





### Transition of Each and Every Need (TEEN) matters

Dr Karen Horridge, Clinical lead, Paediatric Disability, South Tyneside and Sunderland NHS Foundation Trust

In collaboration with:

Maureen Morris, Sunderland Parent Carer Forum

Hayley Cook, Specialist Nurse, Learning Disabilities Transition team, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Lyndsay Stephenson, Specialist Nurse, Learning Disabilities, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Dr Duncan Mitchell, Consultant in Neurorehabilitation, South Tyneside and Sunderland NHS Foundation Trust Dr Lisa Baker, Consultant in Palliative Medicine, St Benedict's Hospice, Sunderland, South Tyneside and Sunderland NHS Foundation Trust

Dr Ellie Bond, Associate Specialist in Palliative Medicine, St Benedict's Hospice, Sunderland, South Tyneside and Sunderland NHS Foundation Trust, Associate Specialist CHiPs team (Children's Holistic Integrated Palliative service) across Northern region

Dr Sara Carr, Consultant Clinical Psychologist, Learning Disabilities team, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Julie Bennett, special school nurse, Portland Academy, Sunderland, South Tyneside and Sunderland NHS Foundation Trust

Joanna Clark, project manager, Divisional manager, community services, South Tyneside and Sunderland NHS Foundation Trust

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"As parents of young people with any additional needs it is so important to have the conversation about what happens when my child moves from children's to adult services. This project gives parents one less thing to worry about and gives the child their voice into adulthood". Parent carer

Sunderland Parent Carer Forum were fully involved in the important project. The report has been reviewed and agreed by the Forum Steering Group.

### Recommendations

- 1. Identify a **learning disability champion** in all paediatric teams, to lead on the early identification, documentation and flagging of children and young people with learning disabilities. Consider using the learning disability screening tool within the multimedia resources for families available <u>here.</u>
  - Outcomes
    - Named **paediatric learning disability champion** in place.
    - Number of families notified about identification of learning disability in their child or young person.
- 2. **Proactively notify general practice teams about children and young people identified with learning disabilities**, so that they can include them in their learning disability registers, offer reasonable adjustments when healthcare is needed and annual learning disability health checks from 14 years onwards, also annual influenza immunisations.
  - Outcomes
    - Number of children and young people with learning disabilities notified to GP teams.
    - Number of young people aged 14-25 years completing annual GP learning disability health checks.
    - Number of children and young people receiving annual influenza immunisations.
- 3. Lead paediatrician to consider, for all young people approaching 14 years of age, **which care pathway is most appropriate to their needs** on transition to adulthood and adult services and communicate this with the young person, family and wider team who need to know. Consider using the <u>Needs4Pathways</u> tool to calculate and analyse needs to inform choice of care pathway.
  - Outcome
    - Documented transition plan, shared with family, GP and team who need to know.
- 4. Lead paediatrician to identify a **lead clinician in the adult medical team**, to lead on receiving disabled young people who require ongoing secondary healthcare and establish joint transition clinics to ensure robust hand over of secondary healthcare.
  - Outcome
    - Named medical lead in place in adult service to receive disabled young people who require ongoing secondary healthcare.
    - Clear care pathway in place for transition of disabled young people identified to need ongoing secondary healthcare.
- 5. Establish a **transition pathway with the adult medical lead**, including joint clinics to hand on the baton for leadership of secondary medical healthcare and input from the **learning disability nursing team** as needed.
  - Outcomes
    - Number of young people seen in joint transition clinics.
    - Number of young people graduating to adult secondary healthcare clinics.
    - Number of young people receiving input from the learning disability nursing team.
    - Documentation of collated, detailed needs of young people on this pathway, to inform future service planning and design to achieve the best outcomes.

- 6. Lead paediatrician to establish links with the **adult palliative care team**, including setting up a care pathway for safe transition of the most medically frail young people with the most complex needs, assessed:
  - To be at risk of early death
  - As having 11+ health conditions + family reported needs + technology dependencies +/need for round the clock care using the <u>Disability Complexity Scale</u>, supported as need be using the <u>Needs4Pathways</u> tool.
    - Outcomes
      - Named lead in place in the adult palliative care team for transition of the most medically frail young people.
      - Clear care pathway in place for transition of disabled young people identified to benefit from input from the adult palliative care team.
- 7. Establish a multidisciplinary, interagency transition pathway for the most medically frail young people, to involve input from the:
  - Young person and their family.
  - GP and primary healthcare team.
  - Learning disability nursing team where appropriate.
  - Adult secondary healthcare medical lead and
  - Adult palliative care team.

Transition on this pathway is more likely to be a process over months, or even a year or more, to ensure build-up of confidence in and relationships with the new teams in adult services and robust handing on of the baton for care for each and every need.

- Outcomes
  - Number of young people receiving care on this care pathway.
  - Documentation of collated, detailed needs of young people on this pathway, to inform future service planning and design to achieve the best outcomes.
- 8. Identify a **paediatric data champion** in all paediatric teams, to lead on data capture at the point of care to make visible all of the multifaceted needs of children and young people, including those aged 14 years+ approaching transition to adulthood and adult services. This would allow real data to inform service commissioning and design. **Reflect on data captured at the point of care** to inform the commissioning and design of transition care pathways.
  - Outcomes
    - Named **paediatric data champion** in place in all paediatric teams.
    - Paediatric teams able to evidence analyses of and reflection on local data captured at point of clinical care and use of real data, in discussions with commissioners, managers, children, young people, parent carers and other stakeholders, to inform service commissioning and design to achieve the best outcomes across the lifespan.
- 9. Support of all staff involved in the care of young people and their families to be able to have appropriate level communication skills to respond to difficult and sensitive conversations in real-time. This should include school and nursing staff. Offer staff training to enhance and develop communication skills to hold these conversations.
  - Outcomes
    - Number of staff attending training sessions
    - Evaluation of training sessions

**Transition** is defined in the <u>National Institute of Health and Care Excellence (NICE) guideline</u> <u>43</u> as the process of moving from children's to adult's services.

If health needs are to be adequately met for adults, they must first be accurately identified and documented for children and young people, with clear arrangements as to how each and every need is to continue to be addressed and who is responsible for taking the lead for clinical care. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) 2018 report, Each and Every Need reported on an in-depth review of the healthcare of children and young people with neurodisabling conditions. Recommendation 16 of the report states:

"Patients with a neurodisabling condition who need ongoing medical and therapeutic input should always have a named lead clinician to co-ordinate care across healthcare services and all age groups. Any change in lead clinician should include planning and a thorough handover".

Paediatricians have responsibilities not only to the children and young people who are referred to their clinics, but to all children and young people in the populations they serve, to ensure the best and most equal outcome opportunities for everyone. The first two principal recommendations of the NCEPOD <u>Each and Every Need</u> report call for improvement in clinical coding and quality of routine data about the needs of disabled children and young people.

Care pathways for children and young people in Sunderland are underpinned by a wellestablished tradition of <u>data capture at the point of care</u>, so that the needs of all children and young people can be made visible and equity of outcomes evidenced. These population data gathered in clinics are augmented by additional data gleaned from the paediatric review of all Education, Health and Care plans, to identify, document and flag the medical records of every child and young person with a learning disability and/or autism.

### Recommendation 19 of NCEPOD's Each and Every Need report states:

"All medically frail patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians, must be offered the opportunity to discuss with their lead clinician, their care wishes in the event of serious illness or sudden collapse. This should be recorded in their patient-held Emergency Health Care Plan. This may include discussing Do Not Attempt Cardio Pulmonary Resuscitation decisions and palliative care plans, which should be validated at each point of care according to the existing legal requirements and professional guidance. This is particularly important to have in place at handover during transition to adult services." The paediatric disability medical and community children's nursing teams in Sunderland provide palliative care for children and young people as needed, as an integral part of holistic care. Proactive identification of children and young people at risk of early death, including early sudden death is embedded, with proactive advance care planning. Advance care planning with and for young adults aged 18 years and over is underpinned by the Advance Care Planning framework agreed across the Northern region. Free e-learning on Advance Care Planning can be found here. A blog about ethical considerations and decision-making about the resuscitation of very sick children can be found here. Examples of the sensitive discussions that underpin advance care planning for children and young people can be found here.

Recommendation 20 of NCEPOD's <u>Each and Every Need</u> report concerns planning for transition from children's to adult services:

"To facilitate transition to adult services there must be a clear, documented plan developed between the young person with complex needs and their multidisciplinary team. NCEPOD supports the <u>National Institute of Health and Care Excellence (NICE) guideline 43</u> that transition planning should have begun by the age of 14".

Recommendation 9 of NCEPOD's <u>Each and Every Need</u> report confirms our responsibility as clinicians to identify and document learning disability in medical records:

"As for all patients, those with a neurodisabling condition who also have a learning disability should have this clearly documented in their clinical records by all healthcare providers (e.g. in primary and/or specialist healthcare)".

In Sunderland, three steps of transition care pathways have been developed over a number of years, tailored to the complexity of needs of the young people.

- All young people with a learning disability access step one.
- Young people identified to need ongoing secondary healthcare as adults also access step two.
- Young people with the most complex needs who are most medically frail also access step three.

The three steps are described in more detail below, also in the presentation accessible <u>here</u>. Anonymised data about the multifaceted needs of children and young people who have followed, or are projected to follow in future, the various pathways are presented in the appendices. Such data can inform care pathway commissioning and design to continue to meet the needs of young people as they approach transition to adulthood and adult services. These data are shared in the spirit of transparency, to give others an idea of the range of needs of young people as they approach transition to adulthood and adult services.

### Step One:

### Identification of learning disability

The goal of step one is to identify every child and young person with a learning disability, so that they can access the right services as children, young people and on into adulthood.

Identification of learning disability in childhood matters, because women and men with learning disabilities are known to die 29 and 23 years sooner respectively than those without learning disabilities, as evidenced in the <u>Confidential Inquiry into Premature Deaths of People with</u> <u>Learning Disabilities</u>. Learning disability is synonymous with <u>Disorders of Intellectual</u> <u>Development</u> as defined in ICD-11.

The challenge for practitioners working with children and young people is that different agencies use different language when it comes to describing learning abilities. Education practitioners use the term 'learning difficulty', whilst health and social care practitioners use 'learning disability'. Learning difficulty as used by education practitioners is a broad umbrella term that includes children and young people with learning disabilities, but also includes children and young people with more specific learning needs, that health practitioners would describe as <u>Developmental Learning Disorders</u> as defined in ICD-11.

This matters, because when a young person becomes a young adult, access to services is determined by the identified needs of the young person. A young adult with an identified learning disability in England will be able to access an <u>annual learning disability health check</u> with their GP team from the age of 14 years, as well as their annual influenza immunisation. They may also be eligible for support from <u>social care</u>. If the learning needs of the young person are described as learning difficulties rather than learning disabilities, these avenues of support will not be open to them. When a learning disability is identified, the paediatrician should <u>notify</u> the general practitioner, so that their name can be added to the practice learning disability register to act as a prompt for reasonable adjustments if healthcare is needed, as well as ensuring the annual health checks and influenza immunisations are offered.

To read more about why identification of learning disabilities matters, read the editorial in <u>Developmental Medicine and Child Neurology</u> and/or watch the <u>video podcast</u>.

Paediatricians, multidisciplinary and interagency teams have responsibilities in each local area to identify every child and young person's needs, including their learning needs.

Here is a presentation on <u>Variation in child development: A structured approach to assessment</u>, investigation and identification of learning disability.

The <u>traffic light tool</u> captures the views of the child, young person, family and carers about their needs and priorities to inform paediatric consultations. The completed tool can act as a catalyst for discussions with the paediatrician as well as forming the basis for <u>data capture by the</u> <u>clinician at the point of care</u>.

There is a way to go yet, before all children with learning disabilities are correctly identified during childhood. Paediatricians need to be imaginative in how they reach as many as possible.

One way to achieve wider reach is for the Designated Medical Officer for children with Special Educational Needs and Disabilities (SEND) to look for evidence of learning disabilities when reviewing the Education, Health and Care plans of children and young people in their local area.

Not all areas have a Designated Medical Officer for children with SEND. Teams may then want to think about identifying a **learning disability champion**, to take on the responsibility of ensuring the most comprehensive possible identification of children and young people with learning disabilities.

Not all practitioners have easy access to formal psychological assessments to inform decisionmaking about whether a learning disability is present or not.

A validated screening tool for learning disability is freely available as part of the Learning Disability Matters for Families suite of multimedia resources. The screening tool is just that. It is not a diagnostic tool, but the report generated can be used in advocacy to inform the need for further assessments with the education team. These resources, co-produced with learning disabled people, their families and other experts, were designed to inform and support families when a child or young person has, or may have, a learning disability. Our local practice is to send links to these resources for all families when a child or young person is identified to have a learning disability.

Within the Learning Disability Matters for Families resources is information about GP learning disability registers and GP learning disability annual health checks. This information includes a video of a GP explaining why annual health checks are so important for everyone with a learning disability.

### **Measurable outcomes**

A local area should be able to count how many children and young people have been identified to have a learning disability.

In Sunderland, from January 2015 to March 2020, 1034 children and young people with learning disabilities were identified. Their families were informed and sent the supporting resources as above. Their general practice teams were notified, with a request to include their names on GP learning disability registers, to prompt reasonable adjustments and access to annual learning disability health checks from 14 years as well as annual influenza immunisations.

The number of GP learning disability health checks and influenza immunisations taken up.

### Step two

# Young people whose health needs require ongoing secondary healthcare at the point of transition

Whilst the first point of contact with health services is primary care, some young people have more complex health needs that require ongoing input from secondary healthcare providers. It is the responsibility of the paediatrician to identify the group of young people who will benefit from ongoing secondary healthcare and also to identify who will take on the baton for leading secondary healthcare in adult services. This will vary depending on the specific needs of the young person.

Identification of a lead clinician for adult secondary healthcare is important, so that:

- All of each young person's needs continue to be met, with the best outcome opportunities.
- Families continue to be robustly supported and don't experience 'falling off a cliff' of services.
- General practitioners and primary care teams are appropriately supported with more complex aspects of healthcare.

In Sunderland, there has been a long tradition of handing on the lead for secondary healthcare to the neurorehabilitation consultant, for those young people with ongoing significant postural management needs, epilepsies and technology dependencies, where it would not be reasonable to expect the general practice team to manage everything in primary care. The handover happens in a face-to-face joint clinic, where all current needs are identified and the new lead consultant is introduced to the young person and family. All young people with a learning disability who require ongoing secondary healthcare are also offered support from the <u>learning disability transition nursing team</u>. This is to ensure that holistic needs are assessed and addressed and that transition occurs as smoothly as possible, in line with <u>National Institute for Health and Care Excellence (NICE) guideline 43</u>.

Young people with more complex epilepsies, or with epilepsies without learning disabilities, transition to the adult neurologist with epilepsy expertise for medical lead care and to the epilepsy nurse specialist in the adult service for nursing care.

Young people with neurofibromatosis type 1 (NF1) transition to the regional NF1 nurse specialist-led service, although those with more complex needs also follow the neurorehabilitation pathway, with input also from the learning disability nursing team as needed.

In areas without a neurorehabilitation service, paediatricians should identify which colleagues in secondary healthcare are appropriate to continue to lead healthcare for young people, on a case-by-case basis. This may be the neurologist, respiratory, gastroenterology or learning disability consultant, depending on the specific needs of the young person. In some areas, transition to the care of the healthcare of the elderly consultant is being piloted, as this team is experienced in managing multifaceted needs.

To assist paediatricians and other practitioners in identifying which young people may benefit from ongoing secondary healthcare, the <u>Needs4Pathways</u> tool has been developed. This tool allows the practitioner to add up and analyse all the needs of the child or young person. A spreadsheet is then generated that includes all the SNOMED-CT codes that underpin each need, to help with data capture and coding. The clinician can add this to the patient electronic record. The spreadsheet also includes **prompts for which step of the transition pathway to consider at transition to adulthood.** The Needs4Pathways tool is underpinned by the <u>Disability Complexity Scale</u>, whereby the needs of the person are added up, including health conditions, family-reported needs, technology dependencies and need (or not) for round the clock care. The user guide for Needs4Pathways can be found <u>here</u>.

### Measurable outcomes

In Sunderland each year, 15-20 young people are introduced to the neurorehabilitation consultant in joint transition clinics. Please see appendices for examples of local data collected at the point of care.

All young people with a learning disability following the neurorehabilitation and epilepsy pathways are also supported by the learning disability transition nurse specialist team.

### Step three

### Young people who may benefit from input from adult palliative care

Young people with the most complex needs are surviving longer, due to improvements in proactive clinical care and technological support. Some young people are significantly medically frail as they approach the time of transition to adulthood and may benefit from input from the adult palliative care team, in addition to steps one and two in the pathway, with ongoing appropriate secondary healthcare and input from learning disability teams.

Again, the <u>Needs4Pathways</u> tool can be used by practitioners to help to identify the group of young people who may benefit from this. More information about how this integrated palliative care pathway works in Sunderland can be found <u>here</u>.

Identification of the most medically frail group of young people is important so that:

- Relationships can be built to allow sensitive conversations with families.
- Risk of early death is identified and discussed with families, enabling their views to be taken into account in all decision-making, including about resuscitation and any specific care wishes.
- All holistic needs continue to be identified and all symptoms and wishes can be discussed openly with young people and their families, with documentation including actions to be taken, on an Emergency Health Care Plan, to achieve the best possible quality of life for the young person, however long that may be.

### Measurable outcomes

Of 6959 children and young people seen in 14113 paediatric consultations in Sunderland April 2017-March 2019 where data were documented at the point of care, 75 were identified to be at risk of early death.

This group's needs were highly complex, including 1494 health conditions, 179 family-reported needs, 73 technology dependencies and 72 required round the clock care.

Of the 75 children and young people assessed to be at risk of early death:

- Six have sadly died, all of whom had more than 11 health conditions + family-reported needs identified using the Needs4Pathways tool.
- Two who died were in the step three pathway, with shared care from the adult palliative care team and paediatric team.
- Five have transitioned on step three of the pathway, with ongoing input from the primary care team, learning disability nursing team, neurorehabilitation team and adult palliative care team.
- Five have transitioned to the neurorehabilitation team, of whom one then went on to receive input from the palliative care team and died in the hospice.
- Of the 75 children and young people:
  - One child had 1-4 health conditions + family-reported needs + one technology dependency.
  - One child had 5-10 health conditions + family-reported needs, had severe epilepsy at risk of Sudden Unexpected Death in Epilepsy (SUDEP).
  - Three children had 5-10 health conditions + family-reported needs + technology dependencies + need for round-the-clock care.
  - One child had >11 health conditions + family-reported needs and has since died.
  - 18 children and young people had >11 health conditions + family-reported needs + need for round-the-clock care, of whom none have died to date, one young person is on the step two pathway with neurorehabilitation lead and one on step three, with adult palliative care lead.
  - 50 children and young people have >11 health conditions + family-reported needs + technology dependencies + need for round the clock care. Of this group, five have died in childhood, four have transitioned to the adult neurorehabilitation-led pathway and four to the adult palliative care-led pathway.

### Data captured and coded at the point of care in Sunderland paediatric clinics

Examples of data captured and coded at the point of clinical care in Sunderland paediatric clinics are shared in the appendices below. These are shared in order to encourage others in their local services to collect and analyse such data, in order to inform appropriate care pathway choice at transition to adulthood and adult services and to ensure that each and every need of all young people are made visible at the point of transition and that clear, ongoing person-centred support plans are in place, with a clearly identified lead for ongoing healthcare.

All of the charts below are based on data captured routinely at the point of care in Sunderland paediatric clinics between April 2017 and March 2019. Families contributed to the data, by completing the traffic light tool prior to consultations.

At the time these data were captured, the paediatric service in Sunderland in north-east England served the local populations of Sunderland, Washington, the Coalfields and parts of south east County Durham including Seaham and Murton.

- ~350 000 total population.
- 70 350 infants, children and young people aged 0-19 years.
- Sunderland is one of the 20% most deprived districts in England (<u>https://fingertips.phe.org.uk/static-reports/health-profiles/2019/E08000024.html?area-name=Sunderland</u>).
- Deprivation, all-cause mortality rates, life expectancy and the proportion of children in poverty are all significantly worse than average for England.
- The local population is relatively static, with low rates of movement in or out of area and is predominantly white British (96%), with slowly increasing numbers of Black and Ethnic Minority peoples including asylum seekers.

A key to the abbreviations used in the charts is provided.

The charts in **Appendix 1** describe the numbers and needs of young people aged 17 years+ from birth years 1997-2003 who have already transitioned to adult services:

<u>Chart 1</u> shows the **numbers** of young people aged 17 years+ who have transitioned to adult services on the various care pathways, including routine GP care for those without learning disabilities.

<u>Chart 2</u> shows the **numbers** of young people aged 17 years+ who have completed transition to adult services on the various care pathways, this time excluding those without learning disabilities receiving routine GP care.

<u>Chart 3</u> shows the **complexity of needs**, using the Disability Complexity Scale, of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 4</u> shows the **medical needs** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 5</u> shows the **care needs** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 6</u> shows the **congenital and perinatal needs** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 7</u> shows the **learning abilities** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 8</u> shows the **sensory and communication needs** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 9</u> shows the **social, emotional and mental health needs** of young people aged 17 years+ who have completed transition to adult services on the various care pathways.

<u>Chart 10</u> shows the **family-reported needs** of young people aged 17 years+ from birth years 1997-2003 who have completed transition to adult services on the various care pathways.

<u>Chart 11</u> shows the **technology dependencies** of young people aged 17 years+ from birth years 1997-2003 who have completed transition to adult services on the various care pathways.

The charts in **Appendix 2** evidence the needs of the cohorts of children and young people, by birth year, who are approaching transition soon and into the future.

<u>Chart 12</u> shows the numbers of children and young people, by birth year, currently seen in paediatric clinics who have been identified to have early developmental impairment or learning disabilities.

Charts 13-15 show the numbers of children and young people, by birth year, with each level of complexity of needs, using the Disability Complexity Scale.

<u>Chart 13</u> shows the complexity of needs of children and young people by birth year with 1-4 health conditions + family-reported needs.

<u>Chart 14</u> shows the complexity of needs of children and young people by birth year with 5-10 health conditions + family-reported needs.

<u>Chart 15</u> shows the complexity of needs of children and young people by birth year with 11+ health conditions + family-reported needs.

<u>Chart 16</u> shows the complexity of needs of children and young people by birth year **with** learning disabilities.

<u>Chart 17</u> shows complexity of needs of children and young people by birth year **without** learning disabilities.

Chart 18 shows the medical needs of children and young people by birth year.

Chart 19 shows the care needs of children and young people by birth year.

<u>Chart 20</u> shows the **congenital and perinatal needs** of children and young people by birth year.

Chart 21 shows the learning abilities and needs of children and young people by birth year.

<u>Chart 22</u> shows the **sensory and communication needs** of children and young people by birth year.

<u>Chart 23</u> shows the **social, emotional and mental health needs** of children and young people by birth year.

Chart 24 shows the family-reported needs of children and young people by birth year.

<u>Chart 25</u> shows the **technology dependencies** of children and young people by birth year.

The charts in **Appendix 3** describe the specific needs of **children and young people with cerebral palsies**.

Together for Short Lives 'A Guide to Children's Palliative Care. Fourth edition 2018' describes four categories of life-limiting and life-threatening conditions for which palliative care may be helpful. The fourth category is:

"Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.

Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury".

The cerebral palsies are a diverse group of conditions with a wide range of outcomes, from typical life expectancy and quality of life through to highly complex and challenging symptoms and early death.

How can clinicians be confident that they have correctly identified the group of children and young people with cerebral palsies who may benefit from paediatric palliative care and what are the multifaceted needs of these children and young people? The cerebral palsies are the most common cause of physical disability in early childhood, affecting 2 to 3 per 1000 live births. They are a group of permanent disorders of movement and posture resulting from non-progressive disturbances in the developing brain that cause activity limitation. These motor disorders are often accompanied by further disturbances of sensation, perception, cognition, communication, and behaviour, as well as by epilepsies, and by secondary musculoskeletal problems. The cerebral palsies are clinical diagnoses with clear criteria requiring expert clinical assessment by clinicians with expertise in disability and neurology. It is important to check the evidence on which a diagnosis of cerebral palsy was made, in case there is a different diagnosis with different implications for the child or young person.

The National Institute for Health and Care Excellence (NICE) have published guideline NG62 in 2017: <u>Cerebral palsy in under 25s: assessment and management</u>. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) 2018 report, <u>Each and Every Need</u> reported on an in-depth review of the healthcare of children and young people with neurodisabling conditions using the cerebral palsies as exemplar disabling conditions. This evidenced, from scrutiny of more than 600 medical records by expert multidisciplinary teams, that despite there being well established evidence as to how to diagnose and describe the needs of children and young people with cerebral palsies, this was not embedded in clinical practice across the UK. For example, the <u>Gross Motor Function Classification System</u> (<u>GMFCS</u>), first published and validated well over 20 years ago, is still not consistently used to describe the motor function of children and young people with cerebral palsies were found in the medical records of only 28% of cases in the NCEPOD study.

To be confident that the group of children and young people with cerebral palsies who may benefit from paediatric palliative care have been correctly identified, it is important to first be confident that the diagnosis really is cerebral palsy, then to know the GMFCS level and quantify the wider, multifaceted needs of the child or young person. Once again, using the <u>Needs4Pathways</u> tool can assist clinicians in thinking about which young people with cerebral palsies may benefit from input from the adult palliative care team. These are likely to be the most medically frail young people, with >11 health conditions + family-reported needs + one or more technology dependencies + need for round the clock care + risk of death <18 years on clinical assessment.

Some young people with cerebral palsies whose motor function is at GMFCS level I, who have between one and four needs overall, may be appropriately managed in primary healthcare, with those with learning disabilities having access to annual learning disability health checks.

<u>Chart 26</u> shows the transition pathways followed by young people with cerebral palsies aged 17 years+, recognising that the same young person might be on multiple pathways.

Charts 27- show the needs of children and young people with cerebral palsies by birth years, to illustrate the needs of these young people who will need to transition to adult services soon or in the future.

<u>Chart 27</u> shows children and young people's **cerebral palsy subtypes** by birth years.

<u>Chart 28</u> shows the **GMFCS levels** of children and young people with cerebral palsies by birth years.

<u>Chart 29</u> shows **complexity of needs** of children and young people with cerebral palsies by birth years.

<u>Chart 30</u> shows the **medical needs** of children and young people with cerebral palsies by birth year.

<u>Chart 31</u> shows the **care needs** of children and young people with cerebral palsies by birth year.

<u>Chart 32</u> shows the **congenital and perinatal needs** of children and young people with cerebral palsies by birth year.

<u>Chart 33</u> shows the **learning abilities and needs** of children and young people with cerebral palsies by birth year.

<u>Chart 34</u> shows the **sensory and communication needs** of children and young people with cerebral palsies by birth year.

<u>Chart 35</u> shows the **social, emotional and mental health needs** of children and young people with cerebral palsies by birth year.

<u>Chart 36</u> shows the **family-reported needs** of children and young people with cerebral palsies by birth year.

<u>Chart 37</u> shows the **technology dependencies** of children and young people with cerebral palsies by birth year.

**Appendix 4** includes feedback from families who agreed to interviewed 2020 about their experiences of transition.

**Appendix 5** includes feedback from families and professionals about the learning disability transition team (nurses and support worker).

### Key to data charts

Years shown on Y axis are birth year cohorts of children and young people n is the total number of children/young people in each subgroup

HC FRN TD	<ul> <li>Health Conditions</li> <li>Family=reported needs</li> <li>Technology dependencies</li> </ul>
RCC	= Round the clock care
GP I D health checks	= General Practitioner Learning Disability Health Checks pathway
Neurorebab	- Neurorebabilitation care nathway
NE1	- Neurofibromatosis type 1 pathway
Adult polliotivo	- Adult palliativo caro pathway
	- For Noco Throat
	= Cal, NOSE, IIIOal = Castro accombageal reflux diagona
	= Gasilo-besophageal reliux disease
	= Epilepsy that reaches NICE clinical guideline 137 threshold for input from paediatic
	- Englancy that reaches NICE clinical syndaling 197 threshold for input from children's
	= Epilepsy that reaches NICE clinical guideline 137 threshold for input from children's
epilepsy surgical service	e Marramant dia andar
MVtDIS	= Movement disorder
ABI	= Acquired brain injury
GaitAbn	= Gait abnormality
MSKpain	= Musculoskeletal pain
EDI	= Early developmental impairment (synonymous with ICD-11 6A00.4 Disorder of
intellectual development	t, provisional)
LD	= Learning disability (synonymous with ICD-11 6A00 Disorders of Intellectual
Development)	
<28WksGest	= Born at less that 28 weeks of completed gestation
28-37WksGest	= Born between 28 and 37 weeks of completed gestation
CongenAnom	= Congenital anomaly
ChromoGen	= Chromosomal or genetic condition
NeuroMuscDis	= Neuromuscular disease
Vision Imp	= Vision impairment
Hearing Imp	= Hearing impairment
SLCN	= Speech, Language, Communication Needs
ImpSocInt	= Impaired social interaction
ASC	= Autism Spectrum Condition
SensSens	= Sensory sensitivities
Behaviour	= Behavioural challenges
EmotMoodAnx	= Emotional, Mood, Anxiety needs
PEG	= Gastrostomy tube
Jej	= Jejunostomy tube
PŃ	= Parenteral nutrition
DepCPAP	= Dependent on Continuous Positive Airways Pressure
DepTrachv	= Dependent on tracheostomy
DepVent	= Dependent on Ventilator
VP shunt	= Ventriculoperitoneal shunt
VNS	= Vagal nerve stimulator
ITB	= Intrathecal baclofen pump in situ
W-D syndrome	= Worster Drought syndrome
SpCP	= Spastic cerebral palsy, not further described
SpBilat	= Spastic bilateral cerebral palsy
SpUni	= Spastic unilateral cerebral palsy, side affected not specified
SpL	= Spastic unilateral left sided cerebral palsy
SpR	= Spastic unilateral right sided cerebral palsy
Dvskinetic	= Dvskinetic cerebral palsv
Dystonic	= Dystonia-predominant cerebral palsy
ChoreoAth	= ChoreoAthetoid cerebral palsy
Ataxic	= Ataxic cerebral palsy
GMECS	= Gross Motor Function Classification System level
Support	= Family identified need for additional support
11.5	· · · · · · · · · · · · · · · · · · ·

**Appendix 1**: Transition pathways and needs of young people aged 17 years+ who have completed transition to adulthood and adult services.



Chart 1: Transition care pathways, young people aged 17 years+.



Chart 2: Transition care pathways, young people aged 17 years+.



#### Chart 3: Complexity of needs of young people aged 17 years + by lead for care pathway.

Chart 4: Medical needs of young people aged 17 years + by transition care pathway, shown as percentage of all young people in each group.



Chart 5: Care needs of young people aged 17 years + by transition care pathway, shown as percentage of all young people in each group.



Chart 6: Congenital and perinatal needs of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



Chart 7: Learning abilities of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



Chart 8: Sensory and communication needs of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



Chart 9: Social, emotional and mental health needs of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



24

Chart 10: Family reported needs of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



Chart 11: Technology dependencies of young people aged 17 years+ by transition care pathway, shown as percentage of all young people in each group.



**Appendix 2**: What's coming next? Using data captured at the point of care to predict the future needs of young people as they approach transition to adulthood and adult services.



Chart 12: Children and young people identified with learning disabilities (LD) and early developmental impairment (EDI).



Chart 13: Complexity of needs by birth years. Children and young people with 1-4 health conditions + Family-reported needs.



Chart 14: Complexity of needs by birth years. Children and young people with 5-10 health conditions + Family-reported needs.



Chart 15: Complexity of needs by birth years. Children and young people with 11+ health conditions + Family-reported needs.



Chart 16: Complexity of needs of children and young people with learning disabilities.



#### Chart 17: Complexity of needs of children and young people without learning disabilities.



Chart 18: Medical needs of children and young people aged by birth year cohorts.

Chart 19: Care needs of children and young people aged by birth year cohorts.



Chart 20: Congenital and perinatal needs of children and young people aged by birth year cohorts.





Chart 21: Learning abilities and needs of children and young people aged by birth year cohorts.

### Chart 22: Sensory and communication needs of children and young people aged by birth year cohorts.



### Chart 23: Social, emotional and mental health needs of children and young people aged by birth year cohorts.





Chart 24: Family-reported needs of children and young people aged by birth year cohorts.



### Chart 25: Technology dependencies of children and young people aged by birth year cohorts.

**Appendix 3**: Children and young people with cerebral palsies:

Chart 26: Transition care pathways by birth year for young people aged 17 years+ with cerebral palsies. NB Young people can be on multiple pathways, adding steps as needed:



# Chart 27: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Cerebral palsy subtypes



Chart 28: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. GMFCS levels



Chart 29: What is coming next? Projecting the complexity of needs of young people with cerebral palsies at transition over the coming years.



## Chart 30: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Medical needs





Chart 31: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Care needs

# Chart 32: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Congenital and perinatal needs





# Chart 33: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Learning abilities and needs



Chart 34: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Sensory, speech, language and communication needs

# Chart 35: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Social, emotional and mental health needs





# Chart 36: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Family-reported needs



# Chart 37: What is coming next? Projecting the needs of young people with cerebral palsies at transition over the coming years. Technology dependencies

### Appendix 4: Feedback from families about their experience of the Sunderland transition pathways

Letters were sent to 36 families whose young people have transitioned to adult services, inviting them to participate in interviews. This was a difficult time, as this was at the beginning of the first national lockdown of the COVID-19 pandemic, which is likely to have impacted on families' ability and willingness to participate in interviews at this time.

Eight families (22% of those invited) were interviewed May 2020 by 4<sup>th</sup> year medical student, Elizabeth Lawson, who had undertaken prior training using <u>www.disabilitymatters.org.uk</u> e-learning resources.

Four of the young people transitioned to the pathway that included adult palliative care, although two young people died before transition completed.

Five young people transitioned to the pathway that included neurorehabilitation, with input also from neurology in two cases.

All families of the seven young people with learning disabilities were encouraged to take up GP learning disability annual health checks and were introduced to the learning disability transition nurse specialists.

### Positive feedback from families who experienced shared care between paediatrics and adult palliative care:

"Completely uncomplicated"

"Smooth"

"It all went really well"

"The fact that we didn't really notice too much of a change. It just really wasn't a big deal"

"We were not looking forward to it, but [paediatrician] helped us with the transition and eased us into it"

Appreciated flexibility, with additional paediatric appt offered when adult appt delayed.

Two families reported that nothing could have gone better for them, with regard to transition.

"Appreciated the honesty from the palliative care consultant we had. I asked if this was the end for [YP] because I wanted to prepare myself, and he said that he recognised my honesty and just gave me the answer"

### Positive feedback from families who experienced joint paediatric-neurorehabilitation transition clinics:

Families appreciated overlap of healthcare providers during the transition period and being introduced face-to-face to the new lead for secondary healthcare in the annual paediatric and neurorehabilitation clinic – four families specifically commented on this.

"That felt like more of a multi-agency thing, people coming together from different areas".

One family appreciated the traffic light tool and would like it used in adult clinics:

https://hubble-live-assets.s3.amazonaws.com/bacd/redactor2\_assets/files/94/HFWSummary.pdf

"We found this really helpful, to remind us to raise issues. We think that it would be good for other doctors to use this in other clinics. As it acts as a memory jog to raise things in clinic, when there is so much to think of, it is really helpful to raise issues."

### Concerns raised by families about change in ease of access to support in adult services compared to paediatric services:

"We have felt left up in the air. We are less supported now. This might be because [paediatrician] was so good but now we feel very much on our own. [Paediatrician] would give us her phone number to call if we needed something urgently, but they have said if we have a problem now, we should ring 111, but when we do that they don't know [YP] or anything about his condition".

"Different (less) services available in adult services e.g. physiotherapy".

Care in adult services more in silos and not so well orchestrated/coordinated: "Now there was no central person. There were all different services for different needs'.

"The new care does not cover the complete package, whereas [Paediatrician] looked after [YP] as a whole, whereas now the consultant is a palliative consultant and if we try and talk about feed or epilepsy then it has to be referred on to someone else, which then means more appointments".

Three families specifically mentioned concerns about respite care in adult services, suitable to the needs of disabled young people, which 'need to improve', are difficult to access and significantly less available than for children.

Two families specifically stated that they would have preferred continuity of care from the same healthcare team, rather than changing to different consultants.

Lack of meaningful activities once left education, mother was having to leave her job to share care with father.

No continuity of social worker, due to multiple changes and sickness.

### Positive comments from families about GP annual LD review and 'flu immunisation

"Really good because the GP treats her the same as everyone else and doesn't discriminate just because she has a disability. We can discuss everything with the GP and making an appointment where we can discuss everything is reassuring. This works really well. It also helps her to form a relationship with the GP, which will be good for the future when she might need to go just with her carer"

"The GP sends a letter with pictures on, to help her understand and this is really good. Really inclusive really. And they allocate a GP so we get the same one each time and she is lovely, and speaks to her not me'.

## Appendix 5

Transition Learning Disabilities team feedback from families and professionals 2015-2019

Questionnaires were returned from 21 families and three professionals.

Questions included a visual scale for ease of answering:



The findings were as follows:

What are your thoughts on the information your received about the role of the transition team? Poor Average Good 10% Excellent 90%

"Fully comprehensive information provided".

"The transition team have helped me with my daughter so much, I cannot praise them enough. Especially X and X".

"The information received was very easy to understand, both written and verbal".

"Really supportive, attend appointments for support, chase things up on your behalf - a valuable and much appreciated service".

"Yes we know what they are doing and what they are involved with now and for the future".

"Very informative".

"Made sure I understood exactly what their role is".

"Everything was explained".

### How do you think the information could be improved?

"An option of a pdf format via email would help streamline paperwork".

### How would you rate the content of the health plan?

Poor Average Good 12.5% Excellent 87.5%

"Very informative and easy to understand". "The health plan contain all the required information". "The HP content was an accurate reflection of X's health". "Very thorough". "Very thorough".

How do you think the health plan could be improved? "A pdf forma via email".

How did you feel the transition team communicated with you? Poor

Average Good 8% Excellent 92%

"They would ring me when an update was due and always gave plenty of time when they came to my house to listen and resolve any problems, nothing was too much trouble for them, they were always at the end of the phone if I needed them".

"Communication with the team was easy because I could contact them whenever necessary and they were very quick to respond".

"The staff kept in regular contact and were always prompt".

"Very friendly, flexible with appointments".

"My daughter X had to have an operation to remove both her thumb nails under general anaesthetic. X came with me, stayed to support me the whole time and took us home afterwards. She was absolutely amazing and no way could I have got through it without her support".

"Comprehensively. Always followed up on everything discussed, and review appointments in good time".

"Yes, everything was explained, what and why they were doing things".

"Listened and answered my concerns".

"Very well communication and advice given. Lots of useful information obtained".

"Very thorough with their explanations regarding any enquiry".

"The team did communicate very well during the visit in fact they went over things a number of times just to make sure I understood what was going to happen".

"They communicated very well at all my visits that they had with me".

"Very good, easy to talk to".

"They both communicated very well, making sure I understood their role and the services they provide. They also listened very well to my concerns in relation to my daughter's health. Excellent!"

"I understood nearly everything and when I didn't they explained it".

"They were very chatty and helpful too".

"Very good spoke to me as an equal".

**Did you feel the transition team were friendly and showed you dignity and respect?** Poor Average Good

#### Excellent 100%

"They were always very friendly and always listened to any concerns or problems".

"Always very friendly, considerate and helpful".

"The team showed empathy, dignity and respect".

"Yes, always. X has been a huge support and help since she has been involved with my family".

"I don't have enough good words to say about X".

"Yes always caring. Get on with the team very well. Show respect for all the family".

"Listened to our side of the care as well as offering advice themselves".

"Yes, understood my problems".

"Very caring and friendly, always compassionate".

"Very caring".

"Very caring attitude I feel so comfortable talking to them and also feel that they understand my situation".

"Very much so. Overall a very positive feeling I get from the team caring friendly and understanding".

"Very caring attitude at all times and nothing was a problem for them to help me". "They did show us dignity and respect no matter where we were and were really friendly".

"Yes, listened well to our views by having a friendly "chat" as well as questions and answers".

"Very caring. They both showed huge care and concern, whilst being very positive about my child's disability".

"They were very respectful".

"Very much so".

#### Did you feel supported?

"Yes, very much so."

Overall, how would you rate the involvement of the transition team? Poor Average Good 7% Excellent 93%

"All of the transition team have helped me and my daughter a lot, they've given me invaluable support when attending appointments and arranging for her to see a special needs dentist".

"These are a brilliant team who have helped me and my daughter overcome so much".

"The team were very professional. They took the necessary action, i.e. school visit and signposted us to the correct health professionals".

"Thank you so much for all of your help it really makes a difference".

"Absolutely fantastic, X is amazing."

"I have said before, we could have done with this tea years ago!"

"We never realised how much things will change from child to adult services".

"They explain exactly what is going to happen to your child during transition and I feel I have someone I can tur to and ask".

"Excellent quality of service".

"They were very compassionate and I have no doubt they are genuine about the needs of my daughter".

"It's a very well run service and the team work around you".

**Do you have any suggestions on how to improve the transition service?** Poor Average

### Good 14% Excellent 86%

"It was a pleasure to meet the X and X. They are a good team. Thank you for your help and support to my daughter".

"The transition team have been amazing. I just wish I could have them in our life forever 0".

"There is nothing I would want to change about these people they are a godsend I hope they will be around forever People need them They are a brilliant team of people who are very much needed".

"No particular suggestions".

"I don't see how it could be improved. The service is perfect as it is".

"So far everything is OK, can't think of any improvements as yet". "No they are very afishent".

"Keep the friendly approach when visiting clients, I am sure you will be welcomed with open arms".

"I must say that they provide a excellent service and from my experience of the team I cannot place any fault or how they could improve".

"They are doing an excellent job".

"Not sure you can improve! Exceptionally friendly staff makes such a difference!"

"None".

Were you clear on the team's role? No Somewhat Definitely 100%

"They are really helpful and I wouldn't now what to do without their help. Brilliant".

Senior special school staff drop-in sessions with learning disability transition team feedback from school staff

### Overall, how did you rate the drop-in sessions from the team?

Poor Average Good 100% Excellent

"A good discussion with teacher on the team's role, who they will be working with. The team join in with every activity with no hesitation".

"But staff within school need to have more info to why the drops in are taking place, and use it to its full potential".

"The girls have been a huge support to the staff and students, we love their visits and they are always there to help. They keep us updated on developments and offer good advice. We would be lost without them".

Were you clear on the team's role? No

Somewhat 33% Definitely 66%

"The team had a clear discussion with teacher and other staff about their role and other things they will be doing within the drop-in sessions".

"I still think a lot of staff don't understand what the team are about, even after being told several times. If they did then their caseload would increase".

### Is there anything you would like to change?

"X and X are very approachable and are always willing to help where possible".

"Nothing, they meet our needs and are always professional".

### Feedback from Sunderland Carers centre

"The transition team have visited our parent carer groups on numerous occasions and have always been very polite, compassionate, informative and communicated well".