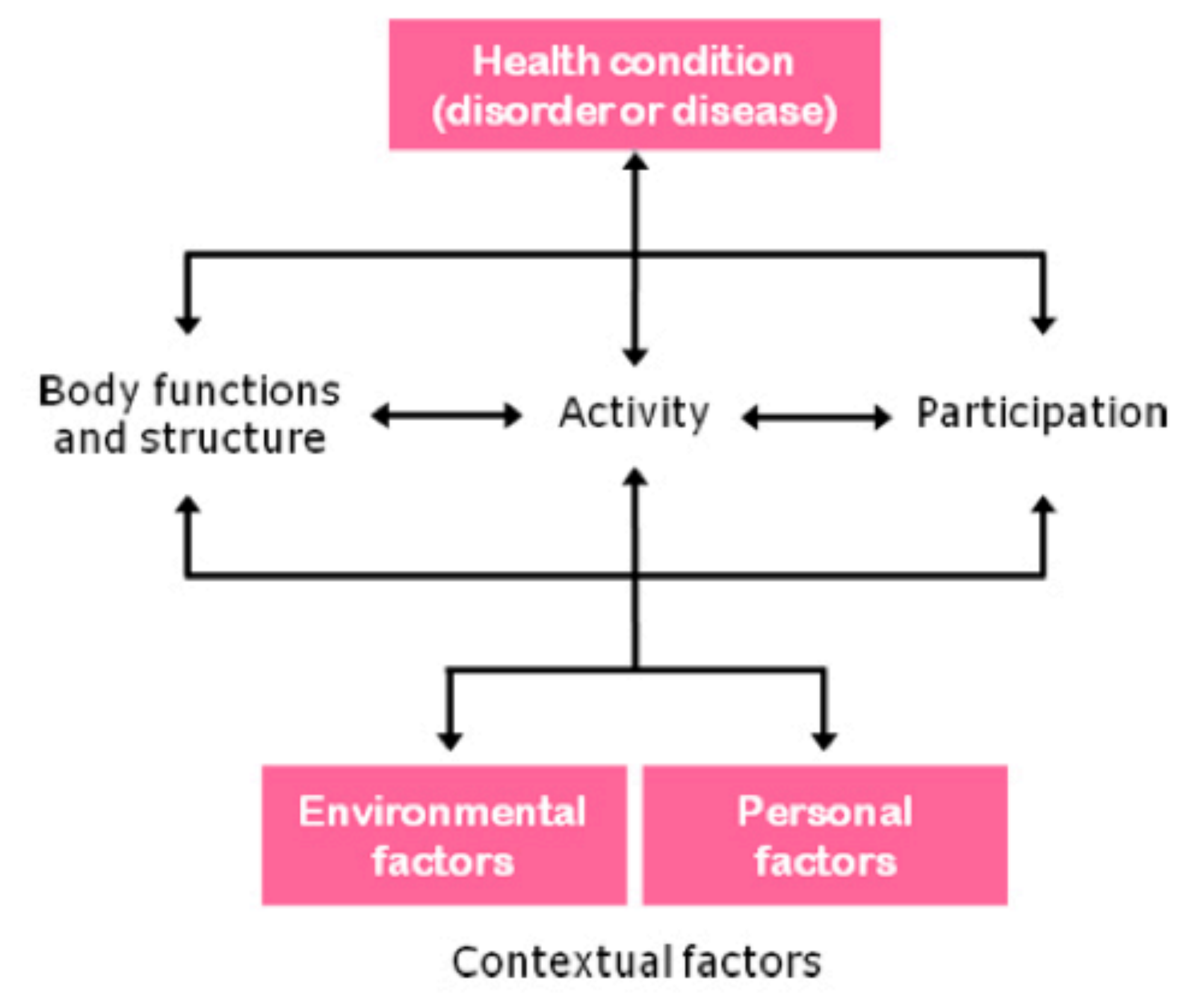
DMO Role: Opportunities and Responsibilities

Dr Karen Horridge
Disability Paediatrician and DMO Sunderland
Chair British Academy of Childhood Disability

Disability: WHO ICF model



Health condition
(disorder or disease)

Body functions
and structure

Activity

Participation

Environmental
factors

Personal
factors

Contextual factors

The best possible:

- Inclusion
- Participation
- Quality of life

For all disabled children, young people and their families that matter to them

Personal reflections from 20+ years of clinical practice..

- Variation and major gaps for disabled CYP in quality of:
  - Basic health surveillance e.g. vision, hearing, growth
  - Healthcare across settings - diagnostic overshadowing - leading to:
    - Premature death
    - Postural deformities
    - Poor nutrition
    - No diagnoses being made
    - Families being poorly informed and poorly supported

Evidence of System Failures for Disabled People

Deat
Following
MEN

HEA

Transformin
A national r
Winterbourn
Department of He
Final Report

Confide
prematu
with lea
Executive s

Pauline Heslop
Peter Blair
Peter Fleming
Matt Hoghton
Anna Marriott
Lesley Russ

Why children die: death in infants, children and young people in the UK
Part A
May 2014

A REPORT BY:

INGRID WOLFE
ALISON MACFARLANE
ANGELA DONKIN
MICHAEL MARMOT
RUSSELL VINER

ON BEHALF OF:

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH
NATIONAL CHILDREN'S BUREAU
BRITISH ASSOCIATION FOR CHILD AND ADOLESCENT PUBLIC HEALTH

British Association for Child & Adolescent Public Health
ncb
RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

What has this got to do with me?

What has this got to do with the DMO role?

Shared responsibilities: Commissioners and Clinicians together

Ensure that ALL disabled CYP and their families receive the best possible services, right from the start that give them the best possible opportunities to:

- Reach their full potential across all domains
- Enjoy the best possible participation and quality of life
- Transition to adult services in the best possible health

Children and Families Act 2014 gives us a structure

Parental expectations are at an all time high

- Are YOU ready to seize the opportunity?
- Are YOU ready to take responsibility?

What does GOOD look like for Disabled children and young people?

- To live in a society that:
  - Respects
  - Values
  - Includes

  - Warmly welcomes everyone as equals
  - Proactively makes adjustments to overcome any barriers or challenges to inclusion, participation and the best possible quality of life

What do we need to get there?

- “Can do”, positive, inclusive attitudes across ALL sectors of society
- Awareness amongst all who work with CYP of the red flags that further expert assessment is needed
- Transparent care pathways leading to timely competent assessment
- Evidence-based interventions, management and adjustments
- Excellent communication at all levels
- Person-centred inter-agency empowerment, care and support: “Nothing about me without me”
- Lifespan vision: setting disabled children up for the best long-term outcomes that matter to them

“Times are Hard”
“Austerity measures..”

BACD

British Academy of Childhood Disability

BACCH

British Association for Community Child Health

Impact of Austerity Measures on families with Disabled Children:

Survey of BACCH and BACD members and Child Development Team leads

November 2014 and January 2015

- 2015 BACD/BACCH Survey of members:
    - Service cuts across the board
    - Down banding of senior therapists
    - Increasing waiting times
    - Retiring colleagues not replaced
- “We can’t do anything else until it is properly commissioned”
- “We don’t have time to do all these reports”

Taking Responsibility in 21st century UK

Help is at hand!

Workforce training:

- To recognise red flags to prompt further assessment
- To challenge and positively change attitudes

www.disabilitymatters.org.uk

WELCOME TO DISABILITY MATTERS

Your free e-learning resource for the UK workforce: Educational, inspiring, informative and inclusive. Together we can challenge and positively change our own and others fears, ideas and attitudes towards disability and disabled children and young people.

About Disability Matters

Group Learning

Resources to help you deliver face-to-face training

Explore E-learning

Search topics and learning packages related to your area of interest

Sign Up Now

The best way to use Disability Matters is by creating a learning account. This means we can recommend specific learning packages for you

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EXPLORE E-LEARNING

Explore Disability Matters full range of topics by clicking through the tabs below. Start your e-learning today!

What is disability?

Reflection Matters

Hidden Disabilities Matter

Disability, cultures and languages

Deaf Communication Matters

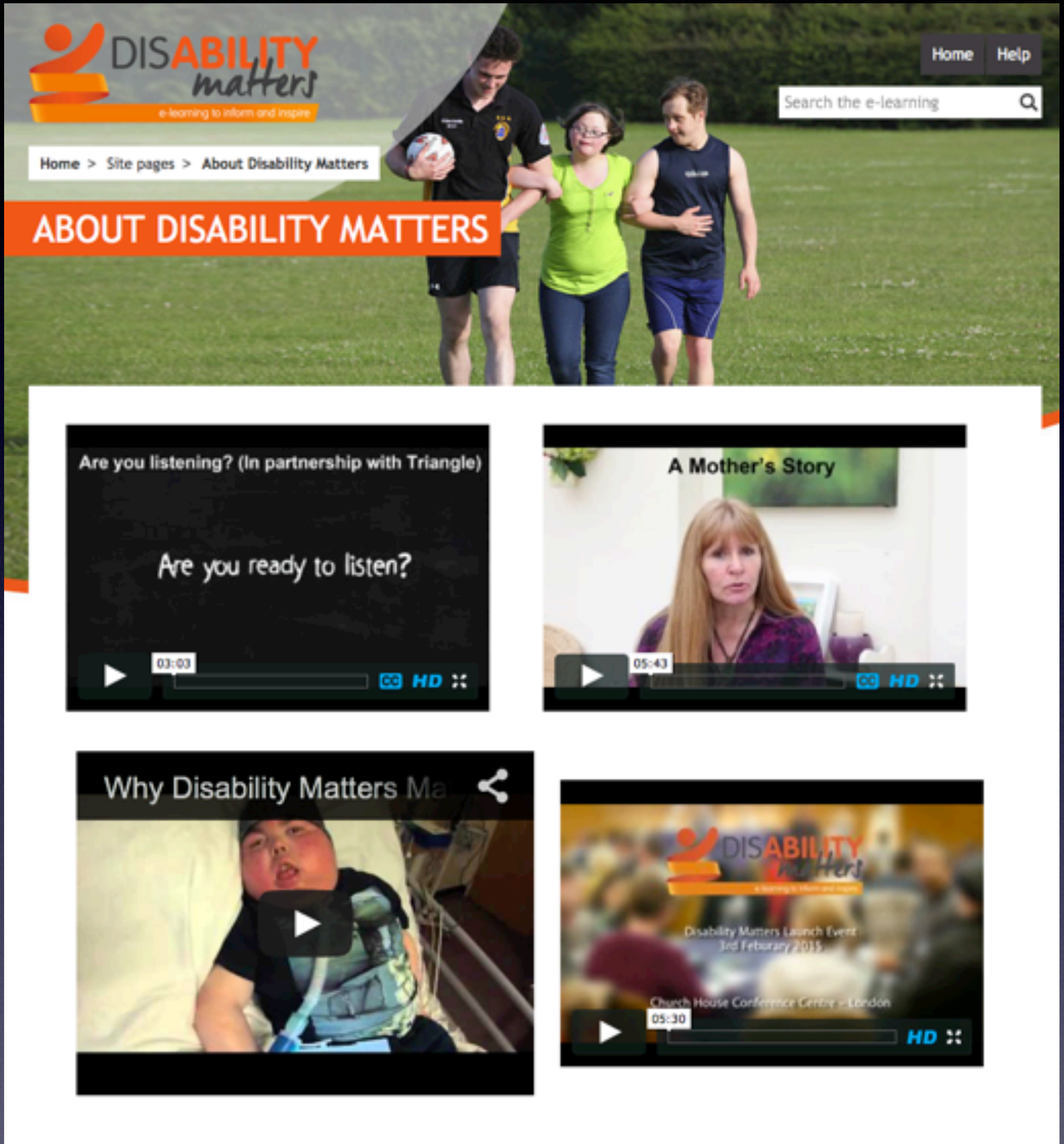
Sign up to access a range of tailored learning packages. **Find out more.**

The best way to use Disability Matters is by creating a learning account and signing in each time you visit. This means you can access the group training resources as well as learning packages that we have recommended specifically for you.

Learning packages are a fun and easy way of exploring the site and will help you develop your record of learning.

Browse our Learning Packages information page to find out more.

- Co-produced by disabled children, young people, parent carers and other experts
- 57 x 20-30 min eLearning sessions + resources for face-to-face training
- Free across sectors
- Easy to understand
- Real case studies and “top tips” to promote reflection and positive change in practice
- Commissioners can embed across agencies
- Option for badged learning pathways, led by RCPCH



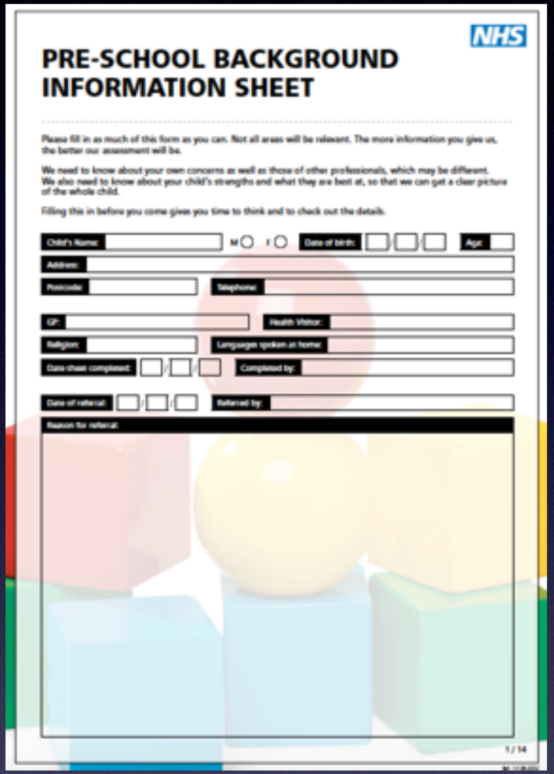
Care Pathways to Competent Assessment and Management

- Clear for everyone to understand
- Timely - adhere to the same ’18 week referral to treatment’ targets as rest of NHS
- Delivered by competent practitioners
- Published in Local Offer
- “Assess Once and Share”

Help is at hand!

Tools to underpin Care Pathways and Competent Assessment of Needs:
Background Information Sheets

- Sent for families to complete before appointment, all HV referrals include one
- Detailed medical, developmental, family and functional history, prompts for clinical examination
- Separate space for referrer and parent concerns and expectations - often different
- Person-centred - celebrate achievements
- Make consultations more focused and efficient
- Helpful for teaching and training



NHS

PRE-SCHOOL BACKGROUND INFORMATION SHEET

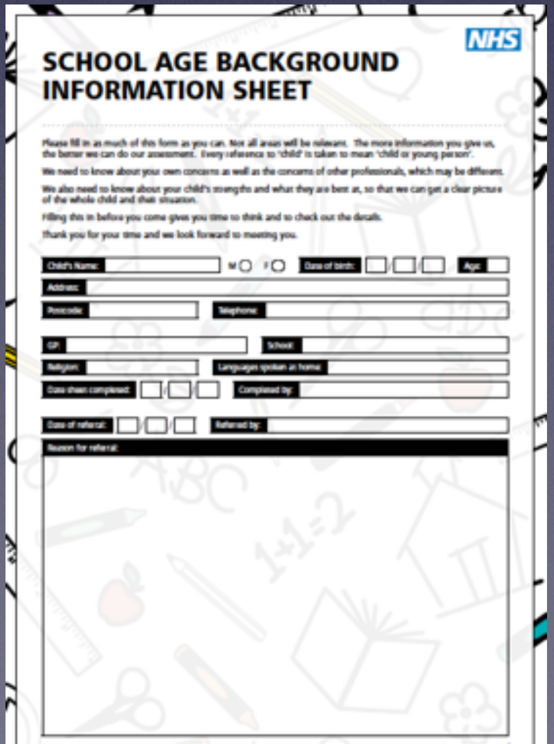
Please fill in as much of this form as you can. Not all areas will be relevant. The more information you give us, the better our assessment will be.

We need to know about your own concerns as well as those of other professionals, which may be different. We also need to know about your child's strengths and what they are best at, so that we can get a clear picture of the whole child.

Filling this in before you come gives you time to think and to check out the details.

Child's Name: M ○ F ○ Date of birth: / / Age:
Address:
Postcode: Telephone:
GP: Health Visitor:
Religion: Languages spoken at home:
Date sheet completed: / / Completed by:
Date of referral: / / Referred by:
Reason for referral:

1 / 14



NHS

SCHOOL AGE BACKGROUND INFORMATION SHEET

Please fill in as much of this form as you can. Not all areas will be relevant. The more information you give us, the better we can do our assessment. Every reference to 'child' is taken to mean 'child or young person'.

We need to know about your own concerns as well as the concerns of other professionals, which may be different.

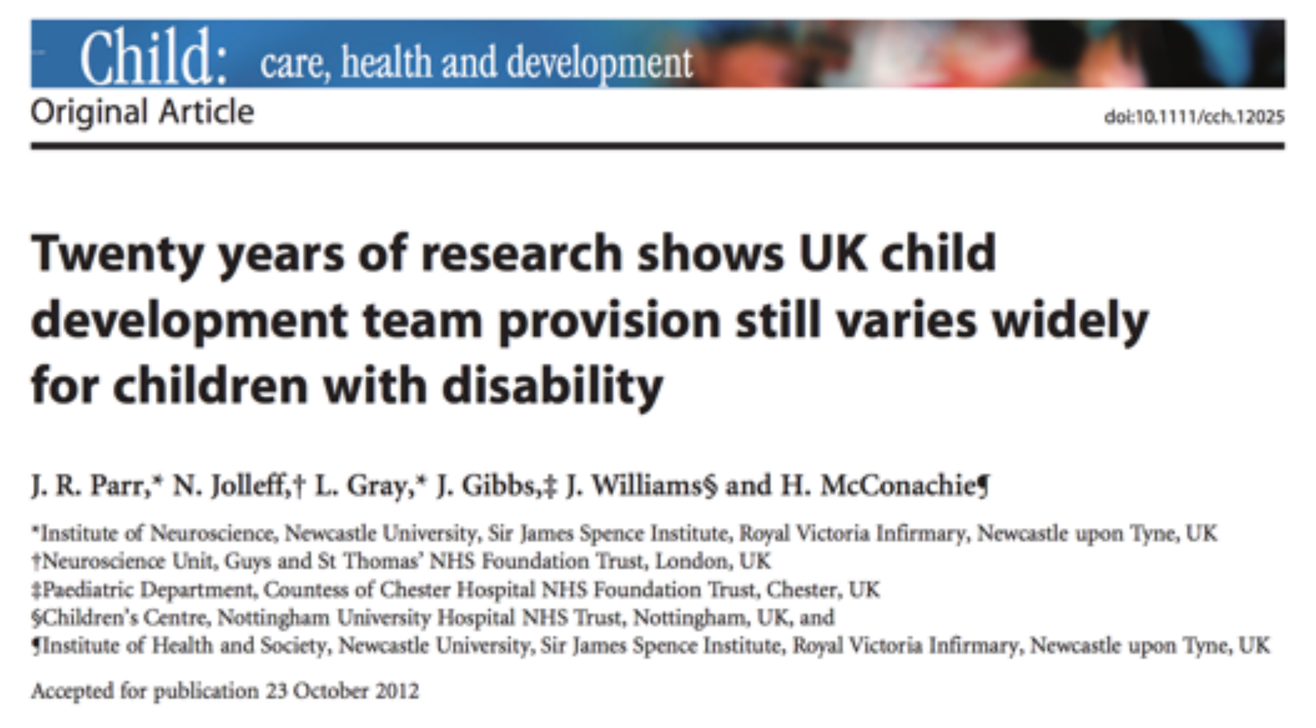
We also need to know about your child's strengths and what they are best at, so that we can get a clear picture of the whole child and their situation.

Filling this in before you come gives you time to think and to check out the details.

Thank you for your time and we look forward to meeting you.

Child's Name: M ○ F ○ Date of birth: / / Age:
Address:
Postcode: Telephone:
GP: School:
Religion: Languages spoken at home:
Date sheet completed: / / Completed by:
Date of referral: / / Referred by:
Reason for referral:

Who does the paediatric assessment?



Child: care, health and development
Original Article
doi:10.1111/cch.12025

Twenty years of research shows UK child development team provision still varies widely for children with disability

J. R. Parr,* N. Jolleff,† L. Gray,* J. Gibbs,‡ J. Williams§ and H. McConachie¶

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†Neuroscience Unit, Guys and St Thomas' NHS Foundation Trust, London, UK
‡Paediatric Department, Countess of Chester Hospital NHS Foundation Trust, Chester, UK
§Children's Centre, Nottingham University Hospital NHS Trust, Nottingham, UK, and
¶Institute of Health and Society, Newcastle University, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle upon Tyne, UK

Accepted for publication 23 October 2012

Significant variation between districts in:

Composition of Child Development teams

Implementation of government initiatives to improve interagency working
e.g. CAF, Early Support, Key working

Transfer arrangements to adult services, with none in place at all for:

- >25% young people with cerebral palsies, epilepsies, complex learning disabilities
- >50% young people with ASD and ADHD

Care pathway commissioning needs to include and set standards of competence for the multi-disciplinary team. This would protect the workforce and drive up efficiency and effectiveness towards better outcomes for CYP

Who does the Paediatric Assessment?

- Not:
  - A tick box exercise to be underestimated
  - Delegated to most junior team member with no supervision
- Needs to include:
  - Comprehensive, competent, medical, developmental and functional assessment across all domains
  - Formulation of possible diagnoses and issues
  - Investigation and onward referrals as needed

MSc thesis 1996: Cross-sectional descriptive survey of the views of Paediatricians (>70% responses) and Chief Education Officers (~40% responses) about the process, content and quality of Medical Advice

- Content of Paediatric Assessment:
  - Physical exam always 65%; Neurological exam always 25%; Behaviour, emotions assessed 30%
- Content of Medical Advice:
  - Health needs always 63%; Functional abilities always 43%; Objectives always 26%; Targets always 14%
- What did Education think about the quality of Medical Advice received?
  - “Quality of reports from therapists usually better than from doctors”
  - “Medical jargon needs explaining”
  - “Medical Advice is to assist, not instruct”
- How would our Medical Advice measure up to this in 2015?

Help is at hand!

Training opportunities for Paediatricians to ensure appropriate competences

- Grid Training in:
  - Paediatric Neurodisability
  - Community Child Health
- MSc Paediatric Neurodisability Sheffield Hallam
- Stand alone courses

Online resources and references to support Competent Paediatric Assessment to underpin Medical Advice

Medical Advice for Education: Recommendations for Paediatricians BACD

Medical advice should be **based on a comprehensive paediatric assessment**[1] of the child or young person (CYP). Anyone newly referred from education/Local Authority (LA) will require timely paediatric assessment in order to meet statutory timelines (i.e. within 6 weeks). Those already known to paediatric services only need additional direct clinical assessment if clinically indicated, where new information is suspected, where there are gaps in previously documented assessments or where previous assessments are not up to date enough to be reliably accurate.

Comprehensive paediatric assessment should include:

Concerns of CYP, family and other professionals

Detailed medical, developmental, family and functional history, including specific domains of:

Health conditions
Mobility and posture
Hand function and personal care
Communication, speech and language
Hearing
Vision
Feeding
Continence
Social communication and relationships
Behaviour and emotions
Sleep
Pain

Systematic physical examination including ascertainment of height, weight and head circumference percentiles and a full neurological examination

Observational assessment for behavioural phenotypes and red flags for neurodevelopmental disorders

Formulation or differential diagnosis

Investigations and onwards referrals for further specialist opinions and interventions

Referral for ***ophthalmological assessment (or at a minimum, orthoptic assessment with onwards referral to ophthalmologist in case of concerns)*** for all with neurodevelopmental disorders, dysmorphisms, genetic syndromes, chromosomal anomalies, neurological, metabolic, storage or cranio-facial disorders, cerebral palsies, congenital infections, hearing impairment, or where there is a family history of eye disease or squint, where there are any ongoing or new concerns about vision or where vision screening assessment has not been possible or has identified concerns

Referral for ***audiological assessment*** for all with significant speech and language difficulties, history of chronic or repeated middle ear disease or upper airway obstruction, early developmental impairment, established learning disability or disruptive behaviours

NB A comprehensive paediatric assessment should underpin the preparation of the medical advice report, but only succinct information of practical relevance to those providing services and support to the CYP in any setting should be included in the medical advice report

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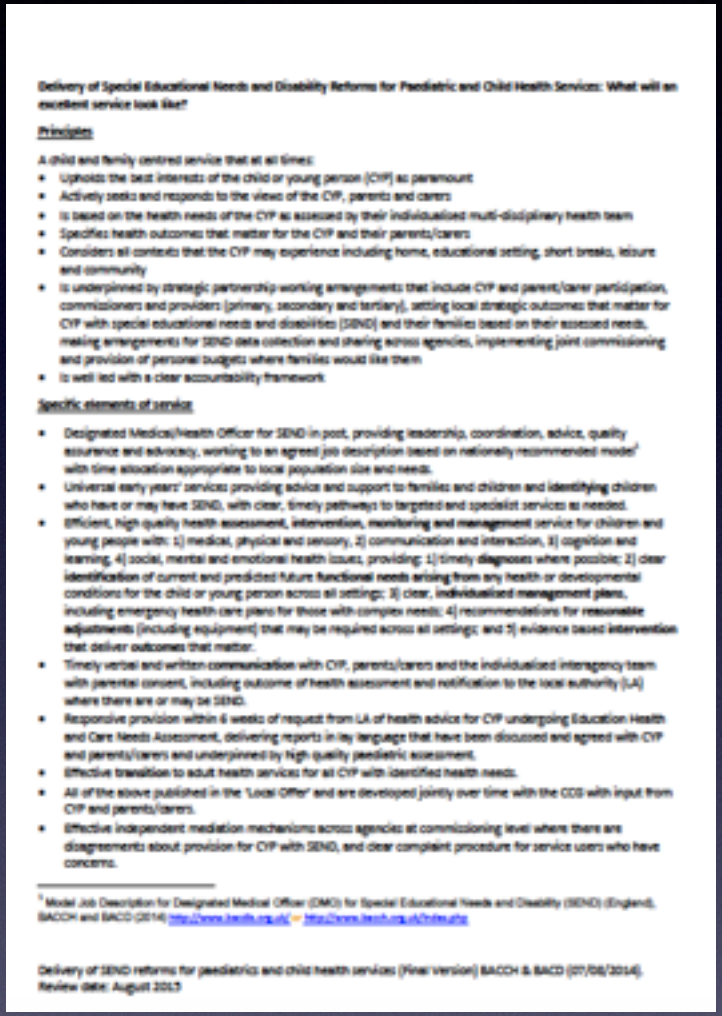
[1] *For more details of the expected standard of structured paediatric assessment including links to Background Information Sheet templates that can be sent out for the family to complete prior to attending the consultation for paediatric assessment to inform preparation of medical advice as part of the Education, Health and Care needs assessment, see:*
Horridge KA. Assessment and investigation of the child with disordered development. *Arch Dis Child Educ Pract.* 2011;96:9-20



Delivery of Special Educational Needs and Disability Reforms for Paediatric and Child Health Services: What will an excellent service look like?

Principles

A child and family centred service that at all times:

- Upholds the best interests of the child or young person (CYP) as paramount
- Actively seeks and responds to the views of the CYP, parents and carers
- Is based on the health needs of the CYP as assessed by their individualised multi-disciplinary health team
- Specifies health outcomes that matter for the CYP and their parents/carers
- Considers all contexts that the CYP may experience including home, educational setting, short breaks, leisure and community
- Is underpinned by strategic partnership working arrangements that include CYP and parent/carer participation, commissioners and providers (primary, secondary and tertiary), setting local strategic outcomes that matter for CYP with special educational needs and disabilities (SEND) and their families based on their assessed needs, making arrangements for SEND data collection and sharing across agencies, implementing joint commissioning and provision of personal budgets where families would like them
- Is well led with a clear accountability framework

Specific elements of service

- Designated Medical/Health Officer for SEND in post, providing leadership, coordination, advice, quality assurance and advocacy, working to an agreed job description based on nationally recommended model[1] with time allocation appropriate to local population size and needs.
- Universal early years' services providing advice and support to families and children and **identifying** children who have or may have SEND, with clear, timely pathways to targeted and specialist services as needed.
- Efficient, high quality health **assessment, intervention, monitoring and management** service for children and young people with: 1) medical, physical and sensory, 2) communication and interaction, 3) cognition and learning, 4) social, mental and emotional health issues, providing: 1) timely **diagnoses** where possible; 2) clear **identification** of current and predicted future **functional needs arising from** any health or developmental conditions for the child or young person across all settings; 3) clear, **individualised management plans**, including emergency health care plans for those with complex needs; 4) recommendations for **reasonable adjustments** (including equipment) that may be required across all settings; and 5) evidence based **intervention** that deliver **outcomes** that matter.
- Timely verbal and written **communication** with CYP, parents/carers and the individualised interagency team with parental consent, including outcome of health assessment and notification to the local authority (LA) where there are or may be SEND.
- Responsive provision within 6 weeks of request from LA of health advice for CYP undergoing Education Health and Care Needs Assessment, delivering reports in lay language that have been discussed and agreed with CYP and parents/carers and underpinned by high quality paediatric assessment.
- Effective **transition** to adult health services for all CYP with identified health needs.
- All of the above published in the 'Local Offer' and are developed jointly over time with the CCG with input from CYP and parents/carers.
- Effective independent mediation mechanisms across agencies at commissioning level where there are disagreements about provision for CYP with SEND, and clear complaint procedure for service users who have concerns.

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[1] Model Job Description for Designated Medical Officer (DMO) for Special Educational Needs and Disability (SEND) (England), BACCH and BACD (2014) http://www.bacdis.org.uk/ or http://www.bacch.org.uk/index.php

Delivery of SEND reforms for paediatrics and child health services (Final Version) BACCH & BACD (07/08/2014).
Review date: August 2015

Best practice

Assessment and investigation of the child with disordered development

Karen A Horridge

► An emergency healthcare template are published online only. To view these files please visit the journal online http://adc.bmj.com.

Correspondence to
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Accepted 7 June 2010

ABSTRACT
Every paediatrician, generalist or specialist, at every level and in every setting will come across the child or young person with disordered development and has a duty of care to ensure that appropriate assessment and investigations are undertaken, if each individual is to be given the best possible opportunities to achieve the highest possible level of participation and enjoy the best possible quality of life. Using a structured approach, all paediatricians have the potential to make a significant positive difference and should seek every opportunity to do so, even if seeing the child for an entirely different reason. Key messages of this article include: (1) each child is unique and requires careful,

every setting should be on the alert to indicators of concern in the domain of child development and know when to extend assessment and when to refer on for more expert assessment.

WHY BOTHER?

It is always important to stop and consider the goals and objectives of clinical practice; for the child or young person with disordered development, these include:

Identification of aetiological factors

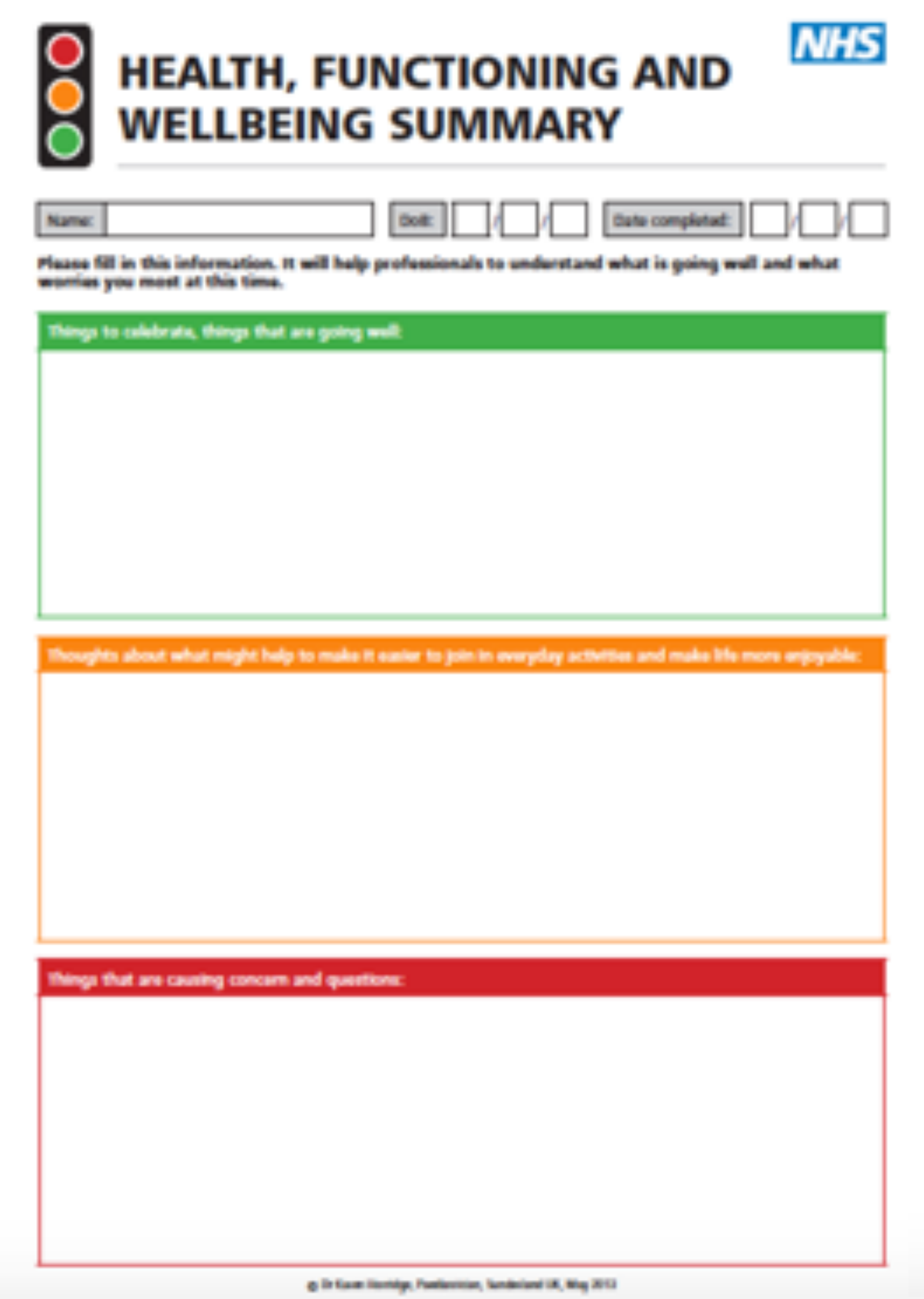
- If their child is 'different', parents are always

- www.bacdis.org.uk/policy/SEND.htm
- www.bacch.org.uk/policy/SEND_reforms.php

Structure ALL Clinical Letters, address to CYP and families, copy to all who need to know, with consent: “Assess Once and Share”

- Active Concerns
- Diagnoses
- Outcomes agreed with family
- SMART actions to achieve outcomes, including:
  - Suggested treatment and interventions
  - Suggested referrals
  - Paediatric follow up plan
- Summary of consultation
- Opinion and Plan

Traffic Light Tool for Reviews



HEALTH, FUNCTIONING AND WELLBEING SUMMARY

Name: ____ DoB: __/__/__ Date completed: __/__/__

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:

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Name: ____ DoB: __/__/__ Date completed: __/__/__

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.

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

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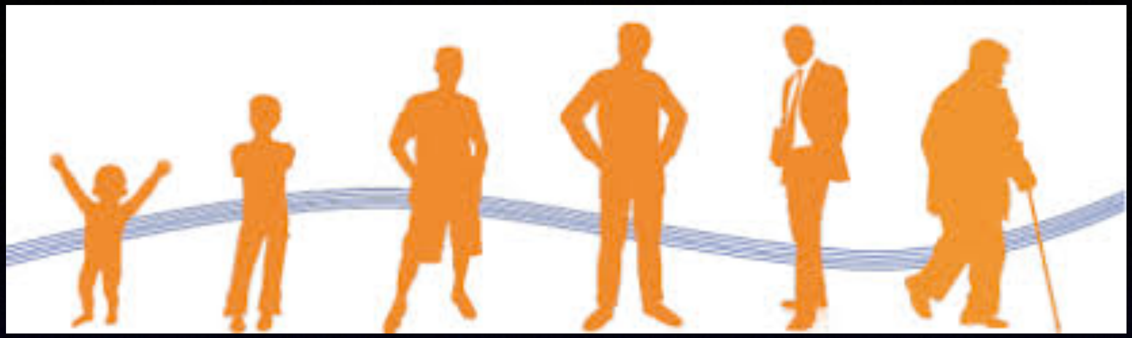
Think Lifespan



- Every time a LEARNING DISABILITY is confirmed in a report or plan, send a ‘flagging letter’ to the GP and LD Liaison Nurse to prompt:
  - Flagging of the Electronic Medical Records to indicate “LD”
  - Reasonable adjustments if healthcare is needed
  - Annual Health Checks for those aged 14 yrs+

Working together to achieve better outcomes: Interagency Strategic Partnerships for Disabled Children and Young People

- Use the Disabled Children's Charter for Health and Wellbeing Boards: www.edcm.org.uk/hwbcharter
- Present Charter to HWB or ask your Trust's rep to
- Encourage your HWB to sign the Charter, it makes perfect sense!
- Solution to delivery of Charter: interagency strategic partnership with the right people around the table

Interagency Strategic Partnership for Disabled Children and Young people: Who needs to be around the table?

Independent Lay chair

Chair of Parent Carer Council/Forum

Children and young people's participation lead

CYP commissioning leads Local Authority and CCG

Provider/Clinical leads: DMO/Paediatric Disability, Therapies, Education, Social Care, Third sector, Independent sector

What can an Interagency Partnership achieve?

- Share intelligence and vision
- Work towards pooled budgets and joint commissioning of services
- Ensure collection of robust data about needs in local population

Why collect population data?

- Delineate and evidence population needs
- Underpin Care Pathway and Service development
- Inform tariffs that reflect complexity of needs
- Highlight variations in care and drive up quality of care for all
- Provide rich platform for research
- Permit measurement and documentation of outcomes
- Inform the Joint Strategic Needs Assessment

What data is already available?
NHS Atlas of Variation in Healthcare for Children and Young People

March 2012

NHS Atlas of Variation in Healthcare for Children and Young People

Reducing unwarranted variation to increase value and improve quality

www.rightcare.nhs.uk

- % School children with SEN statement varies 11x
- % Emergency admissions with epilepsies varies 9x
- Death in hospital with life-limiting condition varies 50-100%

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Variation in health care for children and young people with cerebral palsies: a retrospective multicentre audit study

KAREN HORRIDGE[1] | PETER W G TENNANT[2] | RAJESH BALU[3] | JUDITH RANKIN[2,4]

Significant variation across 15 districts in Northern England in key areas of evidence-based healthcare:

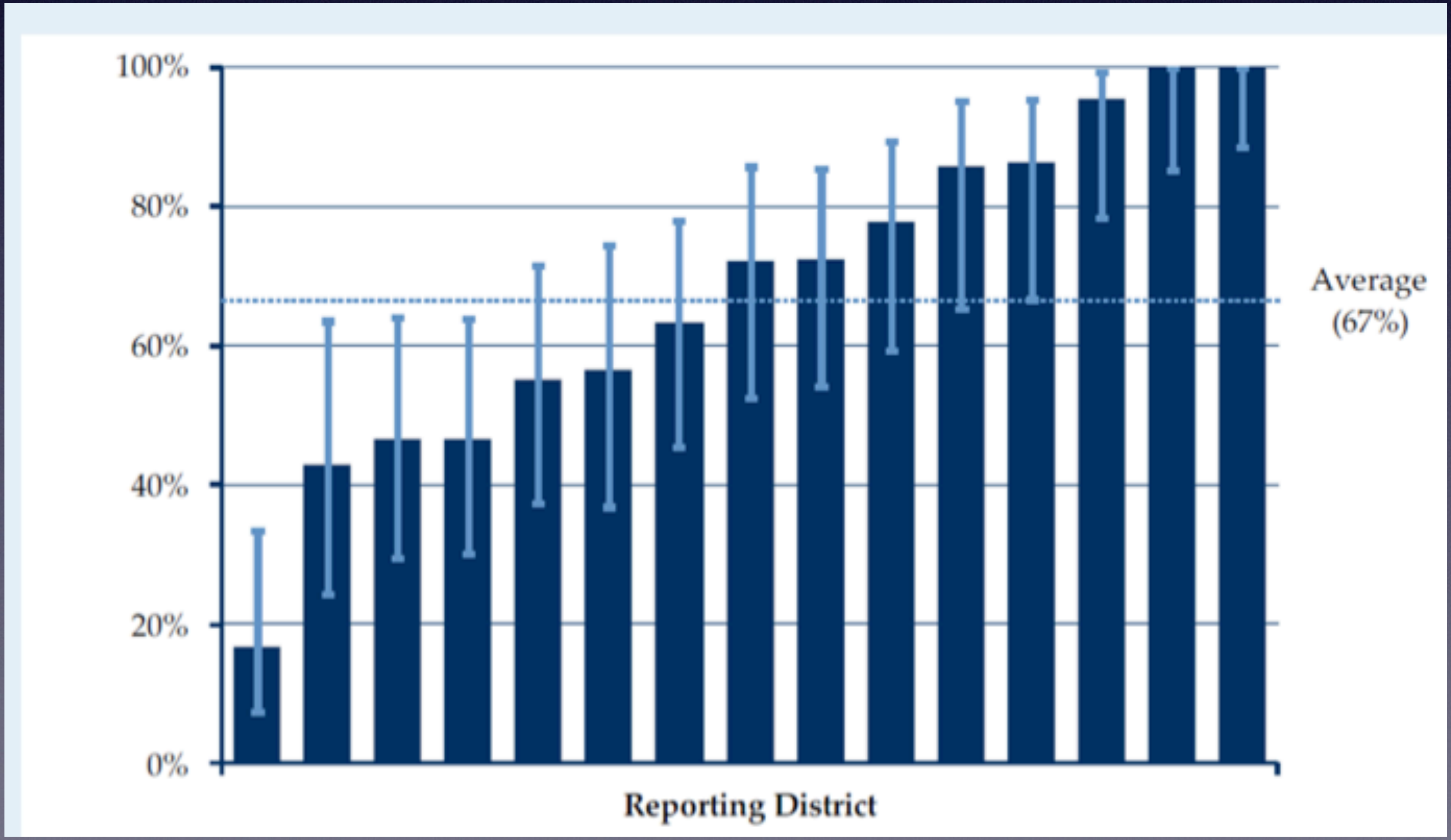
- Access to MRI as marker of aetiological assessment
- Access to orthopaedic surgeons for those with the greatest postural management issues
- Recording of discussions about pain and pain management plans

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Variation in health care for children and young people with cerebral palsies: a retrospective multicentre audit study

KAREN HORRIDGE[1] | PETER W G TENNANT[2] | RAJESH BALU[3] | JUDITH RANKIN[2,4]

Variation in recording a discussion about the presence of pain:



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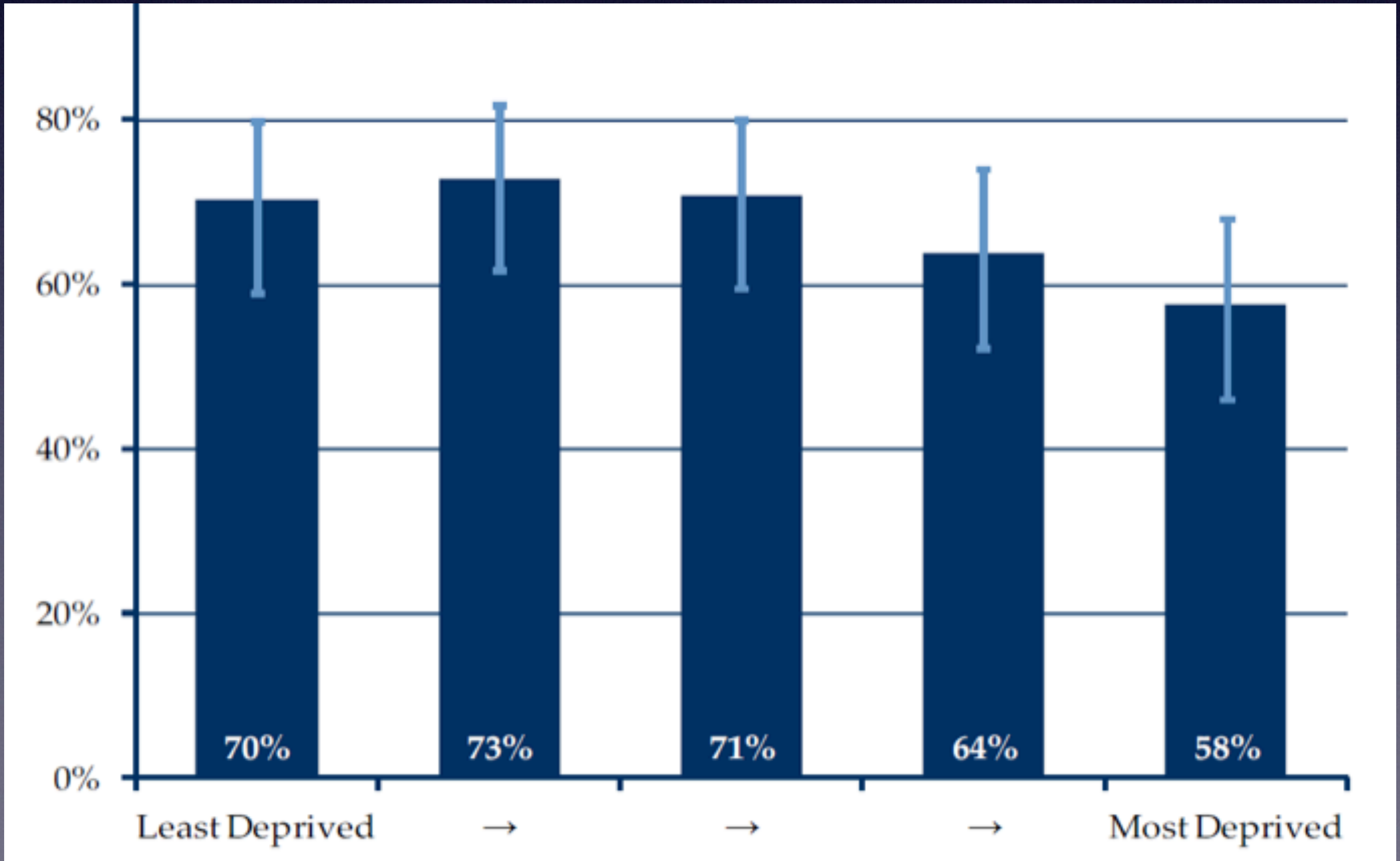
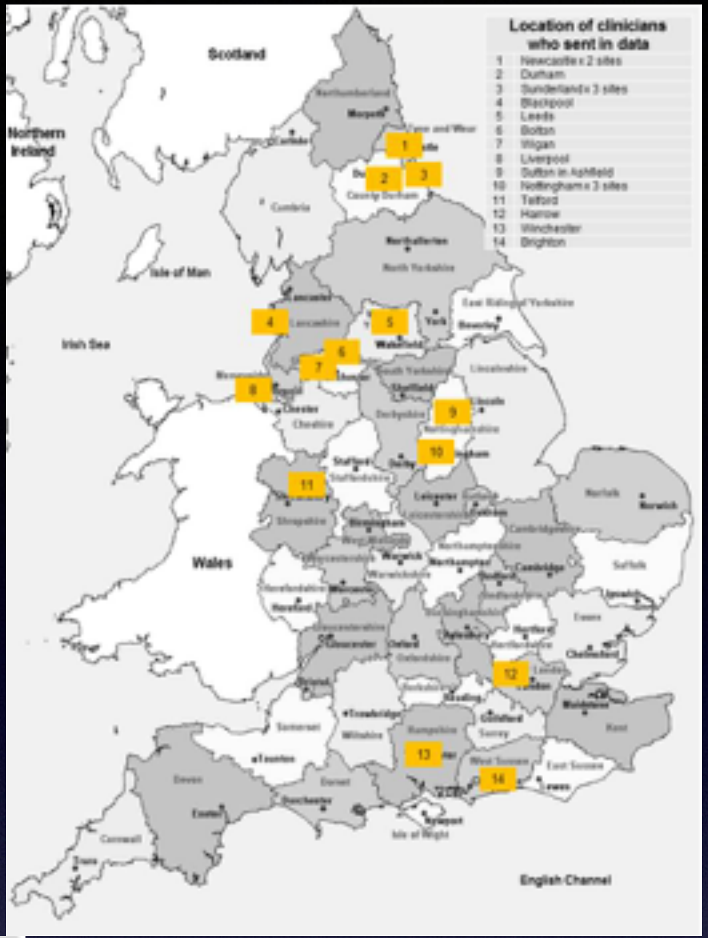
Variation in documented discussions about pain by socio-economic status:

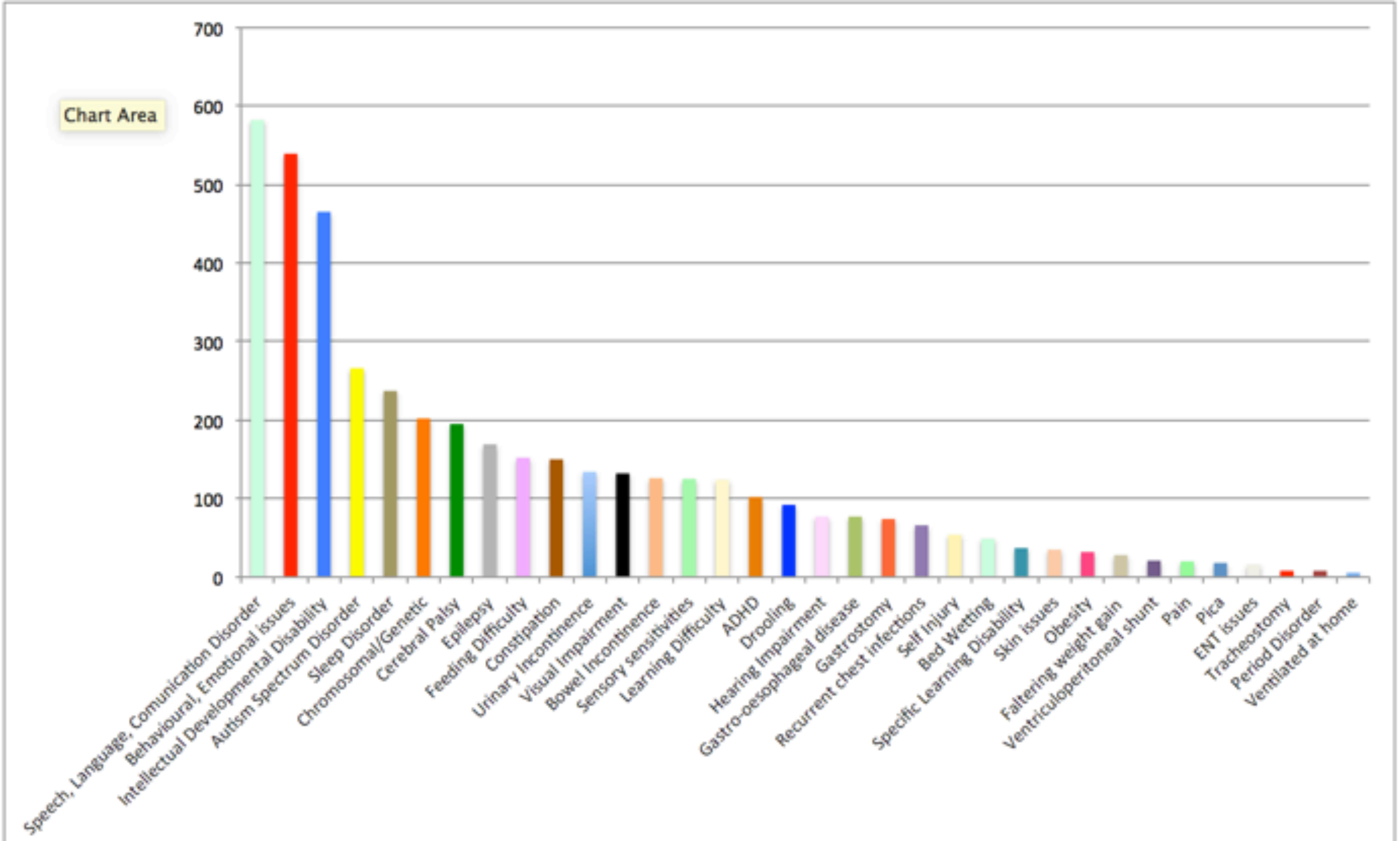


National pilots of prospective data collection by paediatricians at the point of clinical care, Winter 2013/2014

- Terminologies set developed by clinicians + parent: 304 terminologies, detailed explanatory glossary

- Data collection possible without disruption to clinics, easiest when done electronically





Positive differences good data can make: Sunderland’s experience

- Underpinned successful business case for additional:
    - Consultant in paediatric disability
    - Specialist SALT with ASD expertise
- Triggered redesign of Equipment Pathway
- Forum for strategy regarding special school nursing

Help is at hand!

National Data Collection: next steps

- Agreement from NHSE, PHE, HSCIC to include the final 296 terminologies in the Children and Young People's Secondary Uses Dataset

- All NHS providers will be mandated to report against each item

- HSCIC will be able to produce national atlas of variation based on outpatient clinical activity

- Be ahead of the rest: Start collecting data now!

- Terminologies set, explanatory glossary and report from NNPCF about the data project:

  - www.bacdis.org.uk/policy/dataset.htm

Drivers for Better Outcomes that Matter for Disabled Children, Young People and their families

- Positive attitudes that value, respect, warmly welcome and fully include all disabled children and young people as equals in our society
- Accurate population data about the multifaceted needs of disabled children and young people
- Competent workforce following evidence-based care pathways
- Embed outcomes and action plans in all clinical communications
- Robust interagency strategic partnerships
- Nothing about me without me

The future for
disabled
children and
young people
is in your hands

Are YOU ready to seize the opportunity?

Are YOU ready to take responsibility?

Thank you

Questions?