

Hearing Their Voices: Exploring Children's Perspectives and Enhancing Communication in Pediatric Visits



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Presentation overview:

Part 1: background:

1. Listening as a process of meanings construction
2. The social construction of reality
3. International Legal Framework for Children's participation in Decision-Making Processes
4. Advantages of listening and including children in health care decisions

Presentation overview:

Part 2: two researches on children participation in health care

1. Children's Experiences of Visiting their Pediatrician
2. Improving communication during a visit



Presentation overview:

Part 3: practical tools to enhance children participation



Background



Background: Listening



How many languages
do you know?

100 Languages of the child

The child has
a hundred languages.

a hundred hands,
a hundred thoughts,
a hundred ways of thinking,
of playing, of speaking.

A hundred, always a
hundred,
ways of listening,
of marveling, of loving

a hundred joys,
for singing and
understanding

a hundred worlds
to discover,
a hundred worlds
to invent,
a hundred worlds
to dream.

The child has
a hundred languages
(and a hundred hundred
hundred more).

But they steal ninety-nine.

Background: Listening



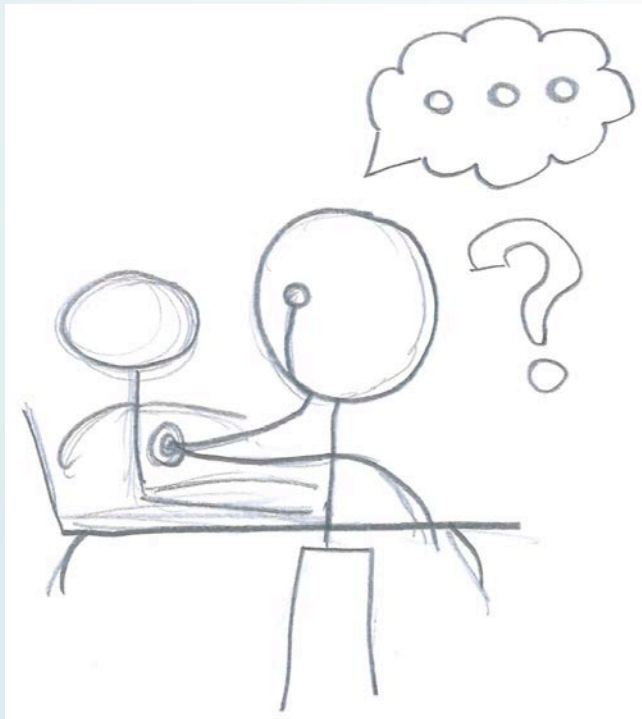
- Active process of communication;
- Involves hearing, interpreting and **constructing meanings**;
- A necessary stage in children's participation;

(Clark, 2006)

- Not limited to the *spoken* world.
- Not limited to the *here and now*.

Listening

- Listening is dynamic process which involves children and adults discussing meanings.



- **Whose meanings?**

Constructing



Credits: blog.apaonline.org/2017/01/19/young-philosophers-of-new-york-interview-with-joseph-s-biehl

- Meanings do not pre-exists.
- They are co-costructed via the relationships with others.
- Meanings are the results of a dialectic encounters.

(Bruner, 1987)

Two approaches to knowledge

I know that I know approach

Biomedical

- Practitioners are experts.
- Children lack specific medical knowledge.
- Children need to be taught about their health by experts.
- Expert tell and teach; children listen and learn.

I know that I don't know approach

Biopsychosocial

- Patients are experts of their lives.
- Patients have their own specific system of meanings, ideas, feelings.
- Practitioners do not know which of the 100 languages the child is speaking.
- Reality is constructed through dialogue.

UN Convention on the Rights of the Child

Establishes the principle that children and young people **are capable** of forming their own views, **have the right** to express those views, and are entitled to **have those views taken seriously** (1989)

As of 2024: Ratified by 196 Parties
(all those eligible, except the United States)

UN Convention on the Rights of the Child



UN Convention on the Rights of the Child

**I have rights,
you have rights,
he/she has rights ...**

All children have the same rights:

- * *the right to a family and to protection of their privacy*
- * *the right to an identity: a name and nationality*
- * *the right to water, a balanced diet and to the best health care possible*
- * *the right to housing and to a healthy environment*
- * *the right to education, leisure and culture*
- * *the right, for those who are disabled, to receive help so that they can live with others while becoming as independent as possible*
- * *the right to speak out, to be heard and to have their opinion taken into account*
- * *the right to get together, to secure and share information, to speak their mother tongue and to practise their religion*
- * *the right to be protected against discrimination, war and all forms of violence and exploitation*
- * *the right to a child-friendly justice system*
- * *the right to the protection of their interests in all decisions concerning them*



Advantages of including children in health care decisions

- **Better treatment:** More effective treatment plans and better adherence to medical advice (Coyne, 2006).
- **Empowerment and autonomy:** take an active role in managing their well-being and fosters a sense of autonomy (Boggis, 2011).

Advantages of including children in health care decisions

- **Enhanced trust and communication:** we need to give children the same trust we expect from them.
- **Better mental and emotional well-being:** can positively impact a child's self-esteem, mental health, and overall emotional well-being (Bray, Appleton, & Sharpe, 2019).

To recap:

1. Listening as a process of meanings construction
2. The social construction of reality
3. International Legal Framework for Children's participation in Decision-Making Processes
4. Advantages of listening and including children in health care decisions

Research 1



Children's Experiences of Visiting their Pediatrician

- **Aim:** to retrospectively investigate various factors related to the portrayal of a typical visit to the pediatrician, as recounted by children.
- **Instrument:** A workbook asking children to recall their last visit to their family pediatrician, containing questions and graphic-eliciting activities focused on narrating roles, actions, communication, and emotions.

Children's Experiences of Visiting their Pediatrician

- **Context:** April and May 2022 in the Umbria region in Italy. Children aged 8-9, 10-11, and 12-13 years old.
- **Participants:** 350 children (50.75% female, age range 8-13 years, $M_{age} = 10.5$, $SD = 5.93$).
- **Analysis:** quantitative content analysis, chi-square analysis to determine differences in responses occurrences between gender and between school-level groups.

Q1: What do you do during the visit?

| Code | Total (%) | M (48%) | F (52%) | Sample narrative |
|-------------------------------|-----------------|-----------------|-----------------|--|
| Child Passive behavior | 307 (93.03%) | 148 (91.36%) | 159 (90.86%) | <i>I do what the doctor asks me to, and I try to stand still (11y m)</i> |
| Talk with the doctor | 26 (7.88%) | 11 (6.79%) | 15 (8.57%) | <i>I tell him about my football match (8y m)</i> |
| Negative emotion | 19 (5.76%) | 10 (6.17%) | 9 (5.14%) | <i>I am worried she could hurt me (8y f)</i> |
| Other | 9 (2.42) | 4 (2.47%) | 5 (2.86%) | |

N = 330. No significant differences between gender and school grades.

Q2: What does the person who accompanies you do during the visit?

| Code | Total (%) | M (48%) | F (52%) | Sample narrative |
|------------------------------------|--------------|--------------|--------------|--|
| Passive behavior | 228 (69.01%) | 111 (69.37%) | 117 (68.82%) | <i>She looks at me and listens to what the pediatrician is saying” (8y f) My mom looks at her phone while I wait (8y m).</i> |
| Supports the child | 72 (21.82%) | 33 (20.62%) | 39 (22.94%) | <i>My father stays close to me and encourages me (8y f) My mother reads me a story while we wait (7y m).</i> |
| Communicates with the pediatrician | 38 (11.51%) | 17 (10.63%) | 21 (12.35%) | <i>My mother explains my symptoms to the doctor</i> |
| Other | 13 (3.94%) | 5 (3.12%) | 7 (4.11%) | |

N = 330. No significant differences between gender and school grades.

Q3: When the pediatrician needs to explain something about your health, who do they talk to?

| Code | Total (%) | M (48%) | F (52%) | Sample narrative |
|------------------|-----------------|-----------------|-----------------|--|
| To the caregiver | 306 (92.44%) | 150 (92.03%) | 156 (92.85%) | <i>He usually tells my dad, and when it comes to medication, he writes it on a piece of paper, and he also writes down the disease I have (11y m).</i> |
| To the patient | 86 (25.99%) | 38 (23.32%) | 47 (27.97%) | <i>First she talks to my mother, then she explains it to me (10y f).</i> |
| Other | 1 (0.30%) | 1 (0.61%) | 0 | |

*N = 331. No significant differences between gender; **39.72% of middle school children felt included during the explanations, while only 21.70% of primary school children felt the same (p = 0.019).***

Reasons for enjoying visits with your doctor

| Code | Total (%) | M (48%) | F (52%) | Sample narrative |
|--------------------------------|--------------|-------------|-------------|---|
| The doctor puts you at ease | 100 (68.97%) | 42 (65.62%) | 58 (71.60%) | <i>She is very nice and kind, and if you don't feel well, she lifts your spirits (11y m). The doctor's welcome makes my anxiety vanish 10y f.</i> |
| Welcoming environment | 29 (20%) | 11 (17.18%) | 18 (22.22%) | <i>The waiting room is welcoming" (13y f) The waiting room is full of colors, games, books, and children to play with (10y f).</i> |
| Positive behavioral reward | 16 (11.03%) | 7 (10.94%) | 9 (11.11%) | <i>The pediatrician is so kind, and at the end, she gives you a sweet (11y m).</i> |
| Open communication with doctor | 9 (6.21%) | 3 (4.69%) | 6 (7.40%) | <i>She listens and is sincere (12y m). You can speak freely with the pediatrician (11y f).</i> |
| No pain or discomfort | 8 (5.52%) | 4 (6.25%) | 4 (4.93%) | <i>He does not hurt when he does the check-up (11y m)</i> |
| Other | 19 (13.10%) | 8 (12.50%) | 11 (13.58%) | |

N = 145. No significant differences between gender and school grades.

QX: The next time you go to see your doctor, would you like a little time to talk alone with them?

| Code | Total (%) | χ^2 | p-value |
|------|--------------|----------|---------|
| Yes | 220 (62.86%) | 11.766 | < 0.001 |
| No | 130 (37.14%) | | |

N = 350. No significant differences between gender and school grades.

Research 2



Enhancing communication

- **Design:** qualitative and quantitative research, quasi experimental
- **Aims:** 1) Evaluate the efficacy of a paper-based facilitator to enhance children's questioning.
2) Investigate children's questions to their pediatrician.

Enhancing communication

- **Context:** June 2022- October 2023 in the Umbria region in Italy.
- **Participants:** 5 pediatricians (4 Female, Mean age 63, SD=3,31, 28,6 mean years of service).
- 174 children, mean age 9,8 (SD=2,10), 63,8% female. Age > 7.
- **Analysis:** quantitative content analysis, chi-square to determine differences in responses occurrences between gender.

Happy to share this and translate.
Get in touch to expand this research:
michele.capurso@unipg.it

Ciao!

Siamo i pediatri che lavorano in questo studio!



Oggi sei venuto a fare una visita da uno di noi, e più tardi ti faremo alcune domande per capire meglio come stai.



Ma sapevi che **anche tu puoi fare delle domande al tuo pediatra?**

Questa scheda serve proprio a raccogliere le domande che vorresti fare al tuo dottore!

Puoi chiedere qualsiasi cosa che riguarda il tuo corpo o la tua salute, oppure puoi raccontargli un tuo pensiero o una preoccupazione.



Non esistono domande giuste o sbagliate. In più, **se vuoi parlare con il tuo pediatra da solo**, barra la casella nella prossima pagina e lui chiederà a chi ti accompagna di uscire.

Quando sei pronto/a ad iniziare, puoi girare la pagina e scrivere le tue domande. Se non hai nulla da chiedere, lascia la scheda in bianco.

La tua età _____. Sei un: Maschio Femmina Data di oggi _____



Scrivi qui le domande per il tuo pediatra.
Non esistono domande giuste o sbagliate.
I pediatri incontrano ogni mese centinaia di bambini, bambine, ragazzi e ragazze e sono pronti ad ascoltarti senza giudicare.

Al mio pediatra vorrei chiedere: _____

Quando il pediatra leggerà e risponderà alle mie domande, vorrei:

- Parlare con il pediatra da solo/a.
 Parlare con il pediatra assieme alla persona che mi accompagna.

La scheda è finita. Puoi piegarla e consegnarla al pediatra durante la tua visita.

Participants

174 Children



Paper based

(n=108)

- Children present their questions on paper to the pediatrician.
- The pediatrician responds and keeps the form even if it is empty.

Oral communication

(n= 66)

- The pediatrician asks the child if they have any questions for him.
- He then records the questions on a website (if no questions are asked, he logs the essential personal data)

Q1: Does introducing a paper facilitator increase the number of questions a child asks the pediatrician compared to a simple verbal request from the doctor to the child?

Children who asked questions to the pediatrician by communicative mode (questions mediated by a written sheet or oral questions; N=174).

| | Total (%) | Oral (n=66) | Paper (n=108) | χ^2 | p-value |
|-------------------------------|----------------|----------------|------------------|----------|--------------|
| Asked a Question | 107 (61.5%) | 33 (50%) | 74 (68.5 %) | 5,933 | .0149 |
| Did not ask a question | 67 (38.5) | 33 (50%) | 34 (31.5) | | |

No significant differences between gender

Questions topics (children who asked a question, N=107)

| <i>Code</i> | <i>N (%)</i> | Child question to the pediatrician |
|----------------------|--------------|--|
| Health/Body | 70 (65,4%) | <i>How can I eat healthily and also why do I get a little smelly under my armpits?</i> |
| Socio-emotional | 15 (14%) | <i>I'm afraid of being poisoned. I'm scared of the visit.</i> |
| Personal question | 10 (9,3%) | <i>Do you have children? How old are you?</i> |
| Menstruation | 8 (14,8%*) | <i>Doctor, grandma and dad's girlfriend keep asking me if I'm ready to deal with my period, if mom has talked to me about it, they tell me to always be ready... I know what it is because I see mom, but I don't know if I should expect it to happen any moment, whether it will be painful, what will happen, and when do you think it will happen?</i> |
| Therapies or disease | 9 (8,4%) | <i>I still wet the bed. It makes me uncomfortable.</i> |
| Sexuality | 3 (2,8%) | <i>Is the condom a safe contraceptive? How are babies born? I have a bit of a strange question: From what age is female masturbation considered normal?" (after the explanation: Ah, I feel relieved, then I am normal.)</i> |
| Screentime | 3 (2,8%) | <i>Is it true that too much TV is bad for your health?</i> |
| Other | 9 (8,4%) | |

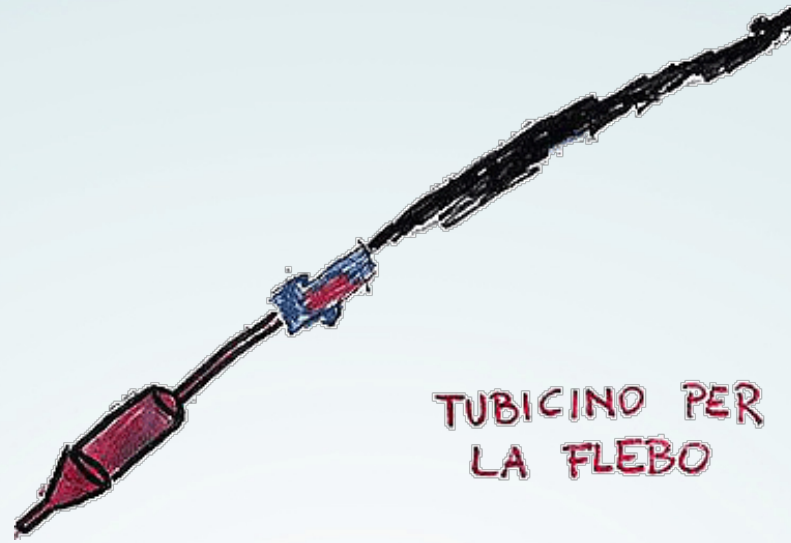
*multiple responses per question were allowed. No significant differences between gender. * female only, N=54*

Discussion and conclusion

- The reason children feel neglected during a visit is not (only) connected to the child's developmental or emotional state.
- It is (also) due to the adults attitude and to the lack of proper communication tools.



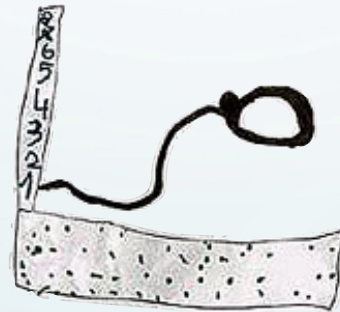
- The use of a communication facilitator improves children's questioning during a visit to their pediatrician.
- Also adults' attitude and tools can be improved...



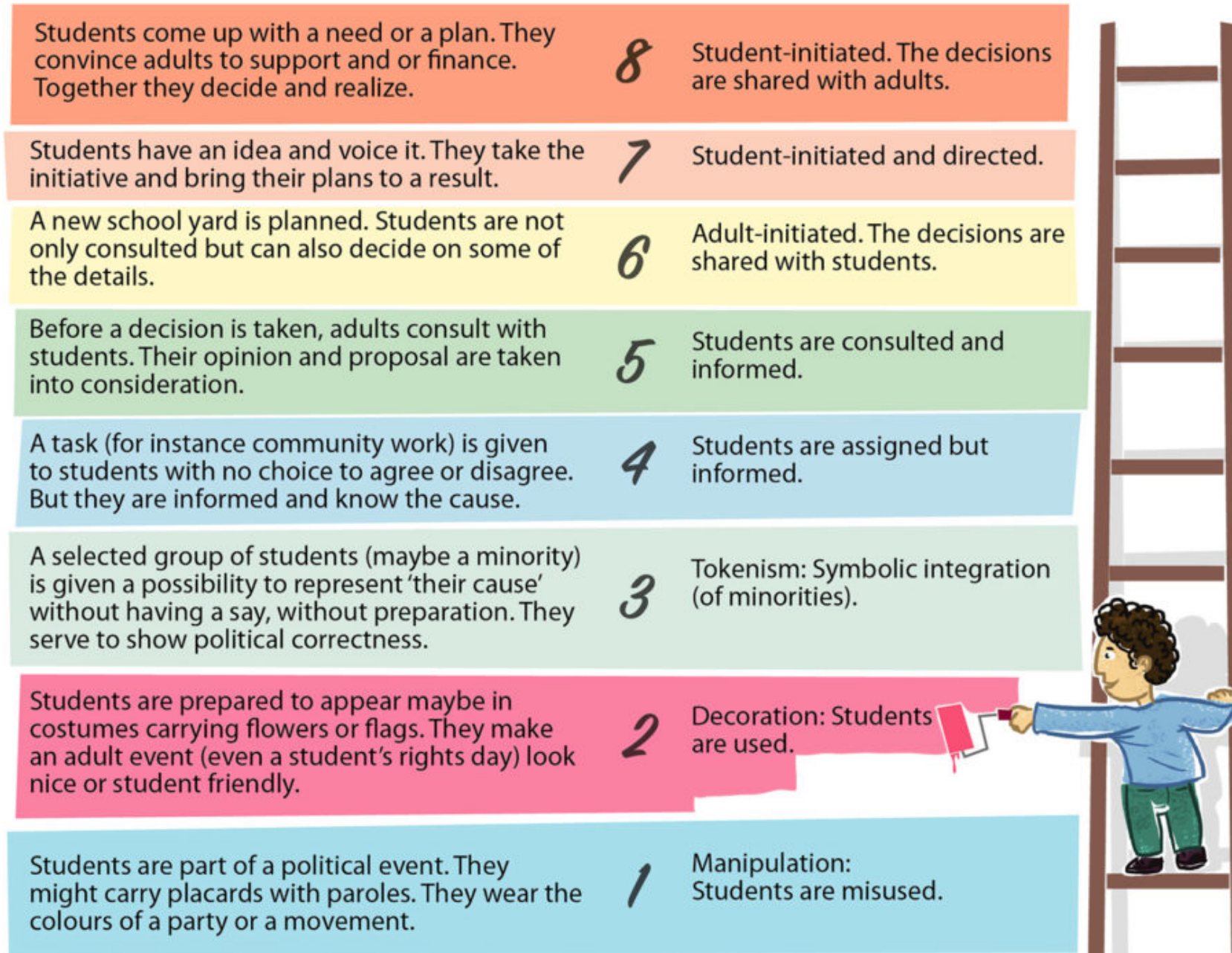
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LA FLEBO



Tools

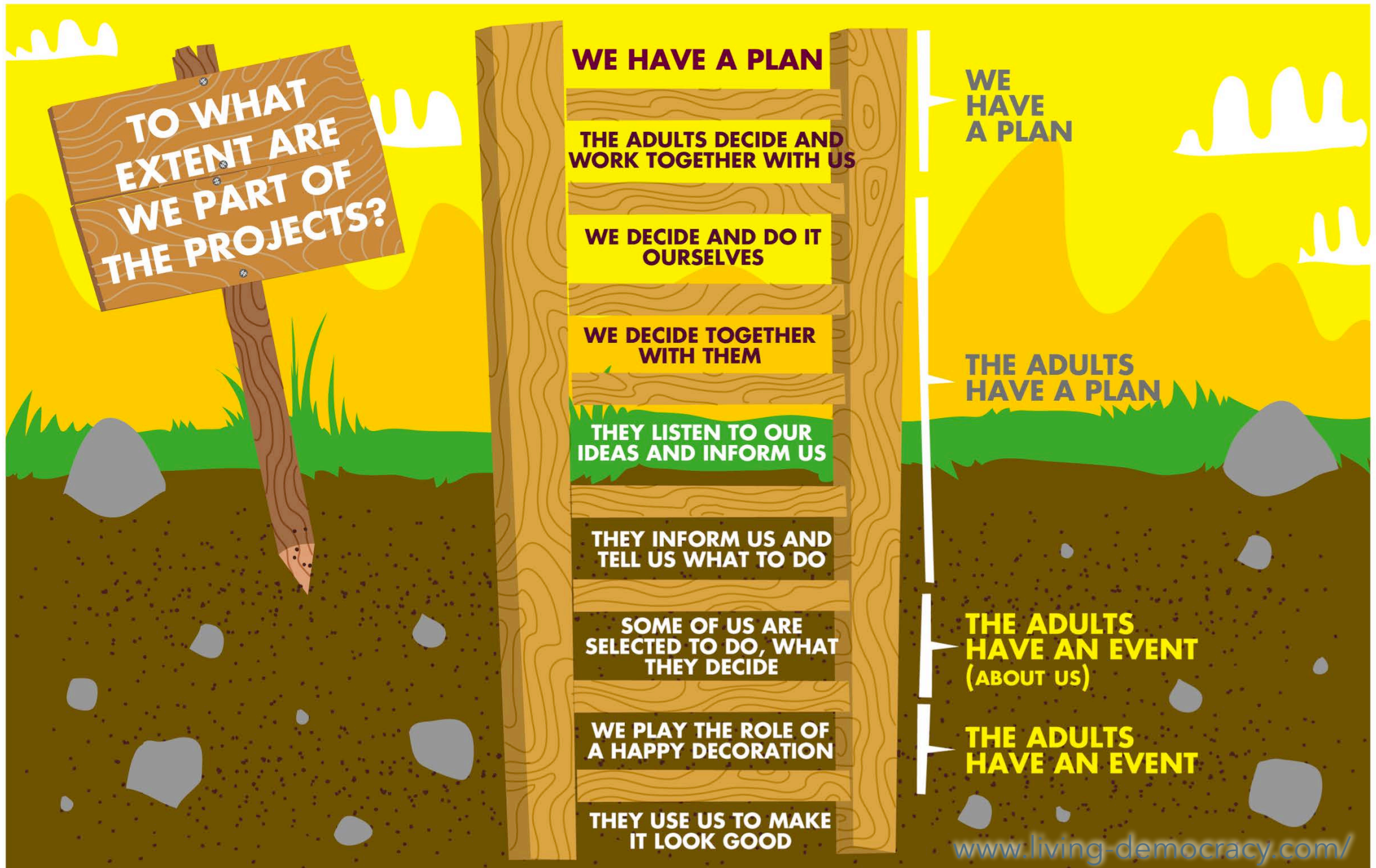


Ladder of Children's Participation



Roger Hart's

Ladder of Children's Participation



FOUR BASIC STEPS OF PARTICIPATION

WE DECIDE TOGETHER



WE PLAN AND IMPLEMENT THINGS TOGETHER



WE SHARE AND DISCUSS IDEAS



WE INFORM EACH OTHER



EU Child Participation Assessment Tool

| Protecting the right to participate | |
|---|---|
| 1 | Legal protection for children and young people's right to participate in decision-making is reflected in the national Constitution and legislation |
| 2 | Explicit inclusion of children and young people's right to participate in decision-making in a cross-sectorial national strategy to implement children's rights |
| 3 | An independent children's rights institution is in place and protected by law |
| 4 | Existence of mechanisms to enable children to exercise their right to participate safely in judicial and administrative proceedings |
| 5 | Child friendly complaints procedures are in place |
| Promoting awareness of the right to participate | |
| 6 | Children's right to participate in decision-making is embedded in pre-service training programmes for professionals working with and for children |
| 7 | Children are provided with information about their right to participate |
| Creating spaces for participation | |
| 8 | Children are represented in forums, including through their own organisations, at school, local, regional and national governance levels |
| 9 | Child-targeted feedback mechanisms on local services are in place |
| 10 | Children are supported to participate in the monitoring of the UNCRC (including in CRC shadow reporting) and relevant Council of Europe instruments and conventions |

Strengthening children participation

- <https://www.coe.int/children>
- <https://www.living-democracy.com/>
- Child Participation Assessment Tool - <https://www.coe.int/en/web/children/child-participation-assessment-tool>
- EU children's participation platform (eu-for-children.europa.eu)
- Eurochild website (www.eurochild.org)

**Take home
objective**

Holy @#%!

They listen

to us!



FRATO'02