

Explanatory Glossary of Paediatric Disability Terms to support data collection by Paediatricians at the point of clinical care

**Includes Guidance for considering Person-centred Outcomes
and Actions for Education, Health and Care planning**

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FREQUENTLY ASKED QUESTIONS

Who is this Glossary for?

Primarily for paediatricians. Others may also find it useful to understand what is meant by the terms that paediatricians use.

What is the Glossary for?

To support the consistent description and recording of the multi-faceted needs of disabled children and young people.

This is important for **individual** children, young people and their families, as all needs must first be accurately identified, described and recorded if they are to be appropriately met, achieving the best possible outcomes.

This is also important for **populations** of children, young people and their families, so that services can be commissioned and designed to meet their needs efficiently and effectively.

What coding system does the Glossary relate to?

SNOMED-CT - specifically, the SNOMED-CT paediatric disability Terminologies Subset. This can be found at: http://www.diseasesdatabase.com/snomed/snomed_subset_browser.asp?dbSubsetID=56931000000136

SNOMED-CT concept ID codes are highlighted in YELLOW

What resources are there in the Glossary?

For each term, the abbreviated and full versions are given, along with the SNOMED-CT code, where one exists. Links to key national guidelines and respected sources of additional information are given. These are not intended to be exhaustive.

Terms and their abbreviations are highlighted in ORANGE

How does the Glossary support Education, Health and Care planning?

For each term, suggestions are given for the paediatrician to consider when developing outcomes and actions for individual children and young people's care plans. These should be of wide applicability. Specifically in England, these should be helpful to paediatricians considering outcomes and actions for Education, Health and Care planning, as per the Children and Families Act 2014 (England) and accompanying Code of Practice.

Suggestions for **Outcomes** are highlighted in GREEN

Suggestions for **Actions** are highlighted in BLUE

An **outcome** is defined as a change in a person's current and future health and wellbeing status that can be attributed to preceding healthcare.

Paediatricians must take great care to write person-centred outcomes and actions that relate specifically to the healthcare that they are delivering, having agreed these with the child, young person and their family. Paediatricians should be careful not to make recommendations or frame outcomes and actions that will be delivered by other professionals, for example therapists, who should make their own expert contributions to the overarching plan.

Linking data collection to consideration of person-centred outcomes and actions will keep a greater focus on what really matters for disabled children, young people and their families.

On which conceptual framework of Disability are the Glossary and Terminologies Set based?

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF), where not only the person's health condition, body structure and function are considered, but also their activities, participation, environmental factors, personal factors and context, as well as how all of these relate to each other (<http://www.who.int/classifications/icf/en/>). In the context of this framework, children and young people with special educational needs are included under the umbrella term 'disability', thus 'disabled children and young people' is synonymous with 'children and young people with special educational needs and disabilities'.

Who has agreed that these are the right terms?

This terminology set was developed by a group of national experts with parent carer and therapy input. It was based on data collected over five years from a large, population-based paediatric disability service. It has been endorsed by the British Academy of Childhood Disability and the Royal College of Paediatrics and Child Health. The terminology set is not designed to be all-inclusive. It is designed for use specifically with disabled children and young people. It covers other specialty areas only at 'headline' level. It is hoped that other specialties will develop their own terminology sets with supporting glossaries in time, so that all children and young people's health issues can be captured and recorded accurately. The terminology set has been piloted and shown to be applicable in a range of clinic settings by acute, community and disability specialist paediatricians.

Systematically using nationally agreed terms to describe the multi-faceted conditions, issues and situations of children and young people and their families will provide robust data to underpin clinical practice, inform research, resource allocation and the revalidation process for individual clinicians.

How will the views of children, young people and parent carers be captured and reflected in the terms that are recorded?

The paediatrician will listen to the views of the child, young person and parent carer/s and should ensure that these views are reflected in the terms that are used to describe their needs and situation. This may be supported by using a consultation facilitation tool such as the 'traffic light tool' that is designed to be completed by the family in the waiting room on the day of the appointment, to capture the issues that matter most to them that day. This can be found at: <http://www.bacdis.org.uk/policy/documents/HFWSummary.pdf>

How do I access and navigate the Glossary?

The glossary is available as a fully searchable pdf file, which can be carried on a portable electronic device or accessed on any computer. Terms can be found either by using the 'Find' function, or by selecting the term from the Index of Terms by Category at the end of the pdf, which are hyperlinked to the relevant pages in the pdf document.

How will data be recorded?

This will vary between different NHS organisations. Pilots showed that data recording is quickest and most efficient when it is captured electronically at the time of the consultation by the paediatrician. As there are many different IT systems in place, it is up to clinicians to discuss with their IT team regarding setting up an interface that allows data to be captured. A template for use in Meditech Version 6 has been built in Sunderland, which pulls terms into the individual electronic medical record. Other templates for other systems are also in development. Contact bacd@rcpch.ac.uk for more information.

If it is not possible to collect data electronically, it can be captured on paper and then later entered onto a spreadsheet for analysis.

What will happen to the data that is collected?

Data collected in an individual's health record can be used to inform their clinical care. For example, if an issue is recorded as active in one consultation, there can be a review at the next consultation to check if the interventions put in place to address it have worked (or not). Thus outcomes can be monitored at an individual level. The process of data collection itself acts as a prompt to improve the quality of clinical care.

Collating the data for a local area can inform strategic planning across agencies. In England, the data can be used to more accurately inform the Joint Strategic Needs Assessment, as in most areas this is currently based on estimates of needs rather than evidence of population data

Where data is collected in England, NHS providers will be mandated to report data to NHS Digital as part of the Children and Young People's Health Services dataset, which from October 2017 will be known as the Community Services Dataset and will cover all age groups. Data will then be analysed. This will allow comparisons between different areas, resulting in atlases of variation of needs and health care. These will act as drivers for improvement in care.

Where data has been collected for some time, it has already been used to support business cases for additional disability paediatricians and therapists, as well as being used to underpin a range of audits and the redesign of care pathways.

What will happen if data is not collected?

If data is not collected, there will be a missed opportunity to improve healthcare both for individual children, young people and their families, also for populations of children and young people. Data currently available evidence significant variations in aspects of healthcare. These lead to unequal outcomes. It will be increasingly difficult to defend services for disabled children and young people without hard evidence of their needs, especially in these times of austerity. In the future, the collection of accurate data will be linked to payment for services.

Who can I contact to ask further questions about data collection or the use of this glossary?

Please contact bacd@rcpch.ac.uk

Also see <http://bacdis.org.uk/policy/dataset.htm>

NAD
= No Abnormality Detected

SNOMED CT: 281900007

At the time of the specific consultation, all is well. The child or young person and their family can be reassured.
Safety net: encourage family to seek medical review if new concerns arise

DiagNotMade
= Diagnosis not made

SNOMED CT: 282293007

At the time of the specific consultation, no diagnosis is made. This does not mean that no diagnosis is present rather that it has not been made at the specific time. Further thought and review is likely to be required. Further clinical opinions may be indicated.
Safety net: ensure robust follow up in place and bring forward in the light of new information

No NeurodevCond
= No neurodevelopmental condition detected

SNOMED CT: 888071000000109

At the time of the specific consultation, no neurodevelopmental condition has been detected. This does not mean that no neurodevelopmental condition is present rather that it is not evident at the time of the specific consultation. There may be other health conditions or issues present, for which appropriate plans should be made
Safety net: encourage family to seek medical review if new concerns arise

No NeurodisCond
= No neurodisabling condition detected

SNOMED CT: 888051000000100

At the time of the specific consultation, no neurodisabling condition has been detected. This does not mean that no neurodisabling condition is present rather that it is not evident at the time of the specific consultation. There may be other health conditions or issues present, for which appropriate plans should be made
Safety net: encourage family to seek medical review if new concerns arise

MedUnexp
= Medically unexplained symptoms

SNOMED CT: 887761000000101

Symptoms reported that are not borne out by the evidence of clinical assessment and/or observation in other settings. This does not mean that the symptoms are any less real for the child or young person, rather that at the time of the consultation, they cannot be medically explained
If reassurance that no medical condition has been identified is ineffective, further clinical opinion/s may be indicated and/or referral to the Child and Adolescent Mental Health Service
Safety net: encourage family to seek medical review if new concerns arise

Dysmorphic
= Dysmorphic features

SNOMED CT: 253978002

This is an umbrella term for all dysmorphic features, which may be red flag for a specific diagnosis. If in doubt, link with expert colleagues in clinical genetics

Person-centred outcomes and **actions** to underpin these should be tailored to the individual, depending on the impact of the dysmorphisms on functioning or their association with a diagnosed chromosomal disorder or genetic syndrome

Outcomes might include:

- The child or young person having positive self-esteem, self-image and self-confidence
- For the child or young person to be able to participate in home, school and/or community activities

Actions towards achieving the outcomes should be led by the health team, in consultation with the child or young person, their family and inter-disciplinary team. Actions might include:

- The child or young person being supported to achieve the most positive possible self-esteem, self-image and self-confidence
- An attitude-check of those working with the child or young person and their peers, to ensure that everyone values and respects the person and guards against any form of discriminatory behaviour, bullying or abuse
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing

Plagioceph
= Plagiocephaly

SNOMED CT: 21850008

This describes a misshapen head, often resulting from uneven pressures on the head during foetal life. It is a benign condition that corrects itself over time in infancy without the need for intervention

There should be no residual disability

ShortStature = Short Stature

SNOMED CT: 237836003

Height that is more than two standard deviations below the mean for age and gender

See www.restrictedgrowth.co.uk and <http://www.shortstaturescotland.co.uk/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their short stature, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric endocrinology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their short stature are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric endocrinology, clinical genetics etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the short stature, for example, hormone deficiencies, genetic syndromes etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their short stature, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's short stature, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

LDiff
= Learning difficulties

SNOMED CT: 161129001

This is a high level term, covering all learning difficulties that have not been more precisely defined. This may be the presenting complaint that a family seek advice about and should be a prompt for referral for further expert assessment to define the difficulties more precisely e.g. with the specialist teacher in the learning support service or educational psychologist

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their learning profile, including strengths, difficulties and any specific, diagnosable learning difficulty or disability
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's learning abilities
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their learning difficulties, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's learning difficulties, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DevAcadDis**= Developmental academic disorder****= developmental disorder of scholastic skill over 4 years**

SNOMED CT: 1855002

This includes all learning disabilities and specific learning disabilities and is a high level term to be used when the exact nature of the learning difficulty or disability has not been further elucidated. This should be a prompt for referral for further expert assessment to define the difficulties more precisely e.g. with the specialist teacher in the learning support service or educational psychologist

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their learning profile, including strengths, difficulties and any specific, diagnosable learning difficulty or disability
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place in all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person and their family

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's learning abilities
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their developmental academic disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's developmental academic disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

TypIAA**= Typical intellectual abilities for age**

Synonym = IQ normal (this is the term that is accepted by terminologists)

SNOMED CT: 165179006

It is important to record this finding, to give a context for other aspects of functioning, e.g. communication, motor functioning, behavioural and emotional etc.

BordIA**= Borderline intellectual ability (IQ 70-85)**

SNOMED CT: 77287004

Children and young people with borderline intellectual abilities can be vulnerable. Many of their needs and issues are more like those of children and young people with intellectual developmental disabilities or learning disabilities than of their peers with typical intellectual abilities

Careful consideration should be given to the needs of children and young people with borderline intellectual abilities, including their need for reasonable adjustments, support and information

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place in all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their borderline intellectual abilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's borderline intellectual abilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

MildIDD

= **Mild Intellectual Developmental Disability (IQ 50-70)**

Synonyms include 'mild learning disability', 'mild mental retardation', 'mild intellectual developmental disorder'

SNOMED CT: 86765009

Equivalent mental age as adult of 9-12 years

Likely to acquire sufficient speech for every day purposes and full independence in self-care (eating, washing, dressing, bladder and bowel control), albeit at a slower rate of skill acquisition

Many children struggle with academic work at school, especially with reading and writing

Many adults will be able to work in roles that demand practical rather than academic abilities

Many adults have good social relationships and contribute to society

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their mild intellectual developmental disabilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's mild intellectual developmental disabilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SigIDD

= **Significant Intellectual Developmental Disability**

= intellectual developmental disability that is more severe than Mild Intellectual Developmental Disability as defined above

SNOMED CT: 931001000000105 Parent term for moderate, severe and profound intellectual disability

This includes moderate, severe and profound Intellectual Developmental Disabilities as defined below and should be used where it is not possible to be more precise about the exact level of the intellectual disability. This should be a prompt for referral for further expert assessment to define the intellectual disability more precisely e.g. with the specialist teacher in the learning support service or educational psychologist

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their learning profile, including strengths, difficulties and the specific level of their intellectual disability
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities
- Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's intellectual abilities
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their significant intellectual developmental disabilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's significant intellectual developmental disabilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

ModIDD

= **Moderate Intellectual Developmental Disability (IQ 35-49)**

Synonyms include 'moderate learning disability', 'moderate mental retardation', 'moderate intellectual developmental disability'

SNOMED CT: 61152003

Equivalent mental age as adult of 6-9 years

Likely to lead to markedly disordered development in childhood, with slow acquisition of language comprehension and use, but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their moderate intellectual developmental disabilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's moderate intellectual developmental disabilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SeviDD**= Severe Intellectual Developmental Disability (IQ 20-34)**

Synonyms include 'severe learning disability', 'severe mental retardation', 'severe intellectual developmental disability'

SNOMED CT: 40700009

Equivalent mental age as adult of 3-6 years

Likely to lead to continuous need for support

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>**Person-centred Outcomes** in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their severe intellectual developmental disabilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's severe intellectual developmental disabilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

ProfIDD**= Profound Intellectual Developmental Disability (IQ <20)**

Synonyms include 'profound learning disability', 'profound mental retardation', 'profound intellectual developmental disability'

SNOMED CT: 31216003

Equivalent to mental age as adult of less than 3 years

Severe limitation in self-care, continence, communication and mobility

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>**Person-centred Outcomes** in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should also be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their profound intellectual developmental disabilities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's profound intellectual developmental disabilities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

EDI/Unsp

= Early Developmental Impairment/Unspecified intellectual developmental disability

SNOMED CT: 716710007

This term should be reserved for the child <4 years of age in whom accurate assessment to define level of intellectual developmental disability is not possible and includes the group with early developmental impairment where it is not yet clear whether the child will emerge to have a cognitive and/or physical impairment, or where development may advance to within the typical range (may also be called 'global developmental delay' a term that needs to be used with care as it implies all will 'catch up' to the typical range, which many do not). This term may also be used for those of 4 years and older who have intellectual developmental disability (learning disability, mental retardation) where the precise level of intellectual disability has not been ascertained. This should be avoided where possible, in favour of the more precise categories as above and should prompt referral for more accurate ascertainment of intellectual functioning. Where an individual is described with the terminology 'unspecified IDD' or related terms such as 'global developmental delay', there should be regular, expert clinical review as these terminologies do not define the individual's predicament accurately enough to inform care planning

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their learning profile, including strengths, difficulties and any specific, diagnosable learning difficulty or disability
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's learning abilities
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their early developmental impairment, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's early developmental impairment, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

IDunknown**= IDD/EDI unknown cause**

= Intellectual developmental disability/early developmental impairment (learning disability, mental retardation) for which no cause has yet been identified

SNOMED CT: 954711000000106

See session on learning disability: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Health and Education teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their intellectual developmental disability or early developmental impairment, their intellectual abilities, strengths and any specific or generalised difficulties or disabilities, including any diagnosed conditions that have caused these
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health and Education teams, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person, including with the wider clinical network that might include experts in paediatric disability, paediatric neurology, clinical genetics, paediatric metabolic medicine, child and adolescent mental health etc. in order to make more specific diagnoses
- Another possible action might be to arrange appropriate, detailed expert assessments of the child or young person's learning abilities
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their intellectual developmental disability, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's intellectual developmental disability, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SpLD
= **Specific Learning Disability**

SNOMED CT: 889211000000104

See session on Hidden Disabilities in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=49> This is the parent terminology that encompasses the group of specific learning disabilities, that can be further subdivided into:

Dyslexia
= **Specific learning difficulties affecting accurate and fluent word reading and spelling**
Includes difficulties with phonological awareness, verbal memory and verbal processing speed

SNOMED CT: 59770006

See <http://www.bdadyslexia.org.uk>

Dyscalculia
= **Specific learning difficulties affecting the ability to acquire arithmetical skills.** Dyscalculic learners may have difficulty understanding simple number concepts, lack an intuitive grasp of numbers and have difficulties learning number facts and procedures. Even if they produce a correct answer or use a correct method, they may do so mechanically and without confidence

SNOMED CT: 55640002

See <http://www.bdadyslexia.org.uk/about-dyslexia/schools-colleges-and-universities/dyscalculia.html>

Dysgraphia
= **Specific learning difficulties affecting the written word, with extreme difficulty with fine-motor skills in spite of having age-typical intellectual abilities**

SNOMED CT: 88278002

Red flags for dysgraphia include:

- Written text very poor considering language development
- Poor motor control
- Writing that is almost impossible to read
- Mixture of printing and cursive writing on the same line
- Writes in all directions, i.e. right slant then left slant
- Big and small spaces between words
- Different sized letters on the same line
- Mixes up capital letters and lower case letters on the same line
- Abnormal and irregular formation of letters
- Very slow writing
- Very slow copying from board
- Does not follow margins
- Grips the pen too tight and with a 'fist grip'
- Holds pen very low down so fingers almost touches the paper
- Watches hand intently whilst actually writing
- Poor spelling
- Bizarre spelling
- Problems with spelling wrong words i.e., 'brot' for brought and 'stayshun' for station
- Problems with spelling words such as i.e. drink as 'brink'

See http://www.dyslexiaa2z.com/learning_difficulties/dysgraphia/dysgraphia.html

Person-centred Outcomes for children and young people with specific learning disabilities should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcomes might include for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team

- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their specific learning disability, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's specific learning disability, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

PhysicalDis = Physical disability

SNOMED CT: 197521000000108

This is a high level term to cover all physical disabilities. If it is not clear from clinical assessment what the cause of the physical disability is, further investigations should be undertaken or further expert clinical opinions sought e.g. paediatric disability, neurology, clinical genetics etc.

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their physical disability, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific physical disability are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed condition, for example, postural deformities, constipation, disordered sleep etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their physical disability, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's physical disability, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Neurological = Neurological disorder or condition

SNOMED CT: 118940003

This is a high level term for all neurological disorders. Where there is diagnostic or aetiological uncertainty, a referral should be made to paediatric disability, neurology, clinical genetics etc.

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their neurological disorder, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific neurological disorder are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed neurological disorder, for example, epilepsies, postural deformities, constipation, disordered sleep etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their neurological condition, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's neurological condition, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

MvtDisorder = Movement Disorder

SNOMED CT: 60342002

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their movement disorder, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific movement disorder are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed movement disorder, for example, epilepsies, postural deformities, constipation, disordered sleep, pain etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their movement disorder, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's movement disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Spina Bifida

This includes all the spina bifidas.

SNOMED CT: 67531005

See <http://www.shinecharity.org.uk/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their spina bifida, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments and reviews to be arranged with specialists in paediatric disability, paediatric neurology, paediatric urology, orthopaedics, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their spina bifida are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, paediatric urology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the spina bifida, for example, neuropathic bladder and bowel, continence issues, constipation, postural deformities etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain and postural issues, constipation, urinary tract infections etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their spina bifida, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's spina bifida, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Neuropathy

SNOMED CT: 302226006

All neuropathies are included here e.g. Hereditary Sensory and Motor Neuropathy (HSMN1A) or Charcot Marie Tooth Disease. See http://www.muscular-dystrophy.org/about_muscular_dystrophy/conditions/140_charcot-marie-tooth_disease_cmt

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their neuropathy, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a specific diagnosis
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific neuropathy are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the neuropathy, for example, postural deformities, pain, fatigue etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their neuropathy, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's neuropathy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

NMuscDis**= Neuromuscular disorder**

SNOMED CT: 909621000000100

This is an umbrella term for a family of conditions.

If there is no more detailed diagnosis than this available, this should trigger consultation with the regional paediatric neuromuscular service, to investigate further to try to reach a more precise diagnosis.

See session on Complex Conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their neuromuscular disorder, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For appropriate expert assessments and reviews to be arranged with specialists in paediatric disability, paediatric neurology, paediatric neuromuscular disorders, clinical genetics orthopaedics, etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their neuromuscular disorder are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, paediatric neuromuscular disorders, clinical genetics orthopaedics, etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the neuromuscular disorder, for example, postural deformities, mobility issues, respiratory issues, constipation, pain etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain and postural issues, constipation, respiratory issues etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their neuromuscular condition, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's neuromuscular condition, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DMD = Duchenne Muscular Dystrophy

SNOMED CT: 76670001

See <http://www.muscular-dystrophy.org/>

See session on Complex Conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Duchenne Muscular Dystrophy, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Duchenne Muscular Dystrophy are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, paediatric neuromuscular disorders, clinical genetics orthopaedics, etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with Duchenne Muscular Dystrophy, for example, postural deformities, mobility issues, respiratory issues, constipation, etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain and postural issues, constipation, respiratory issues etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Duchenne Muscular Dystrophy, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's Duchenne Muscular Dystrophy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Congen MD**= Congenital muscular dystrophy**

SNOMED CT: 111501005

See <http://www.muscular-dystrophy.org/>See session on Complex Conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Congenital Muscular Dystrophy, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Congenital Muscular Dystrophy are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, paediatric neuromuscular disorders, clinical genetics orthopaedics, etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with Congenital Muscular Dystrophy, for example, postural deformities, mobility issues, respiratory issues, constipation, etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain and postural issues, constipation, respiratory issues etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For the child or young person to be supported to engage in home, school and community activities to promote their health and wellbeing
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their congenital muscular dystrophy, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identification of the reasonable adjustments or action that might be required in the knowledge of the child or young person's congenital muscular dystrophy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

NMJDis**= Neuromuscular junction disorder**

SNOMED CT: 128213006

See <http://europepmc.org/articles/PMC2949330/reload=0;jsessionid=20W8MeTL2Z6m92OooWm8.16>See session on Complex Conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Neuromuscular Junction Disorder, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Neuromuscular Junction Disorder are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, paediatric neuromuscular disorders, clinical genetics orthopaedics, etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with Neuromuscular Junction Disorder, for example, postural deformities, mobility issues, respiratory issues, constipation, etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain and postural issues, constipation, respiratory issues etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Neuromuscular Junction Disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Neuromuscular Junction Disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

HSParapl = Hereditary spastic paraplegias

SNOMED CT: 39912006

See <http://www.ncbi.nlm.nih.gov/books/NBK1509/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their hereditary spastic paraplegia, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely).

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific hereditary spastic paraplegia are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed hereditary spastic paraplegia, for example, postural deformities, mobility issues etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their hereditary spastic paraplegia, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's hereditary spastic paraplegia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Skel dyspl = Skeletal dysplasias

SNOMED CT: 105986008

See

<http://www.skeletaldysplasiagroup.org.uk>

www.skeldys.org

www.esdn.org and www.restrictedgrowth.co.uk

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific skeletal dysplasia, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific skeletal dysplasia are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, paediatric neurology, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed skeletal dysplasia, for example, postural deformities, pain, effects of short stature, respiratory issue etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. postural deformities, pain, effects of short stature, respiratory issue etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their skeletal dysplasia, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's skeletal dysplasia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

CongDisH
= Congenital dislocation of the hip

SNOMED CT: 48334007

This should be identified early in infancy and proactively managed to prevent it from causing disability. If it does cause physical disability, the Person-Centred Outcomes and Actions under Physical Disability above may be a helpful guide

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of congenital dislocation of the hip, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the health team the infant or child's family and multi-disciplinary team
Possible actions might include:

- For appropriate expert assessments to be arranged with experts in paediatric orthopaedics

CAMSK**= Congenital physical anomaly of musculoskeletal system**

SNOMED CT: 73573004

This is an umbrella term for a range of conditions

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific congenital physical anomaly of the musculoskeletal system, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, paediatric neurology, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific congenital physical anomaly of the musculoskeletal system are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed congenital physical anomaly of the musculoskeletal system, for example, postural deformities, pain, congenital anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their congenital physical anomaly of the musculoskeletal system, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's congenital physical anomaly of the musculoskeletal system, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Talipes

SNOMED CT: 398309008

See <http://www.nhs.uk/conditions/Talipes/Pages/Introduction.aspx>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their talipes, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their talipes are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, clinical genetics and orthopaedics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the talipes, for example, postural deformities, pain, congenital anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their talipes, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's talipes, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

ULAnomaly = Upper Limb Anomaly

SNOMED CT: 118947000

Includes all anomalies of the upper extremity including brachial plexus injuries acquired at birth. See www.reach.org.uk

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their upper limb anomaly, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, clinical genetics, hand and plastic surgery, orthopaedics etc. in order to make a specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their upper limb anomaly are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, clinical genetics, hand and plastic surgery, orthopaedics, specialist occupational therapy etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the upper limb anomaly, for example, postural deformities, pain, congenital anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their upper limb anomaly, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's upper limb anomaly, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

ConHypo = Congenital hypotonia

SNOMED CT: 33010005

This is a condition that can only be confidently diagnosed once it has resolved. There may be a family history. It should not cause disability sufficient to require outcomes or actions to be written about it

Joint Laxity May also be called Hypermobility

SNOMED CT: 298203008

Joint laxity or hypermobility around joints can be a syndrome in itself, or can be a red flag for chromosomal/genetic/syndromic disorders. If in doubt, link with regional clinical genetics service

The degree of joint laxity may be assessed using the Beighton Score http://www.physio-pedia.com/Beighton_score

Most children and young people with joint laxity will not be disabled by it, but some at the extreme of the range may experience significant pain, activity limitation and fatigue, all of which can be disabling. Not all children and young people with joint laxity require regular input from a paediatrician, only those with other disabling conditions or with severe symptoms

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their joint laxity, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, clinical genetics, physiotherapy etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their joint laxity are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, clinical genetics and physiotherapy.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with extremes of joint laxity, for example, postural deformities, pain, congenital anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their joint laxity, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's joint laxity, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Clumsy

SNOMED CT: 7006003

This term refers to the child presenting with parental or professional concerns that they are 'clumsy'.

A careful assessment is required by the paediatrician, including detailed neurological examination (please refer on if uncertain) to make sure that there is nothing else causing the symptoms.

If a more specific diagnosis is made, please refer to the person-centred outcomes and actions for that diagnosis

**GaitAbn
= Gait Abnormalities**

SNOMED CT: 22325002

Broad category for all those whose gait does not look typical for age. If in doubt, seek an expert opinion.

If a more specific diagnosis is made, please refer to the person-centred outcomes and actions for that diagnosis

**DCD
= Developmental Coordination Disorder**

SNOMED CT: 27544004

See EACD clinical guideline www.eacd.org/file-download.php?id=95

See <http://www.skillsforaction.com/DCD-and-dyspraxia>

See <http://www.movementmattersuk.org/dcd-dyspraxia-adhd-spld/uk-dcd-consensus.aspx>

See session on Hidden Disabilities in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=49>

Most children and young people with developmental coordination disorder do not need ongoing input from a paediatrician, once other health conditions have been confidently excluded.

Advice about reasonable adjustments across settings may be helpful from the physiotherapist and occupational therapist, including how to support the best possible functioning.

For those with the most severe functional limitations, the person-centred outcomes and actions in the physical disability section above may be helpful.

Torticollis

SNOMED CT: 70070008

Person-centred outcomes in this area might include for the torticollis to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician with expertise in neurology/disability and physiotherapist so that an appropriate management plan can be agreed with the child, young person and family

Scoliosis

SNOMED CT: 298382003

Deformity of spine or curvature of the spine is a complication of the cerebral palsies, especially in those less mobile in GMFCS levels IV and V.

Scoliosis can also be a complication in a range of other disabling conditions.

Prompt referral to a spinal orthopaedic surgeon as soon as the curve is recognised can improve surveillance and improve opportunities for early intervention to maximize posture, function and ease of care and reduce risks of chest infections, postural deformity and pressure sores.

Delay in referral has led to some children and young people missing out on the opportunity to consider a surgical intervention to prevent a progressive scoliosis and earlier death, as by the time they are seen their lung function has deteriorated to such an extent that they are not fit enough for surgery to be an option.

See:

Graham H, Selber P. Musculoskeletal aspects of cerebral palsy. *J Bone Joint Surg [Br]* 2003;85-B:157-66.

Hilberink SR, Roebroek ME, Nieuwstraten W, Jalink L, Verheijden JMA, Stam HJ. Health issues in young adults with cerebral palsy: Towards a life-span perspective. *J Rehab Med.* 2007;39(8):605-611.

Tosi L, Maher N, Moore DW, Goldstein M, Aisen ML. Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Dev Med Child Neurol.* 2009;51(S4):2-11.

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their scoliosis, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, spinal orthopaedics, clinical genetics, physiotherapy etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their scoliosis are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, spinal orthopaedics and clinical genetics.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the scoliosis, for example, postural deformities, pain, respiratory complications etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their scoliosis, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's scoliosis, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DislocHip/s**= Dislocation of one or both hips**

SNOMED CT: 157265008

Hip migration is part of the natural history of the cerebral palsies in those children and young people who are least independently mobile, especially those in GMFCS levels III to V. Active hip surveillance using a combination of clinical surveillance and radiological surveillance (x-ray, fluoroscopy or other imaging modality) can lead to preventive interventions to reduce the risk of complete dislocation. Dislocation may be painful and may make care-giving more difficult.

NICE guidance on spasticity management 2012 recommends hip surveillance to reduce the risk of hip dislocation.

Hip dislocation is thus a marker of the quality of the surveillance programme. In Sweden where a population-based hip surveillance programme has been in place for many years the incidence of complete hip dislocation has been reduced to zero.

See NICE guidance <http://guidance.nice.org.uk/Guidance/CG145> and www.nice.org.uk/guidance/ng62

Also: Terjesen T. The natural history of hip development in cerebral palsy. *Dev Med Child Neurol.* 2012, 54: 951-957.

Gordon GS, Simkiss DE. A systematic review of the evidence for hip surveillance in children with cerebral palsy. *J Bone Joint Surg [Br].* 2006;88-B:1492-6.

Wynter M, Gibson N, Kentish M, Love S, Thomason P, Kerr Graham H. The consensus statement on Hip Surveillance for children with cerebral palsy: Australian standards of care. *J Pediatr Rehabil Med* 2011;(3):183-95.

Hagglund G, Andersson S, Duppe H, et al. Prevention of dislocation of the hip in children with cerebral palsy: the first ten years of a population-based prevention programme. *J Bone Joint Surg [Br]* 2005;87-B:95-101.

Elkamil AJ, Andersen GL, Hagglund G, Lamvik T, Skranes J, Vik T. Prevalence of hip dislocation among children with and without a surveillance programme: a cross sectional study in Sweden and Norway. *BMC Musculoskeletal Disorders* 2011;12:284 www.biomedcentral.com/1471-2474/12/284

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their dislocated hip/s, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, orthopaedics, physiotherapy etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their dislocated hip/s are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, orthopaedics and physiotherapy.
- For the paediatric and orthopaedic teams to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the scoliosis, for example, postural deformities, pain etc. so that these can be addressed in a timely way. This may involve surgery or medication
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their dislocated hip/s, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's dislocated hip/s, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

MSKPain
= Musculoskeletal pain

SNOMED CT: 279069000

See Disability Matters session: Pain Matters: <https://disabilitymatters.org.uk/course/view.php?id=64>

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the child or young person's pain to be acknowledged, recognised and alleviated

Action towards achieving the outcome is likely to be for the pain to be assessed and investigated by the appropriate health practitioner, which may be the general practitioner, paediatrician, physiotherapist, orthopaedic surgeon or other specialist, in order to identify the cause and treat this. Where a specific cause cannot be found, the pain itself should still be acknowledged and a pain management plan put in place

SoftTissMass
=Soft Tissue Mass

SNOMED CT: 444905003

Person-centred outcomes in this area should be led by the health team in consultation with the child or young person, their family and multidisciplinary team

- One possible outcome might be for the soft tissue mass to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning. might include for the soft tissue mass to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning
- Another possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of the specific diagnosis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician or paediatric surgeon so that an appropriate management plan can be agreed with the child, young person and family

Haemangioma

SNOMED CT: 400210000

Person-centred outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multidisciplinary team

might include for the haemangioma to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

- One possible outcome might be for the haemangioma to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning
- Another possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of the specific diagnosis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric dermatology, surgery and other relevant specialties
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their haemangioma are and what to expect for the future
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning

Actions will depend on the person-centred outcomes agreed for the child or young person

Lymphaden = Lymphadenopathy

SNOMED CT: 30746006

Person-centred outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multidisciplinary team

One possible outcome might be for the lymphadenopathy to be appropriately investigated and managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

- Another possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of the specific diagnosis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric surgery, infectious diseases, oncology and other relevant specialties
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their lymphadenopathy are and what to expect for the future
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning

Actions will depend on the person-centred outcomes agreed for the child or young person

Arthritis

SNOMED CT: 3723001

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their arthritis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric rheumatology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their arthritis are and what to expect for the future
- For the paediatric rheumatology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the arthritis
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their arthritis be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's arthritis, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

CPalsy = Cerebral Palsies

SNOMED CT: 128188000

The classification system recommended and validated by the Surveillance of Cerebral Palsies in Europe (SCPE) is preferred. See www.scpnetwork.eu Log in to access the Classification system and Reference and Training Manual.

Also see NICE guideline: Cerebral Palsy in under 25s: assessment and management: www.nice.org.uk/guidance/ng62

The cerebral palsies are a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of the cerebral palsies are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.

Children and young people with profound hypotonia and no other neurological signs (often associated with severe intellectual impairment) are thus excluded.

SCPE classification uses the predominant variation in tone to define the cerebral palsy subtype

Definitions are as follows:

Tone

The resistance of a muscle to passive stretch (hypertonia - increased resistance, hypotonia - reduced resistance)

Spasticity

A velocity dependent increase in resistance to passive stretch. Spastic muscles are not necessarily hypertonic, the key is the velocity dependency. Spasticity is an abnormal response to rapid stretch. Usual associated features are clonus, increased deep tendon reflexes and extensor plantar responses

Ataxia

An abnormality in the smooth approach to an object with wide amplitude corrections during the movement. In relation to gait, ataxia means broad based, poorly co-ordinated

Athetosis

The characteristic of slow writhing movement, usually seen in the distal part of the limb during voluntary activity

Chorea

Rapid, high amplitude, sudden involuntary movement

Dystonia

Atypical tone, either high or low. Usually refers to atypical sustained contractions of agonists and antagonists resulting in an unusual and atypical posture, e.g. inversion of foot, retraction of shoulders etc

W-D Syndrome

= Worster-Drought Syndrome

SNOMED CT: 557181000000116

This is cerebral palsy that affects the nerves and muscles needed for speaking, eating, drinking and swallowing. It is a very important and sentinel condition for services for disabled children and young people because it can be tricky to diagnose and requires careful multi-disciplinary care planning

See:

<http://www.gosh.nhs.uk/medical-conditions/search-medical-conditions/worster-drought-syndrome>

SpCP
= Spastic Cerebral Palsy

SNOMED CT: 230773005

SpUniCP
= Spastic Unilateral Cerebral Palsy

SNOMED CT: 909631000000103

SpCPuniR
= Spastic Cerebral Palsy Unilateral Right = Right Hemiplegia

SNOMED CT: 278284007

SpCPuniL
= Spastic Cerebral Palsy Unilateral Left = Left Hemiplegia

SNOMED CT: 278285008

See www.hemihelp.org.uk

SpCPbilat
= Spastic Cerebral Palsy Bilateral

SNOMED CT: 904531000000100

DyskinCP
= Dyskinetic Cerebral Palsy

SNOMED CT: 230780007

Dyskinetic Cerebral Palsy is subdivided into:

DystonicCP
= Dystonic Cerebral Palsy

SNOMED CT: 702315006

ChoreoAth
= Choreo-athetotic Cerebral Palsy

SNOMED CT: 885831000000109

AtaxicCP
= Ataxic Cerebral Palsy

SNOMED CT: 278512001

See Platt MJ, Krageloh-Mann I and Cans C. Surveillance of Cerebral Palsy in Europe: reference and Training Manual. Medical Education. 2009;43:495-496. doi: 10.1111/j.1365-2923.2009.03351.x

Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005.

Dev Med Child Neurol. Aug 2005;47(8):571-6.

The gross motor function classification system levels are graded I to V, using the validated GMFCS – E & R tool published by CanChild: Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston 2007; Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997. CanChild Centre for Childhood Disability Research, McMaster University (Dev Med Child Neurol 1997;39:214-223)

See <http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf>

GMFCSI

= Gross Motor Function Classification System Level I

Walks without limitations

SNOMED CT: 881521000000108

GMFCSII

= Gross Motor Function Classification System Level II

Walks with limitations

SNOMED CT: 881541000000101

GMFCSIII

= Gross Motor Function Classification System Level III

Walks using a hand-held mobility device

SNOMED CT: 882021000000108

GMFCSIV

= Gross Motor Function Classification System Level IV

Self-mobility with limitations; may use powered mobility

SNOMED CT: 882041000000101

GMFCSV

= Gross Motor Function Classification System Level V

Transported in a manual wheelchair

SNOMED CT: 882061000000100

If in doubt about which level applies, ask the physiotherapist!

Distinctions between levels

Distinctions Between Levels I and II

Compared with children and young people in Level I, children and young people in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III

Children and young people in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and young people in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV

Children and young people in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device.

Children and young people in Level IV function in sitting (usually supported) but self-mobility is limited. Children and young people in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V

Children and young people in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/young person can learn how to operate a powered wheelchair.

GMFCS before second birthday

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

GMFCS between second and fourth birthday

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

GMFCS between fourth and sixth birthday

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations

GMFCS between sixth and twelfth birthday

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

GMFCS between twelfth and eighteenth birthday

Level I: Young people walk at home, school, outdoors, and in the community. Young people are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Young people perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Young people may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Young people walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, young people may walk using a handheld mobility device for safety. Outdoors and in the community, young people may use wheeled mobility when traveling long distances. Young people walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Young people are capable of walking using a hand-held mobility device. Compared to individuals in other levels, young people in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, young people may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, young people may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, young people are transported in a wheelchair or use powered mobility. Young people may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Young people use wheeled mobility in most settings. Young people require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Young people may support weight with their legs to assist with standing transfers. Indoors, young people may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Young people are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, young people are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Young people are transported in a manual wheelchair in all settings. Young people are limited in their ability to maintain anti-gravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Young people may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Person-centred Outcomes for children and young people with **cerebral palsies** should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their cerebral palsy, what the specific diagnosis is using the SCPE classification system, what their GMFCS level is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, orthopaedics, physiotherapy, occupational therapy, speech and language therapy etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific cerebral palsy are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, orthopaedics and for those with developmental brain anomalies, clinical genetics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the cerebral palsy, for example, postural deformities, pain, constipation, epilepsies, disordered sleep, drooling, chest infections, feeding and swallowing issues, speech, language and communication issues, hand function issues etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their cerebral palsy, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's cerebral palsy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

NI (CP)**= Neuroimaging in Cerebral Palsies**

This means that for a child or young person with cerebral palsy, neuroimaging has been done (ever). This is important because neuroimaging is a marker of the quality of aetiological assessment for the child or young person with cerebral palsy. It is known that 10-15% cerebral palsies are due to developmental brain anomalies, some of which may be genetically determined and some of which may be associated with e.g. endocrinopathies. Normal imaging with a clinical pattern of cerebral palsy may prompt the need for further neurometabolic investigations.

There may be missed opportunities for more accurate management if neuroimaging is not undertaken.

See:

Krägeloh-Mann I, Petersen D, Hagberg G, Michaelis R. Bilateral spastic cerebral palsy – MRI pathology and origin. Analysis from a representative series of 56 cases. *Dev Med Child Neurol.* 1995;37(5):379-397

Kumara A, Hayakawa F, Kato T, Kuno K, Watanabe K. MRI findings in patients with spastic cerebral palsy I: correlation with gestational age at birth. *Dev Med Child Neurol.* 1997;39(6):363-368

Okumura A, Kato T, Kuno K, Hayakawa F, Watanabe K. MRI findings in patients with spastic cerebral palsy II: Correlation with type of cerebral palsy. *Dev Med Child Neurol.* 1997;39(6):369-372

Ashwal S, Russman SBS, Blasco PA, et al. Practice Parameter: Diagnostic assessment of the child with cerebral palsy: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology* 2004;62:851

Bax M, Tydeman C, Flodmark O. Clinical and MRI correlates of cerebral palsy. *JAMA.* 2006;296:1602-1608

Robinson MN, Peake LJ, Ditchfield MR, Reid SM, Lanigan A, Reddihough DS. Magnetic resonance imaging findings in a population-based cohort of children with cerebral palsy *Dev Med Child Neurol* 2008;51:39-45.

Krägeloh-Mann I, Horber V. The role of MRI in elucidating the pathogenesis of cerebral palsy: a systematic review. *Dev Med Child Neurol.* 2007;49:144–151

Do ensure that any neuroimaging is accurately reported. See Horridge KA, Johnston J, Phatak V, Guadagno A. Magnetic resonance imaging of the brain in children and young people with cerebral palsy: who reports matters? *Dev Med Child Neurol* 2011;53(4):373-7.

Neuroimaging is an investigative tool commonly used for children and young people with a range of neurological and neurodisabling presentations.

Suggested guidance regarding when neuroimaging may be helpful can be found in:

Horridge KA. Assessment and investigation of the child with disordered development. *Arch Dis Child Educ Pract.* 2011;(96):9-20.

If in doubt, discuss with a paediatric neurologist.

NImReq**= Neuroimaging has been requested**

SNOMED CT: 931121000000102

DateNI**= Date of Neuroimaging****NImAbn****= Neuroimaging Abnormal result**

SNOMED CT: 442731005

NImNotDone**= Neuroimaging has not been done**

Classification in neuroimaging findings can be recorded as per the SCPE schemata for post-neonatal or neonatal imaging as found in the SCPE Reference and Training Manual on the SCPE website: <http://www.scpnetwork.eu/en/about-scp/scp-network/tools/>

MalDev

= Maldevelopment of brain on neuroimaging
= SCPE classification A

SNOMED CT: 91441000000107

WhiteMatInj

= predominant white matter injury on neuroimaging
= SCPE classification B

SNOMED CT: 914431000000104

GreyMatInj

= predominant grey matter injury on neuroimaging
= SCPE classification C

SNOMED CT: 914451000000106

Misc

= Miscellaneous finding on neuroimaging
= SCPE classification D

SNOMED CT: 2349791000000112

NImNorm

= Neuroimaging normal result
= SCPE classification E

SNOMED CT: 914931000000105

ConMalBrain = Congenital Malformation of Brain

SNOMED CT: 57148006

These vary considerably in severity and consequences. Some will be of no clinical significance, whilst others cause cerebral palsies, epilepsies, intellectual developmental disabilities, speech and language disorders, visual impairments, endocrinopathies, autism etc.

Person-centred outcomes and **actions** to underpin these should relate to any disabilities arising as a consequence of the brain malformation e.g. cerebral palsy, physical disability, intellectual developmental disability, epilepsy, endocrinopathy, speech, language, communication needs, visual impairment etc.

Hydroceph = Hydrocephalus

SNOMED CT: 230745008

An excess of cerebrospinal fluid that puts pressure on the brain.
See <http://www.shinecharity.org.uk/hydrocephalus>

Person-centred outcomes and **actions** to underpin these should relate to any disabilities arising as a consequence of the hydrocephalus e.g. cerebral palsy, physical disability, intellectual developmental disability etc.

Microceph = Microcephaly

SNOMED CT: 1829003

Occipito-frontal head circumference that is more than three standard deviations below the mean for age, which equates to less than the 0.4th percentile on the standard UK head circumference chart.

Person-centred outcomes and **actions** to underpin these should relate to any disabilities arising as a consequence of the microcephaly e.g. intellectual developmental disability etc.

ABI = Acquired brain injury

SNOMED CT: 702632000

which includes traumatic and atraumatic brain injury

TBI = Traumatic brain injury

SNOMED CT: 127295002

TBI NAI = Traumatic brain injury of non-accidental aetiology

SNOMED CT: 700506009

See <http://www.childbraininjurytrust.org.uk/> and <http://www.cerebra.org.uk>

Person-centred outcomes and **actions** to underpin these should relate to any disabilities arising as a consequence of the acquired brain injury e.g. cerebral palsy, physical disability, intellectual developmental disability, epilepsy, behavioural and emotional issues etc.

CongenInfect = Congenital infection

SNOMED CT: 82353009

See <http://www.patient.co.uk/doctor/congenital-perinatal-and-neonatal-infections>
and <http://www.uptodate.com/contents/overview-of-torch-infections>

Person-centred outcomes and actions to underpin these should relate to any disabilities arising as a consequence of the congenital infection e.g. cerebral palsy, physical disability, intellectual developmental disability, epilepsy, behavioural and emotional issues, visual impairment, hearing impairment etc.

Cleft palate

SNOMED CT: 87979003

See <http://www.patient.co.uk/doctor/Cleft-Lip-and-Palate.htm>

Most children with cleft palate have a repair in infancy. They should not have any residual disability due to the cleft palate. It is rare for a cleft palate not to be repaired.

Person-centred outcomes and actions towards these should be tailored to the individual, linked to the specific issues they experience e.g. speech, language and communication issues, feeding and swallowing issues etc.

CAHead = Congenital Anomaly of the Head, including craniofacial anomalies

SNOMED CT: 87290003

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific congenital anomaly, what the specific diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric disability, specialist craniofacial surgeon, clinical genetics etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific congenital anomaly are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability, specialist craniofacial surgeon, clinical genetics etc.
- For the paediatric team to provide reviews as required, depending on the individual situation, to proactively troubleshoot for any medical conditions that are known to be associated with the specific congenital anomaly, for example, feeding and swallowing issues, speech, language and communication issues, emotional and self-image issues, congenital anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their specific congenital anomaly, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's specific congenital anomaly, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Craniosyn
= Craniosynostosis

SNOMED CT: 57219006

Most infants with significant craniosynostosis that is compromising their development will have this repaired in infancy. Many will have no residual disabilities. Some will have disabilities that relate to a specific syndromic diagnosis.

Person-centred outcomes and **actions** to underpin these from other relevant sections should be considered, depending on the individual circumstances e.g. physical disability, chromosomal anomaly, genetic syndrome etc.

CongenAnom
= Congenital Anomaly

SNOMED CT: 276654001

High-level term covering all congenital anomalies. Should be used to describe all congenital anomalies not otherwise specified by more specific terminologies.

Person-centred outcomes and **actions** to underpin these from other relevant sections should be considered, depending on the impact of the specific congenital anomaly

GUanom
= Genitourinary tract anomalies

SNOMED CT: 287085006

See <http://www.patient.co.uk/doctor/Congenital-Urogenital-Malformations.htm>

Most will not cause disability that necessitates adjustments to be made. Some children and young people with GU anomalies may require surgery.

Person-centred outcomes and **actions** to underpin these should be tailored to the individual, depending on the impact of their GU anomalies e.g. on continence etc.

CHearDis**= Congenital heart disease**

SNOMED CT: 13213009

See <http://www.chd-uk.co.uk/>And <http://www.bhf.org.uk/heart-health/conditions/congenital-heart-disease.aspx>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific congenital heart disease, what the diagnosis is, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric cardiology, clinical genetics, paediatric disability as required etc. in order to make a more specific diagnosis or diagnoses
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific congenital heart disease are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric cardiology, clinical genetics and paediatric disability as required
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed congenital heart disease, for example, chest infections, heart failure, anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. chest infection, heart failure etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their neurological disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's neurological disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

HearingImp
= Hearing impairment

SNOMED CT: 15188001

This is a high level term for all impairments of hearing.
This should prompt referrals to audiology and ENT to more precisely define the nature of the hearing impairment.

SNHL
= Sensori-neural hearing loss

SNOMED CT: 60700002

This term should be used where the level of hearing impairment has not been more precisely defined and should prompt referrals to audiology and ENT to more precisely define the nature of the hearing impairment.

BCSNHL
= Bilateral Congenital Sensori-neural hearing loss

SNOMED CT: 877211000000100

This term should be used where the hearing loss has been identified from the newborn hearing screening programme. The level of hearing loss should be recorded as soon as this has been more precisely defined following audiological and ENT assessments.

ProfBSNHL
= Profound Bilateral Sensori-neural hearing loss (average loss >95 dBNL)

SNOMED CT: 877191000000104

SevBSNHL
= Severe Bilateral Sensori-neural hearing loss (average loss 71-95 dBNL)

SNOMED CT: 898061000000101

ModBSNHL
= Moderate Bilateral Sensori-neural hearing loss (average loss 41-70 dBNL)

SNOMED CT: 898071000000108

MildBSNHL
= Mild Bilateral Sensori-neural hearing loss (average loss 21-40 dBNL)

SNOMED CT: 898081000000105

UniSNHL
= Unilateral Sensori-neural hearing loss

SNOMED CT: 425980006

CondHL
= Conductive hearing loss

SNOMED CT: 44057004

HearingAid/s
= Hearing aid/s of any description in situ

SNOMED CT: 277213009

CochlearImp
= Cochlear implant/s in situ

SNOMED CT: 449840001

See www.hearing.screening.nhs.uk and www.ndcs.org.uk. See Disability Matters sessions:
Deaf Communication Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=72>
Hearing Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=129>

Person-centred Outcomes for children and young people with hearing impairments should be led by the specialist teacher for the Deaf, in consultation with the child or young person, their family and multi-disciplinary team, including the Ear, Nose and Throat surgeon, audiological scientist and paediatric disability specialist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their level of hearing impairment and the options for management, including hearing aid/s, cochlear implant/s etc., what has caused it, what to expect for the future, any associated medical conditions/diagnoses, the potential impact on the activities the child or young person would like to do at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the specialist teacher for the Deaf, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's hearing levels and a holistic assessment to consider what has caused it and to troubleshoot for any associated medical conditions. This may involve the disability paediatrician, ENT surgeon, audiological scientist, teacher for the Deaf, ophthalmologist, clinical geneticist etc.
- Other possible actions, leading on from the above, might be:
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their hearing impairment, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's hearing impairment, so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

VI
= Vision Impairment

SNOMED CT: 397540003

= high level term for all vision impairments. A more precise diagnosis and level of visual functioning should be recorded, following expert ophthalmological and orthoptic assessments.

See Disability Matters session: Vision Matters: <https://disabilitymatters.org.uk/course/view.php?id=128>

Vision Impairments are further caregorised as:

SevBVI
= Severe Bilateral Vision Impairment

SNOMED CT: 813871000000108

= Severely sight impaired (level required to be registered as severely sight impaired (blind)) - corrected vision <3/60 with full visual field, 3/60-6/60 with severely reduced visual field e.g. tunnel vision or 6/60 or above but with a very reduced field of vision, especially if a lot of vision lost in lower part of field.

SevUniVI
= Severe unilateral Vision Impairment

SNOMED CT: 813881000000105

PartVI
= Sight Impaired

(Level required to be registered as sight impaired - 3/60 to 6/60 with full visual field, or up to 6/24 with moderate reduction in field of vision or with central part of vision that is cloudy or blurry, or up to 6/18 if a large part of visual field e.g. a whole half of field of vision, is missing or if a lot of peripheral vision is missing.

SNOMED CT: 813891000000107

CVI = Cerebral Vision Impairment

SNOMED CT: 413924001

Synonymous with cortical visual impairment, although the latter is not as inclusive a term as cerebral visual impairment, which includes visual impairment originating within the cortex and in other parts of the brain.

For more information on vision impairment see:

<http://rnib.org.uk>

<http://www.ncb.org.uk/early-support/resources/new-information-resources>

Disability Matters Session: Vision Matters: <https://disabilitymatters.org.uk/course/view.php?id=128>

Person-centred Outcomes in this area should be led by the specialist teacher for the visually impaired, in consultation with the child or young person, their family and multi-disciplinary team, including the ophthalmologist, orthoptist, paediatric disability specialist, clinical geneticist etc.

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their level and nature of visual impairment and the options for management, including glasses, visual aids etc., what has caused it, the potential impact on the activities the child or young person would like to do at home, school and/or in the community, any associated medical conditions/diagnoses and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the specialist teacher for the visually impaired, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's eyes and vision and a holistic assessment to consider what has caused it and to troubleshoot for any associated medical conditions. This may involve the disability paediatrician, ophthalmologist, orthoptist, teacher for the visually impaired, clinical geneticist etc.
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their visual impairment, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's visual impairment, so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SALD
= Speech and Language Delay

SNOMED CT: 898051000000104

The outlook is usually excellent regardless of interventions or therapy. There should be no residual disability that necessitates adjustments to be made.

SpeechDis
= any disorder of speech production including expressive speech disorder, speech delay, speech sound production difficulties and absence of speech

SNOMED CT: 1145003

LangDis
= any Language Disorder

SNOMED CT: 280032002

FluencyDis
= any disorder of fluency of speech including stammer and bumpy speech

SNOMED CT: 229621000

ImpSocInt
= Impaired Social Interaction

SNOMED CT: 88598008

This includes all children and young people referred where there is a question about ?Autism or not, even if this is not explicitly stated in the referral.

See the following sessions in Disability Matters:

Communication Basics: <https://www.disabilitymatters.org.uk/course/view.php?id=68>

Understanding Matters for Effective Communication: <https://www.disabilitymatters.org.uk/course/view.php?id=69>

Three-way communication Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=70>

Communication support tools: <https://www.disabilitymatters.org.uk/course/view.php?id=86>

Communication Matters in Health: <https://www.disabilitymatters.org.uk/course/view.php?id=87>

Communication Matters in Learning: <https://www.disabilitymatters.org.uk/course/view.php?id=71>

Communication Matters in the Legal System: <https://www.disabilitymatters.org.uk/course/view.php?id=95>

Person-centred Outcomes for children and young people with speech, language and communication needs should be led by the specialist speech and language therapist and/or autism specialist teacher, in consultation with the child or young person, their family and multi-disciplinary team, including the paediatric disability specialist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their speech, language and communication needs and the options for management (including low tech and high tech communication support aids), including what has caused these, the potential impact on the activities the child or young person would like to do at home, school and/or in the community, any associated medical conditions/diagnoses and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the specialist speech and language therapist and/or autism specialist teacher, in consultation with the child or young person, their family and inter-disciplinary team.

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's speech, language and communication needs and a holistic assessment to consider what has caused them and to troubleshoot for any associated medical conditions. This may involve the specialist speech and language therapist and disability paediatrician as well as other members of the multi-disciplinary team (physiotherapist, occupational therapist etc).
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their speech, language and communication needs, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's speech, language and communication needs, so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

FTT = Failure To Thrive

SNOMED CT: 54840006

NICE draft guidance will be available in 2017:

<https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0767>

Person-centred outcomes in this area might include for the failure to thrive to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

RecWgtLoss
= Recent Weight Loss

SNOMED CT: 89362005

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the causes of weight loss to be appropriately investigated and managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning
- Another possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific diagnosis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

FeedingDif
= Feeding Difficulty = any difficulty with eating, drinking, chewing or swallowing

SNOMED CT: 78164000

RiskNutrProb
= Risk of Nutritional problem

= any difficulty with eating, drinking, chewing or swallowing that presents a risk to nutritional sufficiency.

SNOMED CT: 129689002

These children and young people require expert multi-disciplinary assessment including with a specialist speech and language therapist with competence in dysphagia.

This is sub-divided into:

LowRskMaln
= Low Risk of Malnutrition

SNOMED CT: 764891000000105

MedRskMaln
= Medium Risk of Malnutrition

SNOMED CT: 764901000000106

HghRskMaln
= High Risk of Malnutrition

SNOMED CT: 764911000000108

ARFID
= Avoidant/Restrictive Food Intake Disorder

SNOMED CT: 700213005

This includes the challenging situations where a child or young person avoids food/s or has a restricted repertoire of foods they are prepared to eat, for example only 'white foods' etc.

Types of specialist diet: Sub-divided into:

Liquid Diet

SNOMED CT: 10888001

ThFluidDt

= Thickened fluid diet

SNOMED CT: 226213003

Soft Diet

SNOMED CT: 78150000

WgtGainDt

= Weight Gain diet

SNOMED CT: 703977005

Person-centred Outcomes for children and young people with feeding and nutritional issues should be led by the dietician and dysphagia-competent specialist speech and language therapist, in consultation with the child or young person, their family and multi-disciplinary team, including the paediatric disability specialist +/- paediatric gastroenterologist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their feeding and dietary needs and the options for management, including what the cause was, the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future and any associated medical conditions/diagnoses
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the dietician and specialist speech and language therapist, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's feeding and nutritional needs and a holistic assessment to consider what has caused these and to troubleshoot for any associated medical conditions. This may involve the dysphagia-competent specialist speech and language therapist, paediatric disability specialist, paediatric dietician +/- paediatric gastroenterologist
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting
- because of their feeding and dietary needs, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's feeding and nutritional needs, so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

FailureGainWgt

= Failure to Gain Weight = This means weight gain below expected for age.

SNOMED CT: 36440009

Person-centred Outcomes in this area should be led by Health.

The outcomes might include:

- For the child or young person to thrive and gain weight so as to be in good nutritional condition

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely).

Actions towards achieving the outcome might include:

- For the child or young person to have a nutritional assessment and management plan with a paediatric dietician
- For the child or young person to have a general health assessment with the general practitioner or paediatrician, to identify any treatable causes of failure to gain weight, so that these can be addressed in a timely way

Actions will depend on the person-centred outcomes agreed with the child or young person and family

Obesity

SNOMED CT: 414916001

A common childhood condition in its own right, which can be especially challenging to manage when associated with disabling conditions. Usual programmes to tackle obesity may not all be accessible to disabled children and young people, although it is worth specifically enquiring, as it may be possible for reasonable adjustments to be made to accommodate special needs. Otherwise specific inter-agency and multi-disciplinary care plans may be required to adequately address this often complex issue.

NICE clinical guideline 189 weight classes defined based on a person's body mass index (BMI) are as follows:

| | |
|-----------------|-------------------------------|
| Healthy weight: | 18.5 - 24.9 kg/m ² |
| Overweight: | 25 - 29.9 kg/m ² |
| Obesity I: | 30 - 34.9 kg/m ² |
| Obesity II: | 35 - 39.9 kg/m ² |
| Obesity III: | 40 kg/m ² or more |

NB: Black African, African-Caribbean and Asian (South Asian and Chinese) groups can be at increased metabolic/cardiac risk at BMI 23 kg/m² and at high risk at BMI 27.5 kg/m²

NB: BMI may be falsely elevated in the muscular person, hence important for health care professional to be making the assessment
See NICE guideline CG189 Obesity: identification, assessment and management: <https://www.nice.org.uk/guidance/cg189>

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child or young person to reduce their rate of weight gain so as to be in good nutritional condition but no longer obese.

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For the child or young person to have a nutritional assessment and management plan with a paediatric dietician
- For the child or young person to have a general health assessment with the general practitioner or paediatrician, to identify any medical factors contributing to their obesity as well as any complications, for example, diabetes, hypertension etc.

Actions will depend on the person-centred outcomes agreed with the child or young person and family

ASD = Autism Spectrum Disorders

SNOMED CT: 35919005

This term is used to include all the spectrum of disorders including core autism, Asperger's syndrome, pervasive developmental disorder etc. May also be known as Autism Spectrum Conditions.

See:

NICE guidance www.nice.org.uk/Guidance/CG128

DSM-5 299.00: <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>

ICD-10 F84.0: www.icd10data.com/ICD10CM/Codes/F01-F99/F80-F89/F84-/F84.0

DisabilityMatters session: Autism Spectrum Disorders: <https://www.disabilitymatters.org.uk/course/view.php?id=93>

Broad symptom area A

Persistent deficit in social communication and social interaction across multiple context, as manifested by the following, currently or by history:

- 1 Deficits in social reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions
- 2 Deficits in non-verbal communicative behaviour is used for social interaction, ranging, for example, from poorly integrated verbal and non-verbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and non-verbal communication
- 3 Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social context; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers

Broad symptom area B

Restricted, repetitive patterns of behaviour, interests or activities, as manifested by at least two of the following, currently or by history:

- 1 Stereotyped or repetitive motor movements, use of objects, or speech
(E.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)
- 2 Insistence on sameness, inflexible adherence to routines, or ritualised patterns of non-verbal or verbal behaviour
(E.g., extreme distress that small changes, difficulties in transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day)
- 3 Highly restricted, fixated interests that are abnormal in intensity or focus
(E.g., Apparent indifference to pain/temperature, aversive response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with light or movement)
- 4 Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment
(E.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)

Broad symptom area C

Symptoms must be present in the early developmental period

(But may not become fully manifest until social demands exceed limited capacities, and may be masked by the learned strategies in later life)

Broad symptom area D

Symptom cause clinically significant impairment in social, occupational, or other important area of current functioning

Broad symptom area E

These disturbances are not better explained the intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level

Person-centred Outcomes for children and young people with autism spectrum disorders should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team, including the specialist speech and language therapist and paediatric disability specialist and/or child and adolescent mental health expert

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their autism spectrum disorder including their level of intellectual abilities and functioning across a range of domains and to understand the potential impact on the activities the child or young person would like to do at home, school and/or in the community and what it means for the future and any associated medical conditions/diagnoses
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the appropriate team member, depending on the main issues for the child or young person, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's autism spectrum disorder and a holistic assessment to consider what may have caused this and to troubleshoot for any associated medical conditions, for example, epilepsy, disordered sleep, constipation etc. This may involve the specialist speech and language therapist, disability paediatrician, clinical geneticist, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their autism spectrum disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's autism spectrum disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

ChromDis = Chromosomal Disorders

SNOMED CT: 409709004

GenSyndr = Genetic Syndrome

SNOMED CT: 290028006

Information will be unique to the condition.

General sources of support and information include:

- Contact a Family www.cafamily.org.uk
- Council for Disabled Children www.councilfordisabledchildren.org.uk
- Family Fund www.familyfund.org.uk
- Unique the Rare Chromosome Disorder Support Group <http://www.rarechromo.co.uk>
- Syndromes without a name www.undiagnosed.org.uk

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Chromosomal Disorder or Genetic Condition, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains, including their ability to participate in activities at home, school and /or in the community and what this means for their future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- Possible actions might include:
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific Chromosomal Disorder or Genetic Syndrome are and what to expect for the future. This may require networking across all specialists involved, especially with Clinical Genetics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the diagnosed condition, for example, epilepsies, cardiac conditions, renal conditions etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled.
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Chromosomal Disorder or Genetic Syndrome, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Chromosomal Disorder or Genetic Syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DownSynd = Down's Syndrome

SNOMED CT: 41040004

This term covers Down's Syndrome of all types. Typical features include:

- Hypotonia
- Typical facial appearance: upslanting palpebral fissures, epicanthic folds, flat facial profile, brachycephaly with patent posterior fontanelle, short nose with depressed nasal bridge, small ears
- Single palmar creases and sandal gap between first and second toes
- Congenital heart disease eg, perimembranous ventricular septal defect, patent ductus arteriosus, atrial septal defect, atrioventricular septal defect
- Cognitive level: mild to severe intellectual developmental impairment
- Typical behavioural phenotype: relative strengths in visual processing, receptive language and non-verbal social functioning and relative weakness in gross motor and expressive language skills
- Typical associated medical conditions: hypothyroidism, Hirschprung's syndrome, duodenal atresia, leukaemia, autism spectrum disorder

See Down Syndrome Medical Interest Group <http://www.dsmig.org.uk/>

See session on Learning Disability in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Down's Syndrome and implications for their physical health and their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency. Not everyone with Down's Syndrome may need such a plan, but this should at least be considered
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes might be to identify early any of the medical conditions that are known to be associated with Down's Syndrome, so that these can be proactively managed e.g. congenital heart disease, hypothyroidism, visual impairment or refractive errors, hearing impairment, social communication disorders including autism, musculo-skeletal disorders etc.
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education and Health teams, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Down's Syndrome are and what to expect for the future. This may require networking across all specialists involved
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, breathing difficulties, heart complications etc. This should include a statement about resuscitation and intensive care if required, which usually will be a positive statement to confirm that full resuscitation and intensive care should be offered, to protect the person's equal right to high quality assessment and treatment, the same as for anyone who is not disabled.
- For the paediatric team to provide and arrange regular reviews, mindful of the range of possible associated health conditions that might arise
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Down's Syndrome, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Down's Syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

22q11del
= 22q11 Deletion Syndrome

SNOMED CT: 449818005

Other terms that may be used include Di George Syndrome, Velo-cardio-facial syndrome, Shprintzen's Syndrome, CATCH-22 syndrome. Typical features include:

- Intellectual developmental disability can be mild to severe
- Delayed speech milestones, specific difficulties with abstract reasoning and poor problem-solving skills in the school aged child.
- Typical facial appearance: short palpebral fissures with telecanthus, wide and prominent nasal bridge and root, squashed nasal tip, small mouth, ears round in shape with deficient upper helices
- Congenital heart disease (e.g, especially tetralogy of Fallot, ventricular septal defect, interrupted aortic arch etc.)
- Cleft palate, submucous cleft palate, velopharyngeal insufficiency, bifid uvula, hypernasal speech
- Short stature
- Pachygyria, polymicrogyria (especially bilateral perisylvian polymicrogyria)
- Family history of any of the above, marked intrafamilial variability in expression; family history of psychiatric disorder (including bipolar affective disorder and schizophrenia)
- Typical associated medical conditions and complications include:
 - Early feeding difficulties (e.g, mild regurgitation through nose)
 - Hypocalcaemia, especially neonatal (may be associated with seizures)
 - Frequent infections (may have impaired cell mediated immunity especially under 2 years)
 - Mild thrombocytopenia; autoimmune disorder (e.g, haemolytic anaemia, type 1 diabetes mellitus, hypo/hyper-thyroidism)
 - Chronic serous otitis media
 - Sensorineural hearing loss
 - Structural renal tract anomalies

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team.

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their 22q11 deletion syndrome, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely).

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team. Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific 22q11 deletion syndrome are and what to expect for the future. This may require networking across all specialists involved, including paediatric disability, clinical genetics, regional cleft/craniofacial team, ENT, audiology, paediatric cardiology, specialist speech and language therapy, paediatric endocrinology, paediatric immunology, child and adolescent mental health service etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the 22q11 deletion syndrome, for example, cardiac anomalies, velopharyngeal dysfunction, hearing impairment, epilepsies, intellectual disabilities, speech, language and communication needs, immunological deficiencies/disorders etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. chest infections, cardiac issues etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their 22q11 deletion syndrome, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's 22q11 deletion syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

NF1 = Neurofibromatosis Type 1

SNOMED CT: 92824003

To make a diagnosis of NF1, **two or more major diagnostic criteria** are required:

- Six or more café au lait patches measuring at least 5mm before puberty or 15mm after puberty
- Two or more neurofibromas or one plexiform neurofibroma (large, spreading jelly-like subcutaneous lesion)
- Axillary or groin freckles
- Lisch nodules on the iris (require slit lamp examination to identify)
- Optic glioma
- Characteristic skeletal abnormality (tibial bowing, orbital malformation)
- First degree relative with a confirmed diagnosis of NF1

See <http://www.nfauk.org/>

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their neurofibromatosis type 1, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome, for those who are severely affected, might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency

For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>

- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their neurofibromatosis type 1 are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability and clinical genetics.
- For the paediatric team to provide and organise regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the neurofibromatosis type 1, for example, visual pathway tumours, hypertension, scoliosis, attention deficit disorders, autism spectrum disorders, epilepsies, painful neurofibromata or plexiform neurofibromas etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. pain, spinal cord compromise etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their neurofibromatosis type 1, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's neurofibromatosis type 1, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

TS
= Tuberous Sclerosis

SNOMED CT: 7199000

A multi-system disorder, also known as tuberous sclerosis complex, involving multiple hamartomata of the brain, skin and kidneys. There is great variability in presentation and severity and TS can present at any age. The cause is a mutation in either the TSC1 gene on chromosome 9 or the TSC2 gene on chromosome 16. Transmission is autosomal dominant, but 60-70% cases are sporadic and represent new mutations.

Two major diagnostic criteria are required to confirm diagnosis:

- Facial angiofibromas or forehead plaque
- Nontraumatic ungula or periungual fibroma
- Hypomelanotic macules (3 or more)
- Shagreen patch (connective tissue naevus)
- Cortical tuber
- Multiple retinal nodular hamartomas
- Subependymal nodules
- Subependymal giant cell astrocytoma
- Cardiac rhabdomyoma, single or multiple
- Pulmonary lymphangiomyomatosis and/or renal angiomyolipoma
- Pathogenic mutation in TSC1 or TSC2 on gene analysis.

Suggestive features requiring further investigation include:

- Multiple, randomly distributed pits in dental enamel
- Hamartomatous rectal polyps
- Bone cysts
- Cerebral white matter radial migration lines
- Gingival fibromas
- Nonrenal hamartoma
- Retinal achromic patch
- 'confetti' skin lesions
- multiple renal cysts
- skin tags
- positive family history in first degree relative

The current clinical guidelines in the UK recommend full history and clinical examination including fundoscopy and UV light examination of the skin, cranial imaging (MRI or non enhanced CT), renal ultrasound, echocardiography (in infants) and screening of family members.

Associated medical conditions to screen for and manage promptly include:

- Epilepsies
- Neurological problems
- Cardiac symptoms
- Skin lesions
- Kidney complications
- Pulmonary complications
- Developmental and psychological problems.

See <http://www.tuberous-sclerosis.org/>

Person-centred Outcomes for children and young people with tuberous sclerosis should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their tuberous sclerosis, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome, for those who are severely affected, might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their tuberous sclerosis are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric disability and clinical genetics
- For the paediatric team to provide and organise regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the tuberous sclerosis, for example, epilepsy etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their tuberous sclerosis, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's tuberous sclerosis, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

FraX = Fragile X Syndrome

SNOMED CT: 613003

See <http://www.fragilex.org.uk/>

See session on learning disability in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=85>

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Fragile X Syndrome, the implications for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency. Not everyone with Fragile X Syndrome may need such a plan, but this should at least be considered
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Fragile X Syndrome are and what to expect for the future. This may require networking across all specialists involved
- For the paediatric team to provide regular reviews to proactively troubleshoot for any known associated neuro-behavioural disorders or medical associated conditions, keeping up to date via the Clinical Genetics team with treatment possibilities for those with Fragile X Syndrome
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, behaviours that others may perceive to be challenging but that might mean, for example, that the child or young person is in pain, etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to confirm that full resuscitation and intensive care should be offered, the same as for anyone who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Fragile X Syndrome, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Fragile X Syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

TurnerSynd
= Turner's Syndrome

SNOMED CT: 38804009

Complete or partial deletion of one X chromosome.
See <http://www.tss.org.uk>

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- Possible outcome might include: for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Turner's Syndrome, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Turner's Syndrome are and what to expect for the future. This may require networking across all specialists involved, especially with clinical genetics
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the Turner's Syndrome, for example, short stature etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Turner's Syndrome, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Turner's Syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

IEM**= Inborn Error of Metabolism**

SNOMED CT: 86095007

This includes metabolic and neurometabolic disorders.

See:
<http://www.bimdg.org.uk/>
<http://www.climb.org.uk/>
 Disability Matters session: Complex Conditions Matter: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their inborn error of metabolism, their intellectual abilities and functioning across a range of domains, including how these are likely to change over time and the likely impact on their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their health condition are, the likely impact on their ability to participate in activities at home, school and/or in the community and what to expect for the future. This is likely to require networking across all specialists involved, for example in paediatric disability, paediatric neurology, clinical genetics, paediatric metabolic medicine and others as required
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, breathing difficulties, metabolic decompensation etc. This should include signposting to condition-specific web-based resources where these are available as well as a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their inborn error of metabolism, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's inborn error of metabolism, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

PIND**= Progressive, Intellectual and Neurological Deterioration**

SNOMED CT: 931031000000104

This is defined as:

- Progressive deterioration for more than 3 months
- WITH loss of previously attained intellectual/developmental abilities
- AND development of abnormal neurological signs

Excludes static intellectual loss e.g. after head injury, encephalitis or near drowning

Includes children meeting the case definition even where specific neurological diagnosis made; metabolic disorders leading to neurological deterioration; seizure disorders if associated with progressive deterioration; children diagnosed with neurodegenerative conditions but have not yet developed symptoms

See <http://bpsu.inopsu.com/studies/PIND/index.html>See session on complex conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>**Person-centred Outcomes** in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their progressive intellectual and neurological deterioration, their intellectual abilities and functioning across a range of domains, also the likely impact on the child or young person's ability to participate in activities at home, school and/or in the community, how these are likely to change over time, including any diagnosed conditions that have caused these
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- It is crucial that any objectives set really are achievable, that they celebrate the enjoyment and participation of the child or young person, including in making choices and decisions about their life, care and future planning, including where appropriate, about their wishes for end of life care
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their health condition are and what to expect for the future. This is likely to require networking across all specialists involved, for example in paediatric disability, paediatric neurology, clinical genetics, paediatric metabolic medicine and others as required
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, breathing difficulties, pain etc. This should include a statement about resuscitation and intensive care if required
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their progressive intellectual and neurological deterioration, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's progressive intellectual and neurological deterioration, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Mitochondrial dis = Mitochondrial disorders

SNOMED CT: 237986005

See <http://www.ncbi.nlm.nih.gov/books/NBK1224/>

See session on complex conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their mitochondrial disorder, their intellectual and other functional abilities across a range of domains, the likely impact on the child or young person's ability to participate in activities at home, school and/or in the community and how these are likely to change over time
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their health condition are and what to expect for the future. This is likely to require networking across all specialists involved, for example in paediatric disability, paediatric neurology, clinical genetics, paediatric metabolic medicine and others as required
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, breathing difficulties, metabolic decompensation etc. This should include signposting to condition-specific web-based resources where these are available and a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their mitochondrial disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's mitochondrial disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

MECP2Dis = MECP2 Disorders

= All disorders where there are copy number variants or mutations in the MECP2 region of the X chromosome
Includes classical Rett Syndrome, atypical Rett Syndrome, MECP2 duplications and mutations
See session on Complex Conditions in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

SNOMED CT: 68618008

Girls

- Relatively typical early development
- Normal head circumference at birth with deceleration in head growth
- Loss of skills, especially communication and speech
- Gait/truncal apraxia/dyspraxia
- Small, cold feet
- Stereotyped motor mannerisms e.g. hand flapping, complex whole body movements etc.
- Typical behavioural phenotype: stereotypic hand movements e.g. wringing or flapping; social withdrawal during phase of regression, later: alert and interested in the world, but little or no speech; aspects of autism; spontaneous outbursts of laughing or crying, including in sleep; reduced response to pain; disturbed sleep/wake cycle; teeth grinding

Boys

- Neonatal encephalopathy
- Early apnoeas
- Typical facial appearance (not universal): brachycephaly, midfacial hypoplasia, large ears, flat nasal bridge
- Hypotonia
- Delayed motor milestones with progressive spasticity predominantly in lower limbs
- Intellectual developmental disability with limited or absent speech, relatively better receptive language, inquisitive
- Fall off in head growth
- Typical behavioural phenotype: stereotypical movements of hands; aspects of autism; teeth grinding
- Typical secondary disabilities and medical complications: recurrent and increasing respiratory infections; ataxia; escalating epileptic encephalopathy and unusual, autonomic attacks (irregularities of breathing, heart rate and temperature with episodic flushing and pale)

See
<http://www.rettuk.org>
<http://www.mecp2.org.uk>
Disability Matters session: Complex Conditions Matter: <https://www.disabilitymatters.org.uk/course/view.php?id=94>

MECP2Dupl = MECP2 Duplication Syndrome

SNOMED CT: 702816000

Person-centred Outcomes for children and young people with MECP2 disorders should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their MECP2 Disorder, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains, their participation in activities at home, school and/or in the community and how these may change over time
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific MECP2 Disorder are and what to expect for the future. This may require networking across all specialists involved
- For the paediatric team to provide regular reviews to proactively troubleshoot for any known associated medical associated conditions, for example, epilepsies, postural deformities etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. seizures, constipation, pain etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their MECP2 Disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's MECP2 Disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

PerinatalDis
= Perinatal Disorder

SNOMED CT: 415073005

28-37wksGest
= Born at 28-37 weeks of completed gestation

SNOMED CT: 310661005

<28wksGest
= Born at less than 28 weeks of completed gestation

SNOMED CT: 268817004

Person-centred outcomes and **actions** will depend on the effects of the prematurity or perinatal disorder - see other relevant sections

See session on Safeguarding Matters in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=54>

NAI = Non-Accidental injury to Child

SNOMED CT: 158094009

VictNeglect = Victim of infant/child neglect

SNOMED CT: 419686005

VictEmAbu = Victim of Emotional Abuse

SNOMED CT: 419916003

VictChSxAb = Victim of Child Sexual Abuse

SNOMED CT: 700229002

VictExploit = Victim of Exploitation

SNOMED CT: 225823009

VictSexExploit = Victim of Sexual Exploitation

SNOMED CT: 785101000000105

VictDomViol = Victim of Domestic Violence

SNOMED CT: 205171000000107

VictSexAbuse = Victim of Sexual Abuse

SNOMED CT: 225826001

VictOthBehav = Victim of Other Person's Behaviour

SNOMED CT: 225818009

SuspChAb = Suspected Child Abuse

SNOMED CT: 162596006

ChAbFam = Child Abuse in the family

SNOMED CT: 161062006

CYPatRisk = Child or young person at risk

SNOMED CT: 160877008

Person-centred outcomes in this area are very personal to the individual, their resilience, protective factors, situation, vulnerability etc. but are likely to include being and feeling safe and confident at all times and in all settings

Actions towards achieving the outcomes might include having the right support in place, access to any therapy required, to be removed from harm etc.

Documenting family reported barriers to participation and quality of life is a start to acknowledging that they exist and can be a start to addressing them. Making active enquiries about such barriers is appreciated by families and can lead to making a significant positive difference, as the clinician can advocate on their behalf

EHCPagreed
= Emergency Health Care Plan agreed and in place

= family held emergency health care plan in place for all with complex conditions

SNOMED CT: 811871000000107

An emergency healthcare plan is a brief document that follows the child or young person between all settings and includes important information about the child or young person, their active health concerns, diagnosis if there is one, any emergency treatment and potential scenarios that may arise with instructions about what to do and who to contact should a health emergency arise. The purpose of such a plan is to ensure that the child or young person gets the right treatment by the right clinicians in a timely way. It will also include a statement about what has been discussed and agreed about appropriate levels of intervention e.g. mostly this will be to assess and manage as per advanced paediatric life support (APLS) guidance at all times, but for those with known life-limiting conditions who are too frail for this to be appropriate, may state to allow a natural death when the time comes, with full symptom and family support.

Further information and an e-learning module about emergency healthcare plans can be found on the website of the council for disabled children:

www.councilfordisabledchildren.org.uk/what-we-do/work-themes/health/resources/emergency-healthcare-plans and www.councilfordisabledchildren.org.uk/ehp

ImpParticip
= Impaired Participation in every day activities or life situations

SNOMED CT: 926291000000104

Person-centred Outcomes in this area should be led by whichever agency is appropriate in the individual situation.

The outcomes might include:

- To improve the child or young person's participation in every day activities and life situations at home, school and/or in the community

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation in every day activities and life situations that the child or young person might potentially face in any setting, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge, to identify what reasonable adjustments or action might be required, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation in every day activities and life situations that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed with the child or young person and family

Familylss = Family Issues

SNOMED CT: 248539004

There may be family issues going on that are impacting on participation and quality of life at that moment. Encouraging families to write down before a consultation if there are such concerns can facilitate discussion on the subject, which may then lead to being able to do something positive about the issues or signposting to further support

See Disability Matters sessions:

Family Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=110>

Caring for Parent Carers Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=111>

Finance Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=97>

Advocacy Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=67>

Person-centred outcomes in this area will be very specific to the family and the issues they are facing. Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes may include:

- Empowering the family to resolve the issues that they face for themselves
- Advocacy by members of the team, signposting or referral to other sources of support to resolve the issues

Schoollss = School Issues

SNOMED CT: 161155000

Medical advice for education is not just about writing a report as part of formal assessment of education, health and care needs, but being alert to any issues that arise in school where specific advice from the paediatrician, or a referral to a therapist, specialist support teacher or other colleague may make a positive difference. There are an increasing range of accessible websites about specific disabling conditions that include information for teachers and advice on appropriate reasonable adjustments and modifications in the learning environment

Person-centred outcomes in this area will be very specific to the child or young person and the school issues that they are facing.

Actions towards achieving the outcomes may include:

- Empowering the family to communicate with the school team to resolve the issues
- Involvement of the appropriate specialist support teacher or educational psychologist, depending on the child or young person's condition, to resolve the issues

Housinglss = Housing Issues

SNOMED CT: 81877007

See session on Advocacy Matters in Disability Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=67>

Person-centred outcomes in this area will be very specific to the family's housing issues. Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes may include:

- Empowering the family to resolve the housing issues for themselves wherever possible
- Advocacy with housing providers or the local authority where adaptations are required or rehousing. A letter from a paediatrician can definitely make a positive difference to getting housing issues addressed, whether this be re-housing or maintenance or modifications to existing housing, to ensure the needs of the disabled child or young person are safely and appropriately met. The paediatrician can also advocate for those in social housing or in receipt of housing benefits with a disabled child or young person who needs their own bedroom on medical grounds. See <http://www.cafamily.org.uk/news-and-media/important-advice-for-families-on-bedroom-tax/>

Equiplss = Equipment Issues

SNOMED CT: 405651005

For some disabled children and young people and their families, equipment is essential to allow participation in every day activities and enjoyment of the best quality of life

The clinician may need to chase up equipment, or make sure someone else is doing so, or may need to recommend new equipment

Person-centred outcomes in this area will be very specific to the equipment issues faced, but may include having all the right equipment in place and in good working order, based on assessed needs

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes may include:

- Referral for assessment regarding individual equipment needs
- Ensuring pathways for equipment assessment and provision are fit for purpose, providing the right equipment for a range of needs in a timely, efficient and cost-effective way that is acceptable for children, young people and their families

Leisurelss = Access to Leisure Issues

SNOMED CT: 300742006

Disabled children, young people and their families have an equal right to leisure activities as anybody else

Local leisure facilities can be encouraged to accommodate the needs of disabled children and young people and the Equality Act 2010 protects their right to access and can be quoted as necessary as part of advocacy

Person-centred outcomes in this area will be very specific to the child, young person and issues faced

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes may include:

A letter from the paediatrician to explain why medication and specialist feeds and equipment are required to be carried on flights, why excess baggage is required to manage all their equipment and why it is helpful for the child or young person not to have to wait or queue when this can be otherwise avoided

Supportlss = Support Issues

SNOMED CT: 25622003

We may think we are supportive and that families have the support that they need, but unless we specifically ask families for their view on this, we may fall into the trap of making the wrong assumptions and miss an opportunity to signpost to further sources of appropriate support

Person-centred outcomes in this area will be very specific to the child, young person and their family and their individual needs for support

An outcome might be that the child, young person and family have all the support that they need in place

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes may include:

Signposting to sources of support in the local community, regionally and nationally, including peer support, voluntary organisations such as the Council for Disabled Children and Contact a Family etc.

Infolss = Information Issues

SNOMED CT: 720741000000105

we do not know if family's information needs are addressed unless we ask and this is another area where a positive difference can be made easily, by signposting as appropriate

UndPlan**= Family understands care plan**

'Carer demonstrates knowledge of subject's care plan' in terminology-speak

SNOMED CT: 700225008

NotUndPlan**= Family does not understand care plan**

'Carer demonstrates deficient knowledge of subject's care plan' in terminology-speak

SNOMED CT: 700224007

FAMILY EXPERIENCE OF QUALITY OF CARE

Time from first presentation to primary working diagnosis (weeks) = time from first presentation by the family to a health professional with concerns about a potentially disabling condition to the documentation of a working diagnosis and clear management plan. This indicator has come from the children and young people's outcome forum framework and is something that parents particularly want because they are fed up with often long waiting times before a diagnosis is made

ReqConsSup
= Requires Constant Supervision

SNOMED CT: 240451000000106

Person-centred outcomes in this area may include ensuring that adequate arrangements are in place for constant supervision. Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes might include arranging:

- A continuing healthcare assessment
- An assessment with the disabled children's social work team

RiskDth<18
= At Risk of Death before 18 years (expected/unexpected) - clinical judgement

SNOMED CT: 925821000000105

This is VERY important information to share with families. If the clinician thinks that it is possible that the child or young person may die before adulthood, they have a responsibility to share this information with the family, difficult though this may be. It is only being open with families about such a possibility that families can prepare themselves for what may be ahead and have the opportunity to make choices about aspects of care, including choice of place of care. From the evidence of the child death review process and from the pilot "Why children die" that went before it, it is known that disabled children and young people are at increased risk of sudden and unexpected death as well as for a minority, from death in the course of illness progression or increasing frailty.

See

www.education.gov.uk/publications/eOrderingDownload/Working%20Together%20April.pdf

www.publichealth.hscni.net/sites/default/files/Why%20Children%20Die%20-%20a%20pilot%20study%202006-summary.pdf

http://www.injuryobservatory.net/why_children_die.html

Disability Matters session: Advance Care Planning Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=64>

Discussing the possibility of death before adulthood is not the same as changing levels of intervention, because many children and young people at risk of death before adulthood, including many disabled children and young people, may be appropriately continuing to receive full and active treatment including full resuscitation and intensive care if needed.

See: Horridge KA. Advance Care Planning: practicalities, legalities, complexities and controversies. *Arch Dis Child*. 2015; 100:380-385

PrefPIDDisc
= Preferred place of death discussed with patient and family

SNOMED CT: 518811000000106

PrefPIDLoc
= Preferred place of death (location)

PlaceDeath
= Place of death (location)

The preferred place of death may be documented in an advance care plan, a 'wishes' document or in an emergency health care plan.

Whether this is achieved or not can be documented after death. Considerable variation in achieving choice of place of death was evidenced by the Atlas of Variation so there is work to be done towards improving this. See NHS Atlas of variation in healthcare for children and young people. 2012. RightCare (in collaboration with the Child and Maternal Health Observatory).

Person-centred outcomes in this area may include ensuring that the child, young person and family are aware of the risk of expected or unexpected death and have an advance care plan in place. Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes might include:

- Discussion led by lead clinician with child, young person and family about the possibility of unexpected or expected death
- Preparation of an advance care plan by the lead clinician after discussion and consultation with the child, young person, their family and multidisciplinary team

DepCPAP = Dependant on Continuous Positive Airways Pressure

SNOMED CT: 429487005

DepVent = Dependant on Ventilator

SNOMED CT: 444932008

DepTrachy = Dependant on Tracheostomy

SNOMED CT: 302108003

ITB = Intrathecal Baclofen

SNOMED CT: 864041000000108

VNS = Vagal Nerve Stimulator

SNOMED CT: 700210008

DBS = Deep Brain Stimulator in situ

SNOMED CT: 873711000000102

NGT = Nasogastric Tube in place

SNOMED CT: 449842009

PEG = Gastrostomy Tube in place

SNOMED CT: 302109006

Jejunostomy = Jejunostomy tube in place

SNOMED CT: 302110001

TPN = Parenteral nutrition

SNOMED CT: 887441000000107

VPshunt = Ventriculo-Peritoneal Shunt in place

SNOMED CT: 700132008

Person-centred outcomes in each of these areas might include for:

- The technology to be in good working order
- All involved in the child or young person's care to be confident in using the technology or understanding the red flags for technology failure or complications

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes might include:

- Regular review of the child or young person by the appropriate specialists to ensure the technology is in good working order
- Training for all involved in the child or young person's care in all aspects of the technology and its implications for the child or young person, including red flags for technology failure or complications

AltCommSk**= Uses Alternate Communication Skill**

= Needs alternative or augmented communication aids or adaptations to communicate.

This includes children and young people who experience physical barriers to communication and those who experience behavioural barriers or barriers related to autism spectrum disorders

SNOMED CT: 761541000000100

Person-centred outcomes might include for:

- Everyone who works with the child or young person to be familiar with their communication method
- The communication method to be up to date with the vocabulary that the child or young person needs

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes might include:

- Training for all staff and peers to ensure that they are competent to use the communication method to send and receive communication with the child or young person
- Regular reviews with the specialist speech and language therapist to ensure that the communication method remains appropriate and that the child or young person is empowered to have access to the vocabulary that they need

HIE
= Hypoxic Ischaemic Encephalopathy

SNOMED CT: 126945001

Person-centred outcomes and actions will depend on the brain damage caused and its effects on functioning

Epilepsies

SNOMED CT: 84757009

See <http://guidance.nice.org.uk/CG137>

EpPN
= Epilepsy that meets the criteria for referral to paediatric neurology epilepsy specialist input as per NICE guidance CG137

SNOMED CT: 889921000000104

One or more of the following are present:

- The epilepsy is not controlled with medication within 2 years onset
- Management is unsuccessful after two drugs
- The child is under two years of age
- The CYP experiences, or is at risk of, unacceptable side effects from medication
- There is a unilateral structural lesion
- There is psychological or psychiatric co-morbidity
- There is diagnostic doubt as to the nature of the seizures or the seizure syndrome

EpCESS
= Epilepsy that meets one or more of the criteria for referral to highly specialist Children's Epilepsy Surgery Service

SNOMED CT: 889941000000106

One or more of the following are present:

- Children with catastrophic early onset epilepsy with evidence of lateralisation of the seizure onset
- All children under 24 months old with evidence of focality of seizure onset, with or without an MRI evident lesion
- Children of any age with evident focal epilepsy, or lateralised seizures associated with congenital hemiplegia, resistant to two appropriate anti-epileptic drugs (AEDs)
- Children who have epilepsy associated with a lateralised abnormality seen on a brain scan
- Children with epilepsy associated with Sturge Weber syndrome, benign tumours with developmental issues and/or ongoing seizures, or Rasmussen's syndrome
- Children of any age with epilepsy associated with tuberous sclerosis resistant to two AEDs where seizures may arise from a single focus (probably from a single tuber)
- Children who have 'drop attacks' as part of a more complex epilepsy
- Children with epilepsy associated with hypothalamic hamartoma

SeizureDis
= Seizure Disorder

SNOMED CT: 128613002

AbsenceSz
= Absence Seizure

SNOMED CT: 79631006

FocalSz
= Focal Seizure

SNOMED CT: 29753000

Person-centred Outcomes for children and young people with epilepsies should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their specific epilepsy, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team. Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific epilepsy are and what to expect for the future. This may require networking across all specialists involved
- For the lead clinician (paediatrician with epilepsy expertise, paediatric neurologist, disability paediatrician) to review the child or young person's epilepsy regularly, along with the epilepsy nurse specialist, to ensure seizure control is as good as it can be, that medication is being taken/given regularly with minimum adverse side effects, all as per NICE guidance CG137
- For the paediatric team to provide regular reviews to proactively troubleshoot for any known associated conditions, for example, constipation, disordered sleep, behavioural, emotional issues, intellectual disabilities etc. so that these are identified early and promptly managed
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. different seizure types and durations etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
 - All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their epilepsy, be these attitudinal, physical or other
 - Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's epilepsy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
 - Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

WestSyndrome
= West Syndrome

SNOMED CT: 28055006

Triad of infantile spasms, hypsarrythmic EEG and developmental regression.

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the family and multi-disciplinary team

- One possible outcome might be for the family and inter-agency team to achieve a detailed understanding of their specific West Syndrome, the implications of this for their physical health, their intellectual and other functional abilities across a range of domains and impact on their participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child's family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child's family and multi-disciplinary team, what the implications of their West's Syndrome are and what to expect for the future. This may require networking across all specialists involved
- For the lead clinician (paediatrician with epilepsy expertise, paediatric neurologist, disability paediatrician) to review the child's epilepsy regularly, along with the epilepsy nurse specialist, to ensure seizure control is as good as it can be, that medication is being taken/given regularly with minimum adverse side effects, all as per NICE guidance CG137
- For the paediatric team to provide regular reviews to proactively troubleshoot for any known associated associated conditions, for example, autism, intellectual disabilities etc. so that these are identified early and promptly managed
- For the lead health professional to proactively include the child's family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an Emergency Health Care Plan that includes a clear statement that has been agreed with the child's parents and multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. different seizure types and durations etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child might potentially face in any setting because of their West's Syndrome, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child's West Syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child

FebConv
= Febrile convulsion

SNOMED CT: 41497008

NICE guidance for management of febrile convulsions in children under five years:
<https://www.nice.org.uk/guidance/cg47>

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child's febrile convulsions to be recognised in a timely way, assessed and correctly managed so as to keep the child safe with the minimum risk of complications

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Action towards achieving the outcome might include:

- For all who care for the child to be aware of their febrile convulsions and to have received training in what to do if they have one
- Actions will depend on the person-centred outcomes agreed with the family

Dizzy Spell

SNOMED CT: 315018008

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child's or young person's dizzy spells to be recognised in a timely way, assessed and correctly managed so as to keep them safe with the minimum risk of complications

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Action towards achieving the outcome might include:

- For all who care for the child or young person to be aware of their dizzy spells and to have received training in what to do if they have one

Actions will depend on the person-centred outcomes agreed with the child or young person and family

Syncope
= synonymous with faint or vaso-vagal episode

SNOMED CT: 271594007

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child's or young person's syncope to be recognised in a timely way, assessed and correctly managed so as to keep them safe with the minimum risk of complications

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For all who care for the child or young person to be aware of their syncope and to have received training in what to do if they have an episode

Actions will depend on the person-centred outcomes agreed with the child or young person and family

Funny Turn

SNOMED CT: 248228001

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child's or young person's funny turns to be recognised in a timely way, assessed and correctly managed so as to keep them safe with the minimum risk of complications

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For all who care for the child or young person to be aware of their funny turns and to have received training in what to do if they have one

Actions will depend on the person-centred outcomes agreed with the child or young person and family

TensHeadache = Tension Headache

SNOMED CT: 398057008

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the child or young person's pain to be acknowledged, recognised and alleviated

Actions towards achieving the outcome is likely to be for the child or young person to be assessed and managed by the appropriate health practitioner, which may be the general practitioner, paediatrician or other specialist

Migraine

SNOMED CT: 37796009

NICE guidance for management of migraine:

<http://pathways.nice.org.uk/pathways/headaches/management-of-migraine-with-or-without-aura>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multidisciplinary team

The outcomes might include:

- For the migraine to be appropriately diagnosed and managed, so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

For the child or young person their family and inter-agency team to achieve a detailed understanding of the specific diagnosis, what this means for them, how it has come about and what it means for the future

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child's family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatrics, neurology, psychology and other relevant specialties
- For the lead health professional to explain in detail to the child or young person in so far as they can understand and for their family and multidisciplinary team, what the implications of migraine are and what to expect for the future
- For the lead health professional to proactively include the child's family and multi-disciplinary team in any decision-making about their care and future planning

Actions will depend on the person-centred outcomes agreed for the child

Pain

SNOMED CT: 22253000

Important for all children and young people and crucial to have a plan in place to alleviate pain

Pain has been shown in a large, population-based multicentre study across Europe to be a major determinant of the participation and quality of life of children and young people with cerebral palsies. There is no reason to believe it is any less important in a range of other disabling conditions

It is important for clinicians to proactively enquire about the presence of pain and to document this, even if what is documented is that no pain is reported to be present. If pain is present, a clear pain management plan should be made and documented, including in the clinic letter to the family

See Dickinson HO, Parkinson KN, Ravens-Sieberer U, Schirripa G, Thyen U, Arnaud C, Beckung E, Fauconnier J, McManus V, Michelsen SI, Parkes J, Colver AF. Self-reported quality of life of 8-12-year-old children with cerebral palsy: a cross-sectional European study. *Lancet*. 2007;369(9580):2171-2178.

Houlihan CM, O'Donnell M, Conaway M, Stevenson RD. Bodily pain and health-related quality of life in children with cerebral palsy. *Dev Med Child Neurol* 2004;46:305–10.

Hadden KL, von Baeyer CL. Pain in children with cerebral palsy: common triggers and expressive behaviors. *Pain*. 2002;99(1-2):281-8.

Parkinson K, Gibson L, Dickinson H, Colver A. Pain in children with cerebral palsy: a cross-sectional multicentre European study. *Acta Pædiatrica* 2010;99:446–51.

Fauconnier J, Dickinson HO, Beckung E, Marcelli M, McManus V, Michelsen SI, et al. Participation in life situations of 8–12 year old children with cerebral palsy: cross sectional European study. *BMJ* 2009; 338: b1458.

Disability Matters session: Pain Matters: <https://disabilitymatters.org.uk/course/view.php?id=64>

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the child or young person's pain to be acknowledged, recognised and alleviated

Actions towards achieving the outcome is likely to be for the pain to be assessed and investigated by the appropriate health practitioner, which may be the general practitioner, paediatrician or other specialist, in order to identify the cause and treat this. Where a specific cause cannot be found, the pain itself should still be acknowledged and a pain management plan put in place

This is a complex area. Consideration needs to be given to possible triggers are for any unusual behaviours especially if the child or young person is non-verbal and/or has an Intellectual Developmental Disability. Difficulties in this area may prompt consideration of referral on to the child and adolescent mental health service (may have a different name in some districts e.g. children and young people's service) for further assessment and advice about management if physical causes such as pain or discomfort are excluded.

See:

Sisability Matters sessions:

The Different Meanings of Behaviours: <https://www.disabilitymatters.org.uk/course/view.php?id=116>

Responding Positively when Behaviours are seen as Challenging: <https://www.disabilitymatters.org.uk/course/view.php?id=127>

BehavDiff **= Behavioural Difficulties**

SNOMED CT: 277843001

This is a high level term and may be the family's presenting complaint. Further expert assessment is required to more precisely define the nature of the problem.

Pattern of behaviour consistently interfering with the child or young person's social, psychological or physical functioning.

This domain is subdivided into:

DisruptBehav **= Disruptive Behaviours**

SNOMED CT: 248044002

A pattern of behaviour that consistently disrupts the functioning of a family, class or other group.

EmotMdAnx **= Emotional, Mood, Anxiety issue**

SNOMED CT: 268664001

There is often an overlap and expert assessment with the child and adolescent mental health team may be required to precisely define the issues

See:

Disability Matters session: Worry and Anxiety Matter: www.disabilitymatters.org.uk

ODD **= Oppositional Defiant Disorder**

SNOMED CT: 18941000

Diagnostic criteria for ODD from DSM-V:

A. A pattern of negativistic, hostile, and defiant behaviour lasting at least 6 months, during which four (or more) of the following are present:

- (1) often loses temper
- (2) often argues with adults
- (3) often actively defies or refuses to comply with adults' requests or rules
- (4) often deliberately annoys people
- (5) often blames others for his or her mistakes or misbehaviour
- (6) is often touchy or easily annoyed by others
- (7) is often angry and resentful
- (8) is often spiteful or vindictive

Consider a criterion met only if the behaviour occurs more frequently than is typically observed in individuals of comparable age and developmental level

B. The disturbance in behaviour causes clinically significant impairment in social, academic, or occupational functioning

C. The behaviours do not occur exclusively during the course of a Psychotic or Mood Disorder

Person-centred Outcomes for children and young people with behavioural and emotional conditions should be led by an expert in the field who may be a member of the Child and Adolescent Mental Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their behavioural or emotional issues, the implications of this for their physical health, their functional abilities across a range of domains and their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education or Child and Adolescent Mental Health teams, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the child or young person's behavioural or emotional issues to be identified early so that appropriate assessments and inter-agency management plans can be agreed with the child, young person and family and put in place, e.g. with the health visitor, school nurse, general practitioner, paediatrician or child and adolescent mental health service, depending on the level of need
- For practitioners across agencies to be aware of the red flags of serious mental illness in a child or young person, as well as red flags of neurodevelopmental disorders, such as autism and attention deficit disorders and know where to refer on for further expert assessment and advice
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their behavioural or emotional issues, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's behavioural or emotional issues, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting, to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DisAtten**= Disorder of attention, but no more specific diagnosis yet made**

SNOMED CT: 932281000000102

ADD**= Attention Deficit Disorder**

SNOMED CT: 192127007

ADHD**= Attention Deficit Hyperactivity Disorder as defined in ICD-10 F90.X/DSM-V**

SNOMED CT: 406506008

See NICE guidance <http://www.nice.org.uk/cg72> and DSM-5 314.0X, ICD-10 F90.X**Broad symptom area A**

Persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by (1) and /or (2):

1. Inattention: Six (or more) of the following symptoms have persisted for at least 6 month to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities
 - a. Often fails to give close attention to details. (E.g., overlooks or misses details, work is inaccurate)
 - b. Often has difficulty sustaining attention. (E.g., has difficulty remaining focused during lectures, conversations, or a lengthy reading)
 - c. Often does not listen when spoken to directly. (E.g., mind seems elsewhere, even in the absence of any obvious distraction)
 - d. Often does not follow through on instructions. (E.g., starts tasks but quickly loses focus and is easily side-tracked)
 - e. Often has difficulty organizing tasks and activities. (E.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganised work; has poor time management; fails to meet deadlines)
 - f. Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort. (E.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers)
 - g. Often loses things necessary for task or activity. (E.g., school materials, pencils, books, tools, wallets, keys, paperwork, eye-glasses, mobile phones)
 - h. Is often easily distracted by extraneous stimuli. (E.g., for older adolescents and adults, may include unrelated thoughts)
 - i. Is often forgetful in daily activities. (E.g., doing chores, running errands; for adolescents and adults, returning calls, paying bills, keeping appointments)
2. Hyperactivity and impulsivity: Six (or more) of the following symptoms have persisted for at least 6 month to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:
 - a. Often fidgets with or taps hands or feet or squirms in seat
 - b. Often leaves seat in situations when remaining seated is expected. (E.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place)
 - c. Often runs about or climbs in situations where it is inappropriate. (Note: in adolescence or adults, may be limited to feeling restless.)
 - d. Often unable to engage in leisure activities quietly
 - e. Is often 'on the go', acting as if 'driven by a motor'. (E.g. is unable to be more comfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with)
 - f. Often talks excessively
 - g. Often blurts out answers before a question has been completed. (E.g., completes people's sentences; cannot wait for turning conversation)
 - h. Has often difficulty waiting his or her turn. (E.g., while waiting in line)
 - i. Often interrupts or intrudes on others (E.g., that's into conversations, games, or activities; may start using other people's things without asking or receiving permission; for adolescent and adult, may intrude into or take over what others are doing)

Broad symptom area B

Several inattentive or hyperactive-impulsive symptoms are present prior to the age of 12 years

Broad symptom area C

Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (E.g., at home, school, or work; with friends or relatives; in other activities)

Broad symptom area D

There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic or occupational functioning

Broad symptom area E

The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained

ADHDmed**= Attention Deficit Hyperactivity Disorder on medication**

SNOMED CT: 886371000000105

ADHDstimMed**= Attention Deficit Hyperactivity Disorder on Stimulant Medication**

SNOMED CT: 886391000000109

ADHDNonStMed**= Attention Deficit Hyperactivity Disorder on Non-Stimulant Medication**

SNOMED CT: 886411000000109

ADHDinatt**= Attention Deficit Hyperactivity Disorder Inattentive type**

SNOMED CT: 35253001

Predominantly Inattentive presentation: 314.00 (F90.0): Criterion A1 (Inattention) but Criterion A2 (Hyperactivity-impulsivity) is not met for the past 6 months.

ADHDimp**= Attention Deficit Hyperactivity Disorder Impulsive type**

SNOMED CT: 7461003

Predominantly Impulsive presentation: 314.001 (F90.10): Criterion A2 (Hyperactivity-impulsivity) but Criterion A1 (Inattention) is not met for the past 6 months

See session on Hidden Disabilities in Disability Matters: www.disabilitymatters.org.uk

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team, including the paediatric disability specialist and/or child and adolescent mental health service

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their attention deficit disorder including their level of intellectual abilities and functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's attention deficit disorder and a holistic assessment to consider what may have caused this and to troubleshoot for any associated medical conditions, for example, epilepsy, autism spectrum disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their attention deficit disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting, to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's attention deficit disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Tic Disorder
= all tic disorders including Tourette's Syndrome

SNOMED CT: 568005

See <http://www.tourettes-action.org.uk/>

Diagnostic criteria for Tourette's Syndrome from ICD-10:

- A Motor or vocal tics, but not both, that occur many times per day, most days over a period of at least twelve months
- B No period of remission during that year lasting longer than two months
- C No history of Tourette syndrome, and not due to physical conditions or side effect of medication
- D Onset before age 18 years

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team, including the paediatric disability specialist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their tic disorder including their level of intellectual abilities and functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's tic disorder and a holistic assessment to troubleshoot for any associated medical conditions, for example, obsessive compulsive disorder, autism spectrum disorder, attention deficit disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their tic disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's tic disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Self Injury = Self-Injurious Behaviour

SNOMED CT: 248062006

Pattern of behaviour harmful to the self, experienced in the context of a developmental disorder e.g. ASD:
<http://www.autism.org.uk/living-with-autism/understanding-behaviour/challenging-behaviour/self-injurious-behaviour.aspx>

This can be associated with a range of diagnoses. It can sometimes be a symptom of the child or young person's frustration and not being able to more effectively communicate and can also sometimes be a sign that the individual is in pain or is distressed because they are being abused. A very careful and holistic assessment is required and prompt networking with the multi-disciplinary team, including the child and adolescent mental health service

See Disability Matters session on Self Injury: <https://www.disabilitymatters.org.uk/course/view.php?id=89>

RepSelfExcor = Repetitive Self-Excoriation

SNOMED CT: 238958004

A persistent and very damaging form of self injury, resulting in tissue damage over a period of time

Person-centred Outcomes for children and young people who self-injure or show repetitive self-excoriation should be led by health, in consultation with the child or young person, their family and multi-disciplinary team, including the paediatric disability specialist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their self-injuring behaviours, what triggers them and what can be done to avoid them arising
- Another possible outcome might be for the self-injuring behaviours to stop or at least reduce to a minimum so as not to cause harm or distress to the child or young person
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in activities at home, school and/or in the community

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and inter-disciplinary team. Possible actions might include:

- To arrange appropriate, detailed expert assessments of the child or young person's self-injuring behaviours including what triggers them and a holistic assessment to troubleshoot for any associated medical conditions, for example, intellectual developmental disability, speech, language and communication needs, autism spectrum disorder, attention deficit disorder, disordered sleep, child abuse etc. This may involve the disability paediatrician, child and adolescent mental health service, specialist speech and language therapist as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their self-injuring behaviours, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's self-injuring behaviours so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SensSens = Sensory Sensitivities

SNOMED CT: 950451000000105

Often seen in children and young people with autism spectrum disorders and severe intellectual impairments. These may include aversive sensory sensitivities e.g. to particular sounds, textures, foods etc. or craving for sensory experiences such as chewing, sniffing, licking or posting objects into orifices
Careful networking with occupational therapy, autism and learning disability specialists and child and adolescent mental health teams is essential

Person-centred Outcomes in this area should be led by the appropriate expert, in consultation with the child or young person, their family and multi-disciplinary team, including the occupational therapist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their sensory sensitivities, the implications of this for their functional abilities across a range of domains, the likely triggers and how to minimise these
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the appropriate expert, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For the child or young person's sensory sensitivities to be identified early so that appropriate assessments and inter-agency management plans can be agreed with the child, young person and family and put in place, e.g. with the health visitor, school nurse, general practitioner, occupational therapist, paediatrician or child and adolescent mental health service, depending on the level of need
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their sensory sensitivities, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's sensory sensitivities, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Pica
= Eating inappropriate non-food substances

SNOMED CT: 14077003

This can be a red flag for iron deficiency anaemia, which is correctly identified and treated can lead to resolution of the presenting symptoms

Also remember lead poisoning, both as a possible cause and possible complication

Management can be complex and requires a multi-disciplinary approach across all services

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their pica, the implications of this for their functional abilities across a range of domains, the likely triggers and how to minimise these and any treatable causes
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the child or young person's pica to be identified early so that appropriate assessments and inter-agency management plans can be agreed with the child, young person and family and put in place, e.g. with the health visitor, school nurse, general practitioner, occupational therapist, paediatrician or child and adolescent mental health service, depending on the level of need
- For known medical causes of pica to be excluded or identified and treated e.g. iron deficiency, lead poisoning etc.
- For other known causes of pica to be considered and addressed e.g. sensory sensitivities as part of an autism spectrum disorder.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their pica, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's pica, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

AnxietyDis = Anxiety Disorder

SNOMED CT: 197480006

Diagnostic criteria for Anxiety Disorder from ICD-10:

- A. A period of at least one month with recurrence of excessive, disproportionate and intrusive anxieties or worries, as indicated by at least three of the following:
- (1) Excessive concerns about the quality of one's performance in areas such as schoolwork, sports, and other regular activities
 - (2) Excessive concerns about physical health (despite an evident good health, or, if hurt or sick, concerns that go beyond a normal apprehension) or about being injured
 - (3) Excessive concerns or anticipatory worries in relation to particular non-health themes (money or financial well-being, punctuality, appearance, catastrophes, disasters, etc.)
 - (4) Free floating anxiety unrelated to specific situations
 - (5) A frequent need for reassurance that persists in spite of several appropriate attempts to reassure the child
 - (6) Marked feelings of tension, inability to relax or to concentrate, nervousness, difficulty getting to sleep, autonomic symptoms (such as palpitations, sweating, dry mouth, etc.)
 - (7) Recurrent somatic complaints (headaches, stomachaches, etc.) for which no physical basis can be demonstrated
- B. The multiple anxieties and worries occur across at least two situations, activities, contexts or circumstances

Generalized anxiety does not present as discrete paroxysmal episodes (as in panic disorder), nor are the main worries confined to single, major thoughts (as in separation anxiety disorder) or situations (as in social anxiety disorder or phobic disorder in childhood). When more focused anxiety is identified in the broader context of a generalized anxiety, generalized anxiety disorder takes precedence over other anxiety disorders

- C. Onset in childhood or adolescence (below age 18 years)
- D. The symptoms in A interfere daily in a significant way with the child or young person's activities
- E. The disorder does not occur as part of a broader disturbance of emotions, conduct, personality, or of a pervasive developmental disorder, psychotic disorder or psychoactive substance use disorder

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their anxiety disorder including their functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's anxiety disorder and a holistic assessment to troubleshoot for any associated medical conditions, for example, obsessive compulsive disorder, autism spectrum disorder, attention deficit disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their anxiety disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's anxiety disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

CSAD
= **Childhood Social Anxiety Disorder**

SNOMED CT: 64165008

Diagnostic criteria for Childhood Social Anxiety Disorder from ICD-10:

- A. Persistent anxiety in social situations in which the child is exposed to unfamiliar people, including peers, as manifested by socially avoidant behaviour
- B. Self-consciousness, embarrassment, or over-concern about the appropriateness of his or her behaviour when interacting with unfamiliar figures
- C. Significant interference with social (including peer) relationships that are restricted; when new or forced social situations are experienced, they cause marked distress and discomfort as manifested by crying, lack of spontaneous speech, or withdrawal from the social situation
- D. Has satisfying social relationships with familiar figures (family members or peers the subject knows well)
- E. Onset generally coincides with a developmental phase where these anxiety reactions are considered appropriate. The abnormal degree, persistence over time and associated impairment must be manifest before the age of six
- F. Absence of generalized anxiety disorder of childhood (F93.80)
- G. The disorder does not occur as part of broader disturbances of emotions, conduct, personality, or of a pervasive developmental

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their social anxiety disorder including their functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's social anxiety disorder and a holistic assessment to troubleshoot for any associated medical conditions, for example, obsessive compulsive disorder, autism spectrum disorder, attention deficit disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their social anxiety disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's social anxiety disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome, to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

EatingDis
= Eating Disorder

SNOMED CT: 72366004

Code as suspected until confirmed by Child and Adolescent Mental Health Service

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team including paediatrician with expertise in nutrition

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their eating disorder including their functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team including paediatrician

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's eating disorder and a holistic assessment to troubleshoot for any associated medical conditions, for example, refeeding syndrome, vitamin deficiencies, electrolyte imbalance, skin and pressure issues, cardiac complications, depression etc. This may involve the child and adolescent mental health service, paediatrician and paediatric dietician as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their eating disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's eating disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SchNonAttnd = School Non-Attendance

SNOMED CT: 248050007

Lack of attendance sufficient to interfere with academic progress (investigation of)

Person-centred outcomes might include for the child or young person to attend school regularly

Actions towards achieving this outcome might include:

- Identification of the barriers to school attendance
- Assessment with the general practitioner or paediatrician to identify any medical conditions that are contributing to school non-attendance so that these can be appropriately assessed and managed
- Assessment of the child or young person's mental state with the child and adolescent mental health service, to identify any behavioural, emotional or mental health issues so that these can be appropriately managed

PTSD = Post Traumatic Stress Disorder

SNOMED CT: 47505003

Should be coded as suspected pending investigation by Child and Adolescent Mental Health Service.
For definition see: http://www.ptsd.va.gov/professional/pages/dsm5_criteria_ptsd.asp

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their post traumatic stress disorder including their functioning across a range of domains
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's post-traumatic stress disorder to identify its origins so that the issues can be addressed. This may involve the child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their PTSD, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's PTSD so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SelectiveMute = Selective Mutism

SNOMED CT: 71959007

Still known as elective mutism in ICD-10, but Selective Mutism in DSM-V, the diagnostic criteria being:

- Consistent failure to speak in specific social situations (in which there is an expectation for speaking, e.g., at school) despite speaking in other situations
- The disturbance interferes with educational or occupational achievement or with social communication
- The duration of the disturbance is at least one month (not limited to the first month of school)
- The failure to speak is not due to a lack of knowledge of, or comfort with, the spoken language required in the social situation
- The disturbance is not better accounted for by a Communication Disorder (e.g., Stuttering) and does not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder)

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their selective mutism including their functioning across a range of domains and their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's selective mutism and a holistic assessment to troubleshoot for any associated conditions, for example, obsessive compulsive disorder, autism spectrum disorder, attention deficit disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their selective mutism, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's selective mutism so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Substance Misuse

SNOMED CT: 66214007

Intoxication by, or regular excessive consumption of and/or dependence on psychoactive substances, leading to social, psychological, physical or legal problems.

Person-centred Outcomes in this area might include for the substance misuse to stop
Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child or young person's key worker, in consultation with the child or young person, their family and inter-disciplinary team

- Possible actions might be for the root causes of the substance misuse to be identified and addressed, for the child or young person to be supported and empowered to understand why they misuse substances and to be able to stop

Self Harm

SNOMED CT: 248061004

Intentional, direct injuring of body tissue.

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person to stop self harming
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- Possible actions might be to arrange appropriate, detailed expert holistic assessment of the child or young person's self harm and to troubleshoot for any associated conditions, for example, anxiety, depression etc. This may involve the paediatrician as well as the child and adolescent mental health service and other members of the multi-disciplinary team. Appropriate management plans should be put in place, in consultation with the child or young person, their family and multi-disciplinary team

Actions will depend on the person-centred outcomes agreed for the child or young person

Depression

SNOMED CT: 35489007

N.B. Paediatricians should code as suspected unless confirmed by CAMHS. See ICD-10:

- A. Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure
1. Depressed mood most of today, nearly every day, as indicated by either subjective report or observation made by others
 2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day
 3. Significant weight loss when not dieting weight gain, or decreased or increased appetite nearly every day
 4. Insomnia or hypersomnia nearly every day
 5. Psychomotor agitation or retardation nearly every day
 6. Fatigue or a lot of energy nearly everyday
 7. Feelings of worthlessness or excessive or inappropriate guilt nearly every day
 8. Diminished ability to think what concentrate, or indecisiveness, nearly every game
 9. Recurrent thoughts of death, recurrent suicidal ideation without a specific plan, Boris suicide attempt or specific plan for committing suicide
- B. The symptoms course clinically significant distress or impairment in social, occupational, or other important areas of functioning
- C. The episode is not attributable to do physiological effects of your symptoms or to another medical condition
- D. The occurrence of the major depressive episode is not better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified or unspecified schizophrenia

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their depression including their functioning across a range of domains and likely impact on their participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's depression and a holistic assessment to troubleshoot for any associated conditions, for example, disordered sleep etc. This may involve the child and adolescent mental health service as well as other members of the multi-disciplinary team. An appropriate management plan should then be agreed with the child or young person, their family and multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their depression, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's depression so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

InsecAttach
= Insecure Attachment

SNOMED CT: 304868003

Absence of security of attachment (broadly, trust and responsivity) between child and primary carer.

Person-centred Outcomes in this area should be led by the child and adolescent mental health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their insecure attachment and its impact on them
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the child and adolescent mental health service, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's insecure attachment so that an appropriate management plan can be agreed with the child or young person and family. This may involve members of the child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their insecure attachment, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's insecure attachment so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

OCD = Obsessive Compulsive Disorder

SNOMED CT: 191736004

See <http://www.ocduk.org/>

ICD-10 Diagnostic criteria:

- A. Either obsessions or compulsions (or both), present on most days for a period of at least two weeks
- B. Obsessions (thoughts, ideas or images) and compulsions (acts) share the following features, all of which must be present:
 - (1) They are acknowledged as originating in the mind of the patient, and are not imposed by outside persons or influences
 - (2) They are repetitive and unpleasant, and at least one obsession or compulsion must be present that is acknowledged as excessive or unreasonable
 - (3) The subject tries to resist them (but if very long-standing, resistance to some obsessions or compulsions may be minimal). At least one obsession or compulsion must be present which is unsuccessfully resisted.
 - (4) Carrying out the obsessive thought or compulsive act is not in itself pleasurable. (This should be distinguished from the temporary relief of tension or anxiety)
- C. The obsessions or compulsions cause distress or interfere with the subject's social or individual functioning, usually by wasting time
- D. Most commonly used exclusion criteria: not due to other mental disorders, such as schizophrenia and related disorders (F2), or mood [affective] disorders (F3)

Person-centred Outcomes in this area should be led by the Education team, in consultation with the child or young person, their family and multi-disciplinary team, including the child and adolescent mental health specialist

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their obsessive compulsive disorder including their level of intellectual abilities and functioning across a range of domains and likely impact on participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Education team, in consultation with the child or young person, their family and inter-disciplinary team

- One possible action might be to arrange appropriate, detailed expert assessments of the child or young person's obsessive compulsive disorder and a holistic assessment to troubleshoot for any associated medical conditions, for example, tic disorder, autism spectrum disorder, attention deficit disorder, disordered sleep etc. This may involve the disability paediatrician, child and adolescent mental health service as well as other members of the multi-disciplinary team
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their obsessive compulsive disorder, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge in each specific setting to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's obsessive compulsive disorder so that these can be proactively put in place, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life in any setting that have not effectively been overcome to ensure that each of these is appropriately addressed, with any reasonable adjustments made and actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

DisSleep
= Disordered Sleep

SNOMED CT: 39898005

Another common associated diagnosis, whose appropriate management may lead to considerable improvement in quality of life for the child or young person and the rest of the family

See www.york.ac.uk/inst/spru/research/pdf/interventionsSum.pdf

SleepMel
= Disordered Sleep pattern on treatment with melatonin

SNOMED CT: 887881000000101

Person-centred Outcomes in this area should be led by Health.

The outcomes might include:

- For the child or young person to have a refreshing night's sleep

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For the child or young person to have a sleep assessment and management plan with a health practitioner with competence in sleep, for example, health visitor, school nurse, general practitioner, paediatrician

Actions will depend on the person-centred outcomes agreed with the child or young person and family

ENTDis**= Ear, Nose, Throat Disorder**

SNOMED CT: 232208008

This covers upper airway dysfunction, obstructive sleep apnoea, bronchomalacia, laryngomalacia, tracheomalacia and sub-glottic stenosis that can be a complication of intubation, as well as the broad range of ear, nose and throat issues (unless covered in section on sensory impairment above)

Person-centred Outcomes in this area should be led by Health.

The outcomes might include:

- For the child or young person's ear, nose or throat disorder to be recognised in a timely way, assessed and correctly managed so as to have the minimum possible impact on functioning, participation and quality of life

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For all involved in working with children and young people to know and recognise the red flags of ear, nose and throat disorders, when and where to refer for further expert assessment and advice
- For the child or young person to have a prompt access to expert assessment with a ear, nose and throat surgeon and audiologist so that an appropriate management plan can be agreed with the child, young person and family

Actions will depend on the person-centred outcomes agreed with the child or young person and family

Epistaxis

SNOMED CT: 12441001

Person-centred outcomes may include for the epistaxis to be alleviated

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the child or young person and their family

EnTonsils**= Enlarged Tonsils**

SNOMED CT: 301471002

Person-centred outcomes may include for the enlarged tonsils to not cause any difficult symptoms for the child or young person

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the child or young person and their family

RecTonsillitis
= Recurrent Tonsillitis

SNOMED CT: 195677001

Person-centred outcomes may include for the recurrent tonsillitis to be alleviated

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the child or young person and their family

Laryngomal
= Laryngomalacia

SNOMED CT: 38086007

Person-centred outcomes may include for the laryngomalacia to not cause any difficult symptoms for the child

Actions towards this outcome might include for the child to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the family

NasalObstr
= Nasal Obstruction

SNOMED CT: 232209000

Person-centred outcomes may include for the nasal obstruction to be alleviated

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the family

OSA
= Obstructive Sleep Apnoea

SNOMED CT: 1091000119108

NICE Clinical Knowledge summary for management of OSA: <http://cks.nice.org.uk/obstructive-sleep-apnoea-syndrome#!scenario>

RCPCH service standards for OSA:

http://www.rcpch.ac.uk/sites/default/files/asset_library/Research/Clinical%20Effectiveness/Endorsed%20guidelines/Sleep%20Physiology%20Disorders%20%28RCPCH%29/A4350%20Lay%20Summary%20-%20L.pdf

Person-centred outcomes may include for the obstructive sleep apnoea to be alleviated

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon so that an appropriate management plan can be agreed with the child or young person and their family

OME
= Otitis Media with Effusion

SNOMED CT: 80327007

NICE Surgical treatment of OME guidelines:

<https://www.nice.org.uk/guidance/cg60>

Person-centred outcomes may include for the otitis media with effusion not to cause any difficult symptoms or hearing impairment

Actions towards this outcome might include for the child or young person to be assessed by an Ear, Nose and Throat Surgeon, so that an appropriate management plan can be agreed with the child or young person and their family

Drooling

SNOMED CT: 62718007

Drooling can be intrusive for the child or young person, can cause a smell that can lead to difficulties in social situations and again may prompt liaison with the specialist speech and language therapist

Some children and young people can learn self-care and wiping techniques that manage their drooling adequately, whilst others may want to consider medication such as hyoscine patches or glycopyrronium bromide. If these fail and time does not lead to significant improvement, other treatment options include botulinum toxin injections into the salivary glands or salivary gland duct surgery

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their drooling, the implications of this for their functional abilities across a range of domains, the likely triggers and how to minimise these, also the likely impact on participation in activities at home, school and/or in the community
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the child or young person's drooling to be identified early so that appropriate assessments and management plans can be agreed with the child, young person and family and put in place, e.g. with the health visitor, school nurse, general practitioner, speech and language therapist or paediatrician, depending on the level of need
- For known medical causes of drooling to be excluded or identified and treated e.g. dental issues etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- Specialist advice should be sought from an appropriate professional, such as an occupational therapist, when there are issues or potential issues with the child or young person's participation in home, school and/or community activities. This is important to appropriately guide:
- All involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their drooling, be these attitudinal, physical or other
- Consideration of each identified barrier or challenge to identify what reasonable adjustments or action might be required in the knowledge of the child or young person's drooling, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- Consideration of any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting to ensure that each of these is appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Asthma

SNOMED CT: 195967001

See <https://www.brit-thoracic.org.uk/guidelines-and-quality-standards/asthma-guideline/>
<http://cks.nice.org.uk/asthma>
http://www.rcpch.ac.uk/respiratory-medicine#SIGN_BTS_asthma2009

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their asthma, including what triggers it, the implications of this for their overall physical health and functional abilities across a range of domains and likely impact on participation in activities at home, school and in the community
- Another possible outcome might be for the child or young person to have an individual asthma plan or Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their asthma are and what to expect for the future. This may require networking across all specialists involved, including the general practitioner, physiotherapist and in severe cases, the respiratory paediatrician
- For the lead clinician to review the child or young person's respiratory status regularly, arrange any appropriate investigations and agree a management plan with the child, young person and family based on their individual needs
- For the health team to provide regular reviews to proactively troubleshoot for any complications or red flags for medication issues, side effects, technique, compliance etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an individual asthma plan or Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. increased work of breathing, breathlessness, fever and cough etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their asthma, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's asthma, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Wheeze

SNOMED CT: 56018004

See section on asthma above.

Cough

SNOMED CT: 49727002

See <https://www.brit-thoracic.org.uk/guidelines-and-quality-standards/cough-in-children-recommendations/>

Person-centred outcomes may include for the may include for the cough to be alleviated.

Actions towards this outcome might include for the child or young person to be assessed by a health practitioner, which may be the general practitioner, practice nurse or paediatrician, so that an appropriate management plan can be agreed with the family

LRTI**= Lower Respiratory Tract Infection = Pneumonia**

SNOMED CT: 50147007

Person-centred outcomes might include for the lower respiratory tract infection to be successfully treated without complications.**Actions** towards achieving the outcomes might include for the child or young person to be assessed by a health practitioner, for example, general practitioner, nurse practitioner or paediatrician so that an appropriate management plan can be put in place**RecChestInf****= Recurrent Chest Infections = Recurrent Lower Respiratory Tract Infections**

SNOMED CT: 448739000

If these are a regular or frequent problem, further investigations may be required, to check for aspiration or reflux, which may be silent, or immune deficiency, asthma or ENT disorders

Prevention is better than cure. Do ensure that all appropriate preventive immunisations have been offered

Some children and young people with regular chest infections where aspiration has been excluded or addressed may benefit from preventive antibiotics through the winter months, e.g. Azithromycin or Co-trimoxazole once daily on Mondays, Wednesdays and Fridays.

In case of ongoing serious concerns, discussion with or referral to a respiratory paediatrician should be considered

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their recurrent chest infections, the implications of this for their overall physical health and functional abilities across a range of domains and likely impact on participation in activities at home, school and/or in the community
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their recurrent chest infections are and what to expect for the future. This may require networking across all specialists involved, including the physiotherapist and respiratory paediatrician
- For the lead clinician to review the child or young person's respiratory status regularly, arrange any appropriate investigations and agree a management plan with the child, young person and family based on their individual needs. This may include checking the child or young person's immunity, arranging additional immunisations, use of preventative antibiotics in the winter months, consideration of the safety of the child's eating, drinking and swallowing including assessment with the dysphagia specialist speech and language therapist etc.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any known associated conditions, for example, gastro-oesophageal reflux disease etc. so that these are identified early and promptly managed
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. increased work of breathing, breathlessness, fever and cough etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their recurrent chest infections, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's recurrent chest infections, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

CF
= Cystic Fibrosis

SNOMED CT: 448739000

See:
www.cysticfibrosis.org.uk

Person-centred Outcomes in this area should be led by the Health teams, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their cystic fibrosis, the implications of this for their overall physical health and functional abilities across a range of domains and likely impact on participation in activities at home, school and/or in the community
- Another possible outcome might be for the child or young person to have an Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities
- Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their cystic fibrosis are and what to expect for the future. This may require networking across all specialists involved, including the general practitioner, physiotherapist, specialist nurse and respiratory paediatrician
- For the lead clinician to review the child or young person's respiratory status regularly, arrange any appropriate investigations and agree a management plan with the child, young person and family based on their individual needs
- For the health team to provide regular reviews to proactively troubleshoot for any complications so that these can be promptly addressed
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. increased work of breathing, breathlessness, fever and cough etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their cystic fibrosis, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's cystic fibrosis, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue, linking with the physiotherapist and occupational therapist as required
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Heart Murmur

SNOMED CT: 88610006

Person-centred outcomes might include for the heart murmur to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person to be assessed by a paediatrician and/or paediatric cardiologist, so that a specific diagnosis can be made and an appropriate management plan can be agreed with the child, young person and family

VSD**=Ventriculo Septal Defect**

SNOMED CT: 30288003

See <http://www.chd-uk.co.uk/>And <http://www.bhf.org.uk/heart-health/conditions/congenital-heart-disease.aspx>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their ventricular septal defect, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric cardiology, clinical genetics, paediatric disability etc. as required
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their ventricular septal defect are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric cardiology, clinical genetics and paediatric disability as required
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the ventricular septal defect, for example, chest infections, heart failure, anomalies in other systems etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. chest infection, heart failure etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their ventricular septal defect, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's ventricular septal defect, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Palpitations

SNOMED CT: 80313002

Person-centred outcomes in this area might include for the palpitations to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatric cardiologist so that an appropriate management plan can be agreed with the child, young person and family

Cardiomyo = Cardiomyopathy

SNOMED CT: 85898001

= serious, significant complication of e.g. Duchenne Muscular Dystrophy and other neuromuscular disorders, mitochondrial disorders etc. that has significant management and prognostic implications

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their cardiomyopathy, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric cardiology, paediatric disability etc. as required
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their cardiomyopathy are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric cardiology, paediatric disability etc. as required.
- For the paediatric cardiologist to provide regular reviews to proactively troubleshoot for any medical complications of their cardiomyopathy, for example, heart failure
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. heart failure etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their cardiomyopathy, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's cardiomyopathy, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue, linking with therapy colleagues as required
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SNOMED CT: 404684003

GORD**= Gastro-oesophageal reflux disease**

SNOMED CT: 235595009

See www.nice.org.uk/guidance/ng1

This is common in a range of disabling conditions and should be considered and actively sought as timely and appropriate treatment can make a significant positive difference

If in doubt, liaise with the specialist paediatric dysphagia competent speech and language therapist and paediatric gastroenterologist

A trial of anti-reflux treatment with a positive effect can confirm the diagnosis, although further investigations with pH study or endoscopy may be required in serious or treatment-resistant cases

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the child or young person's symptoms and signs from their gastro-oesophageal reflux disease to be acknowledged, recognised and alleviated

Action towards achieving the outcome might include:

- For all who work with disabled children and young people to be aware of the red flags to suggest that gastro-oesophageal reflux might be a possibility and to know when and where to refer for expert assessment and advice
- For the child or young person to be assessed and investigated by the appropriate health practitioner, which may be the general practitioner, paediatrician or other specialist, in order to make a specific diagnosis and recommend a treatment plan.

Actions will depend on the person-centred outcomes agreed for the child or young person

CoeliacDis**= Coeliac Disease**

SNOMED CT: 396331005

See www.coeliac.org.ukwww.nice.org.uk/guidance/cg86

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their coeliac disease, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric gastroenterology, paediatric dietetics etc. as required
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their coeliac disease are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric gastroenterology, paediatric dietetics, nurse specialist etc. as required
- For the paediatric team to provide regular reviews to proactively troubleshoot for any conditions or symptoms that are known to be associated with the coeliac disease, for example, loose stools, abdominal pain, dermatitis herpetiformis etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their coeliac disease, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's coeliac disease, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Constipation

SNOMED CT: 14760008

This must be the commonest associated diagnosis of all. It is always worth considering if prescribed medications are exacerbating this. Also ensure adequate fluid intake and dietary advice, including with the paediatric dietician, before moving on to laxative medications.

See <http://www.nice.org.uk/cg99>

Person-centred Outcomes in this area should be led by Health.

The outcomes might include for the child or young person's symptoms and signs from their constipation to be acknowledged, recognised and alleviated

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For all who work with disabled children and young people to be aware of the red flags to suggest that constipation might be a possibility and to know when and where to refer for expert assessment and advice
- For the child or young person to be assessed and investigated by the appropriate health practitioner, which may be the general practitioner, paediatrician or other specialist, in order to make a specific diagnosis and recommend a treatment plan in line with NICE guidance.

Actions will depend on the person-centred outcomes agreed for the child or young person

Diarrhoea**= Loose stools**

SNOMED CT: 62315008

Person-centred outcomes in this area might include for the diarrhoea to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for all families to be educated in basic management of diarrhoea, maintenance of hydration, hand hygiene etc. Where the diarrhoea is severe or not resolving, the child or young person might need to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

InfBD
= Inflammatory Bowel Disease

SNOMED CT: 24526004

See <https://www.nice.org.uk/guidance/conditions-and-diseases/digestive-tract-conditions/inflammatory-bowel-disease>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their inflammatory bowel disease, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric gastroenterology, paediatric dietetics, specialist nurse etc. as required
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their inflammatory bowel disease are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric gastroenterology, paediatric dietetics, nurse specialist etc. as required
- For the paediatric team to provide regular reviews to proactively troubleshoot for any conditions or symptoms that are known to be associated with the inflammatory bowel disease, for example, blood in stools, loose stools, abdominal pain, etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their inflammatory bowel disease, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's inflammatory bowel disease, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person.

BowelIncont
= Bowel Incontinence

SNOMED CT: 72042002

See Disability Matters session: Continence Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=92>

This includes faecal soiling that is deliberate as well as accidental i.e. where continence has not been acquired, has been lost either temporarily or permanently as well as those with neuropathic bowel who need specialist input including the paediatric surgical team

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child or young person to be continent day and night if this is assessed to be an achievable goal (it is important to have high expectations including for children and young people with complex conditions)
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For the child or young person to have a continence assessment and management plan with a health practitioner with competence in continence, for example, health visitor, school nurse, continence nurse specialist
- For the management plan to include adequate fluid intake and toileting strategies, as indicated and/or provision of continence products adequate in quality and number to meet the person's needs
- Access to accessible toilets or changing places may be required for some children and young people across settings

Actions will depend on the person-centred outcomes agreed for the child or young person

BedWetting = Wetting specifically at night

SNOMED CT: 8009008

See www.eric.org.uk

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child or young person to be continent at night
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Action towards achieving the outcome might include:

- For the child or young person to have a continence assessment and management plan with a health practitioner with competence in continence, for example, health visitor, school nurse, continence nurse specialist
- For the management plan to include adequate fluid intake, toileting strategies, medications and alarms as indicated and/or provision of continence products adequate in quality and number to meet the person's needs

Actions will depend on the person-centred outcomes agreed for the child or young person

UrinIncont = Urinary Incontinence day and night

SNOMED CT: 165232002

See www.eric.org.uk

Disability session: Continence Matters: <https://www.disabilitymatters.org.uk/course/view.php?id=92>

This may occur because the child or young person has not reached the developmental level where bladder control can be acquired. It is always worth a concerted effort to support the family to achieve continence as even those with significant intellectual and other disabilities can be 'trained'

Those with neuropathic bladders need specialist support including from paediatric urology and specialist continence nurses.

This, together with soiling, can have a significant impact on the quality of life of the child or young person as well as parents and carers and should be regularly enquired about and promptly managed, linking as necessary with continence specialist nurses, paediatric urologists and paediatric surgeons

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child or young person to be continent day and night if this is assessed to be an achievable goal (it is important to have high expectations including for children and young people with complex conditions)
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For the child or young person to have a continence assessment and management plan with a health practitioner with competence in continence, for example, health visitor, school nurse, continence nurse specialist
- For the management plan to include adequate fluid intake, toileting strategies, medications and alarms as indicated and/or provision of continence products adequate in quality and number to meet the person's needs
- Access to accessible toilets or changing places may be required for some children and young people across settings

Actions will depend on the person-centred outcomes agreed for the child or young person

UTI
= Urinary Tract Infection

SNOMED CT: 68566005

See:
<https://www.nice.org.uk/guidance/cg54>
<http://www.infokid.org.uk/urinary-tract-infection>

Person-centred outcomes might include for the urinary tract infection to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for all those working with children and young people and parent to be aware of the red flags that might indicate a urinary tract infection and when and where to seek expert assessment. The child or young person should be assessed by a health practitioner, for example, general practitioner, nurse practitioner or paediatrician, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

UDT
= Undescended Testis

SNOMED CT: 204878001

See: NICE clinical knowledge summary:
<http://cks.nice.org.uk/undescended-testes#!scenario>

Person-centred outcomes might include for the undescended testis to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for all parents to be aware of the red flags that might indicate an undescended testis and to know when and where to seek expert assessment. The child or young person should be assessed by a health practitioner, for example, general practitioner, paediatrician or paediatric surgeon/urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

CAKidney
= Congenital Anomaly of Kidney

SNOMED CT: 44513007

Person-centred outcomes might include for the congenital anomaly of the kidney to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

Haematuria

SNOMED CT: 34436003

See <http://www.infokid.org.uk/haematuria>

Person-centred outcomes might include for the haematuria to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

RenalDil = Renal Dilatation

SNOMED CT: 43064006

See <http://www.infokid.org.uk/VUR-and-reflux-nephropathy>

Person-centred outcomes might include for the renal dilatation to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

NephriticSy = Nephritic Syndrome

SNOMED CT: 7724006

Person-centred outcomes might include for the nephritic syndrome to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician or renal paediatrician, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

NephroticSy = Nephrotic Syndrome

SNOMED CT: 52254009

See <http://www.infokid.org.uk/nephrotic-syndrome>
<http://www.infokid.org.uk/nephrotic-syndrome-frequently-relapsing>

Person-centred outcomes might include for the nephrotic syndrome to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician or renal paediatrician, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

PUJobs = Pelviureteric Junction Obstruction

SNOMED CT: 95575002

See: NICE interventional procedure guidance: Endopyelotomy for pelviureteric junction obstruction
<https://www.nice.org.uk/guidance/ipg325>

Person-centred outcomes might include for the pelvi-ureteric junction obstruction to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

RefluxNeph
= Reflux Nephropathy

SNOMED CT: 197764002

See <http://www.infokid.org.uk/VUR-and-reflux-nephropathy>

Person-centred outcomes might include for the reflux nephropathy to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

MCDK
= MultiCystic Dysplastic Kidney Disease

SNOMED CT: 82525005

See <http://www.infokid.org.uk/MCDK>

Person-centred outcomes might include for the multicystic dysplastic kidney disease to be recognised and appropriately managed so as to minimise any impact on the child or young person's health, wellbeing or functioning

Actions towards achieving the outcomes might include for the child or young person should be assessed by a paediatrician, renal paediatrician and/or paediatric urologist, so that a specific diagnosis can be confirmed and an appropriate management plan can be agreed with the child, young person and family

ChrRenImp = Chronic Renal Impairment

SNOMED CT: 236425005

See:

<http://www.infokid.org.uk/CKD-introduction>

<http://www.infokid.org.uk/ckd-stages-3b-5>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their chronic renal impairment, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in renal paediatrics
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their chronic renal impairment are and what to expect for the future. This may require networking across all specialists involved, especially with paediatric cardiology, clinical genetics and paediatric disability as required
- For the paediatric team to provide regular reviews to proactively troubleshoot for any medical conditions that are known to be associated with the chronic renal impairment, for example, hypertension, electrolyte imbalance etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate to the complexity of the individual's health condition, an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. hypertension etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else who is not disabled
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their chronic renal impairment, be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's chronic renal impairment, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Endocrinopathy

SNOMED CT: 362969004

It is important to highlight this group, as decompensation can occur e.g. at times of intercurrent illness that may be life-threatening

Hypopit = Hypopituitarism

SNOMED CT: 74728003

Panhypopit = Panhypopituitarism

SNOMED CT: 32390006

GHdef = Growth Hormone Deficiency

SNOMED CT: 397827003

FaltGrowth = Faltering Growth

SNOMED CT: 909661000000108

DI = Diabetes Insipidus

SNOMED CT: 15771004

Hypothyroid = Hypothyroidism

SNOMED CT: 40930008

Hyperthyroid = Hyperthyroidism

SNOMED CT: 34486009

AdrenalInsuf = Adrenal Insufficiency

SNOMED CT: 386584007

PCOS = PolyCystic Ovarian Syndrome

SNOMED CT: 69878008

Type1DM = Type 1 Diabetes Mellitus

SNOMED CT: 46635009

See

<http://www.nice.org.uk/guidance/cg15>

http://www.bspeg.org.uk/clinical/clinical_endorsedguidelines.html

Type2DM = Type 2 Diabetes Mellitus

SNOMED CT: 44054006

ImpairedGT = Impaired Glucose Tolerance

SNOMED CT: 9414007

Gynaecomias = Gynaecomastia

SNOMED CT: 4754008

Person-centred Outcomes for children and young people with endocrine conditions should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their endocrine condition, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric endocrinology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their endocrine condition are and what to expect for the future
- For the paediatric endocrinology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the endocrine condition
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their endocrine condition be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's endocrine condition, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

AddisonsDis
= Addison's Disease

SNOMED CT: 363732003

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Addison's disease, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely).

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team.

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric endocrinology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Addison's disease are and what to expect for the future.
- For the paediatric endocrinology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the Addison's disease, for example, electrolyte imbalance etc.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise, e.g. Addisonian crisis etc. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else.
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Addison's disease be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Addison's disease, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

CAH = Congenital Adrenal Hyperplasia

SNOMED CT: 237751000

See <http://www.gosh.nhs.uk/medical-information/search-for-medical-conditions/congenital-adrenal-hyperplasia/congenital-adrenal-hyperplasia-information/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their congenital adrenal hyperplasia, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric endocrinology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their congenital adrenal hyperplasia are and what to expect for the future
- For the paediatric endocrinology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the congenital adrenal hyperplasia
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their congenital adrenal hyperplasia be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's congenital adrenal hyperplasia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

UCD
= Urea Cycle Disorder

SNOMED CT: 36444000

See <http://www.bimdg.org.uk/>
<http://www.climb.org.uk/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their urea cycle disorder, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric metabolic medicine
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their urea cycle disorder are and what to expect for the future.
- For the paediatric metabolic team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the urea cycle disorder
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their urea cycle disorder be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's urea cycle disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Organic Acidaemia

SNOMED CT: 898091000000107

See <http://www.bimdg.org.uk/>
<http://www.climb.org.uk/>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their organic acidaemia, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric metabolic medicine
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their organic acidaemia are and what to expect for the future.
- For the paediatric metabolic team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the organic acidaemia.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else.
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their organic acidaemia be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's organic acidaemia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

**VitD Deficiency
= Vitamin D Deficiency**

SNOMED CT: 34713006

See www.rcpch.ac.uk/guide-vitamin-d-childhood

Person-centred Outcomes in this area should be led by Health. The outcome is likely to be for the child's or young person's symptoms and signs that are attributable to their vitamin D deficiency (poor growth, muscle weakness, aches and pains, rickets, seizures, cardiomyopathy etc.) to be alleviated

Action towards achieving the outcome is likely to be for the vitamin D deficiency to be appropriately treated, with ongoing attention to diet, vitamin D supplementation ongoing and sunlight exposure in high-risk groups, to ensure adequate daily intake and prevention of symptoms

PeriodDisorder
= Disorder of Periods/Menstruation

SNOMED CT: 386804004

These include parental concern about how their child or young person and themselves will deal with the onset of periods as well as practical problems with pain, heavy bleeding etc.

Person-centred Outcomes in this area should be led by Health.

The outcomes might include for the young person's symptoms and signs from their disordered menstruation, to be recognised and alleviated

Actions towards achieving the outcome might include:

- For all who work with disabled young people to be aware of the red flags to suggest that menstruation disorder might be a possibility and to know when and where to refer for expert assessment and advice
- For the young person to be assessed and investigated by the appropriate health practitioner, which may be the general practitioner, paediatrician or other specialist, in order to make a specific diagnosis and recommend a treatment plan.
- For the young woman to be supported to understand how their body works, why they have periods, how to manage them and when to ask for expert help, at a level appropriate to their learning ability

Actions will depend on the person-centred outcomes agreed for the child or young person

DelPuberty
= Delayed puberty

SNOMED CT: 400003000

May be associated with a range of disabling conditions or occur in isolation.

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the young person's delayed puberty to be identified in a timely way and any secondary impact on them emotionally to be recognised and alleviated

Action towards achieving the outcome is likely to be for the delayed puberty to be identified, appropriately investigated by a paediatrician with expertise in endocrinology and where necessary, treated

PrecPuberty
= Precocious Puberty

SNOMED CT: 400179000

Look out for the accelerated growth in height on the chart as well as usual signs of puberty. Important to identify early to facilitate referral to paediatric endocrinology in a timely way so that treatment can be possible to delay pubertal progress. If puberty is already complete, it will be too late!

Person-centred Outcomes in this area should be led by Health. The outcomes are likely to be for the young person's precocious puberty to be identified in a timely way and any secondary impact on them emotionally to be recognised and alleviated

Action towards achieving the outcome is likely to be for the precocious puberty to be identified, appropriately investigated by a paediatrician with expertise in endocrinology and where necessary, treated

FeDeficiency = Iron Deficiency anaemia

SNOMED CT: 87522002

See:
NICE CLinical Knowledge Summary:
<http://cks.nice.org.uk/anaemia-iron-deficiency>

Person-centred Outcomes in this area should be led by Health. The outcome is likely to be for the child's symptoms and signs that are attributable to their anaemia (tiredness, lack of energy, pallor etc.) to be alleviated

Action towards achieving the outcome is likely to be for the anaemia to be appropriately treated using a formulation of iron that the child or young person can tolerate without unacceptable side effects

Thalasaemia

SNOMED CT: 40108008

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their thalassaemia, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric haematology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their thalassaemia are and what to expect for the future.
- For the paediatric haematology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the thalassaemia
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their thalassaemia be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's thalassaemia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

BleedingDis = Bleeding Disorder

SNOMED CT: 64779008

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their bleeding disorder, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp> possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric haematology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their bleeding disorder are and what to expect for the future
- For the paediatric haematology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the thalassaemia
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their thalassaemia be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's thalassaemia, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

SickleCellDis
= Sickle Cell Disease

SNOMED CT: 417357006

See:

NICE guidance for management of acute painful episode:

<https://www.nice.org.uk/guidance/cg143>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their Sickle Cell Disease, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric haematology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their Sickle Cell Disease are and what to expect for the future.
- For the paediatric haematology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the Sickle Cell Disease
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their Sickle Cell Disease be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's Sickle Cell Disease, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Anaemia

SNOMED CT: 271737000

Person-centred outcomes in this area should be led by the health team, in consultation with the child or young person, their family and multi-disciplinary team. Possible outcomes might include for the:

- Anaemia to be appropriately diagnosed and managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning
 - Child or young person, their family and inter-agency team to achieve a detailed understanding of the specific diagnosis, what it means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
 - For the child or young person to be able to participate in home, school and/or community activities
- Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving these outcomes should be led by the health team, in consultation with the child or young person, their family and multi-disciplinary team. Possible actions might include for:

- Appropriate expert assessments to be arranged with specialists in paediatric haematology
- The lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their anaemia are and what to expect for the future
- The lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning

**PlateletDis
= Platelet Disorder**

SNOMED CT: 22716005

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their platelet disorder, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric haematology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their platelet disorder are and what to expect for the future
- For the paediatric haematology team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the platelet disorder
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their platelet disorder be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's platelet disorder, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

RecurrentInf = Recurrent Infections

SNOMED CT: No code

Person-centred outcomes in this area might include for the recurrent infections to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

HIV = Human Immunodeficiency Virus infection

SNOMED CT: 86406008

See <http://cks.nice.org.uk/hiv-infection-and-aids>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their HIV infection, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric immunology and infectious diseases
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their HIV infection are and what to expect for the future.
- For the paediatric immunology and infectious diseases team to provide regular reviews to proactively troubleshoot for any medical conditions and complications that are known to be associated with the HIV infection
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their HIV infection be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's HIV infection, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Viral Infection

SNOMED CT: 34014006

Person-centred outcomes in this area might include for the viral infection to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for all parents to be educated about how to manage common viral infections and when and how to seek expert advice

Hepatitis B

SNOMED CT: 66071002

See:

NICE Clinical knowledge summary: <http://cks.nice.org.uk/hepatitis-b>

NICE clinical guidance for chronic hepatitis B: <https://www.nice.org.uk/guidance/cg165>

NICE quality standards: <https://www.nice.org.uk/guidance/qs65>

Person-centred outcomes in this area might include for the hepatitis B to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

Hepatitis C

SNOMED CT: 50711007

See:

SIGN guidance for Hepatitis C:

<http://www.sign.ac.uk/pdf/sign133.pdf>

NICE guidance in progress: <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0666>

Person-centred outcomes in this area might include for the hepatitis C to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

CMPI = Cows Milk protein intolerance

SNOMED CT: 15911003

See:

NICE clinical knowledge summary: <http://cks.nice.org.uk/cows-milk-protein-allergy-in-children>

Contact Allergy = Allergy due to contact

SNOMED CT: 325651000000108

Food Allergy

SNOMED CT: 414285001

See:

NICE guideline for food allergy in children and young people: <https://www.nice.org.uk/guidance/cg116>

Person-centred outcomes in this area might include for the allergy to be appropriately managed so as to cause the minimum possible impact on the child's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child and family

Anaphylaxis

SNOMED CT: 39579001

See <https://www.nice.org.uk/guidance/cg134>

<http://www.anaphylaxis.org.uk/healthcare/guidelines>

<http://www.rcpch.ac.uk/allergy/anaphylaxis>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their anaphylaxis, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric immunology and allergy
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their anaphylaxis are and what to expect for the future.
- For the paediatric immunology and allergy team to provide regular reviews to proactively troubleshoot for any complications that are known to be associated with the anaphylaxis
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their anaphylaxis be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's anaphylaxis, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Allergic Rhinitis

SNOMED CT: 61582004

See:

NICE Clinical Knowledge summary: <http://cks.nice.org.uk/allergic-rhinitis#!scenario>

Person-centred outcomes in this area might include for the allergic rhinitis to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a GP, paediatrician or Ear, Nose and Throat surgeon so that an appropriate management plan can be agreed with the child, young person and family

Eczema

SNOMED CT: 43116000

See <https://www.nice.org.uk/guidance/cg57>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their eczema, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with the general practitioner, paediatrician or dermatologist depending on the severity of the eczema
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their eczema are and what to expect for the future.
- For the health team to provide regular reviews to proactively troubleshoot for any complications that are known to be associated with the eczema.
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their eczema be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's eczema, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Skin Problem

SNOMED CT: 297982009

This includes any skin condition. Do link with a specialist paediatric dermatologist if in doubt about the diagnosis of a skin condition, as accurate diagnosis informs appropriate management. The skin finding may be the 'handle' required to gain an understanding of the child or young person's unifying diagnosis

Person-centred Outcomes in this area should be led by Health

The outcomes might include:

- For the child or young person's skin problem to be recognised in a timely way, assessed and correctly managed so as to have the minimum possible impact on functioning, participation and quality of life

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcome might include:

- For the child or young person to have a prompt access to expert assessment as required, which may be with the general practitioner, paediatrician or dermatologist, so that an appropriate management plan can be agreed with the child, young person and family

Actions will depend on the person-centred outcomes agreed with the child or young person and family

CFS = Chronic Fatigue Syndrome

SNOMED CT: 52702003

See <https://www.nice.org.uk/guidance/cg53>

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their chronic fatigue syndrome, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessment to be arranged with a paediatric team with expertise in chronic fatigue syndrome.
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their chronic fatigue syndrome are and what to expect for the future.
- For the paediatric team to provide regular reviews to proactively troubleshoot for any complications that are known to be associated with the chronic fatigue syndrome
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their chronic fatigue syndrome be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's chronic fatigue syndrome, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

RecAbdoPain
= Recurrent Abdominal Pain

SNOMED CT: 439469002

Person-centred outcomes in this area might include for the recurrent abdominal pain to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

Cramp

SNOMED CT: 55300003

Person-centred outcomes in this area might include for the cramp to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for all parents to be educated about how to manage cramp and to educate their children, for the child or young person to be assessed by a health professional if required, which may be the general practitioner or paediatrician so that an appropriate management plan can be agreed with the child, young person and family

HSP
= Henoch Schönlein Purpura

SNOMED CT: 191306005

See <http://www.infokid.org.uk/hsp>

Person-centred outcomes in this area might include for the HSP to be appropriately managed so as to cause the minimum possible impact on the child or young person's health, wellbeing and functioning

Actions towards achieving these outcomes might include for the child or young person to be assessed by a paediatrician so that an appropriate management plan can be agreed with the child, young person and family

NeoplasticDis = Malignant Neoplastic Disease

SNOMED CT: 363346000

Person-centred Outcomes in this area should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

- One possible outcome might be for the child or young person, their family and inter-agency team to achieve a detailed understanding of their neoplastic malignant disease, what this means for them, how it has come about, the potential impact on the activities the child or young person would like to do at home, school or in the community and what it means for the future
- Another possible outcome might be for the family to have a family-held Emergency Health Care Plan in place that follows the child or young person across all settings to facilitate communication in the event of a healthcare emergency.
- For more information on Emergency Health Care Plans see: <http://www.councilfordisabledchildren.org.uk/ehp>
- Other possible outcomes, leading on from the above, might be for all reasonable adjustments necessary to overcome any barriers to participation, achievement and quality of life for the child or young person to be in place across all settings.
- For the child or young person to be able to participate in home, school and/or community activities

Individual outcomes should be person-centred, include identification of each barrier or challenge that they face, how this will be overcome and be SMART (Specific, Measurable, Attainable, Realistic and Timely)

Actions towards achieving the outcomes should be led by the Health team, in consultation with the child or young person, their family and multi-disciplinary team

Possible actions might include:

- For appropriate expert assessments to be arranged with specialists in paediatric oncology
- For the lead health professional to explain in detail for the child or young person in so far as they can understand and for their family and multi-disciplinary team, what the implications of their specific condition are and what to expect for the future.
- For the paediatric oncology team to provide regular reviews to proactively troubleshoot for any complications that are known to be associated with the specific condition
- For the lead health professional to proactively include the child or young person in so far as possible and their family and multi-disciplinary team in any decision-making about their care and future planning
- For the lead health professional to prepare, if appropriate an Emergency Health Care Plan that includes a clear statement that has been agreed with the child and young person wherever possible, their family and the multi-disciplinary team about appropriate levels of intervention in any scenarios that can be predicted to arise. This should include a statement about resuscitation and intensive care if required, which would usually be a positive statement to protect the child or young person's right to full resuscitation and intensive care, the same as anyone else
- For all involved with the child or young person across agencies and the family to identify in advance any possible barriers or challenges to participation, achievement or quality of life that the child or young person might potentially face in any setting because of their specific condition be these attitudinal, physical or other
- To consider each identified barrier or challenge and identify what reasonable adjustments or action might be required in the knowledge of the child or young person's specific condition, so that these can be proactively put in place across all settings, to avoid the barrier or challenge from arising as an issue
- To consider any current barriers and challenges to participation, achievement and quality of life that have not effectively been overcome in any setting and ensure that each of these appropriately addressed and any reasonable adjustments made or actions taken

Actions will depend on the person-centred outcomes agreed for the child or young person

Consultation outcomes

No abnormality detected
Diagnosis not made
No neurodevelopmental condition
No neurodisabling condition
Medically unexplained symptoms

Appearance

Dysmorphic
Plagiocephaly
Short stature

Intellectual abilities

Learning difficulties
Developmental academic disorder
Typical intellectual abilities for age
Borderline intellectual abilities
Mild intellectual developmental disability
Significant intellectual developmental disability
Moderate intellectual developmental disability
Severe intellectual developmental disability
Profound intellectual developmental disability
Early developmental impairment/Unspecified intellectual developmental disability
Intellectual developmental disability of unknown cause
Specific learning disability
Dyslexia
Dyscalculia
Dysgraphia

Physical, motor, musculoskeletal

Physical disability
Neurological condition
Movement disorder
Spina bifida
Neuropathy
Neuromuscular disorder
Duchenne muscular dystrophy
Congenital muscular dystrophy
Neuromuscular junction disorder
Hereditary spastic paraplegia
Skeletal dysplasia
Congenital dislocation or dysplasia of hip
Congenital anomaly of musculoskeletal system
Talipes
Upper limb anomaly
Congenital hypotonia
Joint laxity
Clumsy
Gait abnormality
Developmental Coordination Disorder
Torticollis
Scoliosis
Dislocated hip/s
Musculoskeletal pain
Soft tissue mass
Haemangioma
Lymphadenopathy
Arthritis

Cerebral palsies

Worster Drought syndrome
Spastic cerebral palsy
Spastic cerebral palsy unilateral right
Spastic cerebral palsy unilateral left
Spastic cerebral palsy bilateral
Dyskinetic cerebral palsy
Dystonic cerebral palsy
Choreoathetoid cerebral palsy
Ataxic cerebral palsy
Gross Motor Function Classification System level I
Gross Motor Function Classification System level II
Gross Motor Function Classification System level III
Gross Motor Function Classification System level IV
Gross Motor Function Classification System level V

Neuroimaging (cerebral palsies)

Neuroimaging requested
Date of neuroimaging
Neuroimaging abnormal
Neuroimaging not done
Maldevelopment
White matter injury predominant
Grey matter injury predominant
Miscellaneous finding
Neuroimaging normal

Head, brain, congenital anomalies

Congenital maldevelopment of brain
Hydrocephalus
Microcephaly
Acquired brain injury
Traumatic brain injury
Traumatic brain injury due to non accidental injury
Congenital infection
Cleft palate
Congenital anomaly of head
Craniosynostosis
Congenital anomaly
Congenital heart disease
Genitourinary anomaly

Sensory impairments

Hearing impairment
Sensory-neural hearing loss
Bilateral congenital sensory-neural hearing loss
Profound bilateral sensory-neural hearing loss
Severe sensory-neural hearing loss
Moderate sensory-neural hearing loss
Mild sensory-neural hearing loss
Unilateral sensory-neural hearing loss
Conductive hearing loss
Hearing aid/s
Cochlear implant/s
Vision impairment
Severe bilateral vision impairment
Severe unilateral vision impairment
Partial vision impairment
Cerebral vision impairment

Speech, language, communication, feeding and nutrition

Speech and language delay
 Speech disorder
 Language disorder
 Fluency disorder
 Impaired social interaction
 Feeding difficulty
 Failure to thrive
 Recent weight loss
 Risk of nutritional problem
 Low risk of malnutrition
 Medium risk of malnutrition
 High risk of malnutrition
 Avoidant/restrictive food intake disorder
 Liquid diet
 Thickened fluid diet
 Soft diet
 Weight gain diet
 Failure to gain weight
 Obesity

Other conditions

Autism spectrum disorder
 Attention deficit disorder
 Attention deficit hyperactivity disorder
 Attention deficit hyperactivity disorder on stimulant medication
 Attention deficit hyperactivity disorder on non-stimulant medication
 Attention deficit hyperactivity disorder inattentive type
 Attention deficit hyperactivity disorder impulsive type
 Attention deficit hyperactivity disorder on medication
 Disorder of attention
 Tic disorder
 Progressive intellectual and neurological deterioration
 Inborn error of metabolism
 Mitochondrial disease
 Down's Syndrome
 Fragile X Syndrome
 MECP2 disorder
 MECP2 duplication
 Chromosomal disorder
 Genetic syndrome
 22q11 deletion syndrome
 Neurofibromatosis type 1
 Tuberous sclerosis
 Turner Syndrome
 Perinatal disorder
 28-37 weeks gestation
 Less than 28 weeks gestation

Safeguarding/Child protection

Non-accidental injury
 Victim of neglect
 Victim of emotional abuse
 Victim of child sexual abuse
 Victim of exploitation
 Victim of sexual exploitation
 Victim of domestic violence
 Victim of sexual abuse
 Victim of other behaviour
 Suspected child abuse
 Child abuse in family
 Child or young person at risk

Markers of complexity

Requires constant supervision
 At risk of death before 18 years (expected/unexpected) – clinical judgement
 Preferred place of death discussed
 Preferred place of death (location)
 Place of death

Family reported barriers to participation and Quality of life

Emergency Health Care Plan agreed
 Impaired participation
 Family issues
 School issues
 Housing issues
 Equipment issues
 Leisure issues
 Support issues
 Information issues
 Understand care plan
 Do not understand care plan

Technology dependent in all settings

Dependent on Continuous Positive Airways Pressure
 Dependent on Ventilator
 Tracheostomy
 Intrathecal Baclofen
 Vagal Nerve Stimulator
 Deep Brain Stimulator
 Nasogastric tube
 Gastrostomy tube
 Jejunostomy tube
 Total Parenteral Nutrition
 Ventriculo-peritoneal shunt in place
 Uses alternative communication skill

Neurological disorder

Hypoxic ischaemic encephalopathy
 Epilepsies
 Epilepsies requiring paediatric neurology input (as defined in NICE CG137)
 Epilepsies requiring children's epilepsy surgical service (as defined in NICE CG 137)
 Seizure disorder
 Absence seizure
 Focal seizure
 Febrile convulsion
 Dizzy spell
 Syncope
 Funny turn
 West's Syndrome
 Tension headache
 Migraine
 Pain

Behaviour, mental health and lifestyle

Behavioural difficulties
 Disruptive behaviour
 Emotional /mood/anxiety disorder
 Oppositional defiant disorder
 Self injury
 Repetitive self excoriation
 Sensory sensitivities
 Anxiety disorder
 Childhood social anxiety disorder
 Eating disorder
 School non-attendance
 Post Traumatic Stress Disorder
 Selective mutism
 Substance abuse
 Self harm
 Depression
 Insecure attachment
 Obsessive compulsive disorder
 Pica
 Disordered sleep
 Sleep disorder on melatonin

Ear, nose, throat and respiratory

Ear, nose, throat disorder
Epistaxis
Enlarged tonsils
Recurrent tonsillitis
Laryngomalacia
Nasal obstruction
Drooling
Obstructive sleep apnoea
Otitis media with effusion
Asthma
Wheeze
Cough
Lower respiratory tract infection
Recurrent chest infections
Cystic fibrosis

Cardiac

Heart murmur
Ventricular septal defect
Palpitations
Cardiomyopathy

Gastrointestinal

Gastro-oesophageal reflux disease
Coeliac disease
Constipation
Diarrhoea
Inflammatory bowel disease
Bowel incontinence

Genitourinary

Bed wetting
Urinary incontinence
Urinary tract infection
Undescended testis
Congenital anomaly of kidney
Haematuria
Renal dilatation
Nephritic syndrome
Nephrotic syndrome
Pelviureteric junction obstruction
Reflux nephropathy
Chronic renal impairment
Multicystic dysplastic kidney disease

Haematological

Thalassaemia
Bleeding disorder
Sickle cell disease
Anaemia
Iron deficiency
Platelet disorder

Endocrine and metabolic

Endocrinopathy
Hypopituitarism
Panhypopituitarism
Growth hormone deficiency
Faltering growth
Diabetes Insipidus
Delayed puberty
Precocious puberty
Hyperthyroidism
Hypothyroidism
Addison's disease
Adrenal insufficiency
Congenital adrenal hyperplasia
Polycystic ovaries
Type 1 Diabetes mellitus
Type 2 Diabetes mellitus
Impaired glucose tolerance
Gynaecomastia
Organic acidaemia
Urea cycle disorder
Vitamin D deficiency
Period disorder

Infection

Recurrent infection
Human Immunodeficiency Virus infection
Viral infection
Hepatitis B
Hepatitis C

Allergy

Cows milk protein intolerance
Contact allergy
Food allergy
Anaphylaxis
Allergic rhinitis
Eczema

Multifactorial

Skin problem
Chronic fatigue syndrome
Recurrent abdominal pain
Cramp
Henoch Schönlein Purpura
Malignant Neoplastic Disease

Paediatric Disability Terms Abbreviated

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| | | | | | | | | | |
|--|--------------------|-------------------|-------------------|--------------------|----------------|------------------|----------------------------|-------------|-------------|
| Consultation Outcomes | | NAD | DiagnosisNotMade | | NoNeuroDevCond | | NoNeuroDisCond | | MedUnexp |
| Appearance | Dysmorphic | Plagioceph | ShortStature | | | | | | |
| Intellectual Abilities | | LDiff | DevAcadDis | TypIAA | BordIA | MildIDD | SigIDD | ModIDD | SevIDD |
| ProfIDD | EDI/UnsiDD | IDDunknown | SpecLD | Dyslexia | Dyscalculia | Dysgraphia | | | |
| Physical, Motor, Musculoskeletal | | | PhysicalDis | Neurological | MvtDisorder | SpinaBifida | Neuropathy | NMuscDis | DMD |
| CongenMD | NMJdis | HSpParapl | SkelDyspl | CongDisHip | CAMSK | Talipes | ULanomaly | CongenHypo | JointLaxity |
| Clumsy | GaitAbn | DCD | Torticollis | Scoliosis | DislocHip/s | MSKPain | SoftTMass | Haemangio | Lymphaden |
| Arthritis | CPalsy | WorsterDr | SpCP | SpUniCP | SpCPuniR | SpCPuniL | SpCPbilat | DyskinCP | DystonCP |
| ChorAthCP | AtaxicCP | GMFCSI | GMFCSII | GMFCSIII | GMFCSIV | GMFCSV | | | |
| NI in CP | NIreq | DateNI | NIabnormal | NInotDone | Maldev | WhiteMatInj | GreyMatInj | Misc | NInormal |
| Head, brain, congenital anomalies | | | ConMalBrain | Hydroceph | Microceph | ABI | TBI | TBI NAI | CongenInf |
| CleftPalate | CAhead | Craniosyn | CongAnom | GUanom | CHeartDis | | | | |
| Sensory Impairments | | HearingImp | SNHL | BCSNHL | ProfBSNHL | SevBSNHL | ModBSNHL | MildBSNHL | UnilatSNHL |
| ConductHL | HearingAid/s | CochlearImp | VI | SevBilatVI | SevUniVI | PartVI | CerebralVI | | |
| Speech, Language, Communication, Feeding, Nutrition | | | | | SALD | SpeechDis | LangDis | FluencyDis | ImpSocInt |
| FTT | RecWgtLoss | FeedingDif | RiskNutProb | LoRskMaln | MedRskMaln | HighRskMaln | ARFID | LiquidDiet | ThFluidDiet |
| SoftDiet | WgtGainDiet | FaltWgtGain | Obesity | | | | | | |
| Other conditions | | ASD | Chromosom | GenSyndr | DownSynd | 22q11delSyn | NF1 | TuberousS | FraX |
| TurnerSynd | IEM | PIND | Mitochond | MECP2Dis | MECP2dupl | PerinatalDis | 28-37wks | <28weeks | |
| Safeguarding/Child protection | | | NAI | VictNeglect | VictEmAbus | VictChSxAbu | VictExploit | VictSxExpl | VictDomViol |
| VictSexAbuse | VictOthBeh | SuspChAb | ChAbFam | CYPatRisk | | | | | |
| Family reported barriers to participation and QoL | | | | EHCPageed | ImpParticip | FamilyIssues | Schoollss | Housinglss | Equiplss |
| Leisurelss | Supportlss | Infolss | UndCarePI | NotUndCaPI | | | | | |
| Markers of Complexity | | ReqConsSup | RskDth<18 | PrefPIDdisc | PrefPIDLoc | PlaceDeath | | | |
| Technology dependent all settings | | | DepCPAP | DepVent | Trachy | ITB | VNS | DBS | NGT |
| PEG | Jejunostomy | TPN | VPshunt | AltCommSkill | | | | | |
| Neurological | HIE | Epilepsy | EpPN | EpCESS | SeizureDis | AbsenceSz | FocalSz | FebConv | DizzySp |
| Syncope | FunnyTurn | WestSyndr | TensionHead | Migraine | Pain | | | | |
| Behaviour, mental health, lifestyle | | | BehavDiff | DisruptBehav | EmMoodAnx | ODD | DisAttention | ADD | ADHD |
| ADHDmed | ADHDstim | ADHDnonst | ADHDinatt | ADHDimp | TicDisorder | SelfInjury | RepSelfEx | SensSens | Pica |
| AnxDis | ChSocAnxD | EatingDis | SchNonAtt | PTSD | SelMutism | SubstAbuse | SelfHarm | Depression | InsecAttach |
| OCD | DisSleep | DisSleepMel | | | | | | | |
| ENT and Respiratory | | ENTdisorder | Epistaxis | EnITonsils | RecTonsil | Laryngomal | NasalObstr | Drooling | OSA |
| OME | Asthma | Wheeze | Cough | LRTI | RecChInfect | CF | | | |
| Cardiac | HeartMurm | VSD | Palpitations | Cardiomyo | | | | | |
| GI | GORD | CoeliacDis | Constipation | Diarrhoea | InfBD | BowellIncont | | | |
| GU | BedWetting | UrinIncont | UTI | UDT | CAkidney | Haematuria | RenalDil | NephriticSy | NephroticSy |
| PUJobs | RefluxNeph | ChrRenImp | MCDK | | | | | | |
| Haematological | | Thalassaem | BleedingDis | SickleCellDis | Anaemia | IronDef | PlateletDis | | |
| Endocrine and Metabolic | | Endocrinop | Hypopit | Panhypopit | GHdef | FaltGrowth | DI | DelPuberty | PrecPuberty |
| Hyperthyroid | Hypothyroid | AddisonsDis | AdrenalInsuf | CAH | PCO | Type1DM | TYpe2DM | ImpGT | Gynaecomas |
| OrganicAcidaemia | | UreaCycleDisorder | | VitaminDdeficiency | | PeriodDisorder | | | |
| Infection | RecurrentInfection | | HIV | ViralInfection | HepatitisB | HepatitisC | | | |
| Allergy | CMPI | ContactAllergy | | FoodAllergy | Anaphylaxis | AllergicRhinitis | | Eczema | |
| Multifactorial | SkinProblem | CFS | RecurrentAbdoPain | | Cramp | HSP | MalignantNeoplasticDisease | | |