

# PARTICIPATION & SUPPORTED DECISION MAKING

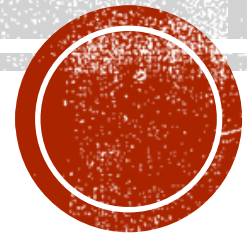
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# WHY?

- ✓ Insider knowledge can make unknown or silenced information visible (sometimes with support from others who know the person well)
- ✓ It can build trust and confidence, for example, better understanding; confident decision making and associated reasoning, evidence and recommendations
- ✓ It *can* be unifying and reduce conflict
- ✓ It's enjoyable, persuasive and can change people's lives for the better (choice, control, capacity)
- ✓ Implementation of human rights (the right to make choices)
- ✓ Its about '**with**' not '**for**'
- ✓ It fosters self-determination & person-centred outcomes
- ✓ ... the law says so....CA / MCA / MHA / HRA / EA / CRPD



# CONSEQUENCES OF NOT DOING

- No participation = frustration, anger or passivity /withdrawal = exclusion
- No participation means no supported decision making
- Will miss vital information
- Dilute people's choice, control & independence
- Remove potential to maximise capacity
- Reduce self expression which can lead to frustration & anger
- Damage trust & relationships
- Lead to professional confirmation bias
- Risk of procedurally-driven, less enjoyable practice
- Is unlawful, disempowering & potentially oppressive
- Makes our professional lives more difficult



# BARRIERS

- The historical context – custom & practice
- Types of decisions (*not important / too important*)
- Level of impairment:
  - *If P can, they do*
  - *If P can't, they can't*
  - *Diagnostic overshadowing*
- Whose responsibility is it anyway?
- System / infrastructure issues / resource constraints / time pressures
- Lack of training: *the law says.. vs. implementation*
- Skills / confidence / embarrassment / fear of getting it wrong
- Competing philosophical approaches to understanding / responding to the 'problem'



# HOW? COMMUNICATION

- ✓ Communication is the means we use to control our existence – it's fundamental to being included in society
- ✓ There can be no relationship, and thus, no participation without communication
- ✓ There can be no supported decision making without communication & participation
- ✓ We must presume that everyone communicates – **we cannot not communicate**
- ✓ Lack of verbal skills doesn't amount to an inability to communicate
- ✓ Be careful of assumptions: a P may speak, but not understand & a P may not speak, but understand okay
- ✓ Communication is idiosyncratic & we must take a **person centred approach** to providing support

**In essence, person centred communication is the adaptation of different forms of communication to the uniqueness of the individual you are working with and their communication style. The onus is upon us to step outside of our communication comfort zone, in order to ascertain and work within the person's own communication style...** It doesn't matter how it's achieved as long as:

- 1) *It conveys the intended message;*
- 2) *is decoded by the recipient;*
- 3) *a response is made based on the interaction*



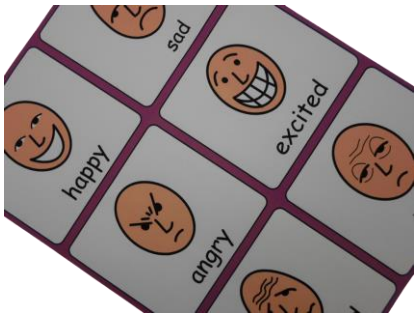
# HOW? COMMUNICATION DETECTIVE WORK

**What is the person's communication style? - Not, what is their diagnosis...**

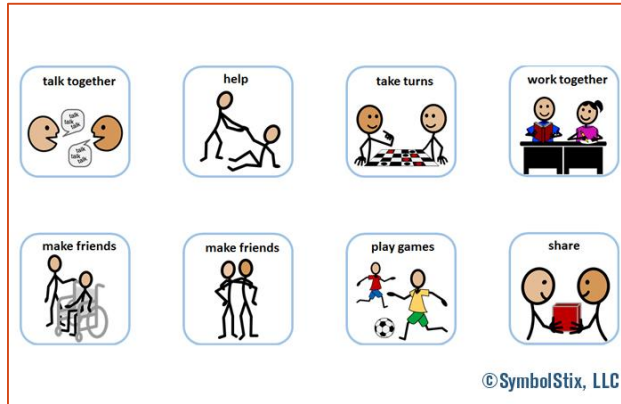
- ✓ The **impact** of cognitive impairment on understanding, retention, using & weighing, expression?
- ✓ P's use of language? Oral, written, symbolic, pictorial, electronic, sign language, other, a combination?
- ✓ Is an **interpreter** required?
- ✓ What is P's idiosyncratic **paralanguage**? The subtle signals that accompany speech (vocal sounds, pace, pitch & tone)
- ✓ Idiosyncratic **body language**? Eye contact, facial expression, gesture, touch, hand & body movement
- ✓ **How** do the above denote happiness, sadness, anxiety, pain, agreement, disagreement, upset etc. for the person
- ✓ **How** do the above change in different environments (home, placement, inside, outside, with people, when alone, at different times)
- ✓ How do the above alter in the **presence of certain others** (family members, friends, carers & professionals)
- ✓ What communication **equipment** does P use? A hearing aid / glasses, false teeth – do they work?
- ✓ **Be led by the person**: Visit when works best for P: are they a morning or afternoon person? How might medication have an impact? What will be the impact of disrupting their routine?
- ✓ Learn from the **know-how** of what does & doesn't work for them / or from other people who know the person better than you
- ✓ **Spend time** in the person's company & observe their communication - this will provide a sturdy foundation upon which to base your communication, build a rapport & positive communication relationship



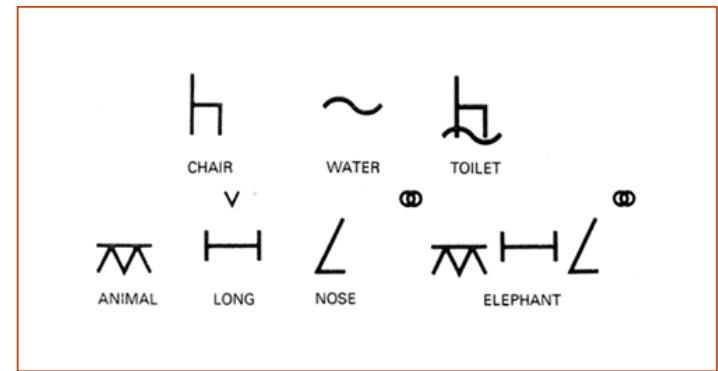
# COMMUNICATION AIDS



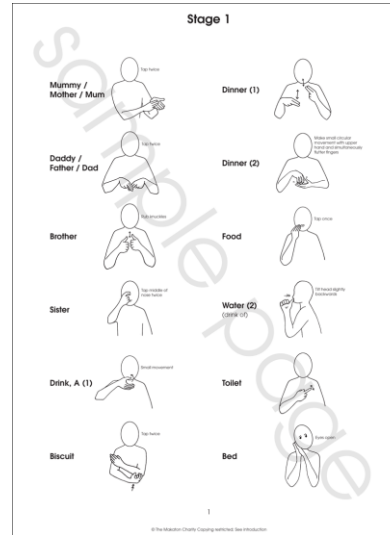
**Widgit Symbols**



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**Blissymbols**



**Makaton**



**SALT Apps**

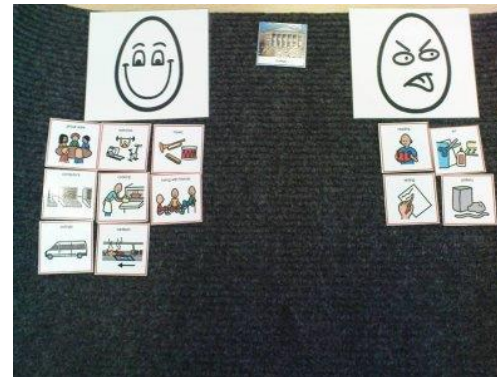
2012 Japan-Taiwan Symposium on IGO Technology 2012/12/10-11  
1. Introduction: Finger Braille and Smartphone

Conventional braille × Finger braille

- Good Portability
- Good Communication Function
- High Performance



**Voice Output Communication Aids**



**Talking Mat**



**Picture Exchange Communication**

# HOW? PREPARATION, PREPARATION, PREPARATION

Once we know *how* the person communicates, we should use our **second-order** communication skills:

- ✓ **Plan** your communication strategy (use a specialist e.g., SALT, intermediary, or other suitable person / advocate)
- ✓ Different strategies may be required for **differing situations / decisions / context**
- ✓ Think through **what you wish to communicate** – what is the ‘relevant information’ for each decision (LoI)
- ✓ Provide **balanced** information about **all options**
- ✓ **Clarify P’s understanding of key words** ‘home’, ‘live’, ‘contact’ - how do we know this & how consistent is it?
- ✓ What **format** should this take – what will work best for the person?
- ✓ What resources will we need? Can we access them when required?
- ✓ Are established tools available, or do we have to **create something bespoke?**
- ✓ Can we **prepare in advance** - what has to happen in the moment?
- ✓ What is the most appropriate **environment** & time of day etc. for the person
- ✓ Determine the best flow, structure, pace, the need for breaks etc.
- ✓ **Use a note taker**
- ✓ **Contingency plan** for anxiety, distraction, interruption etc.





# PC COMMUNICATION CAN SUPPORT PARTICIPATION IN LEGAL CASES

## APPROACH:

Who is *this person*, and how will *they* communicate best in *this specific* context

- ✓ Participation is important whether P attends court or not (it might be about the matter for the court, written communication / the bundle, or providing their views)
- ✓ Explain the *who, what, where, when, why & how* of the court process – there's a lack of accessible information about the Court
- ✓ **Is the court accessible** for P? Is physical adaptation necessary? Is it emotionally / socially accessible?
- ✓ Find out the **best method for P**, whether it's about explaining the court process, P 'telling their story', or explaining the outcome: e.g. in-person, via video (live or otherwise), in writing, use of gesture, symbols or pictures, verbal, or a combination of...)
- ✓ Who is the **best person** to facilitate this?... It will likely depend on the **type of participation** being considered



# PC COMMUNICATION CAN SUPPORT PARTICIPATION IN LEGAL CASES

**Consider a ground rules hearing with an intermediary or other suitable person: Get advice on all the above. Understand how best to help P settle, be calm & keep focused, as well as how to respond to their anxiety / emotional state:**

- ✓ Review the **intermediary's report** (if available) & allow sufficient time to implement their recommendations
- ✓ Flag up & address **potential difficulties** in advance of P attending court
- ✓ Agree the **communication aids** that will be used
- ✓ Agree the length & timing of scheduled **breaks** & how to request unscheduled breaks
- ✓ Consider whether all breaks need to be adjourned or non-adjourned / does P's participation need to be spread over more than one day (e.g., over two consecutive mornings)
- ✓ Agree the **best date / day / time**, being mindful of P's routine & personal care needs
- ✓ Agree the **phrasing & chronology of the questions** to be posed
- ✓ Agree how P and / or the intermediary will **intervene** / get the court's attention
- ✓ Plan the **pre-hearing familiarisation** **AND** implement the lessons from it



## **Do:** Use concrete / tangible resources:

- ✓ If P can't verbalise, writing or drawing can aid focus, improve recall (& be an aide memoire) = reduced stress
- ✓ Use **short sentences** / plain language. Easy read court documents / social stories / photos / models can be useful in explaining the court process
- ✓ **Visual timelines** for times, dates, events etc
- ✓ Arrange a **pre-hearing** familiarity visit: who's who, seating / location of parties, test options via role-play, agree a break-space (*aim for a person-led set up*)
- ✓ Enable the intermediary / supporter to assist P's communication & intervene as appropriate
- ✓ **Meet the P beforehand** (*a great way to tune-into a P's communication!*)
- ✓ **Anticipate stress & anxiety:** Reduce cognitive load with emotional scales, calming objects, the person-led use of breaks & card rules (*to request a break, summon support, stop the questioning, express anxiety, pace (too fast / slow), stop/pause/topic change (tell the truth/ be honest / say if you don't know / understand/ if someone gets it wrong)*)

- ✓ **Be reflexive:** Ask yourself: *How's it going? What's working / not working?* Don't stick to a rigid plan if it's not working – adapt to the P's communication
- ✓ **Be flexible** re: non-standard presentation / participation (*receptive & expressive delay, unusual eye contact, tics, rituals, agitation, specific clothing, unexpected behavioural responses, egocentrism, pedantic speech*)
- ✓ **Watch NVC:** look for signs of misunderstanding / confusion (*puzzled look, knitted brows, long pauses / repeated 'don't know' / acquiescence*) or stress (*agitation, withdrawal*). Allow extra time. But don't fear short periods of silence
- ✓ **If you don't understand P,** ask them to repeat e.g. *'thanks, but I didn't hear that properly / to make sure I understand / could you repeat'* BUT explain why, or they may think they got the Q wrong and change it to please you. Pause to check understanding & that your interpretation is accurate
- ✓ **Use P's name.** Be a good listener. Give the person your full attention and resist the temptation to finish sentences or talk for the P
- ✓ **Remain open to review** – P's communication needs might change during the process. Provide an easy read follow up summary / outcome

# DON'TS

- **Don't rush**
- Don't use statements, front loaded sentences, or forced-choice questions: '***I suggest to you...***' / '***You like living at X house don't you***'
- **Rephrase:** *'Do you want to live at X, Y or somewhere else?'*
- **Avoid 'why'** questions which usually require complex reasoning
- **Limit & alternate closed questions** to monitor understanding & reduce acquiescence
- **Be aware of your power** (re: NVC & assertions as an authority figure)



# PREPARING FOR COURT



**A Social Story for Court**

<b>3</b>	I need to stop for a break now so you need to stop for a little while.
<b>2</b>	It's getting hard to think and concentrate. Please slow down.
<b>1</b>	I'm OK and can carry on.

**Anxiety Scale**

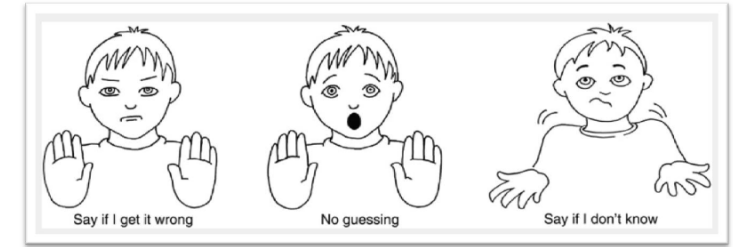
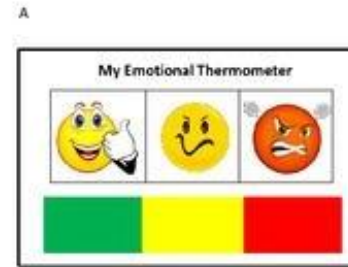
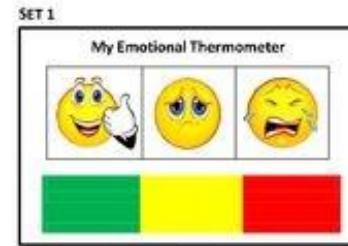


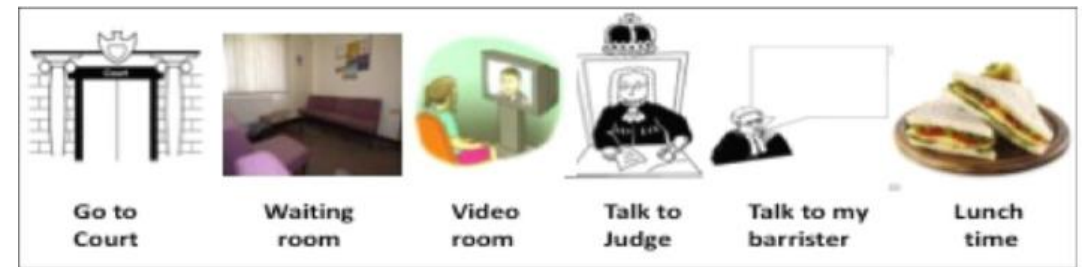
Figure 6. Rule cards with symbols.

<b>Yes</b>	I don't know	I don't understand	What do you mean? Please explain	Please ask that question again	<b>No</b>
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Figure 7. Rules presented in text format.



**Advocate's Gateway: Courtroom Model**



**Advocate's Gateway: A Visual Timeline for Court**



# FROM PARTICIPATION TO SUPPORTED DECISION MAKING

Imagine for a moment that you're standing in front of a vending machine full of food

You're hungry and you know you have some change in your pocket, but you don't know how to count it. How do you decide what to do?

You could start putting money in the machine and pressing buttons until something falls out

You could also just give all your money to someone else and hope they buy you something

Neither option is likely to get you what you want.....

([supportmydecision.org](http://supportmydecision.org))



# FROM PARTICIPATION TO SUPPORTED DECISION MAKING

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences

Preferences can be built up into expressions of choice and these into formal decisions

From this perspective, where someone lands on a continuum of capacity ***is not half as important as the amount and type of support they get to build preferences into choices***

(Beamer & Brookes, 2001 p.4)



# FROM PARTICIPATION TO SUPPORTED DECISION MAKING

Most of us seek support in our decision making from time to time – regardless of mental capacity - autonomy is exercised socially, not just individually:

- ✓ The **person** is the lynchpin
- ✓ Prior communication **detective work is key**
- ✓ **Learn who the person is** – not diagnosis, but their uniqueness & world view (goals, values, preferences)
- ✓ What is **important *to*** the person, as well as **important *for*** them
- ✓ Identify **what support the P wants** / needs for each specific decision - this is not concrete or global
- ✓ Give as little or as much support as required – **‘competency’ is attached to the SDM process, not the person**
- ✓ Harness the person’s **strengths**
- ✓ Engage in **positive risk taking**
- ✓ Consistent, trusting **relationships** are key- engage family / others as appropriate
- ✓ **Establish a person-led ‘board of directors’ / ‘circle of support’ around the person to assist their decision making**
- ✓ The group should know the person well & be able to communicate with them successfully > cumulative effect
- ✓ The aim is to help the P gather, understand & consider the relevant information, assist them to weigh the pros & cons of available options & predict the likely consequences & outcomes



# BARRIERS TO SUPPORTED DECISION MAKING

- **Diagnostic overshadowing** and / or lack of capacity = a best interest determination, not supported decision making
- SDM can be manipulated as a way of **advancing others interests**
- **Conflicts of interest** (e.g. providers of care packages)
- Invasive supporters **taking over** / falling into best interest decision making
- Overlooking the **least restrictive** principle
- Plagued by an innate desire to **standardise everything**
- The elephants in the room: **safeguarding, protection, risk & harm** can overshadow balanced thinking
- Tendency to apply a **higher threshold to others** than ourselves
- Failure to discuss & debate **risk** with P & balance risk aversion with empowerment & supported decision making
- **CRPD** - where significant efforts have been made to work this out, but have been unsuccessful then a '**best interpretation**' *of that person's will and preferences should be used*
- But what about '**hard cases**', e.g., coma, self harm, suicidal ideation? These are not straightforward...



# TIPS FROM PRACTICE...

- ✓ **Diagnosis** – does this help plan communication with P?
- ✓ **Reflexivity:** how have others constructed P & their family?
- ✓ **My values:** humanity; AOP; *everyone* has potential; what have I got to lose by trying?
- ✓ **Who** is this person? – This is my starting point
- ✓ What does the **bundle** say about P's communication? Is there a SALT report & has it been implemented?
- ✓ If P has significant communication needs – can I meet the person / get to know them prior to the assessment / speak to others who know them well & can advise – this is crucial
- ✓ **Immerse myself** in P's context & their communication
- ✓ **I'm primarily verbal, but is P?** If not, how can I adjust my approach? (*NVC, paralanguage / body language*)
- ✓ Facilitated person centred participation is vital – are bespoke communication aids required? Be creative!
- ✓ **It's easier to speak than listen**

- ✓ **Plan** the assessment (*where / when / with whom / how long / breaks / format / address P's specific communication needs / pre-prepare resources & the associated engagement strategy (LoI)/ allow for contingencies / arrange & brief the note taker*)
- ✓ **What does P want to convey?** What do they want the Court to know?
- ✓ Pause, reflect, tweak, repeat, revisit if necessary
- ✓ **Professionals often think others are doing this work as part of the Court process, but are they?**
- ✓ **Consult others** re: the matter for the Court *after* the assessment with P (*in person if possible*)
- ✓ The more person centred the approach, the more likely it is to work, but there are no guarantees & its not always successful
- ✓ **However, even rubbish art can be transformational re: participation & supported decision making: For example...**

# LBX... missed opportunities

**LBX v K, L and M [2012] EWHC 439 (Fam), [2012] MHLO 185:** *'L is borderline capacity* re: residence, care & contact...the court must seriously consider steps that would enable him to either regain capacity, or enable him to make informed choices and decisions'

**LBX v K, L, M [2013] EWHC 3230 (Fam)**

Assessment of capacity by a psychiatrist = lacks capacity re: residence, care & contact

Best interests assessment by moi = analysis of wishes & feelings = further questions about L's capacity

## Key issues:

- ✓ Not imposing too high a test of capacity
- ✓ Need for clarity on what is the 'relevant information' for specific decisions
- ✓ The importance of using tangible resources, like drawings & pictures, to assess & improve the person's level of understanding
- ✓ Re-assessment of L's capacity was requested for residence, care & contact

**LBX v K, L and M [2013] EWHC 4170 (Fam), [2013] MHLO 149:** *'In the judgment I handed down this morning I concluded that L has capacity in relation to decisions about where he should live, the care he receives and contact with his family'*

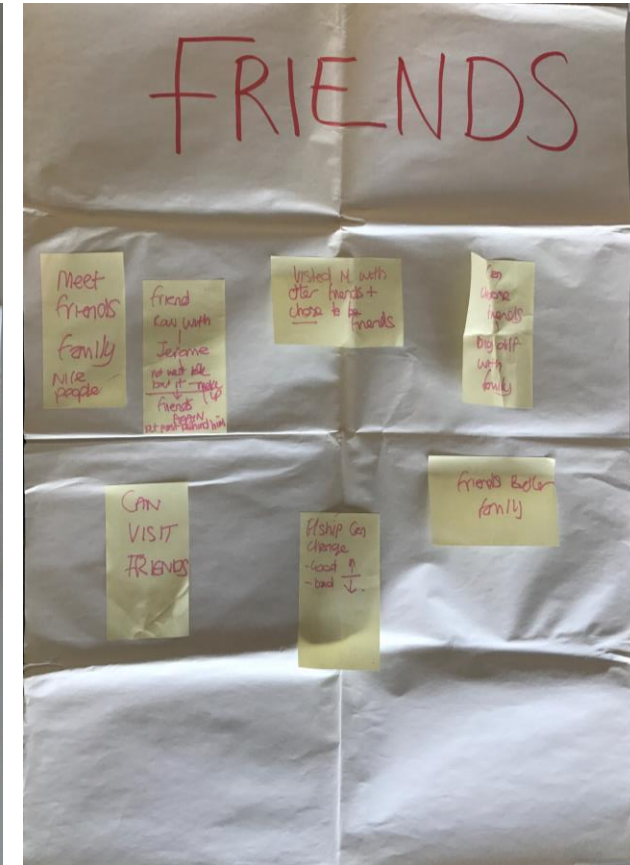
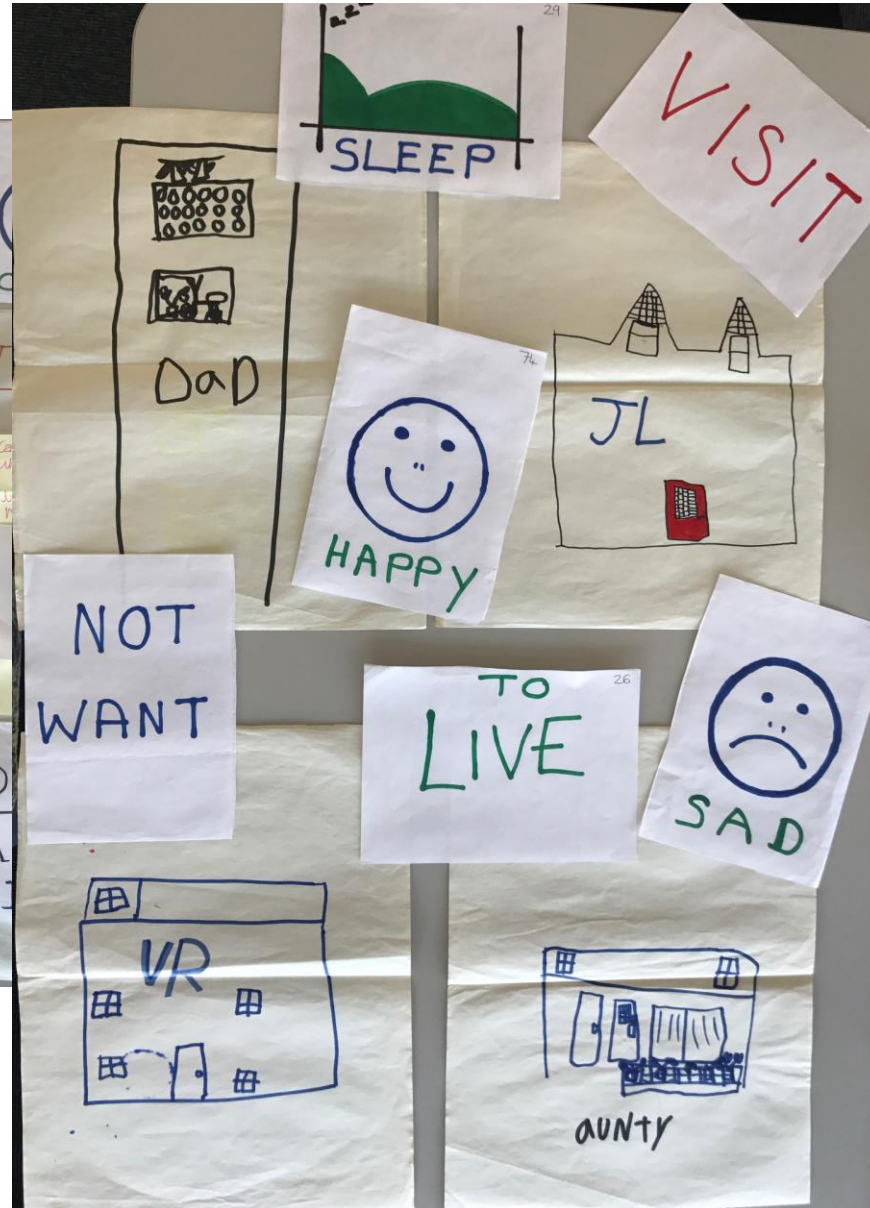
- ✓ Careful, person-centred application of P.2 MCA can enable some with borderline capacity to regain it = autonomy
- ✓ **BUT:** concern there needs to be *'a proportionate structure in place that enables L to maintain his capacity in a relatively calm environment, free from the emotional maelstrom, resulting from the relationship he has with his father'*

**Re L: K v LBX [2016] EWHC 2607 (Fam), [2016] MHLO 47:** Challenge by K re: L's capacity

- ✓ There is no evidence that L's capacity has changed...



# MY RESOURCES... SIGNIFICANT PREPARATION INVOLVED!!



## A 4-Pronged Approach:

1. **Verbal communication** (*aided by*)
  2. **Personalised visual prompts** – shared understanding assessed & confirmed (*aided by*)
  3. **L's lived experience** (*aided by*)
  4. **'Let's pretend' scenarios**
- ✓ L's expressive speech was clear & understandable
  - ✓ His response to Q's was coherent across all 4 approaches
  - ✓ Content was consistent & congruent, **despite** the significant potential for inconsistent thinking
  - ✓ Helped by the lengthy, recapping nature of the assessment (over 3 days) – 100% consistency!

**LBX v K, L, M [2013] EWHC 3230 (Fam): Best Ints**

**LBX v K, L, M [2013] EWHC 3230 (Fam): Capacity**



# ADDITIONAL RESOURCES

- ✓ The **person** & their skills
- ✓ **Others** who know P well (family / advocacy)
- ✓ Specialist advice (SALT's & intermediary's)
- ✓ **You** & your skills & commitment
- ✓ **Your** relationship with P
- ✓ Pens / paper / post-its / pictures / photos / google earth / IT / creativity & no embarrassment
- ✓ The advocate's Gateway
- ✓ *A County Council v (1) AB (2) JB (3) SB [2016] EWCOP 41* / LBX case & similar case law
- ✓ *Case study written by Nicola Mackintosh QC (Hon):*  
<https://courtofprotectionhandbook.com/2016/09/30/guest-post-facilitating-participation-of-p-in-court-of-protection-proceedings/>

