DATA MATTERS!
DEVELOPMENT OF A DISABILITIES TERMINOLOGY SET AND DISABILITIES COMPLEXITY SCALE

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OVERVIEW

• Why SNOMED CT?
• Terminology set development group
• Choosing the terms
• Building the explanatory glossary
• Peer review and buy in from the specialty
• Development of a Disabilities Complexity Scale
• Publication
WHY SNOMED CT?

- Internationally recognised
- Allows capture of much more than DIAGNOSES and CONDITIONS
- Anything can be coded - all aspects relevant to person-centred care
  - Situations
  - Family-reported issues
  - Technology dependencies
  - Need for round-the-clock care
- Can be linked to outcome measurement
- Terms relate to each other in sections: ‘parent’ and ‘child’ terms
- Outdated terms can be ‘retired’
- Synonyms allowed
TERMINOLOGY SET DEVELOPMENT GROUP

- Clinicians working in the field
  - Paediatricians with a range of expertise
  - Allied Health Professionals
- Parent carer/s
- Specialist terminologists
CHOOSING THE TERMS

- Must be rooted in clinical practice

- Disabilities Terminology Set:
  - Based on active concerns listed in review of >8000 electronic clinic letters
  - ~2000 children and young people attending paediatric disability clinics in a large district over a five year time window
  - Initial 83 terms, augmented to 122 by national working group
  - Community and general paediatricians had separate working groups
    - Community paediatric working group – 178 terms
    - General paediatric working group – 117 terms
  - Most of work done by email, with some teleconferences and face to face meetings
  - Much discussion and debate where terms overlapped to reach consensus on the final 296 terms
BUILDING THE EXPLANATORY GLOSSARY

- Underpins the whole terminology set
- Each term defined in precise detail
- Resources relevant to clinical practice included e.g. NICE guidance, support groups etc.
- Utility for clinicians increased by adding suggestions for ‘Outcomes’ and ‘Actions’ relevant for Education, Health and Care planning
PEER REVIEW AND SPECIALTY ‘BUY IN’

• Careful peer review essential to ensure credibility
• For Disability Terminology Set, a number of experts reviewed the full glossary from different perspectives
• Process of updating agreed: data governance group established from the executive members of the British Academy of Childhood Disability
• Glossary and terminology set easily available on the BACD website
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 to enable paediatricians, 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 Terminology Subset. This can be found at:
SNOMED-CT codes are highlighted in YELLOW

What resources are there in the Glossary?

For each term, the abbreviation and full-vendor 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 professions, for example therapists, who should make their own explicit contributions to the over-arching 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, but also their mentalstate and social function are considered, but also their activities, participation, environmental factors, personal factors and context, as well as how all these relate to each other (http://www.who.int/classifications/icf/en/). In this context of the 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 a 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 a range of stakeholders.

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 paediatricians will listen to the views of the child, young person and parent carers 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.bcald.org.uk/PolicyStatements/00060Summary.pdf

How do I access and navigate the Glossary?

The glossary is available as an ebook, that can be read on any ebook reader such as (Kindle, Kobo etc). If you do not have an ebook reader, you can search on the internet for one that is compatible with the technology being used e.g. Mesic, PC, tablet, android, iphone etc. There are many available that are free to download.

The glossary is also available as a pdf file. The advantage of the ebook format is that it is fully searchable and can be carried on a portable electronic device.

The table of contents can be used to search for the required term: this can be accessed via the icon at the top of the ebook screen.

The Search facility can also be used to find a term. Again, this can be accessed from the tool bar at the top of the ebook screen.

How will data be recorded?

This varies between different NHS organisations. Plots showed that data recording is quickest and most efficient when it is captured electronically at the time of the consultation by the paediatrician. At the time of the consultation, the paediatrician will be aware of many different IT systems in a place, it is important to discuss with their IT team regarding setting up an interface that allows data to be captured. A template for use in Medicode 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 bioadprep@nhs.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). These 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.

Collecting the data for a local area can inform strategic planning across agencies. In England, the data can be used to be 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 the Health and Social Care Information Centre as part of the Children and Young People’s Health Services dataset. It will then be analysed. This will allow comparisons between different areas, resulting in a wider view of needs and how these are being met. This will act as a driver for improvement in care.

Where data has been collected for some time, it has already been used to support business cases for additional disability pediatrics and therapists, as well as being used to undertake 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, as well as 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 skilled 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 baed@nphc.org.uk. Also see http://bcald.org.uk/privacy/cookie.htm
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
- Lesion nodules on the irises (require slit lamp examination to identify)
- Optic glioma
- Characteristic skeletal abnormality (ibibial bowing, orbital malformation)
- First degree relative with a confirmed diagnosis of NF1

See http://www.nf1uk.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.nf1.org.uk/keepingchildrensafe
- 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.
- 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 neurofibroma 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.
• Too many to count!
• Development of a Disabilities Complexity Scale
• Ability to compare subgroups with the same or different conditions including across different geographical areas
• Improved understanding of the multi-faceted needs of disabled children, young people and their families
Health conditions (C)

- Attention Deficit Hyperactivity Disorder
- Chromosomal, genetic, syndromes
- Term Neonatal Intensive Care
- Cerebral Palsies
- Neurofibromatosis type 1
- Autism Spectrum Disorder
- Continence issues
- Epilepsies
- Scoliosis
- Behavior issues
- Acquired Brain Injuries
- Visual impairments
- Feeding, swallowing issues
- Gastro-oesophageal reflux disease
- Other congenital anomalies
- Prematurity (<37 weeks gestation)
- Recurrent chest infections
- Congenital heart disease
- Bilateral Sensorineural Hearing Loss

Family-reported issues (F)

- Child Protection Plan in place
- Equipment issues
- Access to leisure issues

School issues

- Housing issues
- Alternative/Augmentative communication

Technology dependencies (T)

- Cochlear implant
- Ventilated at home

Gastrostomy

- Naso-gastric tube
- Tracheostomy

Round-the-clock care (R)

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Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale

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Prospective pilots of routine data capture by paediatricians in clinics and validation of the Disabilities Complexity Scale

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REFERENCES

• Spencer A, Horridge K, Downs D. Empowering clinical data collection at the point of care. Arch Dis Child. 2015;100:815-817
