Patients with Additional Needs

Moving on from Children's Services to Adult Services at Dorset County Hospital

Resource pack for family carers of young people with a learning disability or autism

This pack will cover the following information for family carers:

- Learning Disability or Learning Difficulty (p2)
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- Making Decisions about Health Care and Treatment (p4)
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Additional information and leaflets are available below:

- Transitioning to Adult Services (easy read)
- Mental Capacity Act 2005 (easy reading guide)
- Mental Capacity Act Resource Pack
- Guidance notes to help you complete This is me: My Care Passport
- SBAR - Communicating the signs that a person you care for is unwell (advice for carers)

Information for Family Carers

Many children with learning disabilities and or autism will see a paediatrician if they have to attend hospital for treatment. They may also see professionals from the community child health service. In most areas of the UK, the expectation is that between the ages of 16 to 18 a young person with learning disabilities or autism will transfer to adult health specialists or be seen in an adult clinic. This means that it will depend upon the young person's health needs as to where they are seen or which ward they are admitted.

Learning Disability or Learning Difficulty?

A **learning disability** is the same as intellectual disability. It is described by the Department of Health as:

"A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; A reduced ability to cope independently (impaired social functioning); which stared before adulthood, with a lasting effect on development."

A **learning difficulty** is described by The Foundation for People with Learning Disabilities as:

"Having specific problems processing certain forms of information. Unlike a learning disability, a learning difficulty does not affect general intelligence (IQ)."

Some examples of specific learning difficulties include:

- Dyspraxia
- Dyslexia
- Attention Deficit Hyperactivity Disorder (ADHD)

Autism

Autism is a lifelong developmental disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them. It is a spectrum condition which means it affects people differently. Some people are relatively independent others may also have accompanying learning disability.

Asperger's is a form of autism – a hidden disability where you can't tell if someone has it from an outward appearance. People with Asperger's Syndrome are often above average intelligence, they have fewer problems with speech but still difficulty in understanding or processing language.

All people with autism share three main areas of difficulty:

- Difficulty with social communication – both verbal and non-verbal communication
- Difficulty with social interaction – recognising or understanding other people's emotions or feelings or expressing their own
- Difficulty with social imagination – allowing you to predict or understand other people's behaviour

Mainstream Health Services

Primary Care is care that everyone accesses to maintain their health: GP services, dental services, opticians, pharmacies, minor injuries units and the hospital Emergency Department or ‘A&E’ which is for emergencies only.

Secondary or Acute Care is specialised services that can guide GP care and treatment in complex cases. When people need some tests or investigations they may have to attend hospital. When people need some treatments or operations they may need to be admitted to hospital as an inpatient. Some treatment can be provided at hospital but as a day patient so you don’t stay overnight.

Some examples of secondary or acute care include:

- Orthopaedics - complex problems relating to bones and joints
- Gastroenterology – complex problems relating to the gut, stomach, intestines
- Neurology – complex problems relating to the nervous system such as epilepsy
- Endocrinology - complex problems relating to glands and hormones, such as diabetes
- Psychiatry – complex mental illnesses
- Cardiology – complex problems relating to the heart and blood circulation

There are many other secondary care specialists; these are just a few examples.

In adulthood, if someone develops a new health problem it is likely that their GP will be able to diagnose and manage that condition. If it is very complex, the GP may refer to a secondary care service for extra investigations or advice. They would refer to the most appropriate secondary care service.

What does ‘mainstream’ or ‘mainstreaming’ mean when talking about care for people with a learning disability?

These words are used when talking about the care of people with learning disabilities. They mean that people with learning disabilities should be able to access the same specialists that people without a learning disability do.

For example, if people usually see a neurologist for diagnosis and to make a treatment plan for their epilepsy, someone with learning disabilities should also have the same access to those mainstream services.

Or, if people with a complex heart condition usually see a cardiologist for diagnosis and to make a treatment plan, someone with learning disabilities should also have the same access to those mainstream services.

Or if there is a health screening programme like mammograms for older ladies, people with learning disabilities should be included in these too. It also means that usually, once a plan is in place, people with a learning disability will be discharged back to their GP, just as someone without a learning disability would be. There are very few conditions where someone with or without a learning disability would be permanently under a specialist team.

Specialist Health Services

Mainstreaming happens in mental health services too. This means if you have a complex mental health problem and mild learning disability, adults may be referred to a Community Mental Health Team (CMHT).

Other people with learning disabilities and mental illness may be referred to the psychiatrist working within the Community Learning Disability Team – a Learning Disability Psychiatrist. They are needed because for some people, mainstreaming in psychiatry may not be appropriate. In psychiatry, a diagnosis and care plan is usually made by listening to people's descriptions of their thoughts, feelings and behaviour.

If someone doesn't use words to communicate, or the way they express themselves is very different to most people, mainstream psychiatry services may struggle to help them. A learning disability psychiatrist is more familiar with how mental health problems may be expressed by people with learning disabilities, so more likely to be able to recognise and help when a mental health problem is the cause of a change in someone.

It is important to remember that a Learning Disability Psychiatrist is a specialist in mental health. They are not a Learning Disability Paediatrician for adults. So usually, only those people with a learning disability and complex mental health problem would be seen by a Learning Disability Psychiatrist.

Community Learning Disability Teams (CLDTs)

CLDTs are made up of Social care staff (Dorset Council) and health care staff (NHS) who specialise in learning disability. Teams are generally made up of social workers or review workers, nurses, occupational therapists, a physiotherapist, a psychologist, a learning disability psychiatrist, speech and language therapists and different team assistants.

There is more information about them on the Dorset HealthCare website or the Learning Disabilities Dorset website.

Referrals are usually made via the Dorset Council Adult Access Team.
01305 221016
adultaccess@dorsetcouncil.gov.uk

Making Decisions about Health Care and Treatment

Consent to Care and Treatment

Between the ages of **0–16 years** those with parental responsibility, can make decisions on behalf of their child.

Between ages **16-18** the Family Law Reform Act (1969) enables a child of 16 to consent to surgical, medical and dental treatment (if they have capacity). If a young person has capacity to agree to treatment, their decision to consent must be respected. Difficult cases can arise if a young person has legal and mental capacity and refuses consent - especially if a person with parental responsibility wishes to give consent on the young person's behalf. The Family Division of the High Court can hear cases where there is disagreement.

The Mental Capacity Act (2005) applies from the age of 16. This means that if a young person lacks capacity for a specific healthcare decision, the healthcare staff providing treatment can carry out the treatment with protection from liability whether or not the person with parental responsibility consents. The Mental Capacity Act, Code of Practice acknowledges there is an overlap between the Children Act (1989) and the Mental Capacity Act for 16-17 year olds who lack capacity to make a particular decision. Where a 16 or 17 year old has been deemed to lack capacity to make a certain decision, either the MCA of the Children Act may apply, depending on the particular circumstances.

When using the Mental Capacity Act, healthcare staff must follow the Act's principles and make sure that the actions they carry out are in the young person's best interests.

Click here for a really helpful film outlining the Mental Capacity Act for parents and carers.

Mencap have produced an MCA Resource Pack.

The pack outlines the two stage test of capacity as well as what is meant by 'best interests'. It explains who can make decisions when your relative can't. This includes detail on how you can apply to be a 'Court Appointed Deputy'.

You can apply to become someone's deputy if they 'lack mental capacity'. As a deputy, you will be authorised by the Court of Protection to make decisions on their behalf. There are two types of deputy:

- Property and financial affairs deputy. You will do things like pay the person's bills or organise their pension
- Personal welfare deputy. You will make decisions about medical treatment and how someone is looked after

For more information please visit https://www.gov.uk/become-deputy

Reasonable Adjustments

There are some key ways in which hospital staff can support young people and adults with a learning disability or autism.

Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to the way staff communicate and provide support to individuals to ensure that services work equally well for people with learning disabilities or autism.

Some examples include:

- **Flagging** - this means that an 'alert' can be added to the young person's record to say they have a learning disability or autism. This highlights to staff that they need to make reasonable adjustments. If you would like a flag adding, please let staff know.

- **This Is Me: My Care Passport** - is about the person at the time the document is completed and will need to be updated as necessary. This form can be completed by the person with learning disabilities, autism or their carer with help from the person where possible. This will enhance the care and support given while the person is in an unfamiliar environment. A copy can be sent to the department ahead of any appointment. A copy can also be held in the Emergency Department.

- **Time/appointments** - longer appointments are an important adjustment to help ensure that people have time to communicate, understand information and have the support they need to make decisions. Some people may benefit from familiarisation visits prior to planned investigations or procedures to help reduce anxiety. If there is a 'best time' for an appointment, then please contact the department to discuss.

- **Communication Aids** - include information on communication within the 'This Is Me: My Care Passport' document. The Hospital Communication Book is in all ward areas along with some laminated widget aids. Please ask staff if these would help. Staff also have access to pain assessment tools.

- **Summary Care plan for emergency care and treatment** - if a young person has complex health needs and their care is overseen by lots of health professionals (sometimes in different hospitals across the country) it may be appropriate for them to have one of these. This can help keep track of who is involved in the young person's care and areas of key responsibility. A copy can be held in the Emergency Department and in the young person's notes.
- **Easy Read information** - the Trust has some easy read information as well as some photo stories which may help explain what is happening. Please ask a member of staff if this is something that would help.

Useful Links
Dorset County Hospital, Patients with Additional Needs

Dorset Council Mental Capacity Act Team
Email: mcateam@dorsetcouncil.gov.uk

Dorset Healthcare NHS Foundation Trust, Specialist Learning Disability Services

Office of the Public Guardian

Mencap

National Autistic Society

Public Health England, spotting signs of deterioration

For further advice and information or if you would like this information in another format please contact:

Patient Experience Team
Dorset County Hospital NHS Foundation Trust
Williams Avenue
Dorchester
Dorset
DT1 2JY

Email: pals@dchft.nhs.uk
Tel: 0800 7838058

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If you have feedback regarding the accuracy of the information contained in this leaflet, or if you would like a list of references used to develop this leaflet, please email pals@dchft.nhs.uk

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