

14th European Symposium on Congenital Anomalies

Congenital anomalies: parents' concerns and opinions towards public health policies and improved effectiveness of health services.

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BACKGROUND

The birth of a child with an unexpected diagnosis can **increase family interactions with health services** and professionals.

Evidence suggests that when **parents are engaged partners** with health care providers in decision making and **report satisfaction with the health care services** they receive, health care **costs are reduced**, and **child health outcomes improve** in this population.

Hence it is important to acknowledge what type of interactions and services parents perceived as sufficient or as lacking within the National Health Services.

Aim: describe parents perceptions of health services and public health policies in Portugal.

Target population: parents of children diagnosed with severe heart anomalies; *spina bifida*; orofacial clefts, Down syndrome and cerebral palsy.

Data collection: semi-structured online questionnaire.

Procedures: a web link to an online questionnaire was sent to focal points of 5 parents associations and professional institutions in Portugal in may 2018. Those associations then disseminated the web link to parents registered with each association.

Data analysis: thematic content analysis and descriptive analysis (frequencies).

Returned questionnaires: 254

Completed and returned questionnaires: 186 (73%)

Questionnaire returned by

Down Syndrom parents association (Pais21)



Cerebral Palsy intitutions



Others



Oral cleft association



Spina Bifida and Hydrocephalus Association



National Health Institute

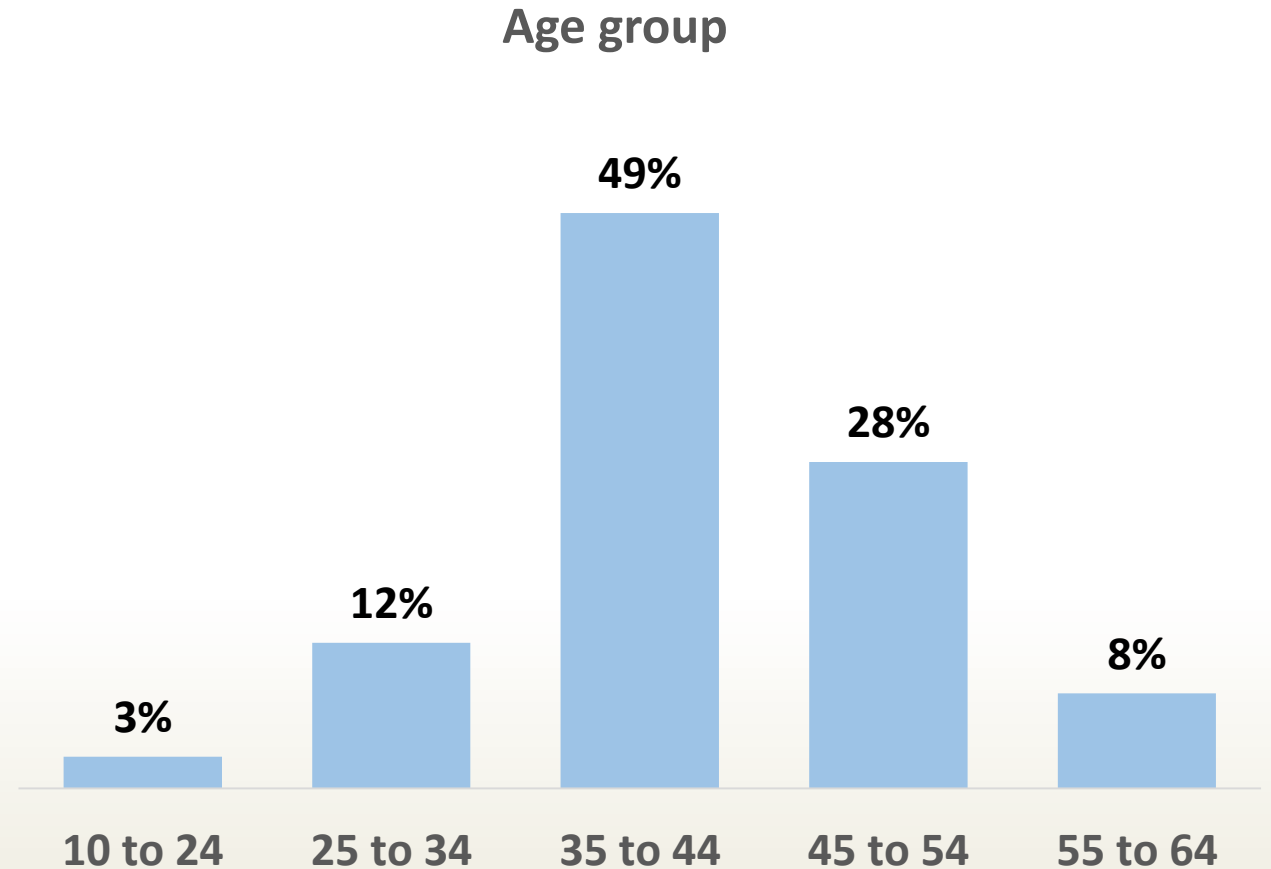


Informal social network

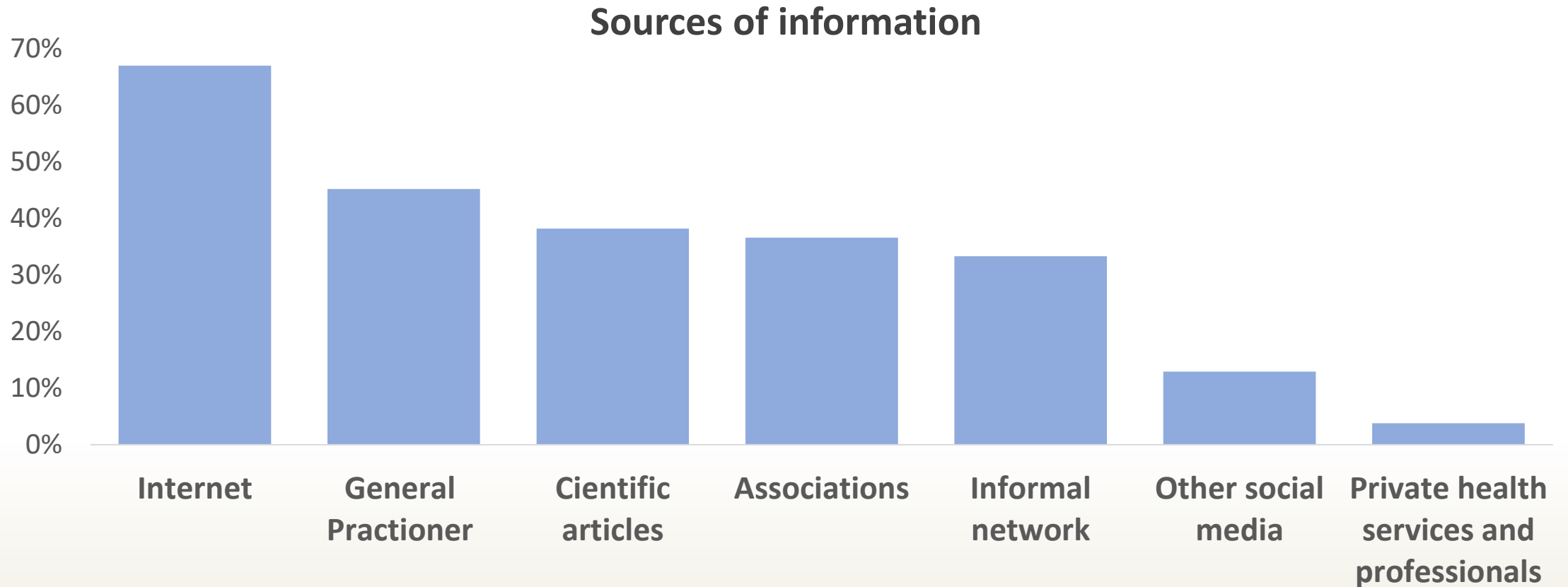


Parents who responded

- **Women (88.7%) and Men (11.3%)**
- **Married/ civil union (79.6%)**
- **Up till secondary education (12 years of schooling) (66%)**



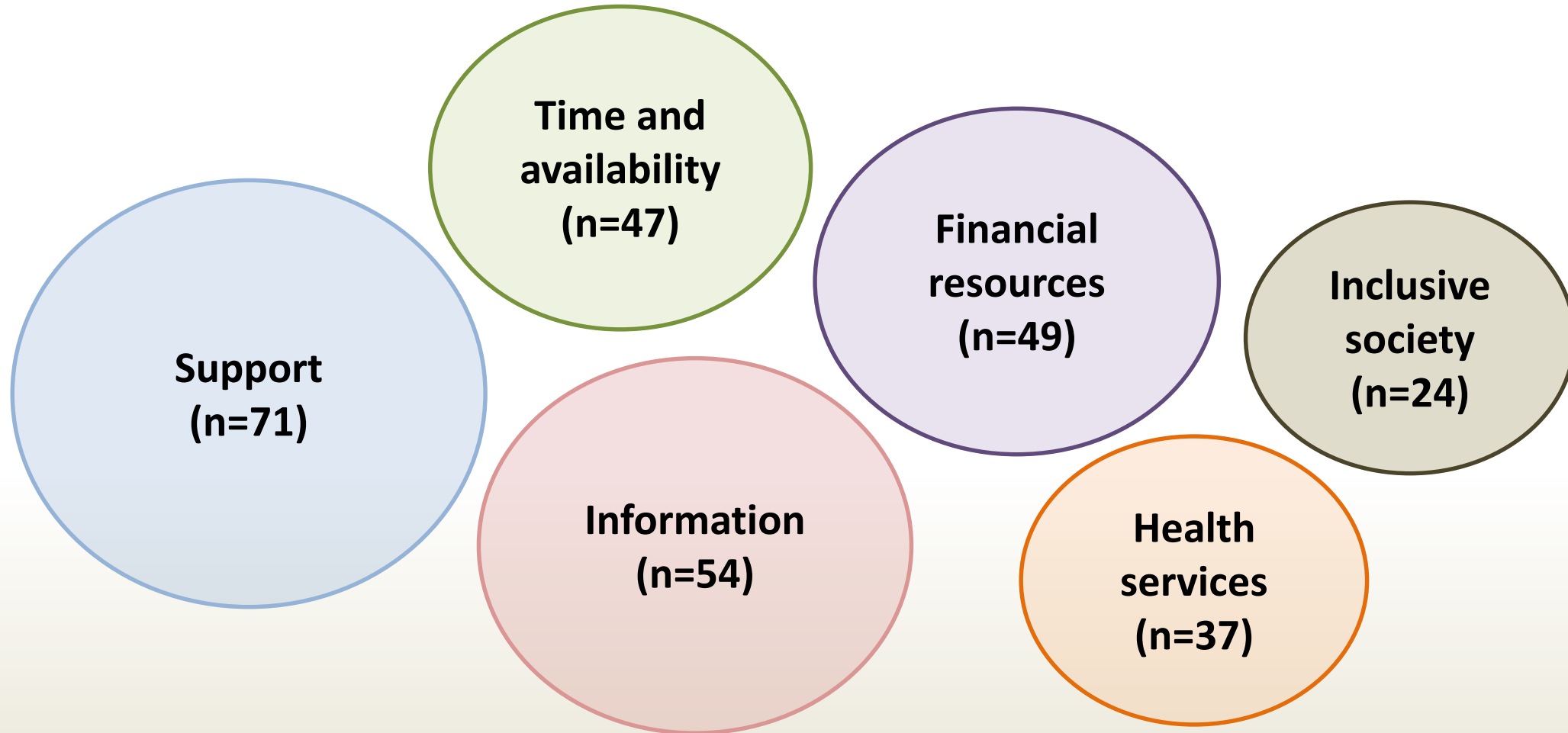
- 87.3% of parents felt they had **got insufficient information** around the time of the diagnosis
- 98.3% of parents felt the needed to **look for further information** around the time of diagnosis



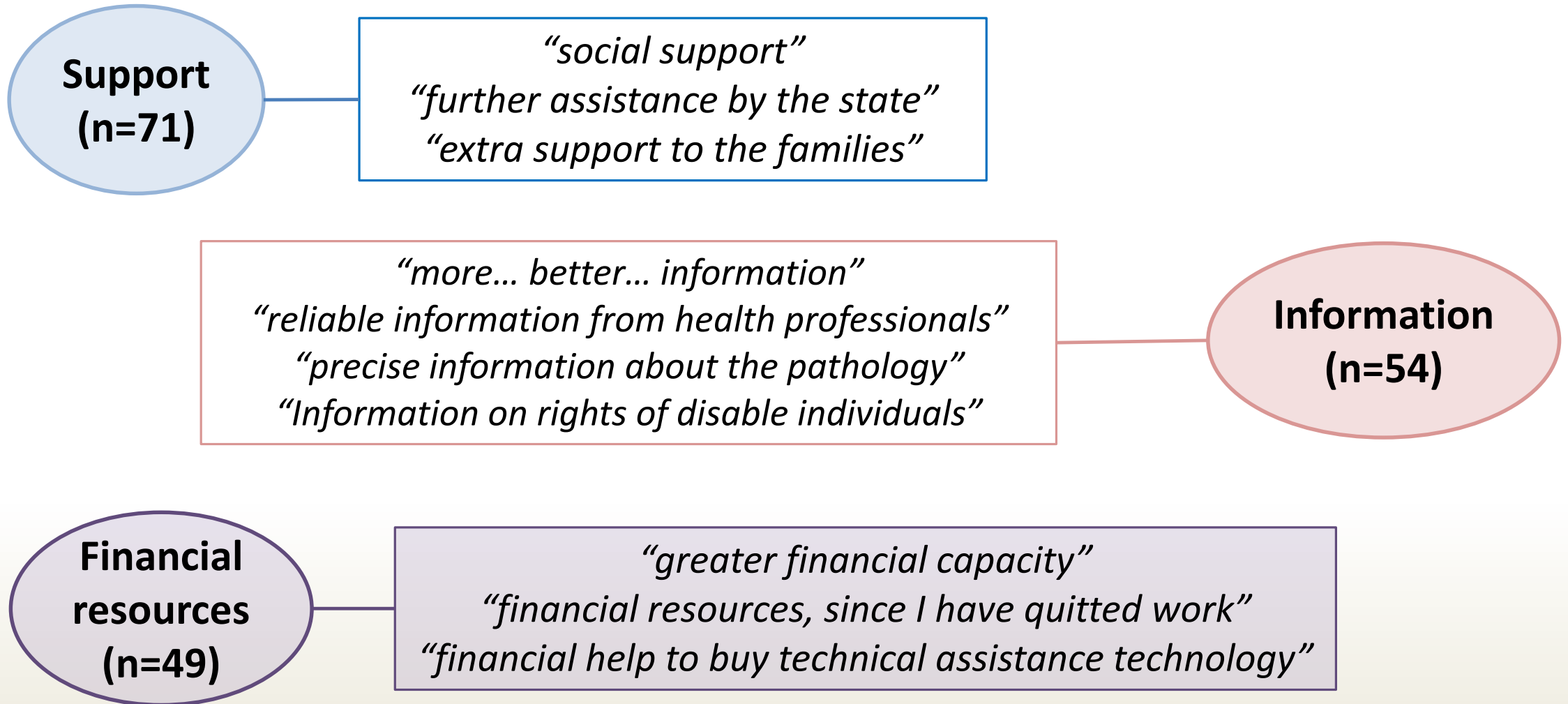
- **33.6%** found the **information to be sufficient**
- **66.6%** found the **information to be comprehensible**

What do you feel would help you to play more effectively your role as a parent?

Open response thematic units



What do you feel would help you to play more effectively your role as a parent?



What do you feel would help you to play more effectively your role as a parent?

Time and availability
(n=47)

“time to accompany my son”
“time and availability for the medical appointments and therapies”
“flexibility in my work schedule”

“more accessible and more emphatic health services, with less bureaucracy and more available schedules”
“physicians with increased know-how”

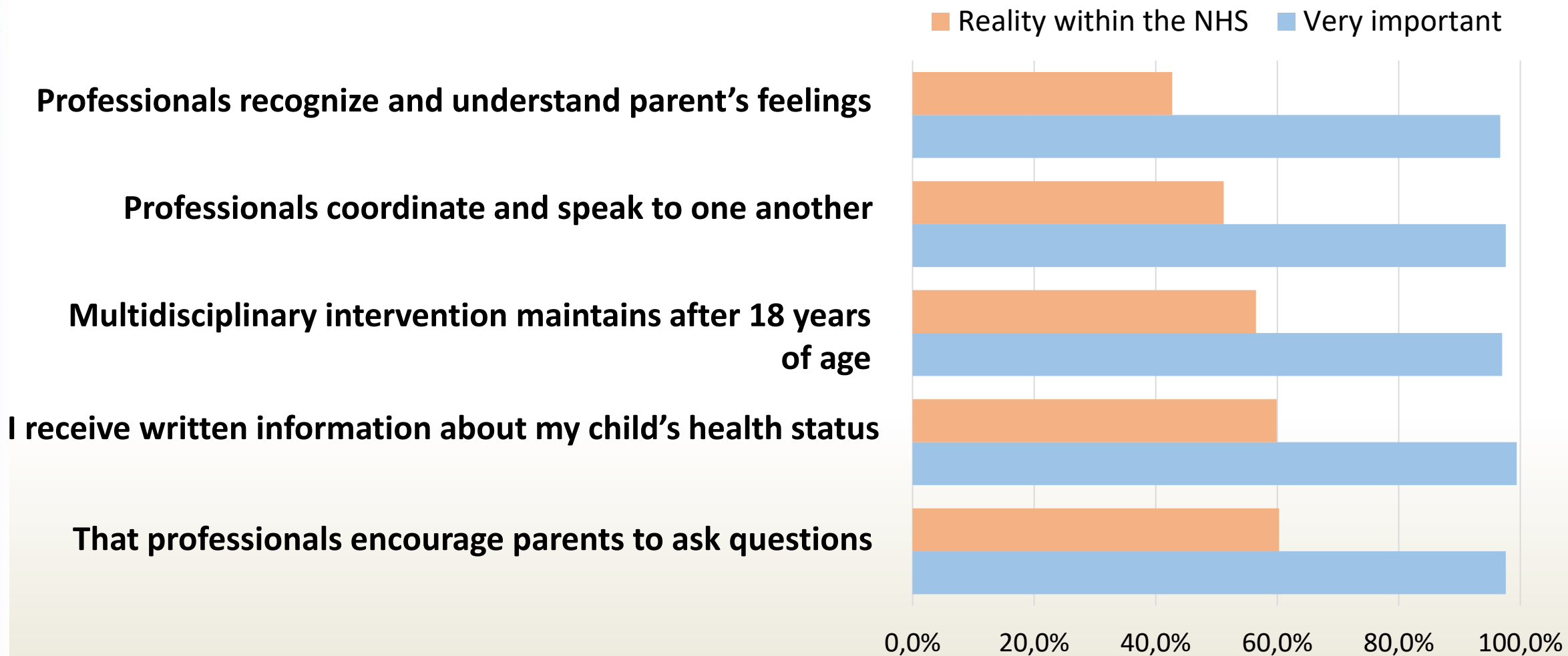
Health services
(n=37)

Inclusive society
(n=24)

“Inclusive society”
“true integration”

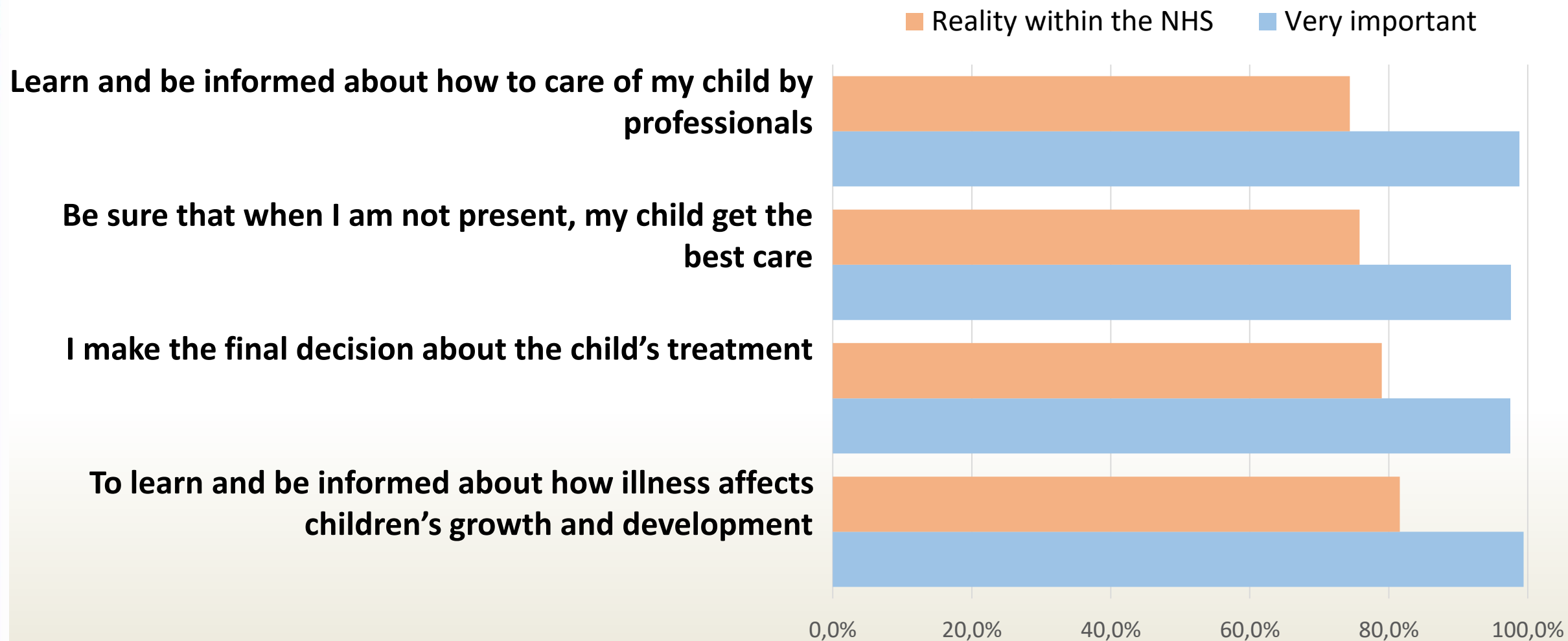
Need statements about National Health Service (NHS)

(Higher) Disparity between parents perception of importance and reality within the NHS



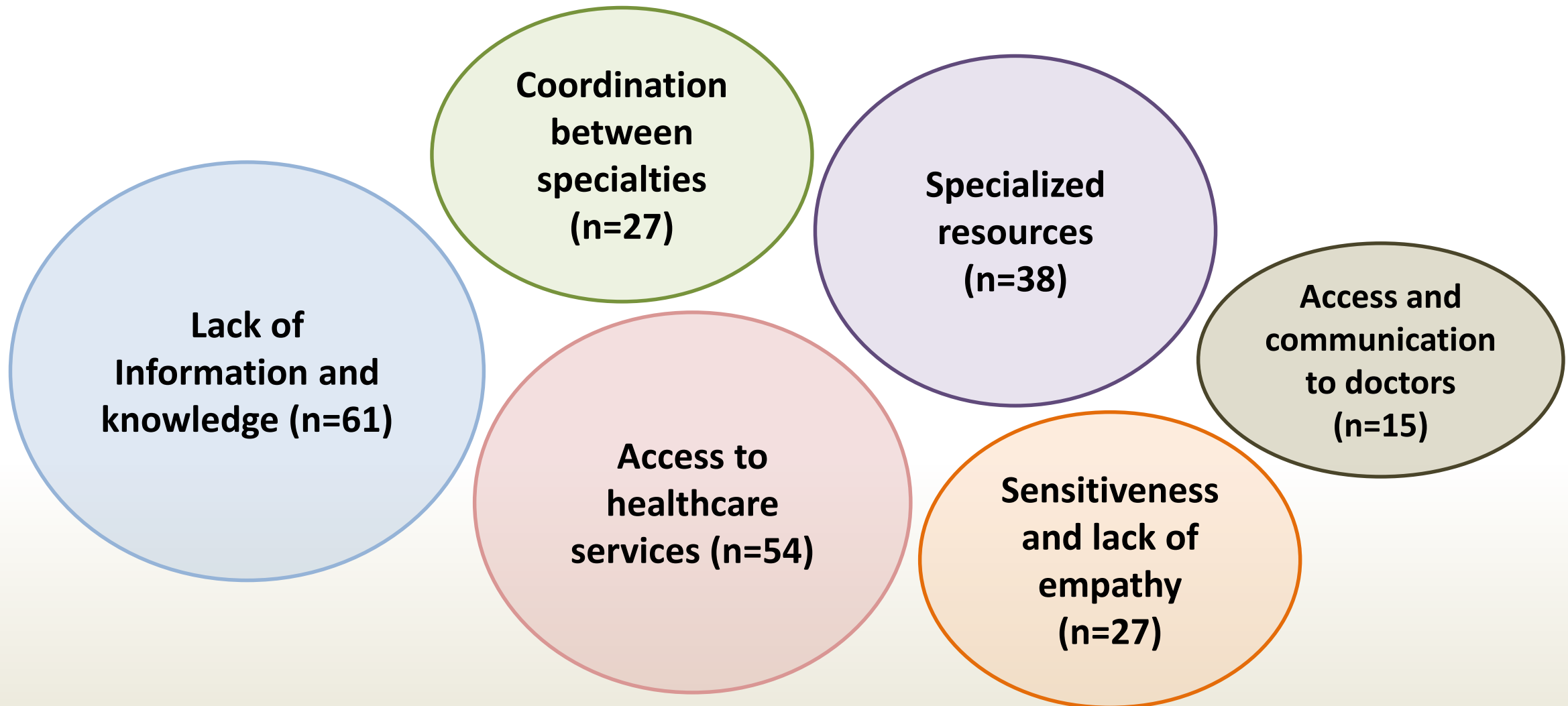
Need statements about National Health Service

(Lower) Disparity between parents perception of importance and reality within the NHS



What were the main problems when dealing with the NHS?

Open response thematic units



What were the main problems when dealing with the NHS?

**Lack of
Information
and knowledge
(n=61)**

“lack of information”

“lack of know how”

“Ignorance of the problem”

“Lack of information from clinical staff on correct referral”

“A considerable degree of ignorance of the condition”

“the long waiting period for exams and appointments”

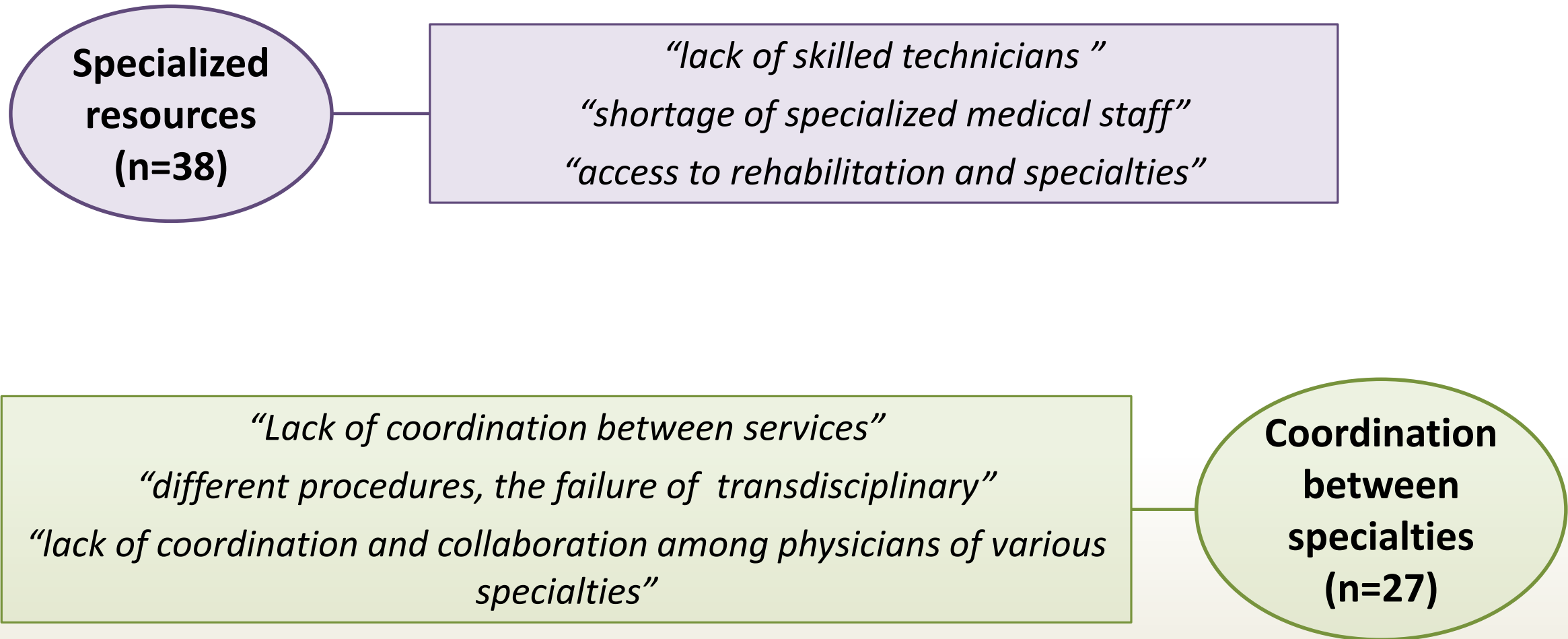
“a lot of bureaucracy”

“the fact that the specialty is to far away”

“he was referred to the hospital for a development appointment. [...] A year later we were called to the first hospital visit”

**Access to
healthcare
services
(n=54)**

What were the main problems when dealing with the NHS?



What were the main problems when dealing with the NHS?

**Sensitiveness
and lack of
empathy
(n=27)**

*“a lack of empathy towards our anxiety”
“I also find problematic the use of the term “poor baby” and
“poor little thing” by health professionals”*

*“Difficulties (sometimes total impossibility) of contact when
dealing with professionals from the NHS”
“to be able to reach physicians in critic moments”*

**Access and
communication
to doctors
(n=15)**

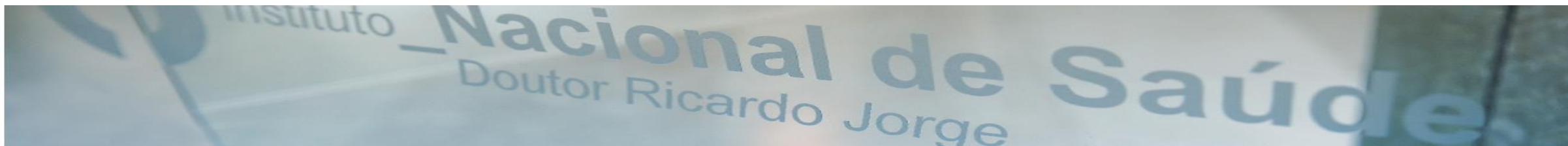
Information

- Parents perceived a lack of available information;
- Lack of adequate, reliable and precise information
- Information on the implications of treatment are however provided.

Health services can be displaced and unordered

- Parents perceived a lack of multidisciplinary interventions;
- Lack of coordination or communication between professionals and;
- There are difficulties accessing needed therapeutic interventions.

Parents felt overall confident on the health care provided and on the “training” they get from interacting with the professionals.



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Thank you for the attention

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