested, you can actually access most of the information from there, but I will also have my email address details in this presentation if anyone wants to contact me as well.

What we're hoping to do is at the end of our study, we have a Facebook page where students can follow the — interested people can follow the process that we're going through, can share recruitment information that we post up there as well, and then once we have our outcomes and some data we can share with people, we're hoping to share it on that page. So, it's building a small community to… yeah, so that we have a place to share that information broadly as well. So, if anyone's interested, please pop along to that page if you do want to hear about the results of the study. We're hoping that we might be able to present some of the findings, well, online conferences, I guess, at this stage and webinars, hopefully, at the end of this year and we'd be more than happy to share some of that information at that point.

Also, hopefully, throughout next year and through some publications once we're finished as well. But we're more than happy to connect with anyone who might have any questions about our study or who may want to contribute or support us with that as well.

So, if anyone is interested in finding out some more information, I'm hoping that we will be able to give some answers to some questions that I know people are definitely looking for through, really, asking the students themselves and getting their perspective on things.

So, if anyone does want to get in contact and talk a bit further, my email address is on-screen. It's Alison.Nuske@Flinders.edu.au. I want to thank Jane and Darlene for giving us an opportunity to share some of this information. As I said, I feel really privileged to have had the time to commit to doing this and to be able to commit time to doing this and I'm hoping along the way, it's going to be supportive for future practice as well.