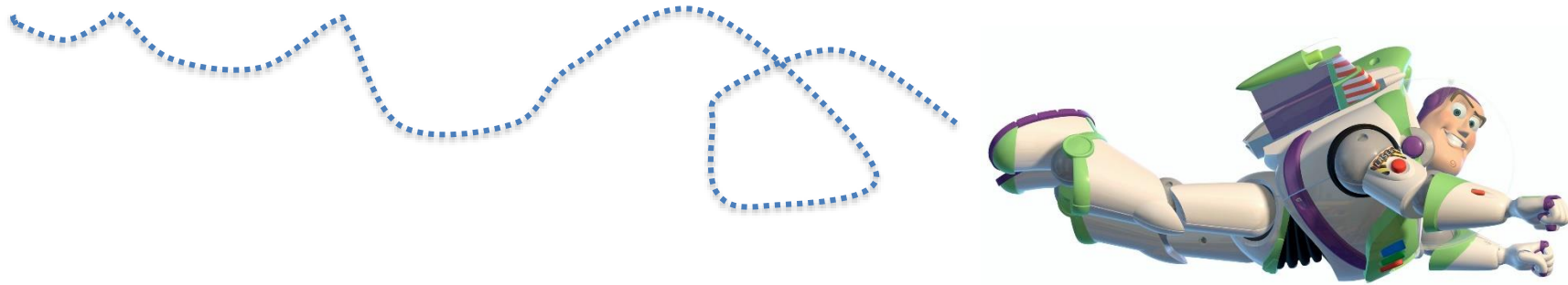**Special Measures Project :**

equality and diversity in feedback and outcome measures: progressing practice and

practice-guidance on measures and methods for children and young people with learning

disabilities (CYP-LD), their families and networks

Ro Rossiter

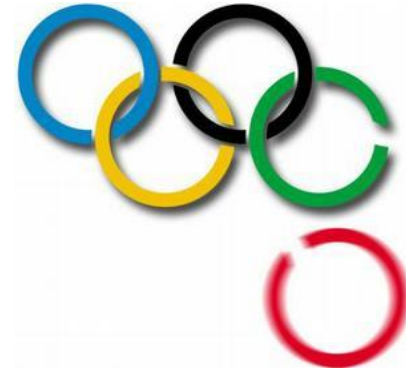r.rossiter@kent.ac.uk

.... or who'd have thought ROMS could create such a buzz?

......WHERE HAS THIS 'BUZZ' TAKEN US?

- Background

- Special Measures project

- Issues

- Questions

Where were we in 2012?

Limited, largely anecdotal evidence of measures to use (many not standardised with CYP-LD)

+
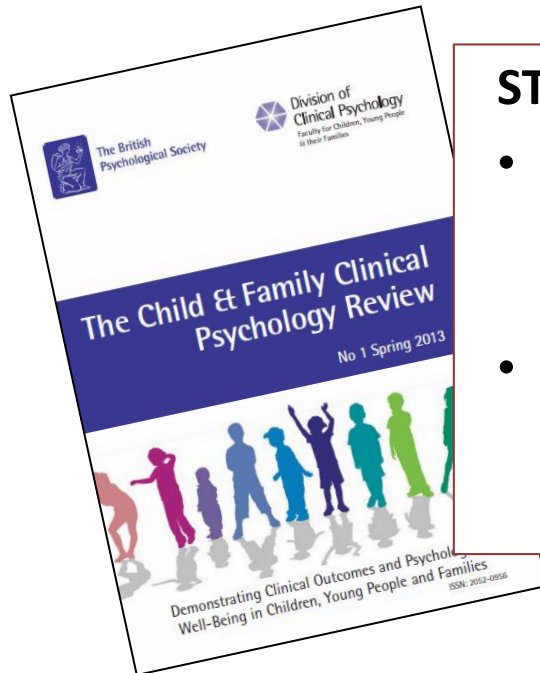
Range of services operating in isolation

=

LACK OF CONSENSUS

First steps towards consensus: practice sharing

**STEP 1: Initial discussions**

- Initial informal practice discussions
- mini-survey of BPS Division of Clinical Psychology (DCP) Faculty for Children, Young People and their Families LD Network

STEP 2: A wider audience

- Publication of articles to stimulate discussion *(Rossiter et al, 2013; Phillips et al, 2014).*
- Participation in CYP-IAPT OEG (Outcomes and Evaluation Group) 2012-2014
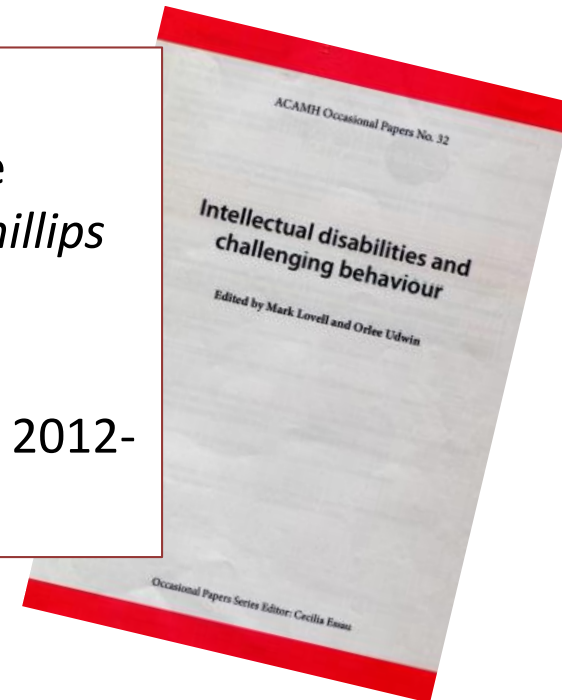
First steps towards consensus: practice sharing

STEP 3: Survey
- Replication of project for adults with learning disabilities whose behaviour challenges services by BPS DCP Faculty for Learning Disabilities *(Morris et al, 2012)*

- 109 participants
- Range of services
- Range of professions
- UK wide

First steps towards consensus: practice sharing

STEP 4: Sharing clinical practice (2014/15)

- 2 practitioner days organised/supported by CYP-IAPT OEG and London & SE, and CORC

  - *120 CYP-LD practitioners, managers, CYP-IAPT and non CYP-IAPT plus CORC team from all over UK (and Norway)*

- Chapter in 'Guide to Using Outcomes and Feedback Tools - COOP Document' *(Rossiter et al 2014)*
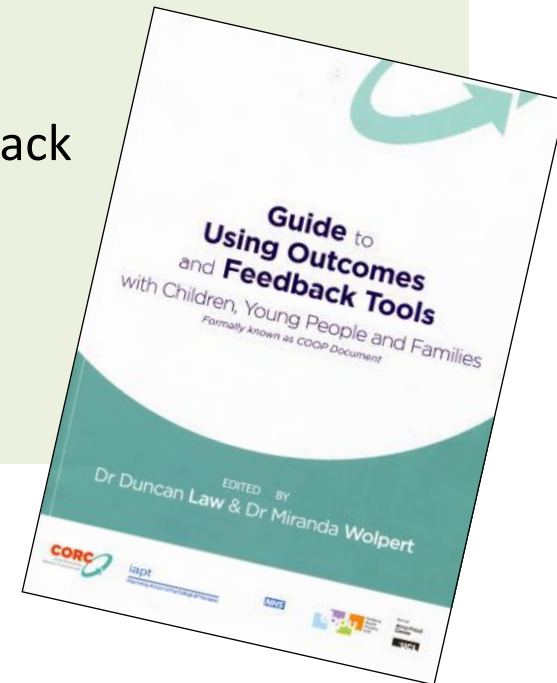
Emerging consensus:
Building from survey and practice sharing days

STEP 5:

http://www.corc.uk.net/ldworkshop/
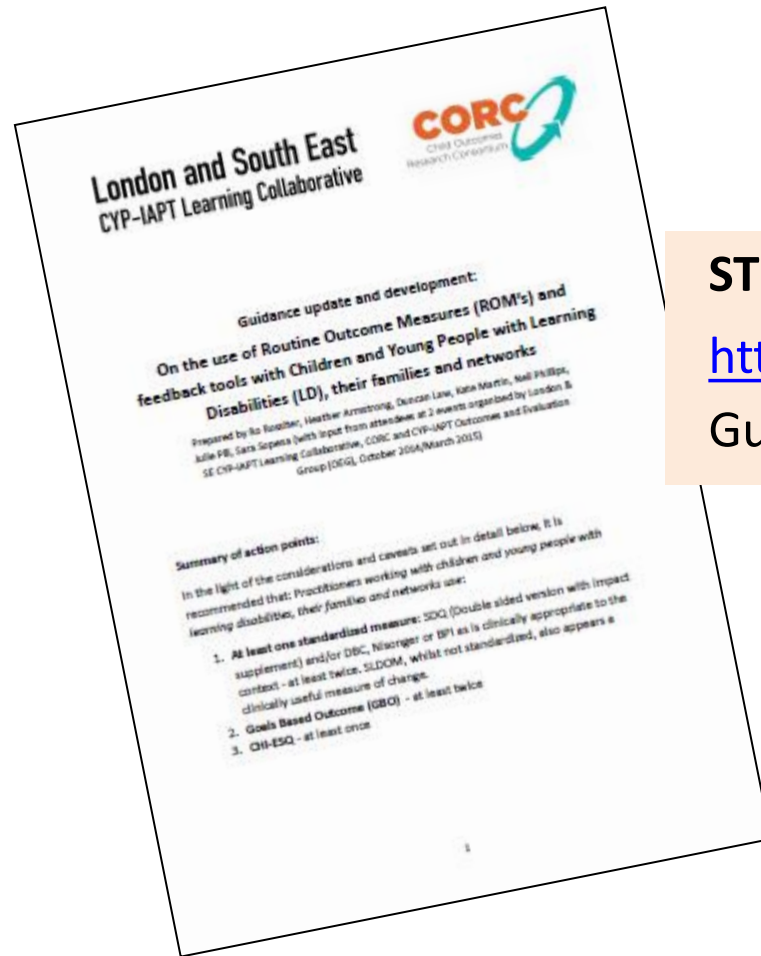
Guidance paper drafted

Emerging consensus:
Building from survey and practice sharing days

London & SE CYPT-IAPT/CORC/practitioner guidance (June 2015) with caveats, principles, references (http://www.corc.uk.net/ldworkshop/):

It is recommended that …… *practitioners working with children and young people with learning disabilities, their families and networks use*:

1. **At least one standardised measure** :
   SDQ (Double-sided version with impact supplement) and/or DBC, Nisonger, BPI as is clinically appropriate to the context - at least twice

   SLDOM, whilst not standardised, also appears a clinically useful measure of change

2. **Goals Based Outcome (GBO)** - at least twice

3. **CHI-ESQ** - at least once

Special Measures Project team/streams :   January 2019 – December 2020

Jeni McElwee (Wales) leads for Profound and Multiple LD participation & service users. Mapping, lit review, links, framework and guidance development.

Neil Phillips (Worcestershire) leads for the survey update and analysis supported by Emi Demjen. Survey ran July/August 2019.

Ro Rossiter - Project Manager. "Mini-guidance update" end 2019; workshops - spring 2020

Eric Emerson leads for interrogation of Millennium Childhood Cohort Survey data and any other relevant national databases. Draft report of SDQ analysis from MCCS

Nick Tait leads for CORC (host and data analysis- existing CYP-LD data; NHSE/CORC survey)

Project Management Group includes above plus Commissioner, Duncan Law
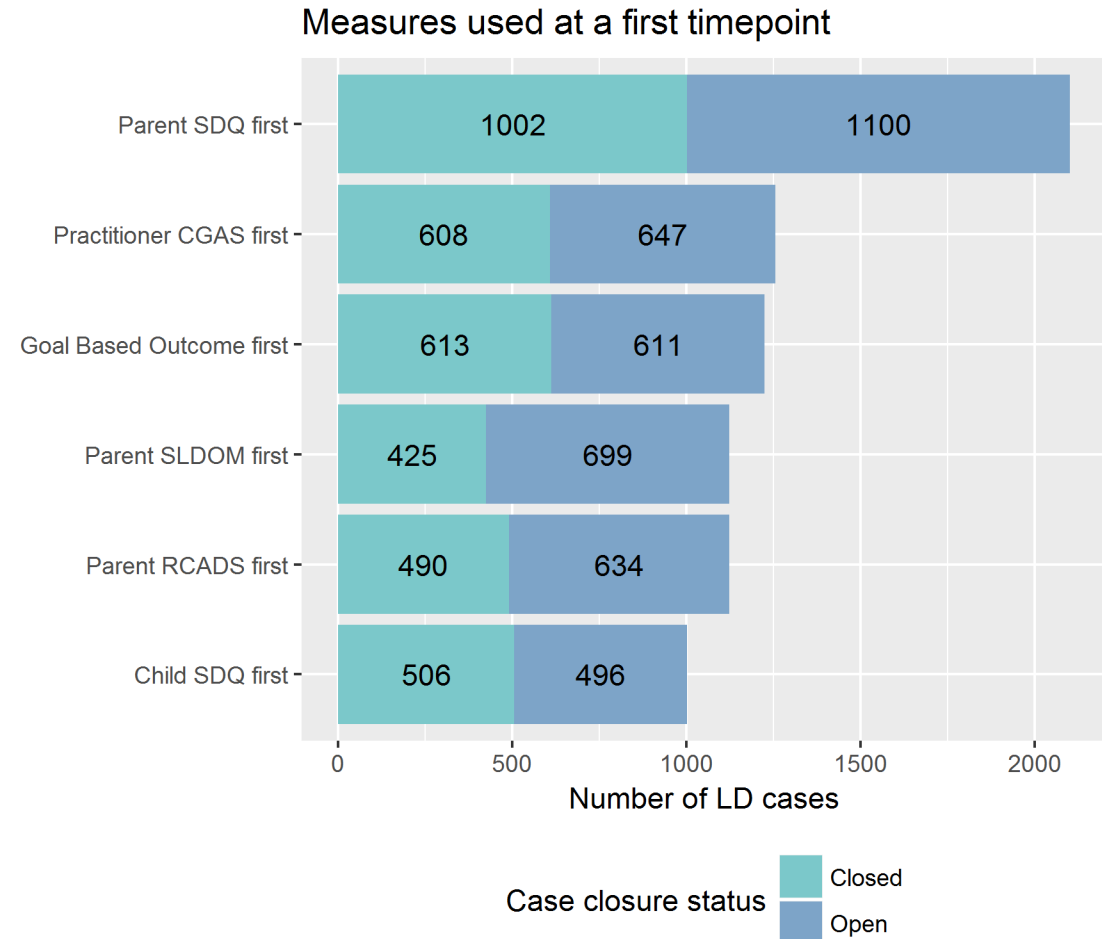
Measure	CYP-LD Practitioner Survey 2014 N = 109	NHSE/CORC CYP practitioner survey 2018 N = 101/862	BPS DCP/CORC CYP-LD Survey 2019 N = 111
Generic			
CGAS (Children's Global Assessment Scale)/Developmental Disabilities DD-CGAS)	12%	-	11.25%
GBO (Goal Based Outcomes)	70%	42%	54%
RCADS – P	-	42%	24%
SDQ (Strengths and Difficulties Questionnaire) child/young person	?	-	34%
SDQ (Strength and Difficulties Questionnaire) – Impact Supplement only	?	-	21%
SDQ (Strengths and Difficulties Questionnaire) parent	54%	59%	40%
CYP-LD Specific			
BPI-01 (Behavior Problems Inventory)	4%	-	17.7%
DBC (Developmental Behaviour Checklist)	38%	-	24%
Nisonger Child Behaviour Rating Form (Parent)	5%	-	10%
SLDOM (Sheffield Learning Disability Outcome Measure)	63%	25%	41.25%

In the CORC data, what are the frequently used outcome measures in learning disability cases?

- The chart shows the outcome measures* most frequently used at a first time point in the sample of 6,734 learning disability cases identified in the combined CORC+ and CYP IAPT datasets

- To note: The frequency of use of the parent-reported SLDOM is partly due to use of this measure being one of the criteria to select the sample of learning disability cases

- Open and closed cases are considered here to give an indication of the measures used

- When considering outcomes on subsequent slides, closed cases will be looked at separately, as it is generally considered to be more meaningful to consider the outcomes of cases that are closed

Measures used at a first timepoint

Measure	Closed	Open
Parent SDQ first	1002	1100
Practitioner CGAS first	608	647
Goal Based Outcome first	613	611
Parent SLDOM first	425	699
Parent RCADS first	490	634
Child SDQ first	506	496

Number of LD cases

Case closure status
- Closed
- Open

* The analysis of the most frequently used outcome measures shown here is restricted to those outcome measures that CORC hold data on in the CORC+ and CYP IAPT datasets. These outcome measures were selected for inclusion in the datasets during 2011-2015, according to various principles such as clinical utility, coverage of a wide range of contexts and public consultation.
For further information on the principles used to select outcome measures for inclusion in the datasets see page 21 of Wolpert et al (2016) Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015.
For the full list of outcome measures included in the datasets, see the CORC+ data set specification on the 'Sending Data to CORC' page of the CORC website.

In closed learning disability cases, how often are outcome measures used at two timepoints?

- To consider outcomes for closed cases, measure scores at a first and a last timepoint are needed to calculate the change in the score

- The chart shows the number of cases where measures were completed at both a first and last timepoint, a first timepoint only, or a last timepoint only

- The measure used most at two timepoints in closed learning disability cases is the Goal Based Outcome tool

- The Goal Based Outcome tool was used as often at two timepoints as at a first timepoint only

- Other measures were used more often at a first timepoint only than at two timepoints

When measures were used (closed cases)
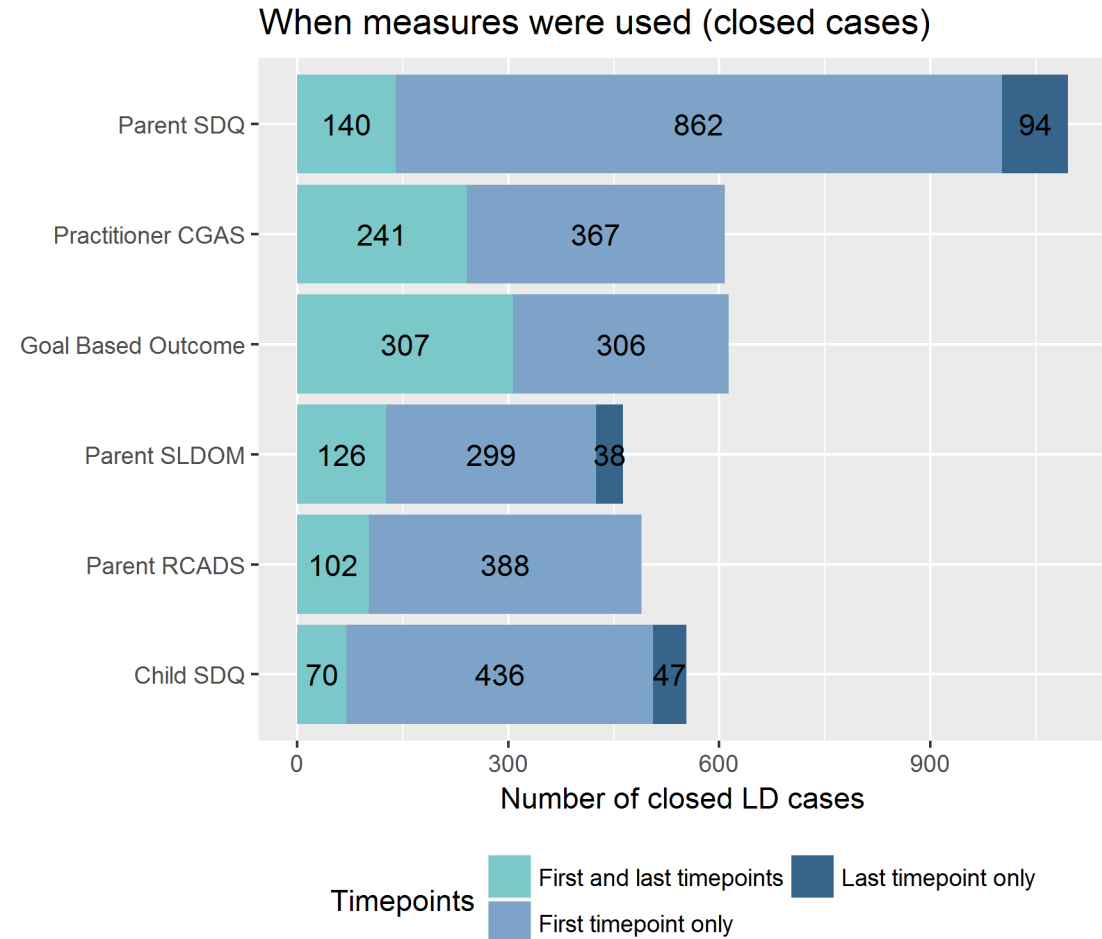
Example approach to feedback & outcomes: CAMHS-LD/ Family Intensive Support Service

A teaching trust of Brighton
and Sussex Medical School

Sussex Partnership **NHS**
NHS Foundation Trust

What is the Problem?	Referral form including Behaviour Grids, SDQ, DBCL, Current View
What do you want to change?	Goal based measures
How are we getting on together?	Alliance Measure, Session Feedback Questionnaire/Bullseye
How are things going?	Goal based tracking, behaviour monitoring, Behaviour Grids, SDQ, DBCL, formal review, CHI-ESQ (from Sept 2014)
Have we done as much as we need to?	Goal based tracking, behaviour monitoring, Behaviour Grids, SDQ, DBCL, formal review
How has the experience been generally?	Alliance Measure, Session feedback questionnaires, FISS Service Evaluation, CHI-ESQ since Sept

Service Constructed Behaviour Grids
Sussex Partnership NHS Trust

Designed to let parents specify and prioritise up to 3 behaviours of concern in relation to:

• Severity of the behaviour

• Frequency of the behaviour

• Distress caused by the behaviour

• Confidence in managing the behaviour

• Coping

Accessible support: Visual Analog Scales (VAS) & This Much! Helping professionals to help children 2012 David V Glasgow https://itunes.apple.com/gb/app/this-much!/id571631245?mt=8 (also This Much! for iPad)

Eg Bipolar scale with icons and context. The colours were selected to be relatively easily discriminated by individuals with red-green colour blindness.
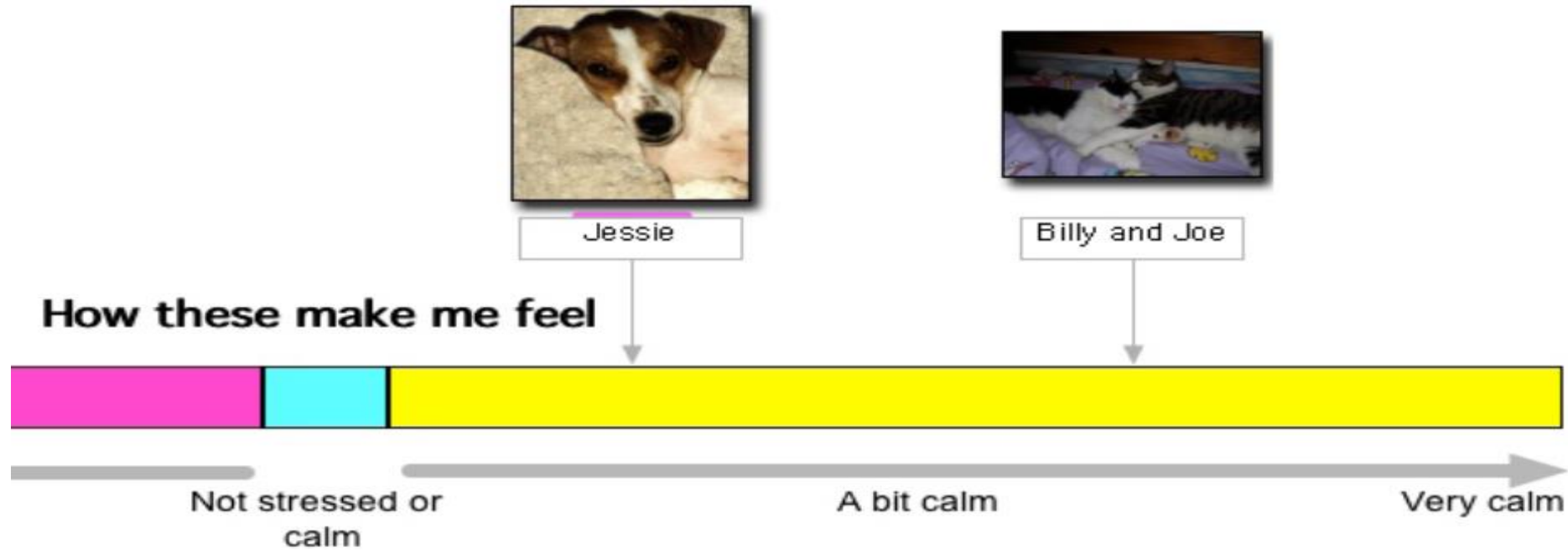
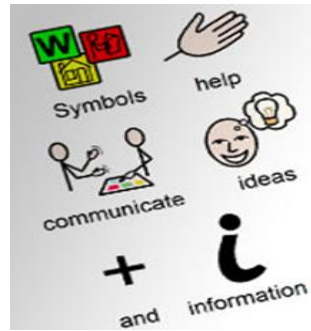**When my Mum goes to work**

Very angry	Quite angry	Just OK	Quite happy	Very happy

Unipolar scale

No pain at all	A little pain	Quite a lot of pain	Great pain	Extreme pain

Accessible support: This Much! Customise with pictures;   words eg squirmy, anxious; situations

Jessie

Billy and Joe

How these make me feel

Not stressed or calm

A bit calm

Very calm

Accessible support: symbols and pictures

eg Widget/Communicate in Print; http://www.widgit.com/about/index.htm

photosymbols: http://www.photosymbols.com/
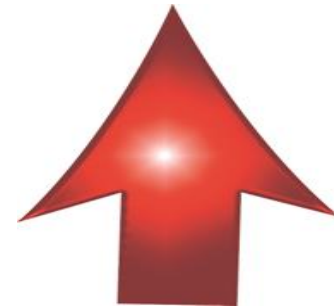
Talking Mats info & video demos at http://www.talkingmats.com/

- Talking Mats is a communication framework for helping staff to support children and young people to organise their thoughts and express their views about particular issues.

- Talking Mats communication symbols allows for easy consultation of children and young people especially children with communication difficulties.

- Talking Mats is an interactive resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can be a physical, textured mat, or a digital space, eg tablet, smart board or computer screen using the app.

Top Scale

Options

Aids for education

Family background

Carer

Communication support

School

Health services

Money

Emergency services

Respect for belief

Teachers

Neighbours

Support for Learning assistant

Visitors to my house

Where I live

My wider world

Topic

Including people with more severe impairments **"If you listen, you will hear us "** Leicester Partnership NHS Trust; video:
https://www.youtube.com/watch?v=Hp4PW17U_h8

Expression through nonverbal gestures, day-to-day behaviours:

"If you listen, you will hear us " Leicester Partnership NHS Trust

Personalised ways of communicating-small change in face, blink of eye, posture, colour in face etc; hard to interpret by people who do not know them well; use of communication passports …..

"If you listen, you will hear us " Leicester Partnership NHS Trust

……… so that they are not left without a voice in decisions which impact on lives & no way of commenting on services they receive. Need to pull together information for evaluation and planning of services

Special Measures Survey: Where does data go and use of data?

ANSWER CHOICES	RESPONSES	
CORC (Child Outcomes Research Consortium)	10.67%	8
CYP-IAPT (Children and Young People's Improving Access to Psychological Therapies)	10.67%	8
MHSDS (Mental Health Services Dataset)	2.67%	2
Local commissioners	38.67%	29
Saved on your own database	62.67%	47
Don't know	16.00%	12
Other (please specify)	20.00%	15
Total Respondents: 75		

Issues:

- Existing measures/data so far:
  - Further analysis - qualitative, less used measures (both NHSE/CORC & BPS DCP/CORC surveys)

  - Some other measures - general (eg's: CORS/session by session, FQoL, HONOSCA, PHQ9, PSI, SCORE 15, Vineland) & CYP-LD (eg's: Adaptive Behaviour Assessment System ABAS, Challenging Behaviour Attributions Scale CHABA, The Emotional Reactions to Challenging Behaviour Scale ERCBS)

  - Analysis of: ease of completion, usefulness for professionals, parents, child, how well detects change

- Involvement of CYP-LD, parents and networks

- Demographics- what kinds of services and service users – massive range

- Social & health inequalities:
  - higher rates of emotional, behavioural & mental health problems but less access to services and support (Foundation for People with Learning Disabilities, 2002; Emerson and Hatton, 2007, Overshadowed, CYPMHC 2019);

  - numbers increasing - low birth wt babies, FASD, complex health needs, etc (Carpenter et al., 2011; Blackburn et al., 2010; DCFS, 2010);

  - higher rates in "vulnerable" populations,e.g. C&YP in care, EBD/mental health (Emerson & Hatton, 2007) & criminal justice system (Talbot 2007, DH & Bradley 2009a, 2009b, Bryan 2012)

  BUT

  - unrecognised in schools, mental health, care, criminal justice settings (Simonoff et al. 2006, Emerson & Baines 2010; Talbot 2007) and are "All Our Children" (Lenehan 2018)

- Symptoms/problems vs quality of life; standardised vs personalised; triangulation

- Data – for who, for what? Where to flow, report, reflect?

- Process- Goal Attainment Scaling Reliable Change Index

- Since CYP-IAPT OEG (Outcomes and Evaluation Group) stopped meeting, no practice forum

- …………