SUPPORTING PEOPLE WITH AUTISM TO LIVE THEIR LIVES

Summary Sheet

The purpose of the suite of vignettes is to provide a range of examples of situations that people could experience in their lifetime including autistic people.

They are targeted at all people involved in the lives of autistic people from a range of backgrounds, roles and circumstances.

They aim to provide a range of examples and key areas of areas of consideration when supporting an autistic person that is experiencing key life experiences so that they can be prevented from getting worse or becoming a crisis.

The change in autism diagnostic criteria is recognised with the removal of Asperger syndrome in DSM – 5 (American Diagnostic and Statistical Manual) and ICD – 11 (Diagnostic Manual used in the UK) Future diagnosis of 'autism spectrum disorder' (ASD) will become the most commonly given diagnosis. People's existing diagnosis will not change and individuals will choose how they refer to their autism.

For the purposes of the individual vignettes the reference to Autism Spectrum Disorder may change in an attempt to reflect the different terminology used.

How to learn more

Fulfilling and Rewarding Lives: the strategy for adults with autism in England www.gov.uk. Published on 3 March 2010 by the Department of Health, the strategy sets out guidelines for public sector agencies to work together for adults with autism.

Autistic people's experiences; (videos and written); http://www.healthtalk.org/peoples-experiences/autism/life-autism-spectrum/topics

Autism resources for health and social care workers – videos and short guides including how to conduct assessments and how to be a great PA or great autistic employer, and a list of resources for specific professionals including nurses, GP's and psychiatrists; https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/autism/Autism.aspx

E-learning courses about autism focusing on children and young people; https://www.minded.org.uk/ (search 'autism')

NAS (National Autistic Society) helpline; https://www.autism.org.uk/get-involved/about-us/contact-us.aspx 0808 800 4104

NAS info on strategies and approaches; https://www.autism.org.uk/about/strategies.aspx

Autistica; focuses on research about autism; https://www.autistica.org.uk/

The National Institute for Health and Care Excellence - Clinical guidelines on the diagnosis and management of autism https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/autism

Autism in women and girls including free online training; https://www.autism.org.uk/womensday

Summary table:

Providing an outline of each situation described in the vignettes and key messages.

Also including targeted resources and links to more information available.

Person	Their situaiton	Key message	Resources that might be helpful
Aiysha - A planned hospital admission and discharge	Is 27 and lives in a bedsit in a supported living situation after some time in a mental health hospital. She has Hight Functioning Autism and a diagnosis of borderline- personality disorder.	 Considers the importance of receiving the right diagnosis Importance that staff understand how autism presents. Recognises the challenges a mental health ward is for someone with Autism. Importance of revisiting less restrictive approaches when provided with new information Importance of working as a team, including all areas of support. 	https://www.autismresearchtrust.org/News/ borderline-personality-disorder-or-autism NAS info on autism and mental health hospitals; https://www.autism.org.uk/about/health/ mental-health-care.aspx Royal College of Psychiatrists guidance on good practice in the management of autism; https://www.rcpsych.ac.uk/usefulresources/ publications/collegereports/cr/cr191.aspx NAS info on managing money (and link to online course for autistic people on this topic); https://www.autism.org.uk/about/adult-life/ managing-money.aspx Health talk series; http://www.healthtalk.org/ young-peoples-experiences/psychosis- young-people/topics and http://www. healthtalk.org/peoples-experiences/autism

Declan - Planning to prevent risk / falling through the gaps	Declan is 18. He spends most of his days, sleeping or online. He loves technology and is very active on social media but does not always see the inappropriateness of some actions. He's autistic and has a mild learning disability and cerebral palsy, but Declan rejects these 'labels' and any offers of support or help.	 'The system' need to be joined up and proactive to help prevent needs arising rather than waiting for people to have a crisis. Skills is needed to get people to engage and understand their own needs. People with a milder learning disability can slip through the gaps and suddenly need expensive services from the criminal justice system. 	NAS info on transitions; https://www.autism. org.uk/about/transition.aspx NAS info on autism and sleep; https://www. autism.org.uk/about/health/sleep.aspx NAS info on managing money (and link to online course for autistic people on this topic); https://www.autism.org.uk/about/adult-life/ managing-money.aspx Preparing for adulthood; https://www. preparingforadulthood.org.uk/
Emmanuel - Having a relationship, leaving home	He's 26 and has High Functioning Autism. He lives in his own flat with a little support. He's embarking on an adult life and wants a relationship, his own place and a job. He also needs help with his money and coping strategies	 People are entitled to the full range of adult experiences, including relationships, jobs and taking risks; simply being able to cook a meal and do the washing up each day isn't enough for a fulfilling and rewarding life. People will want to keep some aspects of their lives private. People might need some help to negotiate this –understanding their own needs and also a partners and negotiating relationships. 	http://www.healthtalk.org/peoples- experiences/autism/life-autism-spectrum/ love-autism Online international group of autistic people who are LGBTQI+ https://www.twainbow.org/ https://www.youngstonewall.org.uk/ https://community.autism.org. uk/?Redirected=true https://different-together.co.uk/ Different Together is a safe, supportive and understanding community for the partners of adults affected by Asperger's Syndrome (AS) NAS info for partners of autistic people; https:// www.autism.org.uk/about/family- life/partners.aspx Asperger's Syndrome and Sexuality: From Adolescence Through to Adulthood, Tony Attwood

Gordon - Health and wellbeing in older age	Gordon is 70 and has suspected autism and is aware of his challenges. He has autistic family members. Since his wife died last 2 years ago he has stopped attending regular appointments for his diabetes and begun turning up at the doctors and A&E in a "crisis" and being rude and aggressive towards the reception staff which is out of character.	 It's important to look beyond the behavior and ask the question why someone may be behaving in a particular way. Grief and loss of a person/job/ routine are especially difficult to cope with as often they may be providing vital support to a person with ASD practically and emotionally. A bespoke team approach with creative problem solving can lead to small adjustments meaning that an individual can access the medical care that he is entitled to in the short and long term. When autism awareness and training is placed on the agenda 	Living Safer Sexual Lives, Patsie Frawlie Sex, Sexuality and Aspergers Syndrome, Wendy Lawson Aspergers in Love, Maxine Aston Aspergers in Long-Term Relationships, Ashley Stanford NAS info on autism and bereavements; https://www.autism.org.uk/about/family-life/ bereavement.aspx Experiences of life skills and having help; http://www.healthtalk.org/peoples- experiences/autism/life-autism-spectrum/ autism-life-skills NAS info on growing older; https://www. autism.org.uk/about/adult-life/ageing.aspx
		a team can respond quickly and effectively in a crisis.	
Jim - Criminal Justice: Risk of vulnerability and drug abuse	Jim is in his early 20's, he has made friends with a group that has resulted in him leaving his family home getting into trouble with the police. He has spent time in prison on remand. The police and other people are concerned about his vulnerability to reoffend.	 There is no clear evidence that autism increases the risk of criminality or victimisation. However Autistic people may not fully recognise the consequences or impact of their actions or the actions of others. 	NAS info for workers in the criminal justice system; https://www.autism.org.uk/ professionals/others/criminal-justice.aspx Autism and CJS network; https://www.autism. org.uk/professionals/others/criminal-justice/ signup.aspx

		 Non diagnosed Autistic people can be a puzzle to the criminal justice system as they known there is a risk of vulnerability or exploitation but with no 'diagnosis' they cannot offer the same mitigating circumstances. Many public agencies and professionals (health, police, courts, legal professionals, probation, third sector organisations) can plaa role in recognising the possibility of autism and triggering an appropriate assessment. This could result in improved outcomes, including appropriate sentencing, such as the provision of community order and a request for an assessment. 	NAS info for prison officers; https://network. autism.org.uk/knowledge/policy-guidance/ autism-basic-guide-prison-officers Resources: PACE Act updated 2018 See National Appropriate Adult PACE update July 2018 Care not Custody 2018: The Care not Custody Coalition www.gov.uk Care Act Fact Sheets
Julia - Making Reasonable Adjustments: Mental Health and Autism	Julia is 27 and was diagnosed with Autism at 12 years. During a significant deterioration in her mental health Julia presented herself at A&E late at night.	 People with autism use mainstream services such as mental health. It is important that mental health staff understand autism and how to support the individual's needs. Enables staff to deliver personalise care, using reasonable adjustments in order to minimise anxiety and reduce sensory overload. 	The Green Light Toolkit (NDTI 2017) ensures mental health services meet the needs of people with a learning disability or autism. Further information about reasonable adjustments that can be made to support people can be found here: https://www.ndti.org.uk/resources/ publications/green-light-toolkit https://www.ndti.org.uk/uploads/files/NHS_ Confederation_report_Submitted_version. pdf www.mind.org Supporting people living with autism spectrum disorder and mental health problems: A guide for practitioners and providers October 2015

Laura - Avoiding an admission, using PBS	Laura is 18 years old. She is 'borderline diabetic', has autism and a severe learning disability. She lives in a specialist residential home but they are struggling to meet her needs.	 Families are experts in a person's life and key partners in making good decisions on behalf of people. Positive regard and relationships between those providing and receiving care are essential. Sharing a home won't work well for some people. 	<pre>www.scie.org.uk NHSE Information on Care and Education Treatment Reviews (CETRs) https://www.england.nhs.uk/learning- disabilities/care/ctr/care-education-and- treatment-reviews/ Positive Behavioural Support Academy; http:// pbsacademy.org.uk/ NAS info on pica; https://www.autism.org.uk/ about/behaviour/challenging- behaviour/pica.aspx Experiences of autistic people's siblings; http:// www.healthtalk.org/peoples-experiences/ autism/having-sibling-autism-spectrum/ topics For a range of information on autism including gender and joint working https://www.scie.org.uk/autism/references</pre>
Michael - Living 'independently'.	Michael is 36 and received a diagnosis of autism in his late teens whilst at university. He has a full-time job working for the health service and purchased his own home about five years ago. He appears to be living independently but it is a struggle.	 Autistic people can struggle to see the links particularly in different spheres of living (e.g., home and work). Autistic people often struggle to see cause and effect between different spheres of living (e.g., home and work). 	NAS info on social care assessments for people with autism; https://www.autism.org. uk/get-involved/media-centre/position- statements/adult-services-england2.aspx Experiences of life skills and having help; http://www.healthtalk.org/peoples- experiences/autism/life-autism-spectrum/ autism-life-skills

Michael - Living 'independently'.	Michael is 36 and received a diagnosis of autism in his late teens whilst at university. He has a full-time job working for the health service and purchased his own home about five years ago. He appears to be living independently but it is a struggle.	 It may require sympathetic others (in this case Michael's line manager) to understand the root causes of concerning behaviour. A person with autism may have adequate if not excessive abilities in some areas of functioning yet find other apparently simple and straightforward skills deeply challenging. Don't make assumptions and be mindful of mis -interpretation of behaviour being laziness or, worse, deliberate failings or misdeeds. Low level support, if targeted effectively, can bring major beneficial outcomes to some individuals on the autism spectrum. 	NAS info on managing money (and link to online course for autistic people on this topic); https://www.autism.org.uk/about/adult-life/ managing-money.aspx
Paul - Staying independent and at home	Paul is 55 years old, he was suspected of having autism but does not have a diagnosis that he is aware of. He and his mum have cared for each other but now his mum is nearing the end of her life. Paul wants to stay in his family home.	 The importance of working together with other agencies. The importance of working with the person, being clear of their strengths and challenges. Providing time initially to develop an understand the situation for the person. Using clear communication. Not making assumptions. Providing the right targeted support to help with the current need /issue. Taking one step at a time. 	National Police Autism Association; http://www.npaa.org.uk/?doing_wp_cron=15 40814056.4714119434356689453125 http://www.healthtalk.org/peoples- experiences/autism/life-autism-spectrum/ feelings-about-being-diagnosed-autism NAS info on autism and bereavements; https://www.autism.org.uk/about/family-life/ bereavement.aspx NAS info on managing money (and link to online course for autistic people on this topic); https://www.autism.org.uk/about/adult-life/ managing-money.aspx

			Age Uk bereavement advice: https://www. ageuk.org.uk/information-advice/health- wellbeing/relationships-family/end-of-life- issues/talking-death-dying/ Understanding Death and Illness and What They Teach About Life: An Interactive Guide for Individuals with Autism or Asperger's and Their Loved Ones, Catherine Faherty YouTube/Sky News - A Good Death: The inside story of a hospice; https://www.youtube.com/ watch?v=nyPZEtCa88k
Ramesh - Supporting children at school during breaks and eating, working in partnership with families	Ramesh is seven. He's having trouble at school, particularly at lunchtime. This is resulting in him absconding. His parents aren't confident in the support he gets.	 Individuals with ASD and their parents and carers need to be given time and space to express anger and fear in a non-judgmental environment. Giving both the child and parents/ carers time space to express their feelings promotes a positive atmosphere of cooperation, no blame and non-judgement. Communicating feelings without speaking can be facilitated using simple methods bespoke for that individual. Promoting self-awareness in individuals with ASD enables them to become more independent. Problem solving as a team is often more successful and promotes communication and trust. 	NAS info about autistic children and food; https://www.autism.org.uk/about/health/ eating.aspx Information about autism for teachers; https:// www.autism.org.uk/professionals/teachers. aspx Information about autism and education for families; https://www.autism.org.uk/about/in- education.aspx Autistic people's experience of school; http:// www.healthtalk.org/peoples-experiences/ autism/life-autism-spectrum/autism-going- school Presentations from Autism in Black, Asian and Minority Ethnic (BAME) Community Symposium 2018; https://www.autismvoice.org.uk/ autism-in-black-asian-and-minority-ethnic- bame-community-symposium-2018/

Robert - Transition from school and taking exams. Preparing for adult life	Robert is 16 and has a diagnosis of autism. He has until recently managed school well with minimal support interventions for his autism in the school environment. He is clear about his priorities and what he wants to do, and recently earned mock-GCSE grades. He has recently found things to be challenging and has outbursts at school and fights with some other students. He refuses to engage in any conversation with the school support and the situation is impacting on his relationship with his parents.	 Don't make assumptions, look at behavior as an expression of emotions. We might not readily understand the behavior but should respect the emotions being communicated. Given time, space and a trusted member of staff enables individuals to express and communicate fears and anxieties. Anger is closely associated with fear and anxiety. Self-awareness of this promotes resilience and a self-care. Robert and his parents were involved in a team approach and the subsequent problem solving. This enabled effective and powerful participation validating their challenges and promoting constructive problem solving at school and at home. 	Transition to adulthood for young people IRISS Discussion Paper with autistic spectrum disorder (ASD) https://www.iriss.org.uk/sites/ default/files/iriss-insight-5.pdf Care Act Fact Sheets https://www.gov.uk/ government/publications/care-act-2014-part- 1-factsheets/care-act-factsheets#factsheet- 11-transition-for-children-to-adult-care-and- support National Autistic Society: Transitioning into adulthood https://www.autism.org.uk/about/ strategy/2010-strategy/transition.aspx Council for Disabled Children Transition Information page https:// councilfordisabledchildren.org.uk/ transition-information-network/information- and-support/transition-guides
Sarah - Health and wellbeing and the workplace	Sarah is 24 and has recently graduated and started work at the local council. She has recently been diagnosed as having 'Asperger Syndrome' She has disclosed this to the human resources department but did not want to inform her line manager. Sarah presents to her GP with range of health problems. She is doubting her ability to do her job and her confidence is low so she's using alcohol to try and cope.	 Times of transition can be challenging for individuals with Autism. This leads to anxiety/stress/ depression and physical symptoms. Being autism aware enables a professional to "un-pick" the situation and find out what may be contributing to the symptoms. Time out from school or work allows a person time and space to engage positively and effectively with professionals. 	NAS info for autistic people about employment – finding it and keeping it!; https://www.autism.org.uk/about/adult-life/ work.aspx NAS Information about autism for employers; https://www.autism.org.uk/professionals/ employers.aspx Reference NAS: https://www.autism.org.uk/ about/diagnosis/criteria-changes.aspx

		 Sensory issues can have a profound impact on individuals with ASD causing overload, stress and anxiety and interrupt normal coping strategies they may have. A team approach allows an individual to be able to access the work environment with a few simple reasonable adjustments and some flexibility, enabling them to perform the job to the best of their abilities. Increasing self-awareness in a person with Autism promotes self-care, independence and resilience. 	The change in autism diagnostic criteria is recognised with the removal of Asperger syndrome in DSM – 5 (American Diagnostic and Statistical Manual) and ICD – 11 (Diagnostic Manual used in the UK) Future diagnosis of 'autism spectrum disorder' (ASD) will become the most commonly given diagnosis. People's existing diagnosis will not change and individuals will choose how they refer to their autism. Therefore, Sarah won't lose her Asperger Syndrome diagnosis and she may choose to say she has Asperger's or Autism.
Victoria - Getting a diagnosis	Victoria is a secondary school IT teacher in her late twenties, has been unemployed for over a year. Following difficulties in adapting to changes in her working situation she is prompted to seek an assessment for autism.	 Obtaining a diagnosis in adulthood begins with the person deciding whether it is relevant to their difficulties and needs. People need to be able to understand where to go know what to expect when in accessing a diagnosis including how long it will take. Different agencies should be able to advise on this including occupational health and a local Job Centre officer. Following a diagnosis autistic people should be able to access a range of sources of support and expect reasonable adjustments in work and many public settings. 	Experiences of getting a diagnosis; http://www. healthtalk.org/peoples-experiences/autism/ life-autism-spectrum/trying-get-autism- diagnosis NAS info for autistic people about employment – finding it and keeping it!; https://www. autism.org.uk/about/adult-life/work.aspx

Zoe - Supporting positive education experiences	Zoe is 6 year old and may have autism; she's midway through assessment at her local Child and Adult Mental Health Services. Zoe was unable to attend nursery school due to tantrums and anxiety driven meltdowns. She is now at school but despite her 1:1 LSA (learning support assistant) support she finds it difficult crying and screams a lot.	 Transition times, unsupervised times and noisy overwhelming environments can lead to overstimulation, stress, tantrums and then shut down in a child with ASD. Giving both the child and parents/ carers time space to express their feelings promotes a positive atmosphere of cooperation, no blame and non-judgement. Including parents and carers in the team empowers them and allows them to work constructively and closely with the school towards solutions for school and the home. Working together promotes consistency and routine/structure. Parents/carers often have solutions used at home that can be transferred into the school environment. Reasonable adjustments and flexibility allow a child to access school and the school curriculum in a meaningful way to the best of her abilities. 	Information about autism for teachers; https://www.autism.org.uk/professionals/ teachers.aspx Information about autism and education for families; https://www.autism.org.uk/about/in- education.aspx Autistic people's experience of school; http:// www.healthtalk.org/peoples-experiences/ autism/life-autism-spectrum/autism-going- school
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