Paediatric Disability Data Project
Parent Carer and Family perspective

NNPCF Steering Group
May 2014
1 Document

Name: Paediatric Disability Data Project - Parent Carer and Family Perspective

Version: Version 1.0

Date: May 2014

1.1 Contents

1 Document ........................................................................................................................................... 2
1.1 Contents ........................................................................................................................................... 2
2 Introduction ........................................................................................................................................ 2
3 The National Network of Parent Carer Forums .............................................................................. 2
4 Context .................................................................................................................................................. 3
5 A broad range of disabilities/impairments ...................................................................................... 5
6 Understanding the lives of families with disabled children .......................................................... 6
7 Parent Carer/family considerations in the development of the data set ........................................ 8
8 National agreement to use the data set .......................................................................................... 9
9 Conclusion .......................................................................................................................................... 9
9.1 Authors ........................................................................................................................................... 11
Annex A: New Commissioning Arrangements ............................................................................... 12
Annex B: NNPCF Structure and Sphere of Influence ...................................................................... 13
Annex C: Traffic Light Tool .............................................................................................................. 14

2 Introduction

The National Network of Parent Carer Forums (NNPCF) strongly supports the Paediatric Disability Data project.

3 The National Network of Parent Carer Forums

The NNPCF was launched in 2011, and is funded by central government. The NNPCF membership is made up of parent carer forums of which there is one in almost every local authority area in England. Each parent carer forum in receipt of the Department of Education participation grant is a member of the NNPCF.

The function of the NNPCF is to develop cohesive good practice and effective parent carer participation and a solution focussed approach at all levels, locally, regionally and nationally. Annex D demonstrates our structure and sphere of influence.

The NNPCF is a network of local forums meeting in regional settings, working together to effect local and national service improvement. The steering group of the NNPCF is made up of representatives of the nine regions. The aims of the NNPCF are:
• to ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen,

• to develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England and

• to strengthen pan disability, parent lead model of local forums and boost our collective voice.

4 Context

1 There are a number of serious problems with existing national indicators of numbers of disabled children in England:

   a. this information is not based on accurate data
   b. there is no agreed data collection template or agreed terminologies
   c. there is no agreed mechanism to collect the data
   d. the complexities of disabled children's health needs are not well understood or at all
   e. disabled children's health and other services cannot be planned for locally or nationally or effectively commissioned on the basis of the existing arrangements.

2 Against the background of many previous failed attempts at finding a way through, a group of health professionals and a parent carer came together at the end of 2012 with a mandate from Sheila Shribman, the outgoing National Clinical Director for Children Young People and Maternity, to find a solution as a matter of urgency.

3 The timing of the challenge was opportune in that:

   a. We have a neurodisability specialism within paediatrics
   b. Neurodisability had been selected as one of the first trial areas for a new national terminology system - SNOMED CT – that has been selected and approved as the terminology to be adopted by the NHS in England and can be used across all care settings and all clinical domains.¹

¹ SNOMED CT - http://www.connectingforhealth.nhs.uk/systemsandservices/data/uktc/snomed

"A standard clinical terminology is essential for the interoperability of electronic health records across care settings.
c. We have moved to a new clinical commissioning based system within health that requires accurate and reliable data to ensure the health needs of particular groups are understood and can be met – this presents opportunities but also great challenges for disabled children given the complexity of health areas working with disabled children and their families – see Annex A)  
d. The Children and Families Bill (now Act) was breaking down barriers between health, education and social care that will require more joint working and clearer understanding of the ranges of health needs  
e. the NHS Mandate to the Commissioning Board identifies the need for improvement in this area:

“…there is a particular need for improvement, working in partnership across different services in supporting children and young people with special educational needs or disabilities. The Board’s objective is to ensure that they have access to the services identified in their agreed care plan, and that parents of children who could benefit have the option of a personal budget based on a single assessment across health, social care and education.”


As we move to more integrated care records with information following patients, it is important that information is consistent and transferable within and across all the healthcare settings where a patient may be treated; the use of coded information supports recording in a consistent and transferrable way.

In healthcare, the requirements for coding are extensive. SNOMED CT provides a comprehensive set of such clinical phrases or terms, this is called a terminology. SNOMED CT is much more than just a set of clinical phrases, for example it also includes groups with relationships between terms.

SNOMED CT has been selected and approved as the terminology to be adopted by the NHS in England. It is the most comprehensive international terminology currently available and can be used across all care settings and all clinical domains.

SNOMED CT stands for the ‘Systematized Nomenclature of Medicine Clinical Terms’, and consists of comprehensive scientifically validated content. SNOMED CT is available in more than fifty countries and has been adopted as the standard clinical terminology for the NHS in England.

When implemented in software, SNOMED CT represents clinically relevant information consistently, reliably and comprehensively as an integral part of the electronic health record.

SNOMED CT is managed and maintained internationally by the International Health Terminology Standards Development Organisation (IHTSDO) and in the UK by the UK Terminology Centre (UKTC).”
4 The Health Outcomes Forum also identified the particular problems faced by parent carers and families with disabled children in accessing health services and having health needs understood, coordinated and integrated with other services.

5 A broad range of disabilities/impairments

5 Children and young people with disabilities have a range of diagnoses, comorbidities and health needs. These will include children and young people with:

- Sensory and physical conditions
- Cognitive and learning disabilities
- Acute and long term medical and life limiting conditions.
- Emotional, social and behavioural disorders

6 Young people with these diagnoses will access an array of health services from a range of different places depending on the diagnoses and comorbidities. This will include:
   a. Primary
   b. Community
   c. Acute Hospitals
   d. Specialist Centres and hospitals.

7 Children and young people with more complex disabilities and comorbidities will have to access multiple specialists in different settings. They will be taking multiple prescribed and other medicines. They may not see their GPs in Primary Care very often. The complexity of health needs and numbers of health and other professionals that can be involved for individual young people across these settings can be numerous and interconnected as demonstrated in the diagram below.
6 Understanding the lives of families with disabled children

8 The resulting Paediatric Disability data set brings more to life understanding of the personal challenges, service barriers, societal problems and discrimination families with children with impairments and disabilities face more broadly. From the point of diagnosis children and their families are presented with a series of challenges which are addressed with the support of a vast array of services in Health, Education and Social Care. Families may have to coordinate these issues themselves and are currently the only ones to know all the diagnoses their children and young people have.

9 The challenges faced are alleviated by the services they are introduced to depending upon the nature of their child’s condition. Parents refer to support in areas of:

- The provision of impartial information, advice and support
- Specific skills training to use medical equipment, manage sleep
• Support with developing positive behaviour, healthy eating
• Looking after themselves including safe lifting (should that be moving) and handling techniques
• Developing opportunities for peer support and management of stress

10 However these positive interventions can often be clouded by the many difficulties faced by families caring for a disabled child, which can include:

• **Families with disabled children face challenges on different levels**
  o Negative perceptions of disability.
  o (Sometimes) family rejection.
  o Families dealing with disability in different ways and may need appropriate support to manage their situation.
  o Wider communities (including faiths) not always supportive or inclusive.
  o Societal discrimination
  o Physical barriers to places, goods and services
  o Bullying and harassment
  o Poor or inappropriate housing
  o Poverty and financial hardship

• **Health**
  o Often pathways to diagnosis are not developed, not clear and too slow
  o Lack of understanding of and investment in early intervention in health
  o No prevention e.g. sleep, behaviour, eating
  o Limited support – e.g. around and post diagnosis, psychological conditions
  o Passed to education, who may not understand needs
  o No integration of health needs

• **Health, education and social care systems can add to burdens on families**
  o Families reaching or engaging with services themselves
  o Unable to get help from right services at right time
  o Silo mentality
  o “Passing the buck”
  o Lack of joined up outcomes
  o No appropriate service provision available
  o Family break down
  o Effects on children and young people in terms of less long term stability, happiness and poorer management of long term conditions

• **Choice and Control**
  o Genuine choice and understanding of service availability (e.g. many families want services from social care)
  o Access to Universal Services and “ordinary” leisure facilities
  o Confusion
Families want “ordinary” lives; whatever ordinary is.

7 Parent Carer/family considerations in the development of the data set

11 Parent Carer Forums have brought together parent carers and families from a range of disabilities and impairments. They are pan disability. That has allowed families to see that we have much in common in terms of diagnoses, needs for services, and so on. They work locally, regionally and nationally through the NNPCF.

12 Against this background, and what we know of the common challenges we all face regardless of diagnostic labels, parent carer considerations in being part of this vital work focussed on the following key elements:

- The need for the data set to reflect the range of comorbidities that we know children and young people have – this meant including primary diagnoses and secondary disabilities
- The need for a full glossary of terms so that issues about understanding of diagnoses and diagnostic terms can be standardised
- Maximising the use of SNOMEDCT to code terms such as “pain”, “sleep”, “obesity” that might not otherwise be allowed under previous coding systems, reflecting what families know to be the realities and challenges of living with disability
- The imperative for agreement across all paediatric settings – general, community and disability (this was achieved in June 2013)
- That the data set and glossary should focus on the social and not just the medical model of disability
- Speech and language, physical and functioning needs should also be included reflecting the multidisciplinary nature of the life of disabled children, young people and their families
- Family reported barriers to participation should be included in particular as this “Traffic Lights Tool” had been developed in coproduction with families in Sunderland and in the North East of England. This is enclosed at Annex C. The Traffic Lights Tool allows families to reflect on and frame a constructive dialogue with clinicians in a positive way on what is working well, what are the barriers to participation, if any, to leading a full life within their communities, and what is of greater concern. This is framed very much within the social model of disability.
- Markers of complexity should be included, reflecting the particular challenges families in these circumstances face – and allowed for with the new SNOMEDCT system. These markers of complexity reflect not just medical needs but also behavioural needs which can often be overlooked or, wrongly, not thought of as complex.
- That national best practice was followed for all diagnostic terms in the glossary of terms as it is very upsetting for families when the terms such
as learning difficulty and learning disability are mixed up, speech and language difficulties and speech and language disorders are mixed up and so on

- The need to use the data and information to drive up standards of care and coordination of health services for disabled children

13 The full terminologies and explanatory glossary can be found in the attached document.

8 National agreement to use the data set

14 Following successful trials of the terminologies and glossary across a number of paediatric sites in England (general, community and disability), the successful pilot data collection, even for the most complex disabled children and young people, was presented to RCPCH Informatics Committee on 12 March 2014.

15 On 13 March 2014, the Children and Young Peoples Knowledge and Intelligence Team in Public Health England, NHS England agreed that all 304 terminologies would be built into the Maternity and Children’s Dataset. This means that:

a. By the end of 2014 reporting of all this data will be MANDATORY for provider organisations for ALL children and young people across all settings

b. Data Collection will go live from Summer 2015.

9 Conclusion

16 It is vitally important that we have this Paediatric Disability Data Collection Set. As the vital importance of data is becoming more understood especially for effective clinical commissioning, it will be so powerful to use a data set that has common agreed diagnostic terms, comorbidities, family quality of life information and markers of complexity. There is no need to reinvent the wheel locally or within different areas of paediatrics when we have developed one Paediatric Data Collection Set together. National data collection matters a huge amount not just to fill the missing national gaps on data but also to bring consistency and to inform work on development of national, regional and local clinical care pathways.

17 It is also needed to help understanding of disabilities in the wider communities. The challenges families face on lack of understanding of diagnoses or use of different and incorrect terms (e.g. over learning needs) are enormous. Families also are concerned about the use of certain diagnostic labels being used incorrectly such as global developmental delay. This new data set will address these and other concerns and bring consistency and
understanding for the first time in this vital but until now too often overlooked area of children, young people and family life.

18 This will also aid common understanding across health, education and social care and gives the promise of better lives and outcomes for our children and our families. We need higher quality of information about disabled children’s conditions being passed to education (and social care) in the existing system. The national data set could really help improve this quality issue and increase understanding across health, education and social care.

19 This work has also been a great example of coproduction with parent carers from the outset and that input has been valued all the way through the process.

20 Finally this is the message conveyed by the parent carer from the NNPCF Steering Group who worked with the team developing the data set at the time of the decision to from the outset at the time of the decision on 13 March 2014:

“IT has been an honour to be involved in this great work since that first meeting at the Department for Health chaired by Sheila over a year ago. To have made this achievement in such a relatively short space of time is truly miraculous. You should all be proud of doing that and coming together and agreeing and trailing the data set for the good of families, children and young people.

As a parent carer, I have fully supported this work because I know, after years of working on health issues locally, that data is key, not just to being able to commission and plan well for our children and services at a local and national level but also to address some of the practical problems we have in getting consistent, timely and complete diagnoses. Without all that we cannot get better outcomes for our children and young people.

To have such an intelligent data set, with common descriptors and measures of family and parental satisfaction, will transform lives and for the first time give us all the chance to evidence who our children really are and what is needed to meet their and our needs as families.

I look forward to taking these messages, with you, to families, children and young people including members of Parent Carer Forums through the National Network of Parent Carer Forums. In my small efforts to promote it to date all the feedback from health professionals and families has been 100% positive.

I never gave up hope that together we could achieve this and bring the realities of such transformational change to families and our children and young people.

Thank you all from the bottom of my heart and thank you Karen Horridge for
being an amazing and inspirational leader in all of this.”

9.1 Authors

This report has been produced by the National Network of Parent Carer Forums, based on our understanding and knowledge of our members, parent carers of disabled children who are linked to parent carer forums across England. The document has been contributed to by Members of the NNPCF Steering Group.

To contact the NNPCF for further discussion, information, or future involvement please contact the NNPCF via info@nnpcf.org.uk
### Annex A : New Commissioning Arrangements

<table>
<thead>
<tr>
<th>Clinical Commissioning Groups</th>
<th>Local Authorities</th>
<th>NHS Commissioning Board</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Community health services (inc rehabilitation, speech and language, continence, wheelchair services)</td>
<td>• Healthy Child Programme (School Age)</td>
<td>• Healthy Child Programme 0-5</td>
</tr>
<tr>
<td></td>
<td>• School Nursing</td>
<td>• Health Visitors</td>
</tr>
<tr>
<td></td>
<td>• National Child Measurement Programme</td>
<td>• Family Nursing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Antenatal/ newborn screening</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Immunisation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Promoting early diagnosis as part of primary care</td>
</tr>
<tr>
<td>• Acute Care</td>
<td></td>
<td>Specialised services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• GPs</td>
</tr>
<tr>
<td>• NHS data collection and information reporting systems</td>
<td></td>
<td>NHS data collection and information reporting systems</td>
</tr>
<tr>
<td>• Mental Health Services</td>
<td></td>
<td>Some specialised mental health</td>
</tr>
<tr>
<td>• NHS Continuing Healthcare</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Services for people with LD</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Annex B: NNPCF Structure and Sphere of Influence

Each forum includes parent carers with a full range of experiences in Health, Education and Social Care as their children have a wide range of conditions.

Parents in the network total over 52,000; they contribute to Local, Regional and National consultations.

The NNPCF are involved in a wide range of national groups. These are more fully described in our own progress report which was published in March 2013.

It can be downloaded on-line from the resources page on our web site:

http://www.nnpcf.org.uk/resources

We continue to develop closer working relationships with health at all levels, including local working with CCGs.

Further details about the NNPCF can be found on our web site www.nnpcf.org.uk.
### Annex C: Traffic Light Tool

#### HEALTH, FUNCTIONING AND WELLBEING SUMMARY

Please fill in this information. It will help professionals to understand what is going well and what worries you most at this time.

**Things to celebrate, things that are going well:**

**Thoughts about what might help to make it easier to join in everyday activities and make life more enjoyable:**

**Things that are causing concern and questions:**

© Dr Karen Hurridge, Paediatrician, Sunderland UK, May 2013
For each of the following areas please indicate which traffic light colour best matches your level of concern.

**No Concerns**
Does not limit joining in every day activities or enjoying life.

**Some Concerns**
Regularly but intermittently limits joining in every day activities or impacts on ability to enjoy life.

**Serious Concerns**
Frequently or daily limits joining in every day activities or impacts on ability to enjoy life.

<table>
<thead>
<tr>
<th>Area</th>
<th>No Concerns</th>
<th>Some Concerns</th>
<th>Serious Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>General physical health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Airway &amp; breathing issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent chest infections</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seizures (fits, fainty, funny turns)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating, drinking, swallowing issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drooling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acid reflux (acid, smelly burps), vomiting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation (infrequent stools, hard to pass)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soiling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day time wetting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Night time wetting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Period issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ear, nose or throat issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faltering weight gain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overweight issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility, moving around</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand function</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal care (self feeding, washing, dressing, toileting etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision (eyesight)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech, language, communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friendships and relationships, social communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disruptive behaviour</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional issues (mood, anxiety)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensory sensitivities (e.g. to sounds, textures etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pica (eats inappropriate things e.g. soil, metal etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equipment issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to leisure activity issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you well enough supported?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have enough information about your child’s condition and services?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>