DMO Role: Opportunities and Responsibilities

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Disability: WHO ICF model
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
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..”

- 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
• 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
Who does the paediatric assessment?

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

- [www.bacdis.org.uk/policy/SEND.htm](http://www.bacdis.org.uk/policy/SEND.htm)
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**

<table>
<thead>
<tr>
<th><strong>No Concerns</strong></th>
<th><strong>Some Concerns</strong></th>
<th><strong>Serious Concerns</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>No limit joining in everyday activities or enjoying life.</td>
<td>Regularly but intermittently limits joining in everyday activities or impacts on ability to enjoy life.</td>
<td>Frequently or daily limits joining in everyday activities or impacts on ability to enjoy life.</td>
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**General Physical Health**
- General health
- Ability to perform daily activities

**Symptoms and Issues**
- Headaches
- Fatigue
- Sleep disturbances

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

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

- Are you well enough supported?
- Do you have enough information about your condition and services?
- Other (please specify):
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

• % School children with SEN statement varies 11x

• % Emergency admissions with epilepsies varies 9x

• Death in hospital with life-limiting condition varies 50-100%
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
Variation in recording a discussion about the presence of pain:
Variation in documented discussions about pain by socio-economic status:

- Least Deprived: 70%
- Second: 73%
- Third: 71%
- Most Deprived: 58%
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](http://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?