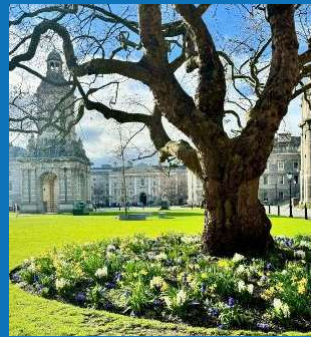




Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



SETTING THE SCENE: CHILDREN'S PARTICIPATION IN HEALTHCARE DECISIONS.

- Professor Imelda Coyne
- Professor in Children's Nursing & Director of Trinity Research in Childhood Centre

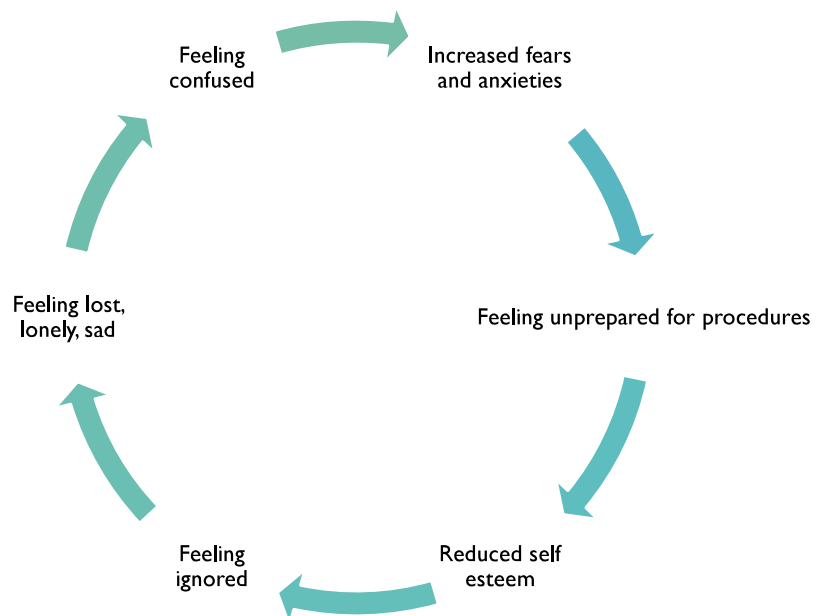
WHAT ARE THE BENEFITS FOR CHILDREN ?

- Enhanced understanding & satisfaction
- Feeling valued
- Decreased fears and anxieties
- Increased cooperation & adherence
- Increased trust
- Increased locus of control and decision-making ability



LACK OF PARTICIPATION

Yea I feel real disappointed because ...I feel like I'm kind of rejected in a way (Boy, 13yr)



Are children involved in healthcare decisions?

- Children are not routinely included in decisions
- Healthcare professionals and parents have a strong influence on children's opportunities to participate.
- Healthcare staff and parents need advice/guidance on how to facilitate and support children's participation

WHAT ARE THE BARRIERS ?

- Time
- Child's capacity
- Communication skills
- Approach/interactions
- Child's age & health
- Parents/carers

*I do think we as a team force a lot on the kids and whether we use different words or options a lot of **the decision is with us. It's either the parent or it's the team.** Very rarely it seems to be the kid (Professional).*

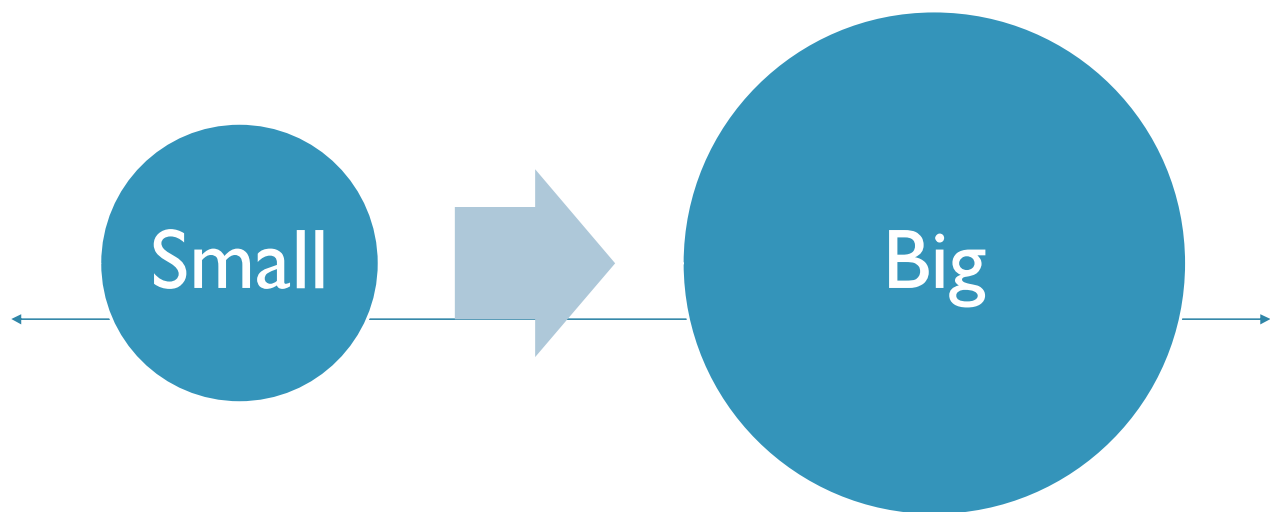
Boland, L et al 2019. Barriers and facilitators of pediatric shared decision-making: a systematic review. Implement Science 14 (1), 7.

What are the barriers from parents' perspectives?

- Doubts about involving their child
- Need to protect
- Parents' decisional authority/uncertainty



- *I don't want to worry him too much by giving him the responsibility of being part of decisions especially when at the end of the day you still need the treatment. We shouldn't be forcing children to be involved in decisions we are the adults, we are here to protect them and to give them the best possible care.*



Coyne, I et al 2014. Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences. *Eur J Oncol Nurs* 18 (3), 273-280.

Children's experiences



I usually don't like making big decisions because I don't really feel like it's my place



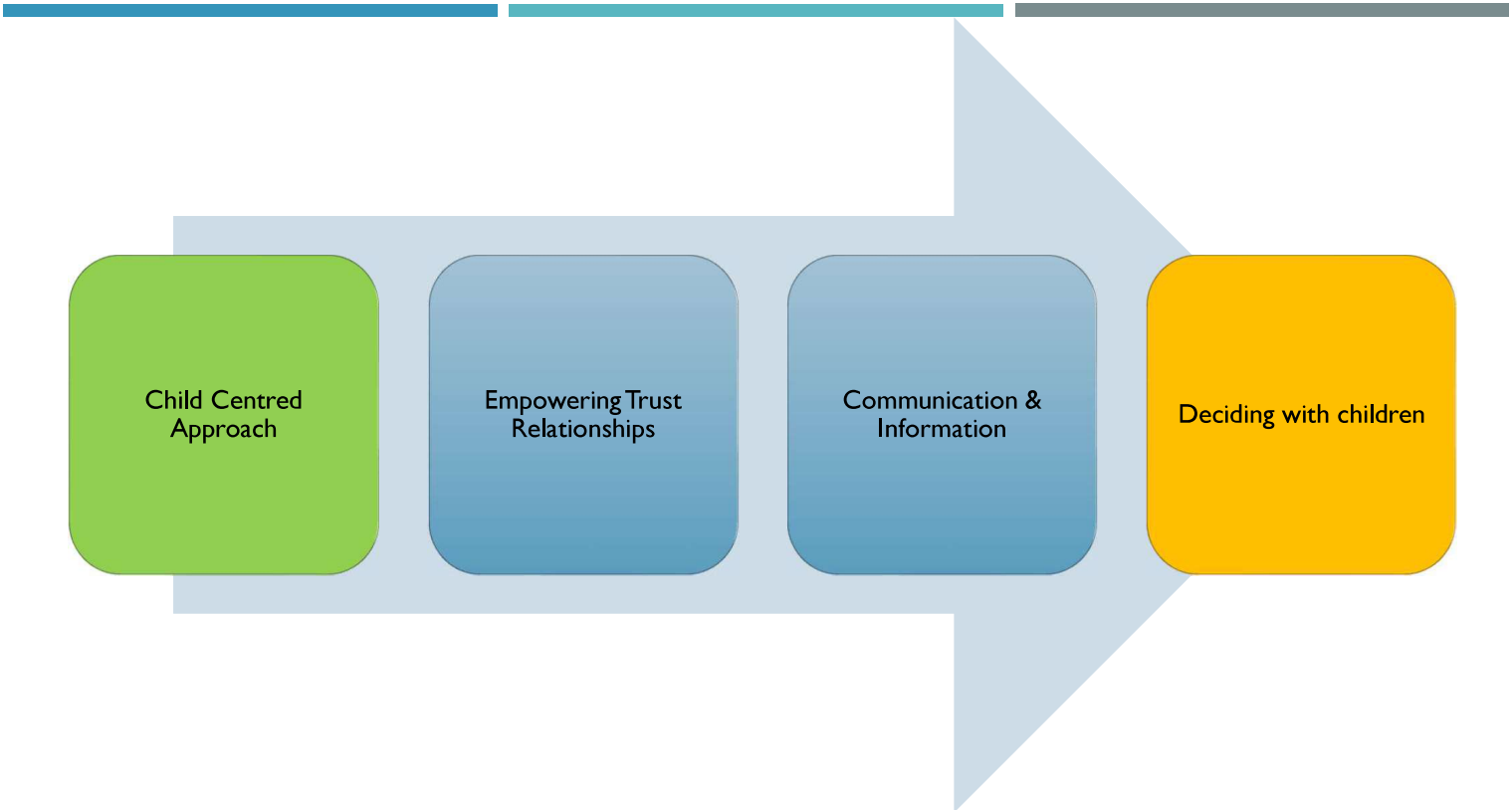
Doctor should explain things to you in a way that you'll understand....instead of using words you don't understand



My wish would be for doctors not to get annoyed with children asking questions because they just want to know what's going to happen to them

NO DECISION ABOUT ME, WITHOUT ME





SUMMARY

- Children need space, time, opportunities, support, information, explanations...
- Decision-making should be seen on a continuum rather than an 'all or nothing' approach.
- Multiple levels and ways to support children's participation in process of decision-making
- Adults need to adopt an individualised flexible approach so that children can have an active, shared or passive role as and when they prefer.



-for listening

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