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

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PUBLICATION DATA
Accepted for publication 20th January 2016.
Published online

ABBREVIATION
DTS Disabilities terminology set

AIMS To pilot prospective data collection by paediatricians at the point of care across England using a defined terminology set; demonstrate feasibility of data collection and utility of data outputs; and confirm that counting the number of needs per child is valid for quantifying complexity.

METHOD Paediatricians in 16 hospital and community settings collected and anonymized data. Participants completed a survey regarding the process. Data were analysed using R version 3.1.2.

RESULTS Overall, 8117 needs captured from 1224 consultations were recorded. Sixteen clinicians responded positively about the process and utility of data collection. The sum of needs varied significantly ($p<0.01$) by level of gross motor function ascertained using the Gross Motor Function Classification System for children with cerebral palsy; epilepsy severity as defined by level of expertise required to manage it; and by severity of intellectual disability.

INTERPRETATION Prospective data collection at the point of clinical care proved possible without disrupting clinics, even for those with the most complex needs, and took the least time when done electronically. Counting the number of needs was easy to do, and quantified complexity in a way that informed clinical care for individuals and related directly to validated scales of functioning. Data outputs could inform more appropriate design and commissioning of quality services.

Population data concerning disabled children and young people* ('children' is used hereafter to mean 'children and young people') are necessary to articulate their multifaceted needs clearly; plan services, measure outcomes and quantify conditions; understand and describe trends, inequalities, and gaps in service provision; and contribute to appropriate commissioning of quality services. Lamentably, there remains a dearth of such data in the UK and internationally.[1,2] Data capture depends on data champions, and where these have inspired local services, data outputs that inform clinical practice and service planning have been generated.[3]

A disabilities terminology set (DTS) that describes the multifaceted health conditions, technology dependencies, and family-reported issues of disabled children and their families was co-developed by a group of community, general, and disability paediatricians with parent carer and therapist input.[4–6] This was based on data collected at the point of care from a district disability clinic population in Sunderland in north-east England and informed by the World Health Organization's International Classification of Functioning, Disability and Health (ICF).[7] The process of developing the terms and outputs from the Sunderland review have been separately reported.[4,5]

This paper describes national pilots of data capture at the point of clinical care, and some outputs generated. The primary aim was to test the feasibility of prospective data capture by paediatricians in a range of clinical settings across England, using an agreed DTS. The secondary aims were to demonstrate the utility of outputs and to confirm that counting numbers of needs per child is a valid method for quantifying complexity.[5]

METHOD

Outputs of the Sunderland pilot from which the DTS was developed,[5] were presented in March 2013 to the executive

*We use the term 'disabled children' deliberately. Generally we prefer 'person-first language' because it is more appropriate to describe people 'with' or who 'have' specified characteristics, such as impairments or specific diagnoses. However, consistent with the International Classification of Functioning, Disability and Health, disability is created as a consequence of interaction between a person and their environment. Disability cannot be considered as intrinsic to the person. Hence, we believe that people are in fact disabled, and not 'people with disabilities'.

committee and regional representatives of the British Academy of Childhood Disability. The 20 paediatrician committee members were encouraged to participate in data collection pilots in their routine clinics, as were colleagues in general and community paediatrics who had expressed interest. Pilots were conducted in hospital and community clinics across Newcastle upon Tyne, Sunderland, Durham, Blackpool, Leeds, Bolton, Wigan, Liverpool, Sutton-in-Ashfield, Nottingham, Sandwell, Harrow, Winchester, and Brighton.

The following documents were circulated to participating paediatricians: a Microsoft Excel spreadsheet of the final 296 terms; an explanatory glossary of the terms (detailed descriptions of each, with links to relevant resources for clinicians and families);[8] a single sheet of abbreviated terms, for printing and completion by hand in clinics where direct electronic data capture was not possible; and a consultation facilitation 'traffic light' tool for completion in the waiting room (the Health, Functioning and Wellbeing Summary).[9] Designed by clinicians, young people, and parent carers, this traffic light tool captures issues that matter most to families on the day so that these can inform the consultation, which is more focused, efficient, and effective as a consequence. This allows the family's views to inform data captured by the clinician at the end of the consultation.

Colleagues were encouraged to collect data for at least one month, anonymize the data, and populate the spreadsheet. Data were collated and analysed using the statistical package R version 3.1.2 (http://www.r-project.org [Bell Laboratories (Lucent Technologies), NJ, USA]).

The number of health conditions, family-reported issues, technology dependencies, and need for round-the-clock care were compared with respect to: Gross Motor Function Classification System (GMFCS) level for children with cerebral palsy;[10] epilepsy severity as defined by the National Institute for Health and Care Excellence (NICE) level of expertise required to manage it for children with epilepsy;[11] and International Classification of Diseases (ICD-10) definitions of severity for children with intellectual disabilities using the Kruskal–Wallis test.[12] Where significant results were identified, post hoc pairwise Wilcoxon rank sum tests were used to identify which pairs of groups varied significantly. Children with cerebral palsy were grouped into those in GMFCS levels I to III and those in GMFCS levels IV and V because numbers in each GMFCS group were relatively small.

To avoid double counting, where more than one term might be entered for the same condition (representing multiple taxonomies of an individual diagnosis), only the lowest taxonomy level (i.e. the most specific term in a domain) was included in analyses. For example, where a clinician had coded 'neurological problem', 'movement disorder', 'cerebral palsy', and 'spastic unilateral cerebral palsy', only the last was counted. A survey about the process of data collection was circulated to all who participated.

What this paper adds

- Prospective data capture by paediatricians at the point of clinical care is possible.
- Outputs useful for service commissioning and planning can be generated with a defined terminology set.
- The Disabilities Complexity Scale is a valid tool for describing and quantifying complexity.

As no patient identifiable data were involved, ethical consent was not required.

RESULTS

Twenty clinicians were invited to participate in data collection. Sixteen clinicians responded to the data collection process survey, of whom one responded to the survey but did not collect data. Data collection was via a purpose-built electronic interface directly into individual electronic patient records (three clinicians; 19%); directly into the spreadsheet (two clinicians; 13%); via an electronic form that auto-populated the spreadsheet (one clinician; 6%); or on paper (nine clinicians; 56%).

Fourteen out of sixteen paediatricians (87.5%) reported that data collection did not affect the running or flow of clinics. One (6%) completed their data forms retrospectively after clinics, and took 20 minutes; 14 (88%) took from 30 seconds to 10 minutes (median 3min; mean 3.1min). Those recording data electronically took the least time.

Barriers to prospective data capture were reported as time (4; 25%), remembering to do it (2; 13%), lack of administrative support (2; 13%), and lack of management support/'needs to be mandated in order to happen' (6; 38%). Six paediatricians (38%) reported no barriers to data capture and seven (44%) reported insufficient terms.

The advantages of prospective data collection were reported as definition of workload (10; 63%), local service planning (9; 56%), many (7; 44%), and to inform commissioning (3; 19%). Six paediatricians (38%) have used data collected for audits or presentations; one (6%) hopes to automate incorporation of needs into letter headings; and one has used data in successful business cases for new consultant colleagues.[5]

Overall, 8117 needs (conditions, technology dependencies, family-reported issues, need [or not] for round-the-clock care) of children seen in 1224 consultations were captured over 9 to 76 (mean 28.2) working days with 13 to 230 (mean 71.9) data sets collected per paediatrician. Only one paediatrician (6%) reported recording two data sets on the same child. A mean of 6.7 (0–46) needs were recorded per child. Headline needs are shown in Table I. General paediatricians were more likely to see children with a single concern – for example, a urinary tract infection or constipation or asthma – while community or disability paediatricians were more likely to see children with multiple concerns – for example, cerebral palsy and constipation and gastro-oesophageal reflux disease and severe intellectual disabilities and epilepsy and gastrostomy and ventriculoperitoneal shunt and so on.

Table I: Headline needs

Needs	Number
Speech, language, communication need	582
Behavioural, emotional disorder	539
Intellectual disability	465
Autism spectrum disorder	266
Disordered sleep	237
Chromosomal, genetic, syndromic condition	202
Cerebral palsy	195
Epilepsy	169
Feeding, swallowing issue	152
Constipation	150
Urinary incontinence	134
Bowel incontinence	126
Sensory sensitivities	125
Learning difficulties	124
Attention-deficit–hyperactivity disorder	102
Drooling	92
Hearing impairment	77
Gastro-oesophageal reflux disease	77
Gastrostomy	74
Recurrent chest infections	66
Self-injury	54
Bed-wetting	49
Specific learning disability	37
Skin issues	35
Obesity	32
Faltering weight gain	28
Ventriculoperitoneal shunt	21
Pain	20
Pica	18
Ear, nose, throat issues	16
Tracheostomy	8
Period disorder	8
Ventilated at home	6

The clinicians reported 195 consultations with children with cerebral palsy (GMFCS levels I–III: n=88, mean 9 needs per child, range 2–27; GMFCS levels IV and V: n=70, mean 17 needs per child, range 2–41; p<0.01). There were 169 consultations with children with epilepsy (paediatrician with epilepsy expertise: n=114, mean 9 needs per child, range 1–27; paediatric neurologist: n=42, mean 16 needs per child, range 2–46; children's epilepsy surgical service: n=13, mean 19 needs per child, range 4–29; p<0.01) and 335 with children with intellectual disabilities (mild to moderate intellectual disability: n=193, mean 8 needs per child, range 1–32; severe intellectual disability: n=82, mean 11 needs per child, range 1–33; profound intellectual disability: n=60, mean 17 needs per child, range 1–41; p<0.01).

Table II shows how the mean number and range of needs vary with these severity scales.

The box plots in Figures 1 and 2 show the mean values and variations of the number of needs shown in Table II. Figure 1a shows the mean and variation of the number of health conditions for children with cerebral palsy by GMFCS level. Kruskal–Wallis tests showed that the results from GMFCS levels I to III were similar, although all groups had outliers. Results from GMFCS IV were closer to those from GMFCS V, while those with GMFCS not classified were significantly different from all the other groups (p<0.001), confirmed by post hoc pairwise differences between the six groups using the Wilcoxon rank sum test.

Figure 1b shows the mean values and variation of the number of conditions for children with epilepsy of different severity. The Kruskal–Wallis test confirmed that statistically significant differences existed between the groups (χ^2=12.766; df=2; p=0.002). The pairwise difference between the groups was determined using the Wilcoxon rank sum test, which showed a significant difference between the number of conditions in the group with epilepsy that required care from a paediatrician with epilepsy expertise compared to both those that required care from a paediatric neurologist (p=0.017) and those that required care from a children's epilepsy surgical service (p=0.023). The difference between those requiring care from a paediatric neurologist and those requiring care from a children's epilepsy surgical service was not significant (p=0.934).

For children with different levels of intellectual disability, Figure 1c showing the mean number and range of health conditions suggests that the three groups (mild/moderate; severe; profound) are significantly different. The Kruskal–Wallis test was highly significant (χ^2=53.454, df=2, p<0.001). The pairwise comparisons using the Wilcoxon tests between the three groups were also significant.

Further statistical analyses showed that for family-reported issues (data in Table II, box plots in Figure 2), children with cerebral palsy in GMFCS level IV had significantly more issues reported than those at other levels of motor functioning (p=0.016). Children with epilepsy at a level requiring input from a paediatric neurologist or children's epilepsy surgery service had significantly more issues reported than those at a level requiring input from a paediatrician with epilepsy expertise (p<0.001). There was no significant difference between the number of issues reported between children with epilepsy requiring input from a paediatric neurologist and those requiring input from a children's epilepsy surgical service (p=0.373). No significant difference was found between the numbers of family-reported issues for children with different levels of intellectual disability (p=0.18).

Cerebral palsy subtype[13] was reported in 86.7% of cases (range from 0% for 2/17 clinicians to 100% for 8/17 clinicians). GMFCS level was reported in 79.5% of cases (range from 0% for 4/17 clinicians to 100% for 5/17 clinicians) and neuroimaging findings in 67.7% of cases (range from 0% for 4/17 clinicians to 100% for 4/17 clinicians).

DISCUSSION

The pilots demonstrated that it was possible for paediatricians to prospectively capture data in a range of outpatient settings without disrupting clinic flow. Data capture was more efficient when directly entered into the electronic patient record at the point of care. There was a learning curve in terms of becoming familiar with the explanatory glossary of terms and abbreviations, but some clinicians could capture data in as little as 30 seconds per patient. The paediatricians who participated in the pilots are

Table II: Complexity and family-reported issues for children with cerebral palsy, epilepsy, and intellectual disabilities

GMFCS level for children with cerebral palsy (*n*=195)	GMFCS I	GMFCS II	GMFCS III	GMFCS IV	GMFCS V	GMFCS not classified
Number of children	37	29	22	27	43	37
Applicable terms per child (mean, range)	9 (2–24)	9 (3–27)	9 (3–26)	14 (2–32)	19 (5–41)	6 (1–28)
Conditions (mean, range)	8 (2–21)	8 (2–23)	8 (3–23)	12 (2–25)	16 (5–39)	5 (1–24)
Technology dependencies (mean, range)	0 (0–1)	0 (0–1)	0 (0–1)	0 (0–2)	1 (0–4)	0 (0–1)
Family-reported issues (mean, range)	1 (0–4)	1 (0–5)	1 (0–3)	2 (0–6)	1 (0–6)	1 (0–7)
Percentage needing round-the-clock care	16	7	19	11	58	16
Percentages of family-reported issues						
Impaired participation in everyday activities	3	3	0	7	7	0
Family issues	8	17	5	30	23	14
School issues	19	21	50	30	7	8
Housing issues	3	0	5	22	14	5
Equipment issues	11	10	32	41	42	5
Access to leisure issues	3	17	5	7	14	8
Support issues	8	17	5	30	21	8
Information issues	3	7	5	19	7	5

NICE Guideline 137 category of severity of epilepsy (*n*=169) Epilepsy should be managed by:	Paediatrician with epilepsy expertise	Paediatric neurologist	Children's epilepsy surgical service
Number of children	114	42	13
Applicable terms per child (mean, range)	9 (1–27)	16 (2–46)	19 (4–39)
Conditions (mean, range)	8 (1–23)	14 (2–39)	16 (3–33)
Technology dependencies (mean, range)	0 (0–4)	0 (0–3)	0 (0–2)
Family-reported issues (mean, range)	1 (0–7)	2 (0–7)	3 (0–7)
Percentage requiring round-the-clock care	29	21	62
Percentage of family-reported issues			
Impaired participation in everyday activities	4	17	23
Family issues	15	24	46
School issues	24	43	46
Housing issues	9	14	31
Equipment issues	14	33	39
Access to leisure issues	13	12	15
Support issues	14	33	31
Information issues	5	21	23

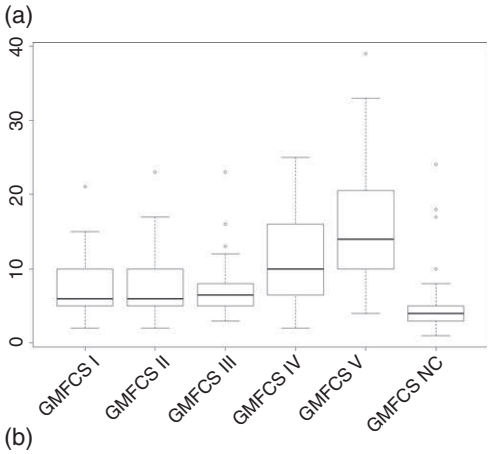
Intellectual disability	Mild/moderate IDD	Severe IDD	Profound IDD
Number of children	193	82	60
Applicable terms per child (mean, range)	8 (1–32)	11 (1–33)	17 (1–41)
Conditions (mean, range)	7 (0–29)	8 (1–24)	14 (1–39)
Technology dependencies (mean, range)	0 (0–2)	0 (0–4)	1 (0–2)
Family-reported issues (mean, range)	1 (0–7)	1 (0–7)	2 (0–7)
Percentage requiring round-the-clock care	15	28	37
Percentage where a chromosomal/genetic diagnosis made	24	33	48
Percentage with behavioural/emotional issues	33	43	33
Percentage of family-reported issues			
Impaired participation in everyday activities	3	10	11
Family issues	24	21	30
School issues	32	20	27
Housing issues	6	15	13
Equipment issues	5	13	37
Access to leisure issues	8	17	18
Support issues	13	23	32
Information issues	7	9	7

GMFCS, Gross Motor Function Classification System; NICE, National Institute for Health and Care Excellence; IDD, intellectual disability.

enthusiastic about the potential value of the outputs and have already made use of data generated locally.

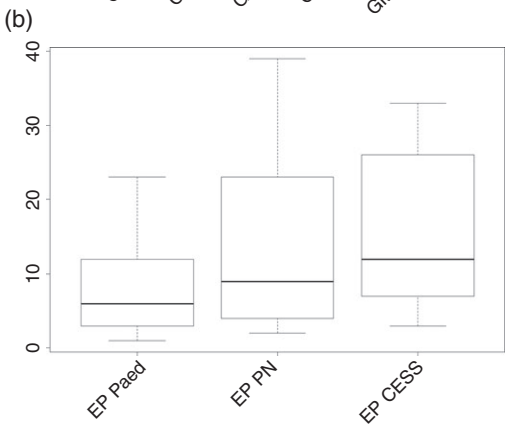
Each identified health condition, technology-dependency, or family-reported issue requires its own care plan within the overarching care plan. The DTS used in this project was developed with a particular emphasis on capturing the multifaceted needs of disabled children, including those with palliative care needs. If other specialties develop their own terminology sets, it should be possible to capture more specific data about the conditions and contexts of a broader range of children.

While many analyses are possible, we report here on some specific examples that demonstrate the potential utility of population data. Prevalence data generated – for example on emotional, behavioural, speech, language, and communication needs – will be very important for service and resource planning locally, regionally, and nationally.



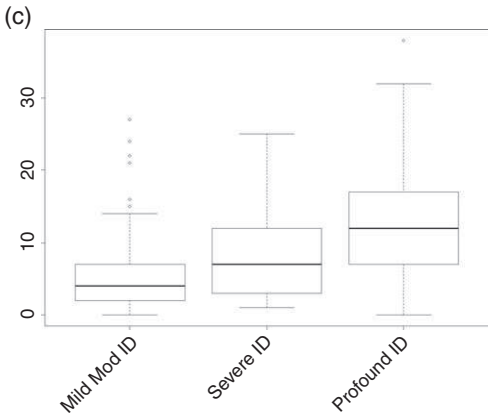
	GMFCS NC	GMFCS I	GMFCS II	GMFCS III	GMFCS IV
GMFCS I	<0.001	-	-	-	-
GMFCS II	0.02	1.0		-	-
GMFCS III	0.009	1.0	1.0	-	-
GMFCS IV	<0.001	0.28	0.27	0.51	-
GMFCS V	<0.001	<0.001	<0.001	<0.001	0.35

Pairwise differences between the six GMFCS groups using the Wilcoxon rank sum test shown as *p*-values



	EP CESS	EP Paed
EP Paed	0.023	-
EP PN	0.934	0.017

Pairwise differences between the three epilepsy severity groups using the Wilcoxon rank sum test shown as *p*-values



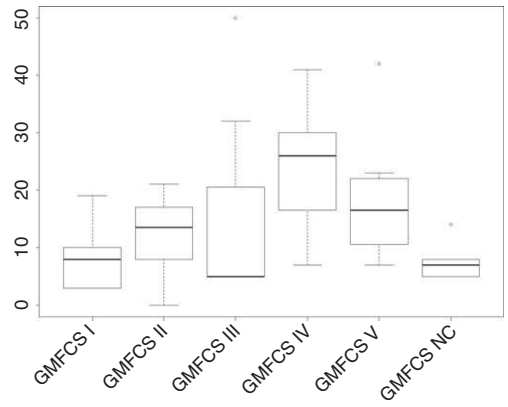
	Mild Mod ID	Profound ID
Profound ID	<0.001	-
Severe ID	0.004	<0.001

Pairwise differences between the three intellectual disability severity groups using the Wilcoxon rank sum test shown as *p*-values

Figure 1: Box plots of numbers of conditions for: (a) children with cerebral palsy (*n*=195) by GMFCS levels I to V and NC (not classified); (b) children with epilepsy (*n*=169) by NICE clinical guideline 137 designation of paediatrician required to provide care; (c) children with intellectual developmental disabilities (*n*=465) by ICD-10 classification. The horizontal line in the centre of the box indicates the median, the rectangular box accounts for 50% of the total data (interquartile range), the two thin arms (whiskers) connect the top 25% (quartile) and bottom 25% (quartile). EP Paed, paediatrician with expertise in epilepsy; EP PN, paediatric neurologist; EP CESS, children's epilepsy surgical centre; GMFCS, Gross Motor Function Classification System; ID, intellectual disability; mild mod, mild or moderate; NICE, National Institute for Health and Care Excellence.

The Sunderland pilot demonstrated that the number of needs identified for a child related directly to the intensity of paediatric clinic appointments required to meet their needs.[5] Proving a significant relationship between the sum of needs and existing validated scales of levels of functioning[10] and condition severity[11,12] confirms the validity of the Disabilities Complexity Scale previously proposed.[5] This should make it possible for tariffs to be set to fund services that reflect and link to the complexity of children's needs and contexts. Linking tariffs to complexity should also drive up the detail and quality of data reporting. Careful quality assurance of data recording and reporting over time will mitigate against over-reporting as a means of attracting more resources. The correlation of the burden of barriers to participation and quality of life reported by families to level of complexity of children's needs and

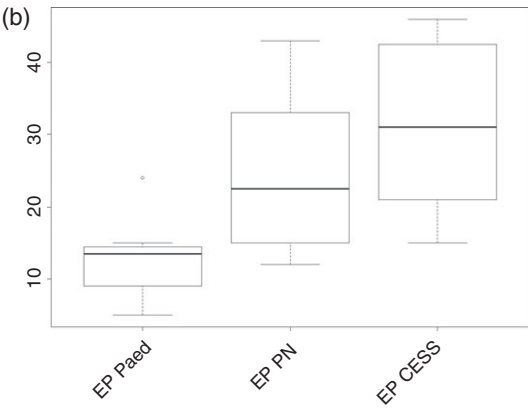
(a)



	GMFCS NC	GMFCS I	GMFCS II	GMFCS III	GMFCS IV
GMFCS I	1.000	-	-	-	-
GMFCS II	0.637	1.000		-	-
GMFCS III	1.000	1.000	1.000	-	-
GMFCS IV	0.063	0.114	0.414	0.877	-
GMFCS V	0.221	0.492	1.000	0.973	1.000

Pairwise differences between the six GMFCS groups using the Wilcoxon rank sum test shown as *p*-values

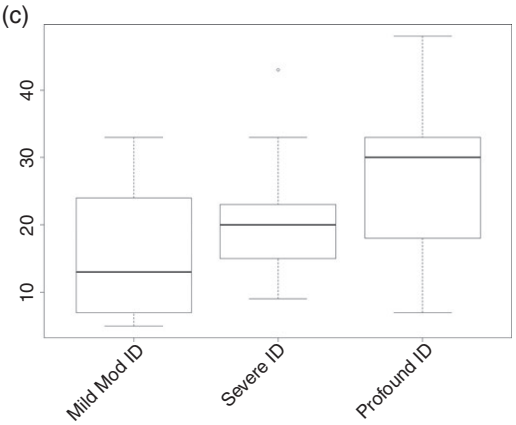
(b)



	EP CESS	EP Paed
EP Paed	0.017	-
EP PN	0.915	0.187

Pairwise differences between the three epilepsy severity groups using the Wilcoxon rank sum test shown as *p*-values

(c)



	Mild Mod ID	Profound ID
Profound ID	0.47	-
Severe ID	1.00	1.00

Pairwise differences between the three intellectual disability severity groups using the Wilcoxon rank sum test shown as *p*-values

Figure 2: Box plots of numbers of family-reported issues for: (a) children with cerebral palsy (*n*=195) by GMFCS levels I to V and NC (not classified); (b) children with epilepsy (*n*=169) by NICE clinical guideline 137 designation of paediatrician required to provide care; (c) children with intellectual developmental disabilities (*n*=465) by ICD-10 classification. The horizontal line in the centre of the box indicates the median, the rectangular box accounts for 50% of the total data (interquartile range), the two thin arms (whiskers) connect the top 25% (quartile) and bottom 25% (quartile). EP Paed, paediatrician with expertise in epilepsy; EP PN, paediatric neurologist; EP CESS, children's epilepsy surgical centre; GMFCS, Gross Motor Function Classification System; ID, intellectual disability; mild mod, mild or moderate; NICE, National Institute for Health and Care Excellence.

issues may seem obvious, but being able to quantify these would be useful for service design and development.

Prospective data collection for a clinic population over time will allow mapping of needs including those of specific subpopulations. Knowing how many children are dependent on specific technologies or have specific needs in the preschool population will, once issues of population data sharing across agencies have been resolved, permit planning for

their needs to be met in early years, educational settings, and subsequently on transition to adult services.

Drilling further into the details of the data is revealing. For example, for children with cerebral palsy, family-reported equipment issues increased with GMFCS level. Although not surprising, this is an environmental factor that services across agencies ought to be better able to address if quantified, by evidencing, planning, and delivering equipment pathway improvement, supported by an appropriate workforce.

Similarly, family and housing issues, and family support and information needs increase as GMFCS level increases, which reflects increasing complexity. Again, this is not surprising. Quantifying this for families in a locality may enable meaningful interagency discussion to support shared, informed resource planning; pathways for appropriately adapted homes; and appropriate and accessible information and support for families.

School issues show a different relationship. There are fewer reported school issues for children with cerebral palsy in GMFCS level V, most of whom have severe intellectual disability and are more likely to be in specialist schools. The greatest school issues arose for those in GMFCS levels III and IV: children with cerebral palsy who need equipment for independent mobility, including frames, walkers, and power or manually operated wheelchairs. Many of these children attend mainstream schools, where their additional needs require special arrangements for them to be fully included. School issues will be reported by families where schools struggle to make these adjustments, where there is less specialist expertise, a less accessible environment, and where staff attitudes are not as 'can do' as they might or should be. Significantly more family-reported issues were found for children with cerebral palsy in GMFCS level IV compared with other groups overall, information highly relevant to services working together to address environmental issues.

For children with epilepsy, all family-reported issues except access to leisure increased with epilepsy complexity (Table II). The significant difference in number of health conditions and family-reported issues between children with epilepsy of different severity, as for children with cerebral palsy, has implications for service design and planning and for informed advocacy for families.

Although the burden of heath conditions varied for children with different levels of intellectual disability (Table II and Figure 1c), the number of family-reported issues did not vary significantly between the different groups. The high proportions of children with all levels of intellectual disability with associated behavioural and emotional issues may be a significant factor here, confirming the urgent need for timely access to competent services to assess and address these issues. It is not possible to accurately compare children with intellectual disability to those without from these prospectively collected data, because there is evidence of under-reporting of intellectual disability. Some children with a diagnosis of Down syndrome were recorded as having 'learning difficulty' rather than intellectual disability, while others were not recorded as having any learning difficulty or intellectual disability at all. Under-reporting is also evidenced by the fact that children with cerebral palsy where no GMFCS level was reported had significantly fewer needs reported overall than those where GMFCS levels were reported (Table II, Figures 1 and 2). It may be possible in future, with bigger data sets to use such under-reporting to quality check the validity of data from districts or clinicians. If data reporting were to be linked to tariffs for services, this should drive up the quality and detail of data overall.

The Disabilities Complexity Scale[5] complements validated scales of function[10] and severity[11,12] by quantifying other important dimensions of the ICF[7] conceptualization of disability, all of which interact to impact on participation and quality of life. Different health conditions give rise to different patterns of complexity, influenced by personal resilience, vulnerabilities, living and system environments as well as by time. Children who require round-the-clock care are specifically highlighted in the Scale, because they and their families who relentlessly care for them are especially vulnerable and likely to require the highest level of support and care. Use of the Disabilities Complexity Scale – underpinned by the supporting explanatory glossary that includes suggestions for outcomes to work towards and actions that may help to achieve these[8] – provides a means to document changes in a measurable way over time for individual children, as well as facilitating comparisons between different populations.

The Sunderland[5] and prospective national pilots have demonstrated the potential utility and feasibility of data collection in a range of paediatric clinic settings. If it is possible for comprehensive data to be routinely collected about children with complex disabilities, then it should be possible to collect data about all patients in any clinic. Although samples in these pilots are not large enough to make meaningful comparisons between services or clinicians, it is possible to see how larger data sets gathered by routine data collection at the point of care may permit quality analysis and drive improvement of aspects of clinical care. For example, it is possible to compare the levels of detail that different clinicians use to describe a child's cerebral palsy subtype, whether GMFCS levels have been captured, whether or not neuroimaging has been done, and the findings described in detail. For children with intellectual disability, it is also possible to calculate the proportion for which a more specific aetiological diagnosis has been made, which could be used as a proxy indicator of the quality of aetiological assessment and investigations. Clinicians involved in the pilots reported that the data collection process often prompted them to consider further tests, ensure they used current accepted terms and classifications, and informed clinical care. Presenting complexity using the Disabilities Complexity Scale proposed in the Sunderland

pilot[5] is easy to calculate and quickly conveys important information useful for clinical practice at individual and population levels.

One of the strengths of this study is that a range of paediatricians spread across England used the same DTS with clearly agreed definitions, allowing 'apples' to be compared with 'apples'. A limitation is that no validity checks were made at individual paediatrician level regarding the accuracy or completeness of data recording, consistency over time, or between observers, and there is definite evidence of under-reporting of data. Ages of children were not reported, which limits interpretation of findings. The DTS is not all-encompassing and in order to identify the unique needs of the individual child it is still important to ask at the end of each consultation, 'Is there anything else that you think might be important to tell me, or that you are concerned about?' The data reported are not perfect, but are good enough to demonstrate what might be possible in future if data collection becomes routine.

Outcome

The results of the prospective pilots were presented on 12 March 2014 to the Informatics for Quality Committee of the Royal College of Paediatrics and Child Health. The next day, there was agreement from NHS England, Public Health England, and the Health and Social Care Information Centre that the DTS developed and piloted in this project should be included in the Children and Young People's Health Services data set. NHS Trusts across England that collect these data are now mandated to report against the terms in the DTS. Once coded, data can flow, linked by NHS number as unique identifier, to the Health and Social Care Information Centre for analysis. Reports will be published by locality to highlight trends and geographical variations. These should act as drivers to improve standards of care across all sectors.

Parent carers have reported on their involvement in the pilots and are eagerly anticipating systematic national data collection, analyses, and reporting,[14] which can be used to inform intelligent local and national commissioning and service planning based on actual needs.

There is hope that at last we will know how many disabled children are in our society, and who and where they are, so that their multifaceted needs will be more clearly defined. This would give clinicians, commissioners, and others responsible for the health and well-being of these children and young people the opportunity to improve their outcomes through evidence-based, data-driven service planning and provision.

ACKNOWLEDGEMENTS

The authors would like to thank Drs Indrani Banerjee, Zahabiyah Bassi, Colin Dunkley, Alison Guadagno, Carl Harvey, Neil Hopper, Jill Kisler, Ian Male, Katherine Martin, Mel McMahon, Rajesh Pandey, Gill Robinson, Megan Thomas, and Toni Wolff who all collected data prospectively at the point of clinical care in their routine clinics; Andrew Prayle, paediatric trainee who designed a data capture tool to auto-populate the spreadsheet used by Colin Dunkley; and Mathew Poole, Systems Coordinator, City Hospitals Sunderland NHS Trust for building an electronic data capture interface for the terminology set used by Karen Horridge, Carl Harvey, and Neil Hopper. The authors have stated they had no interests that may be perceived as posing a conflict or bias.

REFERENCES

1. Davies SC. Annual Report of the Chief Medical Officer 2012: Our Children Deserve Better: Prevention Pays. London, UK: Department of Health, 2013. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf (accessed 13 December 2015).
2. United Nations Children's Fund (UNICEF). The State of the World's Children 2013. Children with Disabilities. New York, USA: UNICEF, 2013. Available at: http://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf (accessed 13 December 2015).
3. Rahman FR, Maharaj V, Yates R, et al. Addressing the inverse care law: the role of community paediatric services. *Perspect Public Health* 2014; **134**: 85–92.
4. Spencer A, Horridge KA, Downs D. Empowering clinical data collection at the point of care. *Arch Dis Child* 2015; **100**: 815–17.
5. Horridge KA, Harvey CJ, McGarry K, et al. Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale. *Dev Med Child Neurol Forthcoming* 2016.
6. Health and Social Care Information Centre. SNOMED subset browser: Paediatric neurodisability outpatient diagnosis description subset. Available at: http://www.diseases-database.com/snomed/snomed_subset_browser.asp?dblSubsetID=56931000000136 (accessed 13 December 2015).
7. World Health Organization. International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organisation, 2012. Available at: http://www.who.int/classifications/icf/en/ (accessed 13 December 2015).
8. British Academy of Childhook Disability. Explanatory Glossary of Paediatric Disability Terms to support data collection by paediatricians at the point of clinical care. Available at: http://www.bacdis.org.uk/policy/dataset.htm (accessed 13 December 2015).
9. Horridge KA. Health, Functioning and Wellbeing Summary ['Traffic Light' tool] (2nd edition). 2013. Available at: http://www.bacdis.org.uk/policy/documents/HFWSummary.pdf (accessed 13 December 2015).
10. Palisano RJ, Rosenbaum P, Bartlett D, Livingston MH. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol* 2008; **50**: 744–50.
11. National Institute for Health and Care Excellence (NICE). Epilepsies: diagnosis and management. NICE guidelines CG137. January 2012. Available at: http://www.nice.org.uk/guidance/cg137 (accessed 13 December 2015).
12. World Health Organization. International Statistical Classification of Diseases and Related Health Problems.10th Revision. Chapter V. Mental and behavioural disorders. 2004. Available at: http://apps.who.int/classifications/apps/icd/icd10online2004/fr-icd.htm?gf70.htm (accessed 13 December 2015).
13. Platt MJ, Krageloh-Mann I, Cans C. Surveillance of cerebral palsy in Europe: reference and training manual. *Med Educ* 2009; **43**: 495–96.
14. National Network of Parent Carer Forums. Paediatric Disability Data Project: Parent Carer and Family Perspective. 2014. Available at: http://www.nnpcf.org.uk/paediatric-disability-data-project/ (accessed 13 December 2015).