

# D2.1 Literature Review Report

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## 1 Background

The Autism&Uni project (<a href="www.autism-uni.org">www.autism-uni.org</a>) aims to supports students during the critical transition periods from leaving secondary education and applying to university through to arriving and settling in at university. It will do this through an interactive toolkit that provides students with strategies for overcoming the challenges they typically encounter, and through the sharing of best practice amongst professionals who support autistic students or influence policy and regulations that affect autistic students.

Work Package 2 aimed to conduct a systematic and critical review of the research literature concerning young adult learners on the autism spectrum, technology enhanced learning for autistic people and higher education practice and pedagogy. It was important to conduct this review in order to fully understand what was accepted and current thinking regarding autism characteristics and the support available in the Higher Education environment. Further, subsequent project deliverables gained credibility from being grounded in a thorough and critical review of the literature to obviate any concern about the fitness for purpose of these deliverables.

Leeds Beckett University, as Work Package leader, designed the research methodology, undertook that main bulk of the literature review, and co-ordinated the efforts of other project partners in sourcing, assessing, summarising and forwarding materials from their countries, often in their native languages. Each partner decided how much time and effort they would put into their contributions to the literature review.

This report summarises the findings from the literature review. It should be noted that the literature review was not the sole basis for subsequent project deliverables (the creation of an online toolkit and a best practice guide). Review findings provided the context for, and guided the analysis of data from a mapping exercise that was conducted in all project partner countries in 2014. By establishing what the literature has to say about young autistic adults in higher education, it added to our understanding of what is good practice in supporting them.

## 2 Research questions

The overarching research question guiding the literature review was:

"What constitutes best practice when using educational technology with Higher Education students on the autism spectrum?"

This question was then further divided into three sub-questions, each of which resulted in a separate review of the available literature:

- 1) What are the characteristics and requirements of academically competent autistic learners that render them different from the general student population?
- 2) What pedagogic principles and initiatives have been used in post-compulsory education to address these differences and support needs?
- 3) What technological interventions have been used to support the social and academic development and independence of autistic students?

### 3 Executive summaries

#### 3.1 English – Executive summary of results

Autistic students are less likely to complete their studies than non-disabled students (25% less) and students with other disabilities (40% less). Autistic students who make it to university often have high expectations of their experience of studying, their own grades and the studiousness of their peers. Parental expectations are a key factor (both high and low) in the success or otherwise of the student in higher education.

At undergraduate level, less than 1/5 of autistic students are female and at postgraduate level, this rises to 1/3. There is evidence of late diagnosis for female students, and indication of a significant number of undiagnosed female autistic undergraduates (in addition to the group of undiagnosed or undisclosed male autistic students).

A third of students on the autism spectrum do not identify as disabled. There is reluctance among autistic students to disclose their disability unless they can perceive real benefits in doing so. Disclosure does not automatically lead to support, or indeed the appropriate support. However, fellow students think and behave more positively when aware of someone's autism diagnosis and, crucially, with sufficient knowledge about autism. Simply knowing/sharing the diagnosis can be counter-productive due to unhelpful stereotypes as portrayed by the media. Lack of disclosure, or lack of information about ASD, may lead to misunderstandings and perception of rude behaviour.

Often the advice given to students is to adapt, change and develop independent thinking skills, which demonstrates a desire to adapt the student to the system, not the other way round. This is difficult where change does not come naturally, and anxiety levels are high. Often there is the perception that the student is the problem, not the institution or the education system. This should be challenged. Inclusiveness is a principle, built on opportunities and equality. However, the 'mainstream' presumes that all students can respond equally to HE conditions. There is the prevalent idea of the 'ideal' HE student who is reflective and independent. During their studies, students move closer to this ideal and HE 'moulds' them into this. This principle does not seem to serve autistic students well.

Self-advocacy is vital for disabled students in meeting individual needs and being successful in study. This can be problematic with 'invisible' disabilities such as autism due to doubts about entitlement to support and having to demand and justify requirements, in addition to existing social and communication challenges.

Eligibility for support at university involves a mixture of needs-based and means-tested processes, depending on the country.

- Disclosure of condition with a formal diagnosis usually required this is a problem if the student does not want to disclose, or does not feel that there is a good reason to disclose.
- The assessment typically focuses on student's problems and deficits because that's what
  determines eligibility for support. There is an opportunity to also focus on student's
  strengths and how they can be encouraged and enhanced

- Forms are long and plenty, autistic students may have trouble completing them. Countryspecific scenarios could help with current forms, the best practice guide can help universities or governments to change these forms.
- A UK study showed that the 'needs assessment' was generally well received but often the support the student eventually received did not match the recommendations from the assessment.

When the support provided to autistic students is appropriate and effective, it can make a real difference to student resilience and retention. However, it can also lead to 'separation' from fellow students, increased social anxiety and a sense of being different from peers. There is an artificial divide between support for study life and social life, whereas student life is a complex and continuous negotiation between the two states. Support for both aspects is sometimes available, but rarely delivered in a joined-up fashion.

Many students say they have few or no friends and they frequently experience difficulties in joining social groups inside and outside their course. Friendships can be very satisfying; especially where mutual interests exist (e.g. walking club) and shared interests can be a very effective catalyst to social adaptation. However, there are barriers to getting involved in such shared interest communities. Often the social rituals involved in joining a group and making friends are difficult to navigate. The groups, or the university, could provide alternative ways to joining.

While much has been written about autistic students in STEM (science, technology, engineering and mathematics), statistics collected from institutions in the UK and US show that subject choices are across the whole range of disciplines. While numbers studying mathematics, sciences and computer science are high, arts and humanities are also very popular disciplines, especially in UK and Poland.

It is difficult to practice inclusive teaching that does not segregate students with disabilities or force them to cope or drop out. Differentiation in teaching has mostly been practiced in schools, where if implemented and supported well, teachers develop a better understanding of individual differences and learners improve their motivation and engagement. A good learner-teacher relationship is very important to the success and self-image of autistic students. Situated learning with authentic activities is effective, whereas there is no evidence that observational learning works for autistic students.

It helps all students, not just autistic students, if teaching staff provide structure, observe routines, and offer previews of upcoming content. Teaching materials, assignment briefs and examinations should use concrete language and unambiguous questions. Teaching staff should be supported to identify causes of anxiety and reduce them, and to spot early signs of anxiety in learners.

Adults on the autism spectrum are generally about three times as anxious as non-autistic adults. Transition to university naturally increases anxiety levels, with a strong expectation to interact socially as part of study and student life. Students often demonstrate no outward signs of distress ('flat affect') until reaching a state of crisis. By this point, continuation of study is unlikely. We need to avoid getting to this point.

Some universities have tried offering summer schools, where autistic students stay in student residences and experience sample lectures and life skills classes on campus. However, the evidence

is weak for the efficacy of these programmes in improving the outcomes most important to students (getting on with their eventual flatmates and other students, coping with the busy early weeks of the course, self-advocacy skills). An alternative approach provided by Glasgow Caledonian University offers training sessions related to the key worries of autistic students, including time management, self-advocacy and managing stress.

Most research into technological interventions for autistic students in higher education and autistic adolescents and adults of normal or higher intelligence is small-scale and limited to pilot studies. Social media has been received positively in a number of studies for effective, liberating, low-stress communication and reducing isolation. Computer mediated communication has also been used for e-mentoring (mentoring via online communication such as email, chat or Skype) with some success.

Despite the plethora of virtual reality, game-based and video-modelling interventions for autistic people of all ages, there is little evidence for the effective transfer of learning and behaviour from the 'simulation' of tasks and situations to realistic settings. It may be more useful to use interventions to show autistic people how to apply knowledge they have already learned in real and complex situations via situated learning and authentic assessment activities.

Where possible, it is better to use mainstream technologies (e.g. mobile phones), as students are more likely to have access to these and feel more comfortable using them in public. Similarly, it is more effective and leads to more engagement from users to provide information and support for the use of mainstream smartphone applications (e.g. calendar, camera, maps, notifications) than to develop specialist applications. Incorporating universal and inclusive design principles and providing better scaffolding and support for the use of existing technology may be more valuable in many cases than developing separate tools and processes.

Stimulating and complex interfaces are not well received by autistic students and tools need to be simple, logical, uncluttered and predictable. This does not however mean that interfaces must be ugly. They just must not sacrifice functionality and usability for aesthetics. Virtual learning environments (VLEs) present both benefits and challenges, and clear presentation of information and structuring of content is a vital part of inclusive design.

Participation from autistic people in the design and implementation of interventions, both technological and pedagogical, is rare. Users need to and want to be involved in tool and intervention design, rather than merely testing an end result.

#### 3.2 Dutch – Uitgebreide samenvatting van de resultaten

Bij autistische studenten is het minder waarschijnlijk dat zij hun studie afmaken dan bij studenten zonder beperking (kans 25% lager) of dan bij studenten met andere beperkingen (kans 40% lager). Autistische studenten die de universiteit bereiken hebben vaak hoge verwachtingen voor hun studieervaring, hun cijfers, en de studie-ijver van hun medestudenten. De verwachtingen van de ouders zijn een sleutel-factor (zowel hoog als laag) in het succes en welbevinden van de student in het hoger onderwijs.

Op undergraduate (bachelor) niveau is minder dan 1/5 van de autistische studenten vrouwelijk, en op postgraduate (master, phd) niveau stijgt dit naar 1/3. Er zijn aanwijzigingen dat vrouwelijke studenten later een diagnose krijgen en dat een significant aantal autistische vrouwelijke bachelor

studenten (nog) geen diagnose hebben (en daarbij is er ook een groep van mannelijke autistische studenten die geen diagnose hebben of die diagnose niet bekend maken).

Een derde van de studenten in het autisme spectrum houdt hun beperking voor zich. Er is terughoudendheid bij autistische studenten om hun beperking te rapporteren tenzij ze een reëel voordeel zien in het bekend maken. Dit rapporteren leidt niet automatisch tot ondersteuning, laat staan tot de meest aangewezen ondersteuning. Maar medestudenten denken en gedragen zich meer positief wanneer ze zich bewust zijn van iemand's autistische diagnose en, dit is cruciaal, wanneer ze voldoende kennis hebben over autisme. Alleen maar de diagnose kennen en meedelen kan contraproductief werken omwille van ongelukkige stereotypes die in de media geportreteerd worden. Het niet bekend maken, of het gebrek aan informatie over het autisme spectrum kan leiden tot misverstanden en kan de indruk van onbeleefd/ongepast gedrag geven.

Vaak krijgt de student het advies zich aan te passen, te veranderen en vaardigheden tot onafhankelijk denken te ontwikkelen, wat de wens demonstreert dat de student zich aan het systeem zou aanpassen, en niet andersom. Dit is moeilijk wanneer deze verandering niet natuurlijk ontstaat, en het leidt tot een hoog angst-niveau. Vaak ontstaat de indruk dat de student het probleem is, niet het instituut of het onderwijssysteem. Dit moet in vraag worden gesteld. Inclusiviteit is een principe, gebaseerd op kansen en gelijkheid. Maar helaas is de gangbare mening dat alle studenten op gelijke wijze kunnen reageren op de condities in het hoger onderwijs. Er is een overheersend beeld van de "ideale" (hoger onderwijs) student die onafhankelijk is en kan reflecteren. Tijdens hun studie komen studenten dichter bij dit ideaal en het hoger onderwijs "kneed" hen in die richting. Dit principe lijkt de autistische studenten niet te helpen.

Zelf-voorzienendheid is van vitaal belang voor studenten met een beperking, om hun individuele behoeften voldaan te krijgen en succesvol te worden in hun studie. Dit kan problematisch zijn bij "onzichtbare" beperkingen zoals autisme omdat er twijfel is over het recht op ondersteuning en omdat ze hun noden moeten rechtvaardigen en opeisen, terwijl ze al sociale- en communicatieuitdagingen hebben.

Het recht op ondersteuning aan de universiteit behelst een mengeling van processen gebaseerd op noden en beschikbare middelen, afhankelijk van het land.

- Het bekend maken van de aandoening door middel van een formele diagnose is meestal vereist – dit is een probleem als de student zijn beperking niet wil bekend maken of geen goede reden ziet om dat te doen.
- De beoordeling legt typisch de nadruk op de problemen en gebreken van de student omdat dit het recht op ondersteuning bepaalt. Er is echter een mogelijkheid om ook de nadruk te leggen op de sterke kanten van de student en hoe die gestimuleerd en versterkt kunnen worden.
- Er zijn veel en lange formulieren, wat het voor autistische studenten moeilijk maakt om ze in te vullen. Land-afhankelijke scenarios kunnen helpen met de bestaande formulieren; de "best practice gids" kan universiteiten en overheden helpen om de formulieren te veranderen.

• Een onderzoek in het VK (Verenigd Koninkrijk) toonde dat een "behoefte-analyse" in het algemeen goed ontvangen werd, maar vaak kwam de ondersteuning die de student uiteindelijk kreeg niet overeen met de aanbevelingen die uit de analyse naar voren kwamen.

Wanneer de ondersteuning die aan autistische studenten geboden wordt passend en effectief is kan dit een echt verschil maken in de weerbaarheid van de student en in het blijvende effect. Maar het kan ook leiden tot een "afscheiding" van medestudenten, een toename van sociale angst en een gevoel anders te zijn dan de anderen. Er is een kunstmatige scheiding tussen ondersteuning voor het studie-leven en het sociale leven, terwijl het studentenleven een complexe en voortdurende "onderhandeling" is tussen die twee toestanden. Ondersteuning voor beide aspecten is soms wel beschikbaar maar wordt zelden in een gecombineerde wijze geleverd.

Veel studenten zeggen dat ze weinig of geen vrienden hebben en ze ondervinden vaak moeilijkheden om tot sociale groepen toe te treden binnen hun onderwijsprogramma. Vriendschap kan erg bevredigend zijn, vooral wanneer er gemeenschappelijke interesses zijn (bijvoorbeeld een wandelvereniging) en gemeenschappelijke interesses kunnen een zeer effectieve katalysator zijn voor sociale aanpassing. Maar er zijn barrières om betrokken te raken bij zo'n gemeenschap met gezamenlijke interesse. Vaak zijn de sociale rituelen om toe te treden tot een groep en vrienden te maken moeilijk te bewandelen paden. De groepen, of de universiteit, zouden alternatieve manieren tot toetreding kunnen aanbieden.

Hoewel er veel geschreven is over autistische studenten in STEM (science, technology, engineering and mathematics, aka wetenschap, technologie, ingenieurs en wiskunde), laten statistieken van instituten uit het VK en de VS (Verenigde Staten) zien dat de studiekeuze over het hele spectrum van disciplines verspreid is. Terwijl de aantallen (studenten) in wiskunde, wetenschappen en informatica hoog zijn zijn ook kunst en geesteswetenschappen erg populair, vooral in het VK en in Polen.

Het is moeilijk om inclusief onderwijs te beoefenen dat studenten met beperkingen niet afzondert of hen dwingt om er zelf mee om te gaan dan wel de studie te staken. Verschil maken in het onderwijs wordt vooral in scholen gedaan, waar, indien het goed wordt uitgevoerd en ondersteund, leraren een beter begrip krijgen van individuele verschillen en waar de leerlingen beter gemotiveerd en ingeschakeld worden. Een goede relatie tussen leraar en leerling is heel belangrijk voor het succes en zelfbeeld van autistische studenten. In situ leren via authentieke activiteiten is effectief, terwijl er geen bewijs is dat leren door te observeren werkt bij autistische studenten.

Het helpt alle studenten, niet alleen de autistische, wanneer onderwijzend personeel structuur aanbrengt, routines volgt en een vooruitblik aanbiedt op de aankomende inhoud. Leermateriaal, opdrachtomschrijvingen en tentamens moeten in concrete taal geformuleerd worden, met ondubbelzinnige vragen. Docenten moeten ondersteund worden in het identificeren van oorzaken van angst, en ze dan reduceren, en ze moeten vroege signalen van angst bij de studenten leren herkennen.

Volwassenen in het autisme spectrum zijn in het algemeen ongeveer driemaal zo angstig als nietautistische volwassenen. De transitie naar de universiteit verhoogt natuurlijk het angst-niveau, door de sterke verwachting om sociale interactie te krijgen als onderdeel van de studie en het studentenleven. Studenten tonen vaak geen uiterlijke kenmerken van ongemak (tonen geen emotie) tot ze een crisis-toestand bereiken. Op dat punt wordt het voortzetten van de studie onwaarschijnijk. We moeten dan ook voorkomen dat dit punt bereikt wordt.

Sommige universiteiten hebben zomerscholen aangeboden, waarbij autistische studenten in studenten-huisvesting verblijven en voorbeelden krijgen van colleges en lessen in overleving op de campus. Echter, er zijn weinig positieve aanwijzingen dat deze programma's effectief zijn in het verbeteren van die punten die het meest belangrijk zijn voor de studenten (omgang met hun uiteindelijke huisgenoten en andere studenten, omgaan met drukke eerste weken van een college, zelf-voorzienend worden). Een alternatieve aanpak (aangeboden door de Universiteit van Glasgow Caledonian) is om training sessies aan te bieden over de belangrijkste zorgen van autistische studenten, zoals tijds-planning, zelf-voorzienend zijn en het beheersen van stress.

Het meeste onderzoek naar technologische interventies voor autistische studenten in hoger onderwijs en autistische adolescenten en volwassenen van normaal of hogere intelligentie is kleinschalig en beperkt tot pilootstudies. Sociale netwerken zijn positief ontvangen in een aantal studies voor effectieve, bevrijdende, niet-stresserende communicatie en in het verminderen van het gevoel van isolatie. Communicatie met behulp van de computer is ook met enig succes gebruikt voor e-mentoring (mentoren die on-line communiceren via email, chat of Skype).

Ondanks een veelheid aan virtual reality, spel-gebaseerde en met video gemodeleerde interventies voor autistische mensen van alle leeftijden is er weinig aanwijzing dat er een effectieve overdracht van het leren en gedrag plaats heeft van de gesimuleerde taken en situaties naar realistische omstandigheden. Het kan nuttiger zijn om interventies te gebruiken om aan autistische mensen te tonen hoe ze reeds geleerde kennis kunnen toepassen in echte en complexe situaties via in-situ leren en met authentieke beoordelings-activiteiten.

Waar mogelijk is het beter om gangbare technologie (vb. mobiele telefoon) te gebruiken, want studenten hebben hier meer waarschijnlijk toegang toe en voelen zich meer op hun gemak om die in het publiek te gebruiken. Zo is het ook meer effectief en leidt tot betere deelname van gebruikers om informatie en ondersteuning aan te bieden voor gebruik met gangbare smartphone toepassingen (vb. kalender, camera, kaarten, notificaties) in plaats van specialistische toepassingen te ontwikkelen. Universele en inclusieve ontwerp-principes gebruiken en bestaande technologieën ondersteunen en samenvoegen kan in vele gevallen meer waardevol zijn dan aparte hulpmiddelen en processen te ontwikkelen.

Stimulerende complexe gebruikers-interfaces worden niet goed ontvangen door autistische studenten. De hulpmiddelen moeten simpel, logisch, overzichtelijk en voorspelbaar zijn. Dit betekent echter niet dat de interfaces lelijk moeten zijn. Ze moeten alleen niet aan functionaliteit en bruikbaarheid inleveren in ruil voor estethiek. Virtuele leeromgevingen (VLEs) bieden voordelen maar ook uitdagingen, en een duidelijke presentatie van informatie en het structureren van inhoud zijn een vitaal onderdeel van inclusief ontwerp.

De deelname van autistische mensen in het ontwerp en de realisatie van interventies, zowel technologisch als pedagogisch, is uitzonderlijk. Gebruikers hebben behoefte aan en willen ook deelnemen aan het ontwerp van hulpmiddelen en interventies, en willen niet alleen maar het eindresultaat testen.

#### 3.3 Spanish – Resumen de resultados

Los estudiantes con autismo tienen mayores dificultades que los estudiantes sin discapacidad de completar sus estudios (25% menor) y que estudiantes con otras discapacidades (40% menor). Los estudiantes con autismo suelen presentar grandes expectativas acerca de sus experiencias con los estudios, sobre sus propios grados formativos y sobre las habilidades educativas de sus iguales. Las expectativas familiares son un factor clave (tanto positivo como negativo) en el éxito de los estudiantes en la educación superior.

Teniendo en cuenta el género la proporción de mujeres cambia de los estudios de Educación Secundaria y de bachillerato donde solo hay una alumna por cada cinco alumnos con autismo, aumentan el ratio de mujeres a una de cada tres en los estudios de grado. Esto evidencia el retraso en el diagnóstico de mujeres y es un indicador de infra diagnóstico en mujeres universitarias con autismo, y de estudiantes masculinos sin diagnosticar.

Una tercera parte de los estudiantes con autismo no identifican que presentan una discapacidad. Existe reticencia entre estos estudiantes a mostrar o declarar públicamente su discapacidad si no van a recibir beneficios que lo compensen realmente.

El conocimiento no conduce automáticamente o necesariamente a la ayuda o al apoyo adecuado. Sin embargo, muchos estudiantes piensan y se comportan de manera más positiva cuando conocen el diagnóstico de autismo de un compañero y, sobre todo si este conocimiento viene acompañado de suficiente conocimiento sobre el autismo. Simplemente saber / compartir el diagnóstico puede ser contraproducente debido a los estereotipos inútiles como los retratados por los medios de comunicación, es necesario acompañarlo de información. La falta de divulgación, o la falta de información sobre los TEA, pueden dar lugar a malentendidos y percepción del comportamiento como algo grosero.

A menudo, el consejo dado a los estudiantes es adaptar, cambiar y desarrollar habilidades de pensamiento independiente, lo que demuestra un deseo de adaptar al alumno en el sistema, y no al revés. Esto es especialmente difícil para los alumnos con autismo ya que el cambio no es algo natural, y los niveles de ansiedad asociados son altos. A menudo existe la percepción de que el estudiante es el problema, no la institución o el sistema de educación. Esto debe ser cuestionado. La inclusión es un principio, construido sobre las oportunidades y la igualdad. Sin embargo, se presupone que todos los estudiantes pueden responder por igual a condiciones que él. Existe la idea predominante de que el estudiante "ideal" es el que es reflexivo e independiente. Durante sus estudios, los estudiantes se acercan a este ideal y él ' molde ' para ellos en esto. Este principio no parece servir bien a los estudiantes con autismo.

La autodefensa y la autodeterminación son prioritarias para los estudiantes con discapacidad en la satisfacción de sus necesidades individuales y en la posibilidad de tener éxito en el estudio. Esto es complejo y en ocasiones supone un problema, ya que el autismo se trata como una discapacidad 'invisible'. Los estudiantes con autismo pueden tener dudas sobre el derecho a recibir apoyos y además de los retos sociales y de comunicaciones existentes que son especialmente complejos para ellos.

La elegibilidad para el apoyo en la universidad consiste en combinar necesidades de la persona, de los procesos universitarios y de las dinámicas universitarias y formativas de cada país.

- Difundir el diagnóstico requiere que exista un documento clínico que lo acredite y contar con el consentimiento del estudiante para que se comunique a los compañeros en modo y forma.
- La evaluación normalmente se centra en los problemas y los puntos débiles de los estudiantes, porque eso es lo que determina la elegibilidad para el apoyo. Es importante cambiar el foco y centrarse también en las fortalezas de los estudiantes y la forma en que se puede fomentar y mejorado
- Los formularios son largos y abundantes, los estudiantes con autismo pueden tener problemas para completarlos. Los escenarios de la herramienta online específicos de cada país pretenden ayudar a estos alumnos y las guías de buenas prácticas pueden ayudar a las universidades o gobiernos para facilitar el acceso a estos formularios complejos de interpretar e inespecíficos.

Cuando el apoyo al estudiante con autismo es apropiado y efectivo realmente se marca una diferencia en la resiliencia y permanencia del alumno. Sin embargo, también puede conducir a un "distanciamiento" de los compañeros de estudios, aumento de la ansiedad social y un sentido de ser diferente. Hay una división artificial entre el apoyo a la vida de estudio y la vida social, mientras que la vida del estudiante es una negociación compleja y continua entre los dos estados. El apoyo a ambos aspectos a veces está disponible, pero rara vez se combina de manera eficaz.

Muchos estudiantes dicen no tener ningún amigo y mostrar dificultades para unirse a grupos sociales tanto dentro como fuera de las clases. Las amistades que ellos logarn las dotan de gran importancia, especialmente cuando existe un interés mutuo compartido, por ejemplo en asociaciones o clubs de senderismo, ajedrez... De cualquier modo encuentran numerosas barreras para incluirse en este tipo de grupos de actividades sin ayuda externa. A menudo todos los rituales sociales para pertenecer o incluirse en un grupo son enormemente complejos para ellos. La Universidad podría facilitar alternativas para ayudarles en el incorporación a estos clubs y agrupaciones.

While much has been written about autistic students in STEM (science, technology, engineering and mathematics), statistics collected from institutions in the UK and US show that subject choices are across the whole range of disciplines. While numbers studying mathematics, sciences and computer science are high, arts and humanities are also very popular disciplines, especially in UK and Poland.

Aunque existe literatura alrededor de los estudiantes de ciencias y tecnología con autismo, las estadísticas que se recogen en países como Reino Unido o Estados Unidos muestran que no necesariamente estas ramas son las predilectas para estos estudiantes, sino que pueden seleccionar cualquier tipo de formación superior y otras disciplinas como arte o humanidades son también muy populares para estos estudiantes especialmente en Reino Unido y Polonia.

Es complejo llevar a cabo una educación verdaderamente inclusiva que no segregue a los estudiantes con discapacidad ni los predisponga al abandono. La diferenciación en la educación se ha desarrollado en prácticamente todo el ámbito educativo desde donde se aportan apoyos especializados para atender a los alumnos con necesidades educativas especiales. Además, los maestros desarrollan una mejor comprensión de las diferencias individuales y los alumnos mejoran

su motivación y compromiso. Una buena relación alumno - profesor es muy importante para el éxito y la propia imagen de los estudiantes con autismo. El aprendizaje situado , con actividades funcionales y realistas es eficaz , mientras que no hay evidencia de que el aprendizaje por observación sea significativo para los alumnos con autismo .

Este tipo de enseñanza es beneficiosa para todos los estudiantes, no es un método exclusivo para alumnos con autismo, todos los estudiantes se benefician cuando se les aporta estructura, se identifican rutinas y se les anticipan contenidos. Mostrar materiales, ser breves y concisos en tareas, exámenes y explicaciones, y evitar preguntas de interpretación ambigua son aspectos especialmente relevantes para tener en cuenta con estos alumnos. La formación del profesorado y profesionales vinculados a la universidad les ayuda a prevenir y reducir la ansiedad ligada a este contexto.

Los adultos con TEA son tres veces más vulnerables de presentar ansiedad que los adultos sin TEA. Las transiciones y específicamente la transición a la Universidad aumenta los niveles de ansiedad, especialmente ante la expectativa de una mayor interacción social como parte natural y consustancial a la vida estudiantil.

Adults on the autism spectrum are generally about three times as anxious as non-autistic adults. Transition to university naturally increases anxiety levels, with a strong expectation to interact socially as part of study and student life. Estos estudiantes no suelen alertar de la ansiedad hasta que llegan a un estado crítico de no retorno, que es cuando rechazan o abandonan los estudios y necesitamos tener en cuenta su especial vulnerabilidad para evitar que se llegue a ese punto.

La mayor parte de investigación centrada en el desarrollo de TIC para apoyar a los estudiantes con autismo en la educación superior, así como los estudios existentes en adultos con autismo sin discapacidad intelectual se limita a muestras pequeñas o estudios piloto .Las redes sociales y medios tecnológicos se evidencia como un método efectivo para reducir estrés y sensación de aislamiento. La mediación a través de las TIC también se muestra eficaz como modo de apoyo y mentorazgo para estos estudiantes (e-mail, Skype, redes...).

A pesar de la gran cantidad de realidad virtual, de intervenciones basadas en vídeojuegos y de modelado para las personas con autismo de todas las edades, hay poca evidencia sobre la transferencia o generalización efectiva de aprendizaje en situaciones reales.

Se plantea como más útil el uso de intervenciones para mostrar a las personas con autismo cómo aplicar el conocimiento que ya han aprendido en situaciones reales y complejos a través de actividades de evaluación auténtica de aprendizaje y situadas en contextos naturales.

Siempre que sea posible, es mejor utilizar tecnologías de uso general (por ejemplo, teléfonos móviles), ya que los estudiantes son más propensos a tener acceso a los mismos y se sienten más cómodos con ellos en público. Del mismo modo, es más eficaz y conduce a una mayor participación de los usuarios para proporcionar información y apoyo para el uso de aplicaciones para teléfonos inteligentes convencionales (por ejemplo, calendario, cámara, mapas, notificaciones) que el desarrollo de aplicaciones especializadas. La incorporación de los principios de diseño universales e inclusivas y ofrecer una mejor andamiaje y apoyo para el uso de la tecnología existente puede ser más valioso en muchos casos que el desarrollo de herramientas y procesos separados.

Estimular y desarrollar interfaces complejas no son bien recibidas por los estudiantes y las herramientas diseñadas para personas con autismo deben mostrar un aspecto simple, lógico, ordenado y predecible. Esto no significa, sin embargo que las interfaces tengan que ser poco atractivas. Simplemente significa que no tienen que sacrificar la funcionalidad y facilidad de uso por la estética. Los entornos virtuales de aprendizaje presentan tanto ventajas y desafíos, y la presentación clara de la información y estructuración de contenidos es una parte vital del diseño inclusivo.

La participación de las propias personas con autismo en el diseño y ejecución de las intervenciones, tanto tecnológicas como pedagógicas, es inusual, sin embargo los usuarios necesitan y quieren estar involucrados en el diseño de la herramientas y las intervenciones, en lugar de simplemente probar un resultado final como sujetos pasivos.

#### 3.4 Finnish – Tiivistelmä tuloksista

Autismin kirjoon kuuluvilla opiskelijoilla on suurempi riski keskeyttää opintonsa kuin vammattomilla opiskelijoilla (25% enemmän keskeyttäneitä) tai muihin vammaryhmiin kuuluvilla opiskelijoilla (40% enemmän keskeyttäneitä). Autismin kirjoon kuuluvilla korkeakouluopiskelijoilla on usein suuria odotuksia liittyen opintokokemuksiin, arvosanoihin ja opiskelutoverien ahkeruuteen. Vanhempien odotukset ovat keskeinen tekijä, joka ennustaa opiskelijan menestystä.

Perustutkintoa suorittavista autismin kirjoon kuuluvista opiskelijosta vähemmän kuin 1/5 on naisia. Jatko-opiskelijoista naisia on 1/3. Naispuoliset opiskelijat saavat todistetusti diagnoosinsa myöhemmin kuin miehet ja merkittävä osa heistä on kokonaan vailla diagnoosia. Myös miespuolisista opiskelijoista osa on vailla diagnoosia tai ei halua kertoa siitä julkisesti.

Kolmannes autismin kirjoon kuuluvista opiskelijoista ei pidä itseään vammaisina. Autismin kirjoon kuuluvat opiskelijat eivät yleensä halua kertoa toimintarajoitteistaan, elleivät he koe siitä olevan olevan todellista hyötyä. Diagnoosista kertominen ei johda automaattisesti tukitoimiin, tai ainakaan asianmukaisiin sellaisiin. Opiskelutoverit ajattelevat ja toimivat kuitenkin positiivisemmin, jos he ovat tietoisia toverinsa autismidiagnoosista, ja ennen kaikkea mikäli heillä on riittävää tietoa autismista. Pelkkä tieto jonkun diagnoosista voi kuitenkin olla myös haitallista, koska median luomat käsitykset autismista saattavat olla hyödyttömän stereotyyppisiä. Jos opiskelija ei kerro diagnoosistaan tai mikäli asianmukaista tietoa ei ole saatavilla, opiskelijan käytös voidaan tulkita virheellisesti töykeäksi.

Autismin kirjoon kuuluvaa opiskelijaa kehotetaan usein mukautumaan, muuttumaan ja kehittämään itsenäistä ajattelua, mikä on merkki halusta sopeuttaa opiskelija systeemiin, eikä päinvastoin. Sopeutuminen on kuitenkin vaikeaa, koska muutokset eivät tapahdu luonnostaan ja ahdistustaso on korkea. Tilanne tulkitaan usein niin, että ongelmat ovat opiskelijassa, eivätkä instituutiossa tai opiskelusysteemissä. Tämä näkemys tulisi haastaa. Inkluusio on periaate, joka perustuu mahdollisuuksiin ja tasavertaisuuteen. Kuitenkin valtavirtanäkemyksen mukaan oletetaan, että kaikki opiskelijat voisivat mukautua samalla tavalla korkeakoulun olosuhteisiin. Vallitsevan ajatuksen mukaan ihanteellinen korkeakouluopiskelija on vuorovaikutteinen ja itsenäinen. Opintojen mittaan opiskelijat lähestyvät tätä ideaalia ja korkeakoulu muovaa heistä sellaisia. Tämä periaate ei kuitenkaan vastaa hyvin autismin kirjolla olevan opiskelijan tarpeita.

Omien etujen puolustaminen on olennaisen tärkeää vammaisille opiskelijoille, jotta heidän tarpeisiinsa voidaan vastata ja jotta he voivat menestyä opinnoissaan. Tämä voi kuitenkin olla hankalaa opiskelijoille, joilla on autismin kaltainen "näkymätön" vamma, koska he voivat olla epävarmoja oikeuksistaan tukitoimiin ja koska heidän pitää sosiaalisista ja kommunikaatioon liittyvistä vaikeuksistaan huolimatta vaatia oikeutettuja mukautuksia.

Oikeus saada tukitoimia korkeakoulussa riippuu joukosta tarveharkintaisia käytäntöjä ja vaihtelee maittain.

- Virallista diagnoosia ja siitä kertomista yleensä vaaditaan. Tämä voi olla ongelmallista, mikäli
  opiskelija ei halua kertoa diagnoosistaan tai hän ei tunne, että siihen olisi mitään hyvää
  syytä.
- Tarvearviointi perustuu tyypillisesti siihen, että keskitytään opiskelijan ongelmiin ja
  toimintarajoitteisiin, koska oikeus saada tukitoimia perustuu niihin. Olisi kuitenkin
  mahdollista keskittyä myös opiskelijan vahvuuksiin ja siihen, kuinka niitä voidaan edistää ja
  vahvistaa.
- Hakemuskaavakkeet ovat pitkiä ja niitä on paljon, ja autismin kirjoon kuuluvilla opiskelijoilla voi olla vaikeuksia täyttää niitä. Maakohtaisesti voi olla käytäntöjä, joista voi olla apua nykyisten kaavakkeiden täyttämiseksi. Hyvien käytäntöjen opas voi auttaa korkeakouluja tai viranomaisia kehittämään ja mukauttamaan kaavakkeita.
- Iso-Britanniassa tehty tutkimus osoitti, että tarvearviointia pidettiin yleensä hyvänä, mutta usein opiskelijan lopulta saamat tukitoimet eivät vastanneet arvioinnin suosituksia.

Jos autismin kirjoon kuuluvan opiskelijan saama tuki on asianmukaista ja tehokasta, se voi todellakin edistää sinnikkyyttä opinnoissa ja vähentää riskiä opintojen keskeyttämiseen. Se voi kuitenkin myös johtaa eristäytymiseen opintotovereista sekä lisätä sosiaalista ahdistusta ja erilaisuuden tunnetta. Opintojen ja sosiaalisen elämän tuissa on keinotekoinen ero, vaikka opiskelijan elämä on monimutkaista ja edellyttää jatkuvaa vuorovaikutusta näiden välillä. Joskus tukea on saatavilla sekä opiskeluun että sosiaaliseen elämään, mutta vain harvoin yhteistoiminnallisesti.

Monet opiskelijat kertovat, että heillä on vain harvoja tai ei ollenkaan ystäviä ja he kokevat toistuvasti vaikeuksia liittymisessä sosiaalisiin ryhmiin sekä opintoihin liittyvillä kursseilla että niiden ulkopuolella. Ystävyyssuhteet voivat olla hyvin mieleisiä, erityisesti jos ystävyksillä on yhteisiä kiinnostuksen kohteita (esim. kävelykerho) ja jaetut kiinnostuksen kohteet voivat edistää tehokkaasti sosiaalista sopeutumista. Yhteisöihin liittyminen on kuitenkin vaikeaa, sillä siihen liittyy erilaisia esteitä. Ryhmiin liittymiseen ja ystävyyssuhteiden muodostamiseen kuuluu erilaisia sosiaalisia rituaaleja, joita voi olla vaikea ymmärtää. Yhteisöt tai korkeakoulu voisivat tarjota vaihtoehtoisia tapoja, joilla autismin kirjoon kuuluva opiskelijakin voisi päästä mukaan.

Vaikka paljon on kirjoitettu autismin kirjoon kuuluvista opiskelijoista matemaattisella ja teknillisellä alalla, Iso-Britannian ja Yhdysvaltain oppilaitoksista kerätyt tilastot osoittavat, että heitä opiskelee kaikilla aloilla. Monet opiskelijat kyllä suosivat matematiikkaa, luonnontieteitä tai tietotekniikkaa, mutta myös taiteen tai humanististen alojen opinnot ovat hyvin suosittuja, etenkin Iso-Britanniassa ja Puolassa.

On vaikeaa harjoittaa inklusiivista opetusta, joka ei syrjisi vammaisia opiskelijoita ja pakottaisi heitä keskeyttämään opintojaan. Opintojen eriyttämistä on harjoitettu enimmäkseen peruskouluissa,

jossa hyvät tukitoimet ovat edistäneet sitä, että opettajat ymmärtävät oppilaiden yksilöllisiä eroja ja oppilaat motivoituvat ja sitoutuvat opiskeluun paremmin. Opettajan ja oppilaan hyvä suhde on erittäin tärkeää autismin kirjoon kuuluvien oppilaiden menestyksen ja itsetunnon kannalta. Tilannesidonnainen ja toiminnallisiin menetelmiin perustuva oppiminen on tehokasta. Sen sijaan ei ole mitään todisteita siitä, että autistiset oppilaat hyötyisivät mallioppimisesta.

Ei yksinomaan autismin kirjoon kuuluvat opiskelijat, vaan ihan kaikki hyötyvät siitä, jos opetushenkilöstö tarjoaa selkeitä struktuureita, noudattaa rutiineita ja tarjoaa ennakkoon tietoa kurssien tulevista sisällöistä. Opetusmateriaali, tehtävänannot ja tenttikysymykset on syytä laatia konkreettisella ja selkeällä, yksiselitteisellä kielellä. Opetushenkilöitä tulee tukea tunnistamaan syitä, jotka aiheuttavat opiskelijoille ahdistusta ja vähentämään niitä, sekä tunnistamaan varhaisia merkkejä opiskelijoiden ahdistuksesta.

Aikuiset autismin kirjon henkilöt kokevat ahdistusta yleensä noin kolme kertaa enemmän kuin neurologisesti tyypilliset henkilöt. Siirtymävaihe korkeakouluopiskelijaksi lisää luonnollisesti ahdistustasoa, koska siihen liittyy paljon odotuksia sosiaalisesta pärjäämisestä opiskelijaelämässä. Autismin kirjoon kuuluvat opiskelijat eivät useinkaan näytä ulospäin merkkejä ahdistuksesta ("tunneilmaisun niukkuus") ennen kuin vasta kriisin hetkellä. Siinä vaiheessa opiskelun jatkaminen on epätodennäköistä. Tähän pisteeseen joutumista tulisi siis välttää.

Jotkut korkeakoulut ovat yrittäneet tarjota kesäopintoja, jossa autismin kirjoon kuuluvat opiskelijat ovat voineet harjoitella opiskeluun ja elämään liittyviä taitoja kampuksella. Valitettavasti näyttö tällaisen menettelyn tehokkuudesta on heikkoa. Opiskelijat eivät juurikaan onnistuneet kehittämään niitä taitoja, jotka olisivat olleet heille tärkeimpiä (tuleminen toimeen asuintoverien ja muiden opiskelijoiden kanssa, pärjääminen kiireisten kurssiaikataulujen kanssa, omien etujen puolustamiseen liittyvät taidot). Glasgow Caledonian Universityssä on kehitetty vaihtoehtoinen lähestymistapa, jossa autismin kirjoon kuuluville opiskelijoille on tarjottu valmentavia tapaamisia liittyen heidän keskeisiin huolenaiheisiinsa, kuten ajanhallintaan, omien etujen puolustamiseen ja stressinhallintaan.

Suurin osa tutkimuksesta joka on liittynyt autismin kirjoon kuuluvien korkeakouluopiskelijoiden tai kognitiivisesti normaalitasoisten tai tavallista älykkäämpien nuorten ja aikuisten autismin kirjon henkilöiden tueksi kehitettyihin teknologisiin interventioihin on ollut pienimuotoista ja rajoittunut pilottitutkimuksiin. Muutamien tutkimusten mukaan sosiaalinen media on otettu hyvin vastaan ja sitä on pidetty tehokkaana, vapauttavana ja vähän kuormittavana tapana kommunikoida ja keinona vähentää eristyneisyyttä. Tietokonevälitteistä kommunikaatiota on myös käytetty e-mentorointiin, eli esimerkiksi sähköpostin, chatin tai Skypen avulla tapahtuvaan mentorointiin ja siitä on saatu jossain määrin hyviä kokemuksia.

Vaikka kaiken ikäisille autismin kirjon henkilöille on kokeiltu monenlaisia interventioita, jotka ovat hyödyntäneet virtuaalitodellisuutta, tietokonepelejä ja videomallintamista, ei ole juurikaan todisteita siitä, että simulaatioiden avulla harjoitettu oppiminen ja käyttäytyminen siirtyisivät realistisiin todellisen elämän tilanteisiin. Saattaisi olla hyödyllisempää käyttää interventioita, joiden avulla autismin kirjon henkilöt voisivat soveltaa niitä tietoja ja taitoja, joita he ovat jo oppineet todellisissa monimutkaisissa tilanteissa tilannesidonnaisen oppimisen ja todellisiin tilanteisiin perustuvien toiminnallisten menetelmien avulla.

Mikäli mahdollista, on hyödyllisempää käyttää yleisesti käytössä olevaa tekniikkaa, kuten matkapuhelimia, koska opiskelijalla on todennäköisesti sellainen käytössään ja koska hän on tottunut käyttämään sitä julkisesti. Samaan tapaan on tehokkaampaa tarjota tietoa ja tukea tavallisten älypuhelimen sovellusten kuten kalenterin, kameran, karttapalveluiden ja muistutusten hyödyntämiseen, kuin kehittää erityistä tekniikkaa. Kaikille sopivan ja inklusiivisen suunnittelun periaatteiden mukaisesti jo olemassa olevan tekniikan käyttäminen on useimmiten hyödyllisempää kuin erillisten uusien välineiden tai menetelmien kehittäminen.

Autismin kirjoon kuuluvat opiskelijat eivät pidä stimuloivista ja monimutkaisista käyttöliittymistä, vaan he toivovat että työkalut ovat yksinkertaisia, loogisia, selkeitä ja ennustettavia. Se ei tarkoita tietenkään, että käyttöliittymän tulisi olla ruma. Opiskelijat vain suosivat käytettävyyttä estetiikan kustannuksella. Virtuaaliset oppimisympäristöt tarjoavat sekä etuja että haasteita. Selkeä tapa esittää tietoa ja jäsentää sisältöä ovat keskeinen osa inklusiivista suunnittelua.

On harvinaista että autismin kirjon henkilöitä osallistetaan suunnitteluun ja interventioiden käyttöönottoon, oli kyse sitten teknologiasta tai pedagogisista käytännöistä. Käyttäjiä pitää ottaa mukaan suunnitteluprosesseihin sen sijaan että he vain testaisivat valmista lopputuotetta.

#### 3.5 Polish – not provided by partner

### 4 Disclaimer

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## 5 Methodology

#### 5.1 The type of review

This review falls under several of the types defined by Grant & Booth (2009): Critical, Mapping, and Overview. Additionally, the review has some characteristics of Scoping (identifying the nature and scope of the sources) and Rapid (overall quality and direction of the literature) types. The presentation takes a mostly narrative thematic form, with some tabular features (Overview) and the authors seek to find the most significant literature for each sub-question, evaluating according to contribution and going beyond description to analysis and synthesis of the ideas presented (Critical). Research for each area is categorised and, where possible, gaps are identified (Mapping).

As is usual for this kind of literature review, with a broad scope, the quality of individual studies was not formally assessed. It quickly became apparent from consulting systematic reviews in this topic area, several of which are cited in this review and recommended to the reader, that formal assessment by the application of common systematic inclusion criteria would lead to a large number of exclusions of studies that could offer insights to the Autism&Uni project, including examples of best practice and also factors that may lead to a poor quality intervention.

#### 5.2 Search terms

The search terms used are included at the end of this section, along with a list of databases and search engines used. The topic being mapped is too broad for the review to be exhaustive. However, given the weaknesses in research in this field, studies with weak or negative results were included in order to engage with methodological flaws and other issues.

As this is an interdisciplinary study, looking at a very specific population, there was some difficulty in refining searches without leading to inadvertent exclusion of useful work, particularly when searching in full text, and these are noted here in order to aid the work of future researchers.

- For example, the ambiguity in different cultures around use of words such as "student",
   "learner" and "college" to represent different age groups and educational contexts is an
   issue.
- A wide range of terms for autistic spectrum conditions and related conditions are used, and focusing on a small number of these is unwise.
- There is a tendency for much material about autistic learners to focus on children and/or learning disabilities rather than older learners in mainstream education of normal or higher intelligence.
- Some relevant studies did not mention "college", "higher education" or "university" at all, with "postsecondary" or "young adults" being preferred terms, and "university" only appearing in searches in relation to the academic affiliations of the authors.
- Due to the paucity of information about university-level learners specifically related to autism, material about wider issues affecting disabled students and students with related conditions such as ADHD and anxiety has been included where relevant.

The following search terms were used:

autism + college, autism + postsecondary, autism + "higher education", autism + technology + education, autism + adolescent, autism + transition, autism + "higher education" -children -economics, autism + university -children -economics, autism + technology -k12 -young, Asperger + college, Asperger + postsecondary, Asperger + "technology enhanced learning", Asperger + pedagogy + students -children -school, Asperger + inclusion + college, Asperger + inclusion + "higher education", Asperger + inclusion + "university" -children, autism + "college students", Asperger + technology + adults, autism + iphone + adults, Asperger + smartphone + students, autism + "self-advocacy" + internet + college, autism + vle + students, autism + lms + students -peptide

#### 5.3 Scientific databases used

- ERIC
- Education Research Complete
- ProQuest Education Journals
- Research Autism
- IMFAR abstracts
- ASSIA
- Scopus
- Web of Science
- Cochrane Developmental, Psychosocial and Learning Problems Group <a href="http://dplpg.cochrane.org">http://dplpg.cochrane.org</a>
- PsycINFO

- CINAHL
- MEDLINE
- EMBASE
- JSTOR
- ScienceDirect
- NHS Economic Evaluation Database
- Social Sciences Abstracts
- Google Scholar
- Individual journals and magazines, e.g. Autism, Your Autism
- Agency websites e.g. HEA, ONS, National Audit Office, UUK.

#### 5.4 Search engines, library catalogues and resource discovery services

- 'Discover' the Leeds Beckett University implementation of EBSCO Discovery Service
- 'StarPlus' the University of Sheffield implementation of Primo by ExLibris
- Leeds Beckett Library catalogue

- University of Sheffield library catalogue
- COPAC
- Google Scholar
- Google
- Bing
- Duck Duck Go

#### 5.5 Inclusion criteria

Generally, inclusion of sources was based on providing a fair narrative overview of the field, choosing representative examples and answering the research questions. Priority was given to sources that were most relevant to the participant age and intellectual ability range for this project.

Most studies in this field are small-scale projects that are not tested for novelty and consistency of theoretical claims for transferability of findings (Mays & Pope, 2000). Excluding all studies that are not empirically rigorous would distort the bigger picture, and would deny the authors the possibility of critically engaging with a large number of studies on a deeper level, including noting common methodological flaws in this area.

It was also useful to include information from non-peer-reviewed sources, such as project reports and guides for academic staff, which would not necessarily meet formal quality criteria.

Attempts were made, where practical, to include literature in other EU languages, guided by suggestions from the project partners and information from the mapping review about popular interventions and support mechanisms in the partner countries. The critical information literacy skills of the authors were key to these decisions, involving awareness of the cultural, political, technical and economic contexts in which studies were conducted and published (Kapitzke, 2003). Analysis, supported by evidence from rigorous systematic reviews, is provided concerning the characteristics and overall quality of the studies relating to each of the sub-questions.

To summarise, for inclusion in this scoping review a source needed to:

- Be written in one of the languages of the Autism&Uni partner countries
- Focus on students in higher education by:
  - o focusing exclusively on higher education, OR
  - o focusing on transition in the latter stages of secondary and further education, OR
  - o focusing on a wider group (such as autistic adults or disabled students) but including sufficient detail to enable the accurate identification of data relating to autistic people over the age of 14 of normal or higher intelligence specifically or relating to similar conditions such as ADHD and dyspraxia.
- Focus on characteristics of autistic students OR interventions in higher education AND/OR technology relevant to this group

#### 5.6 Additional techniques

Hand searches of specific journals, government and charity information websites, recommended sources provided by project partners and following up references from articles and books. The most productive search terms were translated using Google Translate, and checked against other sources such as autism charity websites in those countries, in order to find studies from a broader range of languages.

#### 5.7 A note on language

We recognise that in the English language, 'person-first' expressions such as 'person with autism' or 'student on the autistic spectrum' are favoured by autism professionals and parents. However, they tend to be rejected by people within the autistic community (O'Neil, 2008; Bagatell, 2010), including one of the authors. These groups often favour 'identity-first' terms like 'autistic person'. For the purpose of this literature review, we decided to use both types of language to reflect the range of views held by stakeholder groups, following the example of Pellicano et al (2014).

We have chosen to use the term 'autism spectrum condition' (ASC), where relevant, as it recognises the potential strengths of individuals on the spectrum and is less stigmatising and pathologising than 'autistic spectrum disorder' (Baron-Cohen et al, 2009).

#### 5.8 Researcher bias

One of the authors of this review is autistic and was diagnosed with Asperger Syndrome in 2011 at the age of 30. She has experiences of studying in higher education both before and after diagnosis, via both distance learning and face-to-face study in a range of institutions. These experiences cannot help but inform this review, but the reporting takes an objective stance and the review was cowritten and reviewed by others of different backgrounds.

#### 5.9 Summary of sources used

After initial filtering during searches, 227 sources were included in this review and 126 were rejected. The most common reasons for exclusion at this point were that a) the source did not meet the criteria on deeper reading, or b) other papers were a better example of the same type of study, i.e. more participants, better methodology, better documented, more useful results. What types of papers and publications were considered depended on the sub-question, i.e. the nature of the enquiry:

#### 5.9.1 Sub-question 1

Mainly a mixture of scholarly and authoritative charity-designed and research institute resources with attention also given additional material aimed at parents, students, disability advisors, academic staff and autism practitioners in order to understand the information with which these groups are provided. Informal personal accounts such as blogs and forum posts were also included. The date range was Jan 1994 – Jan 2015.

#### 5.9.2 Sub-question 2

A mixture of scholarly and grey literature, including websites, leaflets, reports and conference presentations. The date range was Jan 1994 – Jan 2015.

#### 5.9.3 Sub-question 3

Scholarly literature and supporting information, charity websites plus conference presentations. The date range was Jan 2004- Jan 2015, taking into consideration that technology dates quickly, even if the principles remain the same.

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### 6 Literature review 1: Autistic learner characteristics

Research Question: What are the characteristics and requirements of academically competent autistic learners that render them different from the general student population?

#### 6.1 Introduction

Autism is a pervasive development disorder that affects reciprocal social interaction, communication and restricted and repetitive behaviours. On its own, autism is not a learning disability, but between 30-55% of people with autism also have an associated learning disability or intellectual impairment (Fombonne et al, 2011). Asperger Syndrome is a type of autism that is differentiated from higher functioning autism by the World Health Organisation (2010) in the ICD-10 by a lack of delay in language development and a lack of learning disability. People with Asperger Syndrome or higher functioning autism are of normal or higher intelligence. The ICD-10 is used for autism diagnosis in the UK, whereas in the US the Diagnostic and Statistical Manual of Mental Disorders (DSM) is used. In the latest edition of the DSM, DSM-5, Asperger Syndrome has been removed as a separate diagnosis and comes under the umbrella term of 'autism spectrum disorder' (American Psychiatric Association, 2013).

Disabled students are underrepresented in higher education, including students with autism, but the number of students diagnosed with autism and Asperger Syndrome is growing (MacLeod and Green, 2009) and this group often face social isolation (MacLeod, 2010). Transition to higher education can be difficult, particularly socially. Some autistic learners may have experienced social skills training; which is usually based on role-play and simulation of social situations. However, it is difficult to assess the generalisation of these skills to real life settings (Howlin and Yates, 1999), especially as the ability to predict social situations and apply information about social rules in different context is impaired in autism (Wing et al., 2011).

According to HESA (2013a), in 2012-13 1765 UK domiciled undergraduate students declared an autistic spectrum condition, which represents 0.31% of the overall student body. At postgraduate level the figure is 230 (0.13%). This data was unavailable for the other European partner countries, as data about ASCs in higher education is not routinely collected in those countries (HESA in the UK have collected this data since 2004). A third of declaring UK postgraduates were female, whilst at undergraduate level this was less than 20%. 56% of all UK domiciled undergraduates in the same period were female, and 59% of all postgraduate students (HESA, 2013b). These figures must be taken into account when looking at who is entitled to support and the gender profile (usually all or mostly male, with a confirmed ASC diagnosis) of those taking part in studies, as women and girls with Asperger Syndrome are diagnosed at a later age than men and boys (Begeer et al., 2013). Female students also seem less likely to declare autism as a disability, even with a diagnosis, until they have gained more confidence.

Students on the autistic spectrum are less likely than non-disabled students to complete their course. In 2012-2013, 3.5% of UK autistic students failed to complete their degree, compared with 2.6% of their contemporaries (Ratcliffe, 2014).

#### 6.2 Disclosure

University students with an autistic spectrum diagnosis are reluctant to disclose their condition (Baines, 2012) relative to other disabilities, unless there are clear benefits for them in doing so (Davidson & Henderson, 2010). Some autistic students reject the 'label' of diagnosis and not only do not tell their peers about their condition, but do not disclose to anyone at the institution (Huws & Jones, 2008). A third of autistic students do not identify as disabled (Anderson et al, 2014), and therefore are unlikely to access support aimed at those who self-identify as autistic or those identified as being in need of autism-specific support by disability services (Shattuck et al., 2014). Some do not view autism as a deficit (Brownlow, 2010).

There is also a procedural and organisational challenge. Disabled students often fear asking for support (Olney & Brockelman, 2003) and may assume that if they have declared their disability via official paperwork, they do not need to disclose this again to individual members of staff. This assumption may be particularly likely for students with autism, due to possible deficits in social imagination and a tendency to be inflexible in their thinking (Beardon et al., 2009). However, it is not universally the case that an initial declaration will result in provision of appropriate support or that information will be shared across the university, including all relevant members of teaching and support staff (Borland & James, 1999).

Autistic learners interact with a wide range of people during their time in higher education. Some may have specific training in autistic spectrum disorders, such as specialist support workers. Others, like disability advisors and librarians, may have some understanding based on having worked with autistic people, even though they are not experts in the condition. However, tutors, peers and other individuals are reliant on their own knowledge and media portrayals of autism (Gardiner & Iarocci, 2014), which are often inaccurate and can lead to harmful stereotypes (Draaisma, 2009). According to Matthews et al (2014), male university students have a more positive attitude towards autistic students than female students, and students are more likely to think and behave more positively towards autistic people if they are made aware of the individual's diagnosis. University staff may need more information about the condition than just the diagnosis in order to interact successfully with autistic students, who they will misunderstand and perceive to be rude if they fail to understand the difficulties these students face (Taylor, 2005).

The literature describing autistic students often presumes that autism and perhaps associated learning difficulties and disabilities and mental health conditions are the only or predominant factors affecting their success at university. However, autistic students can experience multiple intersectional oppressions:

- cultural expectations, myths and language barriers (Chun & Fisher, 2014);
- race and ethnicity (Mandell et al, 2009; Dyches et al, 2004);
- gender (McGill et al, 2013) and LGBT (Jacobs et al, 2014) issues;
- lower economic status (Schultz, 2012); and

• problems caused by other disabilities unrelated to their autism, including physical disabilities and chronic illness (Bauman, 2010).

Support and interventions for autistic students must take all these factors into account, as well as consider the fact that the student may not yet have a diagnosis of autism or may have a diagnosis but choose not to disclose their condition.

There are specific issues autistic students may be experiencing for the first time in post-compulsory study, such as group work, adjusting to independent living and the 'battle' to get appropriate support (Beardon et al, 2009). The traditional methods for supporting autistic students and disabled students generally involves 'reasonable adjustments' that can separate students from their peers, increase social anxiety and exacerbate their sense of difference (Madriaga, 2010), whereas a more socially-just approach that understood the desires as well as problems of disabled students, such as being part of the student body and wishing that lecturers would be more 'interested' in their students (Madriaga & Goodley, 2010), would not require students to disclose their differences or seek extra support, but support all students by default (Madriaga et al, 2011). This is particularly apposite in autism, where so many students do not disclose or seek support.

Many of the challenges faced by disabled students are also problems for non-disabled students, but students are expected to 'cope' and issues such as lecturers speaking too quickly or struggling with the amount of coursework expected are rarely challenged (Madriaga et al, 2010b). Socially just pedagogies move away from traditional teaching methods and the teacher-student division, and value diversity rather than emphasising 'normalcy' (non-marginalised students) and 'deficits' (deviations from the mainstream and expected), placing the student at the centre of curriculum design and teaching (Leveroy, 2013) in order to facilitate the becoming of both learner and educator for both 'student' and 'teacher' (Goodley, 2007). These concepts form the basis of the manual provided to Mexican universities as a guide to inclusive practice in higher education (Asociación Nacional de Universades e Instituticiones de Educación Superior, 2012).

#### 6.3 Self-advocacy

The development of self-determination and self-advocacy skills is recommended for all students with disabilities, in order for their needs to be fully met and their university study to be successful (Adams & Proctor, 2010). This may prove particularly difficult for students on the autistic spectrum, as students with less visible conditions have more difficulties adapting to university, due to experiencing doubts and demands to justify their requirements from staff and peers alike in addition to the social and communication difficulties common to autism (Adams & Proctor, 2010; Adreon & Durocher, 2007; Glennon, 2001).

Autistic students may also feel marginalised and experience negative emotions as transition support and the rhetoric around accommodating students with disabilities tend to focus on their deficits and 'special needs' rather than their academic ability, even if they are particularly gifted students (Schultz, 2012). There is also a perceived need by parents to provide continuing support at a higher level than expected for non-autistic students of the same age (Morrison et al., 2009). Tutors and fellow students sometimes resent or even block reasonable adjustments they are entitled to receive (Madriaga et al, 2011; Schultz, 2012) because they perceive the student as 'gaming' the system or getting something 'extra', which may sometimes be in conflict with learning objectives or

perceptions of fairness. However, the perspective by families of students with autism is often very different: they express a desire for the student to be 'normal' and fit in (Bagatell, 2010). These varying, and at times conflicting perspectives, make it harder for autistic students to adopt a positive identity relating to their autism (Bagatell, 2007), and this can affect their ability to advocate for themselves in some situations.

According to Getzel & Thoma (2008), the areas of self-advocacy important to disabled students are:

- seeking help from disability and student services;
- developing relationships with academic staff;
- constructing their own support systems at university, including peer and professional relationships;
- developing self-awareness about their disability, how it affects their study and their strengths and weaknesses.

In addition to these requirements, autistic students may need to develop strategies around social and organisational issues (Adreon & Durocher, 2007).

In supporting guidance aimed at disabled students and their families, the onus is put mainly on the student to adapt, change and develop all these skills independently (Reid & Knight, 2006; Mulder & Cashin, 2014), despite the difficulty for autistic students in adapting to change where support is minimal and anxiety levels are likely to be high (Lawrence et al, 2010). This adds weight to the perception that in higher education the disabled student is the problem and not the institution, which is an unhelpful and negative view of disability but forms the basis of support offered by the likes of the Disabled Students Allowance in the UK and Germany, which aims to adapt the student to university and not the other way around (Griffin & Pollak, 2009; Ambati & Ambati, 2013). 'Othering' of the autistic student in this way does not promote inclusion in the university environment or encourage the institution and its people to change their practices (Atkinson et al, 2011). However, it remains the case that autistic students with higher levels of self-determination and better self-advocacy skills are more likely to complete their studies and have positive higher educational experiences (Russo Jameson, 2007).

#### 6.4 Stress and anxiety

According to Brady et al (2014), young autistic adults (aged 16-21) of "high average intellectual ability" have the same cognitive intelligence as typically developing peers and yet lower emotional intelligence, putting them at greater risk of mental health difficulties. Students on the autistic spectrum experience high levels of stress and anxiety at university, including students observed to be generally more 'socially competent' than some autistic peers (Liew et al, 2014), while often displaying no outward signs of distress (Glennon, 2001); appearing either neutral or unresponsive until the student reaches the point of acute psychiatric crisis (VanBergeijk et al, 2008). At this point, continuing with the course of study can be difficult or impossible.

Adults with autism are almost three times as anxious as non-autistic adults; particularly in response to change, anticipation, sensory issues and positive and negative events (Gillott & Standen, 2007). These events can be heightened and more regular in the intense university environment, where students are required as part of study and student life to interact successfully socially (Dente & Coles, 2012; Lawrence et al, 2010) and achieve academically. An autistic person can appear to have

no outward signs of distress, displaying a 'flat' or 'neutral' affect or facial expression, while experiencing very high levels of anxiety with unusually raised resting heart rate and electrodermal activity (Picard, 2009). This can make it difficult for others, including those who know the affected person, to recognise the signs of impending crisis in a learner with an autistic spectrum condition.

Autistic students can experience what is referred to as 'genius pressure' (Beardon et al., 2009; Martin, 2006; Atkinson et al, 2011); where the stereotype of the autistic savant, the likelihood of autistic students who reach higher education doing so with generally higher grades than their peers (Martin et al., 2008) and the internal pressure that autistic students place on themselves to do well (Camarena & Sarigiani, 2009) combine to cause problems for the perception of the student and the student's mental health. Parental expectation of academic success is a key factor in successful transition to higher education for autistic students (Chiang et al, 2012), but can also be an additional source of stress. Parents who are mindful of how the educational approach changes when entering higher education, e.g. with regards to independent learning, reflection and critical thinking (Shmulsky & Gobbo, 2013), can support their children better by having realistic expectations (Camarena & Sarigiani, 2009) and providing support, particularly in the first few months of study.

While people without autism believe that they have more knowledge of their own thoughts and feelings than another person would, most autistic adults assign the same amount of knowledge to the other person as they do to themselves (Mitchell & O'Keefe, 2008). Further, adolescents with autism assume that the other person actually has more knowledge about themselves than they do (Dritschel et al, 2010). Depending on their stage of maturity and development, autistic students are likely to fall into the adolescent group, and therefore it can be difficult for them to understand why the people with whom they are interacting do not understand how they feel, particularly if they are having a specifically autistic experience such as sensory overload (Madriaga, 2010; Schlabach, 2008) or 'meltdown' (Eveleth et al, 2012).

This developmental delay in the ability to have self-insight and judge others' perceptions of oneself can have an impact on choosing and making friends (Mitchell & O'Keefe, 2008), an important part of settling into university life. Further, considering someone else as the authority for one's self knowledge – more often than not the autistic student's mother (Dritschel et al, 2010) – may directly affect the student's confidence in the appropriateness of their internal states and emotions experienced, potentially increasing stress and anxiety levels. Interventions that enhance emotion decoding, as suggested by Dritschel et al (2010), may well help alleviate this deficit in self-understanding and the resulting social challenges encountered by students with autism.

#### 6.5 Strengths and weaknesses for study

While autistic students have social communication difficulties, due to the nature of their condition, and often experience bullying (Gelbar et al, 2014; Howlin, 1997), it is important to recognise that this does not automatically preclude the students from making friends – although these friendships may be fewer in number and shorter in length than those of students not on the spectrum (Jobe & Williams White, 2007). According to Carrington et al (2003), autistic students generally express satisfaction with their friendships where mutual interests are shared, and if special interests are given a real place in interactions with autistic students they can lead to greater social adaption abilities (De Jaegher, 2013). In a UK university transition context, autistic students could be encouraged to join student clubs and societies where available to find social contacts based on their

interests (Martin, 2006; Morrison et al, 2009; Okamoto, 2007). However, as Madriaga (2010) notes, the typically busy and noisy environment of university society fairs and other 'freshers week' events in the UK is particularly ill-suited to autistic students, and they may have to find alternative ways to get initially involved with these groups, such as via the website or social media.

Wehman et al (2014) express concern that too much emphasis is put on non-academic skills for autistic young people, confirming their deficits, rather than focusing on the academic abilities and high potential of autistic learners and enabling them to develop in a way that would make them more likely to apply for and graduate from higher education (Chiang et al, 2012). This could be of particular concern for those autistic learners with higher education potential who attend special rather than mainstream schools. In special education, reduced importance is placed on academic achievement and preparation to attend university (Reid & Knight, 2006).

When academic staff are asked to reflect on the strengths of the autistic student, as in Gobbo and Shmulsky (2014), positive traits are highlighted such as expertise and passion for the subject, a desire and commitment to be accurate, a drive to seek knowledge and adherence to the rules. These traits are mostly directly related to academic study. In contrast, the perception of weakness is mostly connected to concerns around social behaviour and anxiety, the academic-related exceptions to this being a perception that students on the spectrum are poor at language-based critical thinking (Griswold et al, 2002) and have issues caused by inflexibility of thought. According to 'Andy', a student with ASD (Charles et al, 2007), interventions at university level should focus on emotional and social issues rather than academic skills. However, focusing on a student's academic strengths, engendering realistic expectations and developing critical thinking skills could be as important a part of a transition plan as supporting their social weaknesses.

#### 6.6 Discipline of study

The popular perception of autistic students is that they predominantly study science (Wei et al., 2013), mathematics and computing. However, while autistic undergraduates are overrepresented relative to other groups in computing and the sciences, and underrepresented in education and health-related subjects, the largest group of autistic students in the UK actually study humanities and the arts, which is also true for non-autistic students (AHEAD, 2012). In Poland, while science students were found to have high levels of autistic traits (Pisula et al, 2013), humanities students also scored higher for these traits than social sciences or medical students.

There have been several initiatives aimed at supporting autistic students in STEM (science, engineering, technology and medicine) disciplines, such as Martin & Cliffe (2011) and Robinson (2012) and these are well conceived. At the same time, the interest of autistic students in other subjects such as literature or history, despite their potentially problematic reliance on analysis rather than just 'facts' (Blamires & Gee, 2002), cannot be ignored and those students' aspirations must also be respected and supported. According to a US study of students in special education, students with autism enrolling in 2-year community colleges were more likely to transfer to a 4-year university if they were studying STEM subjects (Wei et al, 2014). However, this study only looks at students who were eligible for special education, and was not able to capture data about graduation rates or the length of time taken to complete a degree. Overall, it has to be pointed out that the key factors predicting postsecondary success for autistic students are family characteristics, student characteristics and effective transition planning (Chiang et al, 2012) - not discipline of study.

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## 7 Literature review 2: Higher education pedagogy

Research Question: What pedagogic principles and initiatives have been used in post-compulsory education to address these differences and support needs?

#### 7.1 Inclusive education and differentiation

Inclusive education includes rather than segregates the diverse community of learners, including learners with disabilities and specific learning difficulties. It does not just mean that disabled students attend mainstream education, but that the curriculum, classroom and teaching include everyone by default. Difference is perceived as positive, and a welcoming environment is provided for all students with multiple opportunities to participate in learning (Baglieri & Knopf, 2004).

One of the reasons why it is difficult for lecturers and other higher education staff to engage with truly inclusive practice is that while universities do not define an 'ideal student', the institution (whether intentionally or not) provides "discursive and relational conditions of a 'mainstream' that presumes that all students can respond equally to the conditions the university provides" (Hemmings et al, 2013). Learners are expected to adapt to university's idea of what a student is and does, and not the other way around, and both teaching staff and students have to cope with problems such as larger than intended tutorial/seminar groups (Hilsdon, 2011; Hemmings et al, 2013) created by decisions made for practical or economic rather than pedagogical reasons. Support is built around adapting the individual student to the university environment, which is designed for the 'mainstream' group - to which it is clear they do not belong. These issues are discussed more fully in the first part of this review, alongside the implications of employing a more socially just approach. Many of the initiatives discussed here continue in the vein of adapting the student to the situation, rather than making higher education more 'autism-friendly' and accepting of diversity, and this is an important consideration when thinking about their role in developing 'best practice' for working with autistic learners.

Differentiation is the practice of adapting teaching to accommodate the different needs of learners, by using multiple routes to understanding and proactively responding to the needs of every learner (Tomlinson, 2005). Content is adapted according to the abilities, experiences and difficulties of the learner (Tait et al, 2009). This concept is well-understood in primary and secondary education and is employed in both mixed ability classrooms and those including learners with special educational needs. Studies of differentiation in a higher education context are beginning to emerge, such as the work of Konstantinou-Katzi et al (2013) and Chamberlin & Powers (2010) on differentiated teaching of mathematics. The latter study includes disabled learners, but does not provide further information about specific impairments or conditions.

Tait et al (2009) share a 'toolbox' for use in Scottish schools with learners on the autistic spectrum, where it is emphasised that the issue for this group is often not with cognitive levels but lies more with problems around motivation and the way in which information is presented and recorded.

Differentiation improves teachers' perceptions of individual differences and the learner's motivation

and level of engagement (Subban, 2006) and therefore seems particularly appropriate for working with autistic learners if it is supported and consistently practiced by all teaching staff (Humphrey & Lewis, 2008a).

People with autistic spectrum conditions consistently express a desire to fit in (Baines, 2012; Carrington et al, 2003; Pellicano et al, 2014), including throughout their time in education, and some practices common when including an autistic child in mainstream school such as 'shadowing' by teaching assistants (Sheehy et al, 2013) can mark the learner out as different (Martin, 2008) and create barriers for relationships between educator and learner, as the learner's primary relationship in the classroom is then with the assistant and not the teacher (Humphrey & Lewis, 2008b).

The motivation and understanding of the teacher around autism and inclusion, whatever the educational stage, is key to the successful inclusion of learners (Villanueva, 2013), and yet studies on the training of faculty staff related to disabilities like autism and inclusive practice are limited (Zeedyk et al, 2014). Further, the willingness of academic staff to adapt their teaching practices is varied (Riddell et al, 2007). Developing real relationships with teaching staff at university is an important part of inclusion for students on the autistic spectrum, as is the incorporation of universal design principles into teaching and the curriculum (Getzel, 2008). Examples of this, according to Gobbo & Shmulsky (2014), include:

- providing more structure in teaching, such as previewing upcoming topics and observing routines;
- using concrete language and unambiguous questions;
- identifying tasks and situations that may cause anxiety for individual learners, and work to reduce these;
- noticing agitation or anxiety in learners while levels of these emotions are still low.

It is worth consulting a pair of articles from Virginia Commonwealth University (Hendricks & Wehman, 2009; Wehman et al, 2014) that examine provision for autistic young people in the transition from school to adulthood, as their reviews of the literature and subsequent recommendations are useful and there is no need to repeat them in full here. See also McDonald and Machalicek's (2013) systematic review of interventions for autistic adolescents. Less critical reviews in other languages such as Spanish (De La Iglesia & Olivar, 2008) and Finnish (Kirjanen et al, 2014a) exist, but the papers cited are generally all in English.

#### 7.2 Funding and eligibility for disabled student support

The UK funds reasonable adjustments in the form of equipment, software and non-medical helpers for disabled students via the Disabled Students Allowance (Cooper, 2013), which is needs-based and not means tested. Germany has a similar system in place (Ambati & Ambati, 2013). Polish universities offer 'special scholarships' for disabled students, who must provide similar medical information to that required in the UK. The amount of money awarded is dependent on the severity of the student's disability. In some European Union countries, universities are not legally required to provide any support to disabled students or are lax in their enforcement of equality and diversity law (Ebersold et al, 2011). Therefore support received by autistic students can be patchy and even more dependent on the individual institution than is the case in countries like the UK that have a stronger legal framework around disability.

Table 1: Overview of support for autistic students in the partner countries

Country	Typical Provision	Eligibility Criteria	Evidence of Diagnosis Required
United Kingdom	Mentoring, note taking, software such as mind mapping, audio recording lectures, extra time in exams, academic skills support	Needs-based	Yes
Poland	Assistive technology if required, mobility support if required, adjustments to exams and coursework	Needs-based	Yes
Spain	Support for speech & social therapy, subsidised transport and books, extra time in exams	Means-tested	Yes
Finland	'Neuropsychiatric coaching', extra time in exams, alternatives to group work	Needs-based, must be in receipt of state disability benefits for some services	Yes for some provision
Netherlands	Separate interview for disabled students with student counsellor or academic advisor, relaxation of usual criteria for staying on course with too few credits, extra time in exams, adjusted deadlines, study buddy, academic skills support, alternatives to group work	Needs-based, universities (e.g. VU Amsterdam) may charge students directly for support	Yes

Proposed cuts to UK Disabled Students Allowance in 2016 may disproportionately affect students with autism, who fall under the 'specific learning difficulties' category which is earmarked for the greatest cuts (Lewthwaite, 2014) — particularly as it is proposed that the budget is removed for non-medical helpers, which are often offered to this group. These include note-takers (Martin, 2006), mentors and specialist tutors (Gelbar et al, 2014).

All the support schemes mentioned in the above paragraph and many of those provided by individual universities require the disabled student to disclose their condition and provide medical evidence of their diagnosis in order to establish their eligibility for financial assistance and/or support mechanisms. This is also the case in other countries such as Australia (Mulder & Cashin, 2014) and the United States of America (Wolf, 2001). Table 2, later in this section, records what was needed in order for a student to access each intervention or initiative discussed by the authors.

Importantly, as not all students will disclose their condition (see the first part of this review) they will therefore render themselves ineligible for this kind of support (VanBergeijk et al, 2008). It should also be pointed out that typically the focus is only on the problems or deficits faced by students on the autism spectrum rather than on encouraging and enhancing any positive attributes (O'Neil, 2008). Autistic students have been critical of the amount of paperwork required in order to access support, including the assumed ability to fill out forms in a timely manner (Martin, 2008).

Cooper (2013) surveyed autistic students and disability needs assessors on the topic of assessment for reasonable adjustments at universities in the UK. Only 7 students responded, and they found the assessment process to be effective but had difficulties receiving the recommended adjustments and

supports. Assessors were more positive, but felt they needed more knowledge and guidance to support this group properly. Disabled Students Allowance only supports students with their study-related needs, and yet the artificial division between 'daily life' and 'student life' ignores the problems autistic students may have with sleeping, housework and social participation (Fleischer et al, 2013).

Many people at the higher functioning end of the autistic spectrum find themselves to be ineligible for social care support, as they do not have a learning disability or a mental health condition (Social Care Institute for Excellence, 2011), and their needs are judged not to be 'significant'. A person with an IQ under 70 is defined as having a learning disability in the UK and by the World Health Organisation's ICD-10 (World Health Organisation, 2010) – in the US, the term 'learning disability' is used instead of 'specific learning difficulty' and does not imply an intellectual impairment. What the UK and Europe call 'learning disability' and some in the US used to call 'mental retardation', the DSM-V calls 'intellectual disability' (American Psychiatric Association, 2013). Without everyday living support from social services or nearby family, academic and study related interventions may fail. Parental support for transition is considered more significant for autistic students than professional support, and is valued more highly (Mitchell & Beresford, 2014).

#### 7.3 Commonly-received reasonable adjustments and support options

Academic support, academic confidence, peer support, self-advocacy skills, access to mental health support and reasonable adjustments to academic work are all key to student resilience and retention (Hartley, 2013, 2010; Knott & Taylor, 2014; Troiano et al, 2010; Wehman et al, 2014). Support received by students on the autism spectrum at school may have been very visible, but not always welcome, which may affect how autistic students view the support they receive at university (Humphrey & Lewis, 2008b). Gelbar et al (2014) systematically review experiences and support given to autistic learners at college and university, concentrating on 20 articles meeting their inclusion criteria. The authors found evidence of 'academic support' in 12 articles, none of which involve adapting teaching or appear to be autism-specific, but assessment modification seems to be common:

- Lecture notes from lecturer (5 instances)
- Notes from peers (2 instances)
- Separate location for exams (2 instances)
- Extra time in exams (6 instances)
- Professor facilitation of group work (1 instance)

- Extended coursework deadlines (2 instances)
- Modified coursework (3 instances)
- Presentations to tutor instead of large group (2 instances)
- Tutor (3 instances)
- Note-taker (1 instance)
- Oral exams (1 instance)

Evidence of 'non-academic' support was found in 9 articles:

- Peer mentoring (5 instances)
- Counsellors or assistants (5 instances)
- Parental involvement (3 instances)
- Social stories (1 instance)
- Social support groups (1 instance)

- Disability teams (1 instance)
- Video modelling (1 instance)
- Cognitive behavioural therapy (1 instance)

Some of the reviewed articles are discussed in the next section.

A survey of reasonable adjustments provided by 30 universities and colleges in the US was carried out by Barnhill (2014), who found the following accommodations were in place:

- Advisor (30 instances)
- Lecture notes from lecturer (25 instances)
- Separate location for exams (29 instances)
- Extra time in exams (29 instances)
- Modified coursework (26 instances)
- Tutor (29 instances)
- Note-taker (28 instances)

- Peer mentoring (22 instances)
- Life skills instruction (24 instances)
- Social skills instruction (23 instances)
- Priority registration (22 instances)
- Assistive technology (28 instances)
- Summer transition programmes (7 instances)

Barnhill found that social skills programmes were not always effective or welcomed, particularly as many students indicated they had experienced training of this type before. The empirical evidence for the effectiveness of social skills training for autistic young people is limited and weak (Rao et al, 2008). These interventions may improve basic language, tone and turn-taking ability in conversations (Zager & Alpern, 2010), but there is no evidence that they improve the learner's social inclusion, comfort in social situations or friendships at university. Several institutions restrict availability to those students they knew they could support. Parents were viewed by higher education institutions as partners in support programmes and student success. However, autistic students and graduates themselves were not consulted by the survey, and therefore evaluation of success is dependent solely on the perspective of providers.

In Finland, an increasingly popular form of support offered to students on the autistic spectrum is 'neuropsychiatric coaching'. 'Neuropsychiatric' is the word the Finnish give to the subset of neurodevelopmental disorders that in the UK and US are often referred to as 'neurodiverse' conditions such as autism, ADHD and Tourette's Syndrome. This is a narrower interpretation of the term 'neuropsychiatric' than its broader clinical use in English, which relates to "psychiatric comorbidities of neurologic diseases" (Lee et al, 2008), including conditions like Alzheimer's and Parkinson's diseases, and requires related medical qualifications. Neuropsychiatric coaching was developed initially for use with people who have attention deficit hyperactivity disorder (ADHD). The coaching is goal-oriented and systematically works through practical activities, based on the client's need for support, and is intended to develop self-esteem, problem solving abilities and life management skills (Sihvonen, 2011). There is very limited evidence for neuropsychiatric coaching when applied to either ADHD (Swartz et al, 2005) or autism (Kirjanen et al, 2014b), and it is difficult to find support for this intervention at this point, based on the studies that have been carried out.

Sihvonen's (2011) article, published for an audience of doctors and medical students in Finland, draws heavily on the Masters dissertation of Huoviala (2008), adding one more case study of a 40 year old man with Asperger Syndrome. It is worth pointing out that Sihvonen repeatedly refers to 'rehabilitation', positioning autism support and intervention within a medical model of disability and putting the onus on the autistic student to rehabilitate and to adapt to university. Notably, this approach does not involve institutions and organisations changing their practices to become genuinely inclusive (Matthews, 2009). The benefits of time-limited interventions for lifelong conditions and people who prize continuity over change are also not clear.

A better example of an intervention in a non-English-speaking country is the peer mentoring scheme offered by the electronics and engineering department of Universidad de Las Palmas de Gran Canaria (Tobajas et al., 2014) — also included in Table 1 below. This scheme has been running for over ten years, providing two mentors for each autistic student at the beginning of their studies. The mentors are students from the same academic discipline as the mentees, supporting mentees with their academic work, confidence and self-regulation skills, and outcomes have been tracked over time. Students accessing the scheme improved their academic grades and were less likely to drop out of university. This model could be replicated elsewhere. The academic discipline-specific aspect is important as mentors will understand the context in which the student is studying and/or struggling and possibly share common interests (Zeedyk et al, 2014).

The University of Brighton developed a project bringing together the Disability Services Team and the Centre for Learning and Teaching (Morris, 2011). It is clear from this study that accessible learning environments which consider sensory issues and inclusive teaching practices are as important for the success of autistic students as individual support. The recommendations for learning and teaching are as follows:

- reliability and consistency of academic staff
- clear expectations and learning outcomes
- clear communication
- unambiguous language wherever possible
- ground rules
- built-in study skills
- varied teaching methods (including visual methods)
- choice of assessment
- check for understanding

- opportunities to ask for help with academic work, ask questions (e.g. allow time at end of lectures)
- making it explicit that students can ask for help (and being clear about availability)
- opportunities to discuss assignments
- precise questioning
- choice of questions in assignments/exams
- lecture notes available in a variety of formats
- opportunities to take breaks

#### 7.4 Interventions and initiatives

Table 2 gives an overview of the types of interventions and initiatives covered in the literature for age 14 upwards, concentrating on further and higher education and relevant adult studies. The table includes information (where provided) about the methodology of the study and/or intervention itself and the intended audience – e.g. is it direct (aimed at students) or indirect (information or training for educators)? Location and eligibility to access the programme or study are also included as important factors in understanding the initiatives.

Please note that, in common with most autism research (Mesibov & Shea, 2011), the majority of these examples derive from small-scale studies or institutional programmes and have limited evidence of their efficacy, long-term benefit or wider applicability. To systematically review interventions and initiatives would yield no or very limited findings, from a small number of admissible studies and conclusions would be similar to previous reviews – that there is limited high quality research or evidence in this area of study (Bölte, 2015). Instead, examples are provided that show the range of typical interventions.

Table 2: Overview of interventions

Article	Intervention	Date	Methodology or synopsis	Target group	Categories	Autism specific?	Location	Availability
Alexander & Inch (2013)	School leavers' group with social worker and psychologist	2013	8x 2 hour workshop sessions on relevant themes. Participatory (desires of participants influenced programme).	16-18 years old, autistic spectrum	Transition, social skills	Yes	Scotland	By referral, 2 year pilot
Bowman & Scaife (2012)	Blogging to support completion of undergraduate dissertation, helping to formulate ideas and develop writing skills	2012	Action research following a case study pilot: supported blogging by students throughout dissertation process, recording qualitative feedback	Final year undergraduate students, autistic spectrum & neurotypical	Academic support, social media	Yes	England	Pilot scheme, open to all students (including non- autistic) on dissertation module
Disability Resource Centre (2009)	Guidelines to interviewing and supporting autistic students	2009	Quick guide to working with this group.	Academic staff	Transition, access to support	Yes	England	Widely available on web
Gantman et al (2012)	PEERS social skills training programme	2012	Randomised controlled trial; instruction on social etiquette, role play, homework assignments	18-23 years old, autistic spectrum	Social skills	Yes	USA	Diagnosis of an ASC, reported social problems and IQ over 70
Gardner et al (2012)	Occupational therapy programme on-campus	2012	Two day immersion programme at university campus, provided by Masters students. Students kept reflective journals	High school students, autistic spectrum & similar	Transition, occupational therapy, life skills	Yes	USA	Pilot scheme, students at a specific special education school, diagnosis required
Getzel (2008)	Three step support model	2008	Direct coaching, consultation and developing strategies, monitoring progress	Disabled university students	Transition, life skills, technical skills, self- advocacy skills, employment support	No	USA	Students registered with disabled student services

Article	Intervention	Date	Methodology or synopsis	Target group	Categories	Autism specific?	Location	Availability
Gobbo & Shmulsky (2014)	Instructional approaches	2012	Focus group of faculty staff, uncovered techniques: providing structure & predictability in presentation of teaching and assignments, previewing upcoming work, directly stating format of course, clarity of expectation, awareness of and response to potential signs of anxiety, one-on-one discussion, autistic students working through ideas with instructors rather than peers	Autistic undergraduates	Academic support	Yes	USA	All students
Hadley (2011)	Recommendations for administrative and academic staff	2011	Literature review and recommendations using development theory	Staff	Academic and life skills	No	USA	Disabled students (but universal design recommendations for all students)
Hendrickson et al, (2013)	UI Reach program	2013	2 year programme following high school. Aims to improve self-reported scores for: student life, interpersonal relationships, self-advocacy, independent living, and emotional adjustment	Autistic post- secondary students	Life skills	Yes	USA	Autistic 18-25 year olds with a diagnosis, across the US.
Hughes (2009)	Guide to supporting students with Asperger Syndrome for Physics departments	2009	In-depth guide to how to support autistic students in a subject specific context – however much of the advice is more broadly applicable. Includes strategies, case studies from stakeholders and quick	Academic, technical and administrative staff in Physics departments at universities	Academic support	Yes	UK	Autistic undergraduates (diagnosis not specified)

Article	Intervention	Date	Methodology or synopsis	Target group	Categories	Autism specific?	Location	Availability
			guides.					
Korbel et al (2011)	Transition strategies for student engagement	2011	Notes collaboration with disability office from early on.	University staff	Transition support	No	USA	All students
MacLeod & Green (2009)	Collaborative support model	2009	Collaboration between university disability services and voluntary sector to allow earlier intervention. Useful article, less for model than information about barriers to success.	Disability services at universities	Transition support, ongoing disability support	Yes	UK	Students disclosing autism and receiving Disabled Students Allowance
Martin (2006), Martin (2008)	Strategies for success, services for success	2006, 2008	Recommendations for best practice in universities when working with autistic students	Disability practitioners at universities	Transition, academic and pre-exit support	Yes	UK	All students
Martin (n.d.)	Personal statements	No date	Autistic students create personal statements to give to people they meet	Educational practitioners	Transition support	Yes	UK	All autistic students, diagnosis proof not needed
McDowell (2011)	UoHTube project	2011	Learner generated content and video lectures as inclusive practice	Educational practitioners	Inclusive teaching	Yes	UK	All students
Morris (2011)	Aspect Project	2011	Developing inclusive teaching practices by collaboration between disability services and learning and teaching services.	Disability services and educational practitioners	Inclusive teaching	Yes	UK	All students
Ness (2013)	Strategies for College Learning model	2013	Peer mentoring pilot study with three participants.	University students of any age on the autistic spectrum	Self-regulation skills	Yes	USA	Students with a diagnosis at one university, at risk of academic failure
Palmen et al (2008)	Improving question asking skills	2008	Sessions conducted with nine 17-25 year olds, all with diagnosed autistic spectrum conditions.	Autistic adolescents.	Question asking skills	Yes	Netherlands	Adolescent clients of an autistic spectrum condition 'treatment facility'

Article	Intervention	Date	Methodology or synopsis	Target group	Categories	Autism specific?	Location	Availability
Pugliese & White (2014)	Cognitive behavioural therapy (problem solving skills)	2014	5 participants, meeting ADOS criteria for autism spectrum, given group therapy. 2 showed improvement. Please note that NICE guidelines suggest that CBT should only be used for anxiety reduction in autistic adults and not for other purposes.	Autistic undergraduates	СВТ	Yes	USA	Autistic students, 8 pilot sessions.
Tobajas et al (2014)	Peer mentoring	2014	Each student is provided with two peer mentors in their department that they can use for transition support and/or throughout the year. Weekly support is provided. Project has been running successfully for 10 years. Support for inclusive teaching given to academic staff.	Autistic engineering undergraduates, academic staff	Transition support, academic skills	Yes	Spain	Engineering students disclosing autism and requesting support
Wenzel & Rowley (2010)	First year experience	2010	Seminars on topics like life skills, social skills, sexuality and stress management throughout first semester	Autistic undergraduates	Transition support, life skills	Yes	USA	First year undergraduates disclosing autism

# 7.5 Summer schools

Summer schools and pre-induction programmes form a particular category of intervention that is growing in popularity in the UK and US. This section reviews several programmes, which have a number of common features. Autistic students strongly value university visits and 'taster days' during the academic year (Mitchell & Beresford, 2014), with particular interest in extended visits that allow the student to experience the college or university setting in an authentic way, including experiencing teaching and travel to and from campus. There is as yet limited empirical evidence for the effectiveness of summer schools or other programmes that take place at times when the campus is not busy and 'normal' lectures and other regular parts of the university experience are not in full swing. Tait et al (2011) found that students who had attended a summer transition programme at an unnamed Scottish university enjoyed the experience and the disability service reported better progress and retention of students who had attended such a programme. However, the numbers of students attending these programmes are low, the programmes do not appeal to all and this must not be the sole or main form of transition provision for autistic students.

#### 7.5.1 United Kingdom

**University of Bath** have developed and evaluated a transitional pre-university summer school for autistic students (Russell et al, 2014). The content falls into three broad strands: 'Work', 'Rest and Self-Care' and 'Play'. The programme is residential. 23 students attended, 80% of who were male. Aspects of the programme rated positively by those who chose to participate were:

- the normalising experience of being in a group with others on the autistic spectrum
- learning from autistic peers who had experience of studying university
- experiencing aspects of campus life such as sharing a bathroom
- sessions on managing anxiety/stress
- learning about university support services
- learning about academic interactions

#### More negative aspects were:

- difficulties accessing cooking equipment for the group meal task
- using the gym (triggered bad physical education memories from school)
- the food
- overfamiliarity with content of the social skills training this supports the findings of Barnhill (2014)
- duration of summer school (too short)
- would have liked to have found out about the scheme earlier

Some aspects of this summer school could be seen as patronising. If a student of the intellectual capacity to achieve a degree has not learned before attending university how to shop for food and cook it themselves, or managed to visit a restaurant or bar without their family, these are not autism-specific problems but general life skills. One may argue that these skill deficits should not be addressed by a disability service at this level. For example, a British supermarket found that a large proportion of 18-year-olds cannot boil an egg, do the laundry or cook spaghetti (J Sainsbury plc, 2012) – this failure of young adults to successfully undertake household tasks is not caused by disability and should be addressed at home and at school. Incidentally, participants in the Bath

programme did not rate food and cooking as a major concern before attending the summer school and their perception had not significantly changed following attendance.

Getting on with flatmates, fitting in with non-autistic students and issues around 'freshers' week' were much more of a concern for participants, and none of these issues were fully addressed by the programme. The summer school took place in early September, a very quiet time on campus and the polar opposite of the hectic beginning of the academic year. As the programme was solely aimed at students with an autistic spectrum diagnosis, the socialising and skills training took place without the non-autistic students who would form the majority of the participants' flatmates and course peers. Students did however rate the experience as slightly enjoyable.

**Birmingham City University** have a similar programme to Bath's, as briefly described in the Guardian newspaper (Ratcliffe, 2014). The summer school lasts three days and focuses on social and life skills. No critical evaluation of the programme is presented.

The University of Surrey (Fidler & Britton, 2012) run a pre-entry programme based on building a support network for the autistic student with the student at the centre. The other stakeholders are academic staff, disability services, accommodation workers (including security staff) and the counselling service. Students are introduced to these networks, including their personal tutor, which students found helpful and the study found a correlation between the programme and improved retention outcomes. However, the rest of the three day itinerary is similar to the other summer schools, including the group meal task and artificial socialising opportunities, and the students do not mention these aspects as being useful.

Glasgow Caledonian University (GCU) have not documented their Summer Transition Programme (STP) in the form of a public report or journal article. However, the authors spoke to Danny Gallacher, Disability Adviser at GCU, about the programme. The STP started at another local university that no longer has a summer school, but when Gallacher and another member of staff, Catriona Mowat, changed institution to GCU, they took the programme with them and it has been running there for four years. A letter inviting students to the STEP is sent to applicants offered a place at GCU who indicated they had an autistic spectrum condition on their UCAS (UK undergraduate application system) application. No proof of diagnosis is needed in order to access the programme and it is run in partnership with the National Autistic Society (Scotland). In 2014, 15 autistic students at the university participated in the STP whilst 3 new starters declined to take part.

This programme is best suited to students who live in reasonable travelling distance, as it takes place one day a week for three weeks in the run-up to 'freshers' week', in the form of two half day sessions and one full day. After the STP is finished, students have their disability needs assessment for UK Disabled Students' Allowance, which is helpful as they have learned what the university offers and where they may need support. Sessions offered on the first two days covered:

- time management
- changes and differences between school/college and university
- stress and relaxation
- communication and relationships
- self-advocacy and assertiveness
- disclosing your condition

The final full day of the programme introduces the services offered by the university:

- technology available on campus
- the needs assessment process
- study skills support
- mentoring scheme
- careers services
- Student Association

There is no residential aspect to the programme. The STP forgoes the less valued life skills elements of the other programmes. However, this programme does offer self-advocacy training, and this is rarely offered in the UK. Self-advocacy skills are necessary for both an effective needs assessment and a successful university experience (see other sections of this review).

#### 7.5.2 Continental Europe

No information was provided by project partners regarding summer schools or similar transition programmes in Autism&Uni partner countries, outside the UK.

#### 7.5.3 United States

**SUNY Albany** researchers contacted participants of the pre-college transition programme from 1999-2006 by Rothman et al (2008). This project works across a range of disabilities, including autism. The highest rated skills and topics learned on the programme were:

- self-advocacy skills
- · disability rights and entitlements
- mobility and orientation around campus
- better understanding of their own disability and other disabilities
- improved study habits
- managing a disability and college life

A low number of participants responded to the study, but those who did respond felt they did not learn enough about careers and employability. This programme did not aim to teach 'life skills' such as cooking or laundry.

#### 7.5.4 Summer@CIP

12 universities in the US work with the College Internship Program (CIP) for the Summer@CIP programme. This is aimed at young people with documented diagnoses of specific learning difficulties such as autism and ADHD. The programme lasts two weeks and has two strands: a 'high school program' for high school sophomores (10<sup>th</sup> grade/aged 15-16) to recent high school graduates, and a 'beyond high school program' for potential students who have graduated high school and are aged up to 26 years old. This programme cost \$4300 at the time of writing (CIP, 2014), whereas the UK programmes do not charge students or their families. Students gain 1 college credit by attending and are expected to learn the following skills:

- social skills
- executive functioning
- person-centred planning
- cooking

- budgeting
- laundry
- self-advocacy

They also take part in a career readiness assessment exercise.

Some North American universities have autism-specific programmes that go beyond the transition period and last for a full academic year or more. These usually charge fees (additional to regular tuition fees). CIP also run a programme with a number of universities, which costs from \$44,900-\$75,000 excluding accommodation, costs depending on the level of support the student needs (CIP, 2014).

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# 8 Literature review 3: Technological interventions

Research Question: What technological interventions have been used to support the social and academic development and independence of autistic students?

As was discussed in the section on pedagogical interventions, the quality of research into interventions for adolescents and adults on the autistic spectrum is inconsistent and usually involves small numbers of participants and a lack of tailoring to the individual. This is not something that changes with the shift in focus of this section towards technological interventions, with most published work relating to pilot studies, usually with children, in small numbers, with no control group (Aresti-Bartolome & Garcia-Zapirain, 2014). Further, participation from autistic people in the design and implementation of studies is rare.

A key observation in recent reviews is that studies of technology-based interventions that tested for improvements in participants usually report negative results when generalised to similar realistic situations (Wass & Porayska-Pomsta, 2013; Aresti-Bartolome & Garcia-Zapirain, 2014; Georgescu et al, 2014). This was the case even where actual improvements were observed within the technological setting. This is unsurprising, as people with autistic spectrum conditions struggle to generalise learning and behaviour from one specific situation, theoretical or real, to another (Happé & Frith, 2006).

Wass & Porayska-Pomsta (2013) suggest that the focus for future interventions should not be on teaching autistic learners new knowledge, such as social skills or emotion recognition, but instead on how to apply this knowledge in real and complex situations. This is supported by studies of observational learning and its challenges for learners with autism (Plavnick & Hume, 2014), but also the earlier section of this review on summer schools, where findings indicate that autistic students did not gain benefit from general social skills training but worried specifically about relationships with their new flatmates, tutors and peers on their course.

Situated learning, with authentic activities taking place in authentic contexts, is not just better than observational and abstract concept learning for learners on the autistic spectrum but for all students (Seely Brown et al, 1989). 'Authentic assessment' can take place within a virtual environment, but the strategies learned on the computer must then be applied and tested in the real world (Herrington & Herrington, 1998). Tasks should be specialised and situated in real practice, not general role play (Gulikers et al, 2008).

As in previous sections, and mindful of earlier comments on quality in intervention studies, what follows is a scoping review or overview of the types of intervention covered by the literature, with a focus on university students, adults and older teenagers. Recent systematic reviews of technological interventions have been carried out by McDonald & Machalicek (2013), who focused on adolescents, and Grynszpan et al (2014), who focused on children. The main findings of both were that results were promising but inconclusive and more research into autism and technology is needed. Fletcher-Watson (2014) recently produced a targeted review and series of guidelines related to computer-

aided learning for children with an autistic spectrum condition, hinting that there may be welcome spin-off effects from using technology such as a sense of achievement, confidence, increased peer group status and increases in social communication.

A review in Spanish of ICTs and autism argues that autistic people should be involved in the codesign of interventions (Cuesta Gómez & García, 2012), which is a view supported by others (Francis et al., 2009a; Ferrario et al., 2014; Francis et al., 2009b; Frauenberger, 2015) and a principle not limited to technology tools for people with autism, but one that would arguably make better technology for everyone.

The aesthetic properties and usability aspects of technical interventions also have a great bearing on their success. (Grynszpan et al, 2008) found that simple interfaces are preferred by autistic learners. Complex interfaces that stimulated other users were found to be confusing and abstract, and they have a negative impact on task performance and choice/decision-making. If interventions are intended to be inclusive of users with ASCs, the interface must be clean and unambiguous (Biju et al, 2013), without too many choices, and the link between interface elements and modalities, and the task at hand must be made explicit (Grynszpan et al, 2008).

As with the section on pedagogical interventions, it is clear from the published literature on autism and technology that observing universal and inclusive design principles and providing better scaffolding and support for the use of existing technology may be more valuable in many cases than developing separate tools and processes.

## 8.1 Computer-mediated communication

The study of computer mediated communication (CMC) for autistic adolescents and adults is an area of relatively high quality research, and is important to understanding how interactive technological interventions for students with autism could work. Many adults with autism are very confident users of computers and the Internet (Benford & Standen, 2009), and often more positive about and proficient in the use of computer mediated communication than non-autistic people (van der Aa et al, 2014). Communication is not noticeably impaired in autistic bloggers, based on language use, due to the social affordances of the Internet (Newton et al, 2009), and autistic CMC users are able to recognise verbal irony (Glenwright & Agbayewa, 2012) and scan and evaluate websites just as well as their non-autistic counterparts (Deering, 2013).

Perhaps unsurprisingly, people with autistic spectrum conditions perceive greater benefits of CMC than experienced by those without ASCs (Gillespie-Lynch et al, 2014). While feeling detached from mainstream communication, often describing themselves as 'outsiders' (Simmeborn Fleischer, 2012), many high functioning people on the autistic spectrum find online communication to be liberating, as it is more controllable and less stressful than other forms of communication (Benford & Standen, 2009). It enables individuals both to express themselves better and to easily find and communicate with others who share their interests and/or disability (Gillespie-Lynch et al, 2014).

Asynchronous communication enables the autistic person to spend more time on their responses, stay calm and avoid the sensory overload inherent in other communication media and synchronous online communication (Benford & Standen, 2009). CMC is beneficial for initiating social interactions, which may then 'break the ice' for offline conversations in person, but issues of trust, privacy and misinterpretation can lead to dissatisfaction with communicating online (Burke et al, 2010) and

difficulty with sustaining online-only relationships (Gillespie-Lynch et al, 2014; Burke et al, 2010). While people without autistic spectrum conditions (ASCs) prefer to use CMC predominantly to maintain relationships with people they already know, people with ASCs prefer to use CMC to build relationships with new people (Gillespie-Lynch et al, 2014), which leads to improved self-esteem and sense of identity and strong offline relationships with both autistic and non-autistic people (Henderson et al, 2014).

Young autistic adults are more likely to be socially isolated than their neurotypical counterparts, and this increases for those still living with a parent (Orsmond et al, 2013). CMC is therefore useful and important for people with ASCs and should be supported and encouraged. Autistic university students should also be supported and encouraged to move out of the family home in order to reduce social isolation and reliance on parental support for life management (Hume et al, 2009), and CMCs may help them to stay in contact with family and others.

Autistic adults who use social networking services (SNS) are more likely to have close friendships and those who use SNS to engage socially, instead of passively following accounts, report closer relationships as a result (Mazurek, 2013). Use of the internet for communication also decreases feelings of loneliness for those with ASCs (Benford & Standen, 2009; Burke et al, 2010; van der Aa et al, 2014). However, the quantity and quality of offline friendships is a better predictor of decreased loneliness than frequency of SNS use (Mazurek, 2013).

New SNS have been developed specifically for use by people with autism and other learning difficulties and learning disabilities and their caregivers, for example SocialMirror (Hong et al, 2012) AOZORA Dandelion (Ogoshi et al, 2010) or the now defunct InBook (Jisc TechDis, 2014). InBook was an online safety training tool, used in further education colleges in the UK, SocialMirror is a concept intended to empower developmentally disabled people to seek feedback and support for daily living skills, and AOZORA Dandelion is aimed at knowledge creation for families and professionals of the disabled person. All services have in common the fact that they are closed networks, populated solely by trusted individuals (college peers, tutors, family members, caregivers, professionals). Users of SocialMirror experienced similar privacy worries to those using mainstream SNS, and tension was observed between adults with autism using the service and their caregivers (Hong et al., 2012). While such services may have their place in scaffolding support for more vulnerable users in learning how to use CMC, or supporting caregivers, users observed many of the same drawbacks to the closed systems as were observed for mainstream SNS, and by their nature new relationships cannot be developed nor social engagement skills realistically improved via these services.

CMC has also been used for e-mentoring (mentoring by online communication, without regularly meeting face-to-face) disabled students, via email and online chat. This can be successful, as with the peer mentoring described in an earlier section, particularly if the mentor has the same disability as the mentee. Undergraduate and postgraduate students have been used as mentors, including students on psychology and therapy courses (Shpigelman et al, 2008). E-mentoring opens up opportunities for mentoring that are not geographically restricted. Even if it is difficult to find suitable autistic mentors for students on the spectrum, it may be possible to find motivated students in relevant disciplines with an understanding of ASCs , and these would be viewed by the mentee as a peer – unlike an older 'autism professional'. Mentees with limited exposure to appropriate role models with the same disability benefit most from peer mentoring by similarly-disabled mentors

(Britner et al, 2006) and the age appropriate relationship may be more conducive to the mentee going on to develop social relationships outside the programme.

#### 8.2 Video modelling

Video modelling is used in a large number of studies of different populations, including people with autism, for teaching complex skills. A number of reviews of video modelling interventions for autistic people have been published, including Ayres & Langone (2005), McDonald & Machalicek (2013) and Delano (2007). Their conclusions are consistent in that while they are positive about the possibilities of this type of intervention, there is a strong need for higher quality empirical studies with larger numbers of participants, and such interventions are resource and time intensive. It is suggested that self-modelling (where the participant watches recordings of themselves, rather than others) may be the most effective variant of video modelling. Social Stories (short stories that use visual images and text to explain new situations) and video modelling were combined in one study of young children to teach social skills (Sansosti & Powell-Smith, 2008). However, the participants were unable to generalise the skills learned to real life situations following the intervention.

An intervention specifically aimed at higher education students with Asperger Syndrome (Mason et al, 2012) used short video clips to improve conversational skills. Facial expressions, eye contact and conversational turn-taking were improved in participants even after the video modelling was withdrawn. This study took place with only two participants, without researching whether or not the students were able to apply these skills with different people in different settings, and therefore it would be difficult to generalise the results to a wider population or even to attribute the improvement specifically to the intervention.

## 8.3 Task management systems

Memory Aiding Prompting System (MAPS) is a tool that enables caregivers to create 'scripts' that can be used to prompt young adults with special educational needs to carry out tasks (Carmien & Fischer, 2008). Caregivers can use the Windows-based program to bring together steps of a task with accompanying pictures and sound files as a script that can be run on a mobile device. Caregivers are provided with a video that showed the caregiver how to segment a task and turn it into a series of prompts for the young person. This tool or the idea behind it could be adapted to help autistic students, possibly with the support of a mentor or tutor, to break down tasks themselves and set their own prompts via their mobile phone. Task management software for autistic adults using HTML5 and the mobile web is also being explored by researchers (Duncan & Tan, 2012).

#### 8.4 Virtual worlds and gaming

Virtual worlds can enable autistic learners to have experiences and develop skills that they would not have access to in real life, in a 'safe' environment where they have control over their identity and how it is presented (Ball & Pearce, 2008). Experiments have been carried out with users with autism and Second Life (Kirriemuir, 2008; Smith, 2012), a web-based virtual world that is no longer popular with users but was once fashionable with researchers, and Habbo Hotel (Hernández-Serrano et al, 2009), an avatar-based chatroom. The focus of studies is usually on building social skills or improving empathy. Virtual reality has been used for social cognition training (Kandalaft et al, 2013) and social skills training (Mitchell et al, 2007; Parsons et al, 2006; Trepagnier et al, 2011), with limited real world applicability. A recent review found that study sample sizes were generally small, lacked controls or rigour and rarely sought to test whether or not those skills were transferred to

real life situations outside the training programme (Georgescu et al, 2014). The increase in near-affordable virtual reality headsets like Oculus Rift, wearable/pervasive computing (Miranda et al, 2014; Picard, 2009), and genuinely popular and accessible online worlds like Minecraft (Rizzo et al, 2012) will no doubt lead to more studies in this area.

#### 8.5 E-learning and Virtual Learning Environments (VLEs)

The focus of most autism-related studies in this area is in the development of new interfaces, rather than exploring the accessibility and possibilities of the mainstream virtual learning environment (VLE) and portfolio software commonly used by schools, colleges and universities. A notable exception to this is the UoH Tube project (McDowell, 2010), where a university student with Asperger Syndrome found working collaboratively via the Mahara e-portfolio system much easier than face-to-face group work and was using much more collaborative and inclusive language than his non-autistic counterparts, often starting discussions or being the main contributor and increasing his confidence and self-esteem (McDowell, 2011). This is similar to autistic users' experiences of CMC, above. As it was a 'closed' system, limited to people on a specific course, students felt that they owned the space and were less scrutinised than when working with the institutional VLE, which potentially indicates a need to increase privacy and segmentation in VLE use.

VLEs present both benefits and challenges. Online presentation enables students to access lecture notes and recordings without the embarrassment and effort of specifically requesting them, and alternative formats and personalisation options can make VLEs more usable for disabled students than print resources (Rose & Strangman, 2007). HTML and web design principles encourage the creation of clearly structured resources and clean presentation of content (Robinson, 2012). On the other hand, students on the autistic spectrum typically avoid looking at grades when only posted on the VLE, and struggle with online module selection (Hughes, 2009), and these aspects of online presentation need to be scaffolded with inclusive design and support based on solid pedagogic principles (Rose & Strangman, 2007), possibly including offline support, for some students.

iSocial is a "3D-VLE", requiring the use of headsets to experience an immersive learning space that crosses the boundary between a VLE and a virtual world (Laffey et al, 2010). Adolescents with ASCs using iSocial enjoyed using the software and some performed better in this environment than in the face-to-face classroom. The software was used to teach social skills via video, interactive quizzes, a 'conversation console' with speech bubbles to aid discussion and follow-up materials sent to parents at home (Schmidt et al, 2008). The VLE delivered content at a distance that had previously only been taught via experiential learning in a face-to-face context. However, overall results showed no improvement in performance following the intervention (Stichter et al, 2014)

The HANDS project (Øhrstrøm, 2011) is an individualised e-learning toolkit that uses mobile technology, including GPS functionality, via smartphones to adapt student behaviour via persuasive techniques. There are six main components to HANDS.

- 1. The Handy Interactive Persuasive Diary (HIPD), an interactive calendar that supports students with organising their lives and teachers with understanding points at which the student will be most open to adaptation.
- 2. The SimpleSafeSuccess Instructor (SSSI), which teaches students how to deal with new situations.

- 3. The Personal Trainer (TT), also to assist with new situations.
- 4. The Individualizer (TIn), which enables students to adapt the appearance and functionality of the tool.
- 5. The Sharing Point (SPo), which allows the teenagers using the tool to communicate with each other and teachers in the project to share their experiences.
- 6. The CredibilityoMeter (CoMe), which enables the teacher to understand the credibility of the tool from the perspective of the teenager, as well as its influence on behaviour.

The instruction aspects of the tool are based on Social Stories, which have been shown to have limited efficacy in clinical observation (Reynhout & Carter, 2011). In some cases, students found the HANDS tool to be helpful, but the tool was not used as often by participants as the researchers expected and many did not find it to be useful or credible (Øhrstrøm, 2011).

EDUQUITO is a Brazilian VLE with typical VLE features and functionality, except for the addition of a space for collaborative cartoon-based stories and a reflective diary tool (Passerino & Santarosa, 2008). The authors report improved cognitive and social development in learners using the VLE. The AS Interactive project developed a multi-user VLE, as opposed to the usual single-user model, to create a collaborative environment for teaching social skills (Kerr, 2002). A computer animated 'café' focused on interactions between avatars and the project found that users needed more support to use the collaborative environment than a standard VLE (Rutten et al, 2003). The usability of the system was questioned by participants, who found many issues and inconsistencies in the system (Cobb et al, 2002).

Many features of new VLEs specifically designed for disabled users became commonplace in VLE software before the outcomes of those studies were published, possibly due to the usual delays in the scholarly communication system and possibly due to researchers working in isolation from mainstream software development. For example, all of the features in the accessible system described by Fryia et al (2009), such as a clean interface, checklists to track progress, clear colour schemes and simple site hierarchies were available in the Moodle VLE version 1.9 in early 2008 (Moodle, n.d.), used by one of the authors as a student with the Open University.

#### 8.6 Assistive technologies

Assistive technologies are rarely developed for high functioning adolescents and adults on the autistic spectrum, with efforts focused on children and lower functioning people. Clasp, aimed at autistic adults, connects a tactile Bluetooth game controller designed to be like a 'stress ball' (small ball made of foam, squeezed to alleviate anxiety) to an Android-based smartphone (Simm et al, 2014). The tool includes a text message (SMS) and SNS-based peer support system and an anxiety data collection system. If anxiety thresholds are reached via repeated or long squeezing of the controller, the user receives a response such as a trigger to send a message to a friend or a distracting URL to a website or search set previously by the user. The user can also track their anxiety levels, locations and triggers. The published article about Clasp does not set out to evaluate the intervention, although users found the anxiety tracking helpful and had mixed responses to the tactile controller. Instead it focuses on the development process, which involved a short development 'sprint' and working with 'real' adults on the autistic spectrum.

## 8.7 Mainstream technologies and commercial software

There are many studies of iPads, children and autism-specific apps, but these tend not to be relevant for older autistic learners or people of higher intellectual ability. The more portable nature of the iPod Touch (effectively an iPhone without the telephone element) and various smartphone devices has enabled researchers to use mobile technology in a number of projects to support everyday living and academic life. Applications included on the device or in general mainstream use such as calendar, photography cloud-based storage, notifications and note taking apps can be used for task management, picture-based prompts, wayfinding, videos of task sequences (Gentry et al, 2014), communication with coaches and mentors (Gentry et al, 2012), and to improve communication and enable the use of video modelling techniques (Shane et al, 2012).

Past studies into PDAs in employment and academic study, which could now be replaced with ever cheaper and more available smartphones and tablet devices, have shown some improvement in life management and study skills in learners with ASCs when compared with paper alternatives such as wall planners, diaries etc. For example Smith Myles et al (2007) found that the homework performance of high school student 'Joseph' improved when he entered homework information into a PDA, even though he entered the same information as he had previously written in a paper planner. The attraction of the 'gadget' and removal of the handwriting component made the electronic planner more usable to him. The improved affordances of smartphones (Cochrane & Bateman, 2010) and the likelihood of the device being with the participant most of the time mean that executive function skills could be improved even further for autistic learners using the latest technology, as has been observed in learners with ADHD (Moëll et al, 2014; Moëll, 2012).

A Norwegian study of university students with ASCs and ADHD found that the majority of these students already owned smartphones, but were not good at organising themselves or developing systems to cope with executive function tasks (NAV NONITE, 2011). By the end of the project, all of the students were using their smartphones as cognitive aids for communication, organisation, navigation, storage, reduced stress and life management. The apps used were mainstream commercial apps, not developed for the project or for students with these disabilities, and the students took part in workshops on the efficient use of these apps.

Office software, especially presentation programs such as Microsoft PowerPoint, can be used to help autistic learners communicate and organise their thoughts, and to create visual schedules (Bonnin et al, 2012). Students can also use this software to design accessible guides for their tutors and peers (Walters, 2010).

A number of projects have explored the possibilities for using multi-touch table-top hardware in the development of social and collaboration skills for people with autism. These are reviewed by Chen (2012), who notes the need for empirical longitudinal studies into this area but is generally positive about the technology, as the table-top option allows several users to engage with the same piece of hardware simultaneously.

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