

ITALY – SURVEY RESULTS

HEALTHCARE PROFESSIONALS (9 questionnaires)

A – What is your professional discipline?

All our participants were **speech and language therapists**.

B – How many years of experience do you have in working with children and parents with cleft?

A – 20; B – 11; C – 9; D – 5; E – 2; F – 3; G – 2; H – 2; I – 1

Average years of experience: **6,1**

1 - Do you think that patients with cleft face particular challenges in your country? If so, what are these challenges?

All our participants answered **YES** to this question

A - Emotional difficulties related to linguistic and aesthetic aspects.

B - Difficulty of articulation – emotion difficulties related to the aesthetic factor

C – Finding quality rehabilitation services; difficulty in finding professionals with enough expertise in the treatment of the disease; distance from centers of excellence; lack of uniformity at national level in the treatment of surgical and rehabilitative aspects secondary to cleft lip and palate

D – Mainly the need to turn to reference specialists who are often far away, in other regions

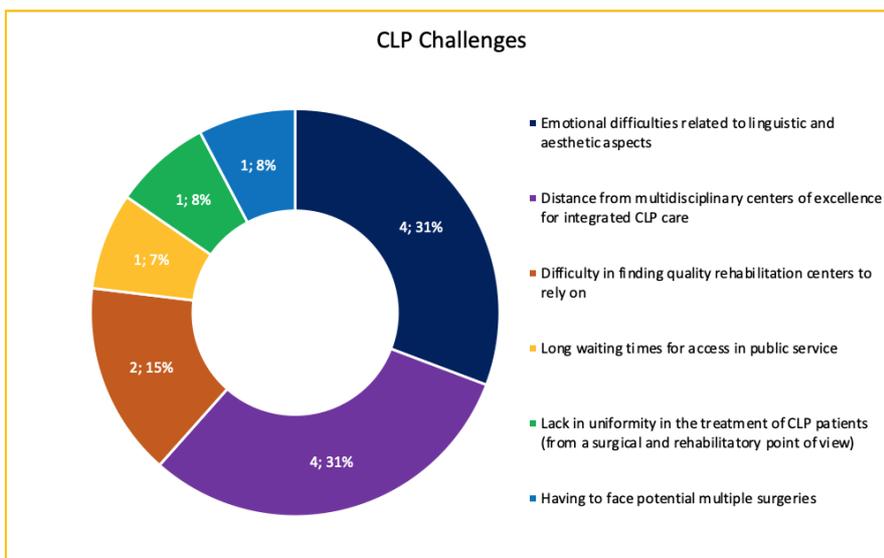
E – Finding healthcare professionals specialized in cleft lip and palate treatments near home that can take care of the kids

F – Mainly socio-relational difficulties, related to possible aesthetic and phonetic alterations

G – From a social point of view, often mockery behaviors by other children/teenagers for aesthetics or speech; from a medical point of view certainly the fact of having to face multiple surgeries

H – Difficulty in choosing the surgical protocol (not all Italian centers follow the same steps); difficulty in carrying out the speech therapy necessary for the long waiting times of the NHS; logistical difficulties for families who are not in the regions where the reference centers exist

I – The choice of the center to rely on for the child's care



(every professional gave more than one answer)

2 - Are any of the challenges for people with cleft made easier/worse for those belonging to socially disadvantaged groups (for example, immigrants; different ethnic/social backgrounds; lower socio economic status)?

Two out of nine participants answered **EASIER** while the other seven answered **WORSE**

Easier why:

A – Less expectation on the part of the environment (family and friends) with respect to performance and achievement of objectives

B – Less economic possibilities, often less choice and therefore they settle for the reference centers in their area (less environmental expectations)

Worse why:

C – Because the specific difficulties linked to the pathology could be added to socio-cultural problems and to difficulties in the access to care

D – Less support from the family in facing and resolving difficulties

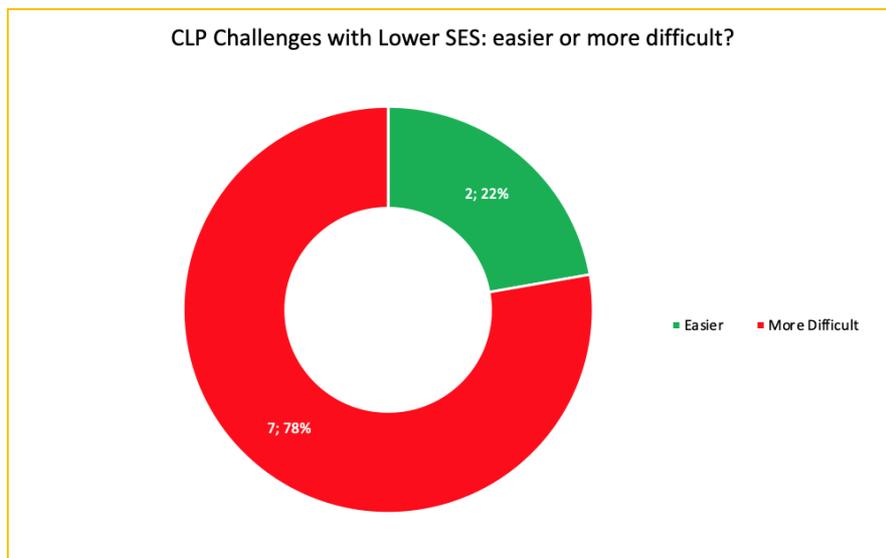
E – Difficulty in finding sufficient resources to begin rehabilitation courses in private practices (it is difficult for patients with CLP to find specialized assistance in the treatment of this particular pathology in the public)

F – More difficult due to difficulties related to the native language (different from Italian) or to situations related to a low socio-economic level

G – Place of residence, socio-economic and cultural status

H – Because of the poor knowledge of the Italian language and because of the limited resources necessary to carry out therapies and be included in protected contexts

I – CLP could be a further ground for discrimination in some environments; few personal tools to face the treatment process; popular, familiar beliefs



3 - In your opinion, what factors are associated with positive adjustment to cleft?

A – Global management by a specialized multidisciplinary team; knowledge of the pathology and its consequences and available therapies

B – Being adequately informed about the pathology and developmental perspectives; be followed by a specialized center within a multidisciplinary team

C – The ability of the professionals involved in welcoming patients and their parents in a serene and reassuring manner; intercepting their needs and addressing any concerns and difficulties with them; mutual trust between professionals and patients

D – Knowing other families who have received the same diagnosis and have already faced the treatment course

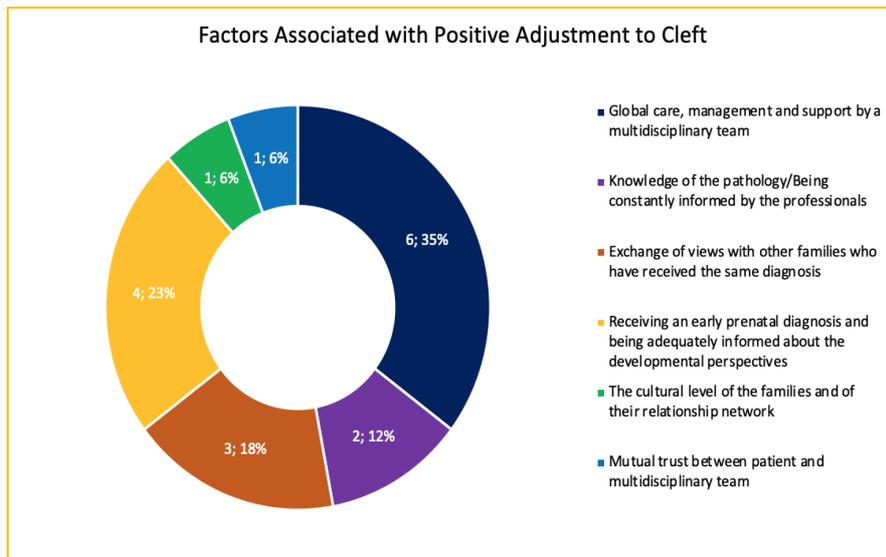
E – Receiving an early diagnosis; support for families by a team that welcomes and supports them at 360 degrees

F – Exchange of views with families with children with cleft palate in order to demonstrate that despite the possible difficulties, children can have totally adequate outcomes

G – An early recognition of the problem, an adequate global care of the of the parents and the patients; in order to do this is therefore necessary to have a multidisciplinary team that includes figures who can take care of the patients and their families from both a medical and psychological point of view

H – The cultural level of the family; a good social network that supports the family

I – Prenatal interview with specialized personnel; teamwork; discussions with relatives of children who have followed the same treatment paths



(every professional gave more than one answer)

4 – Do you offer any training and/or support to parents to optimise outcomes in their children? If so please give examples.

All our participants answered **YES** to this question

A – Speech therapy counseling aimed at supporting school learning

B – Speech therapy counseling about the norms of communicative and linguistic stimulation in children with cleft palate, indications on activities and exercises to be carried out in the home-context in order to reinforce non-stabilized sounds or indications about the need to undertake a specific speech therapy course

C – Practical demonstration during the rehabilitation session of the correct praxic-articulatory scheme for the realization of a certain sound and delivery of exercises to be done at home to continue the articulatory training on a daily basis

D – Individual or group parental counseling sessions, in which information is provided about the development and stimulation of the language of their children, focusing on what could be the compensatory articulatory productions deriving from the presence of cleft

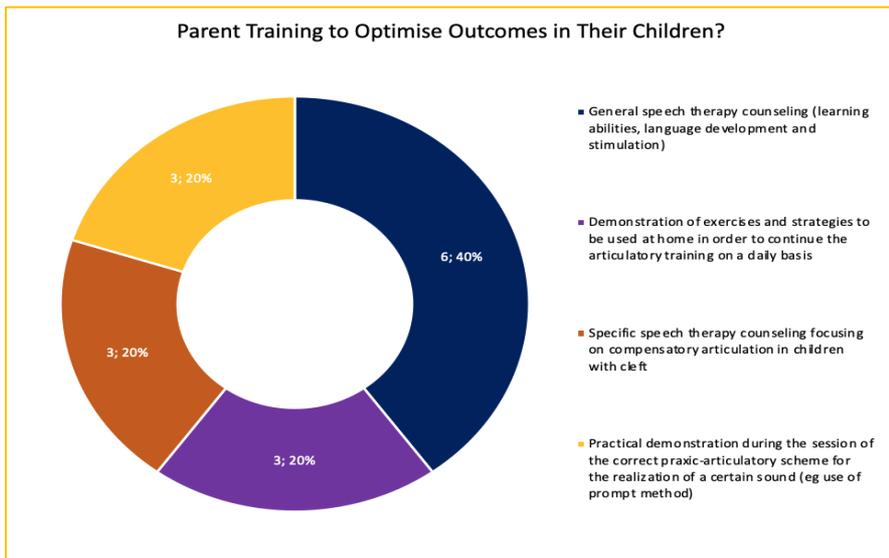
E – Advice about the correct ways of stimulating language

F – Use of the prompt method

G – Do not encourage posterior sounds, associate a sound with a gesture (prompt inspiration), strategies for language stimulation (symbolic games, songs, categorizations, use of booklets) and eye contact

H – I always dedicate time to show the strategies that I consider the most effective in order to have adequate phono articulatory productions

I – I work in a highly specialized center where children are followed from their birth so parental training and support to optimise the language and phono-articulatory development in their kids is always in order



(every professional gave more than one answer)

5 - Have YOU had any training to enable you to help parents to do this? If YES what training have you had?

Three out of nine participants answered **NO** while the other six answered **YES**

A – University training, interact method

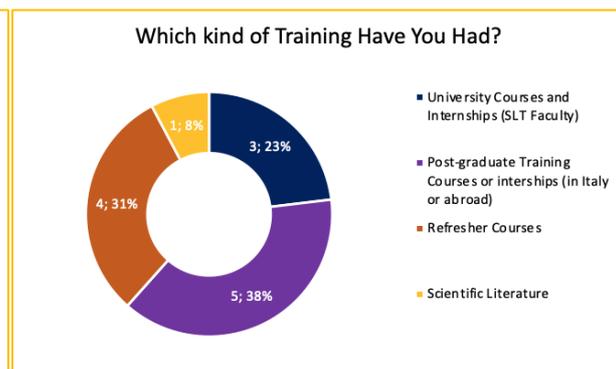
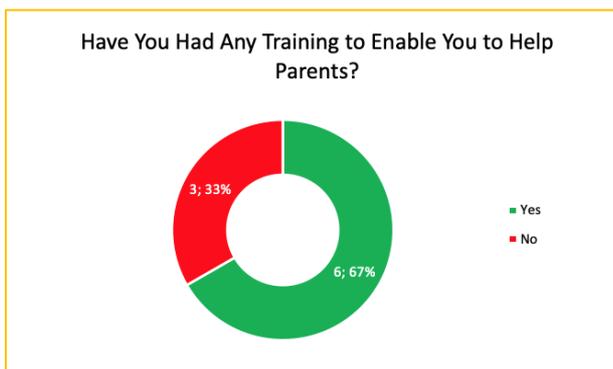
B – University courses, post-graduate training courses, voluntary internships at centers of excellence in the management and treatment of patients with CLP

C – Lessons and university internships, refresher courses on the subject

D – Specific training at the Smile House in Milan, where a team of professionals dedicated to taking care of patients with cleft lip and palate operates

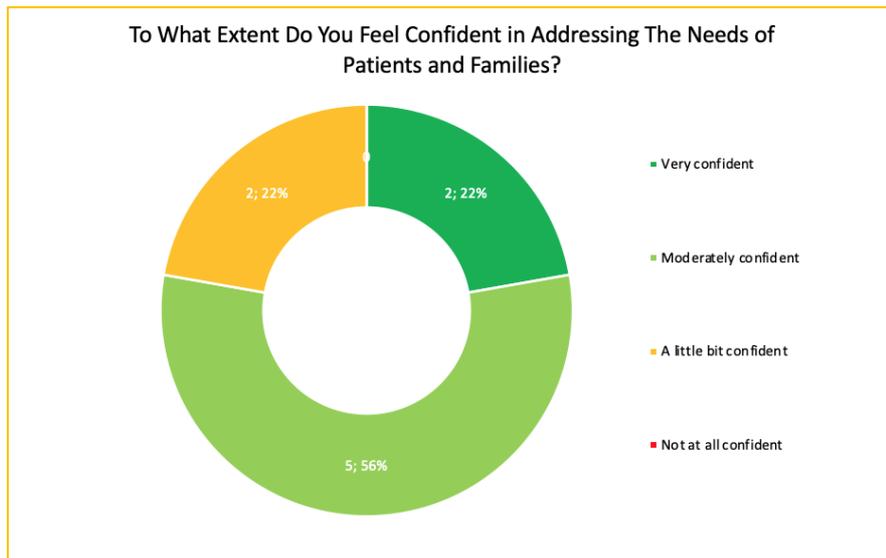
E – Tutoring by a senior speech therapist expert in CLP; reading of scientific material; refresher courses

F – I attended several courses dealing with the pathology both in Italy and abroad and I was able to compare myself with trained colleagues



6 – To what extent do you feel confident in addressing the needs of patients and families?

Two out of nine participants answered **VERY CONFIDENT**, five out of nine participants answered **MODERATELY CONFIDENT** while the other two participants answered **A LITTLE BIT CONFIDENT**



7 – Do you think parents could play a more active role in optimising outcomes for their children? If YES, in what ways?

All our participants answered **YES** to this question

A – By providing the correct linguistic-articulatory model and by encouraging verbal communication through strategies and positive reinforcement

B – Through strategies to reinforce the correct production, following the therapist's instructions at home through specific activities

C – Guaranteeing daily exercise at home in support of the speech therapist rehabilitation program (after receiving training by the speech therapist)

D – Following the indications of language stimulation starting from the first months; supporting the child during the speech therapy program

E – Continuous language stimulation within the family context based on a lexicon studied with the therapist

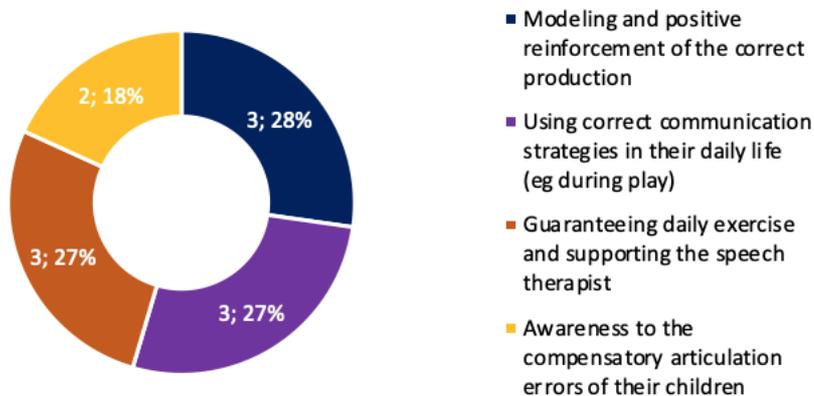
F – By following specific instructions from speech therapists specialized in the treatment of cleft lip and palate

G – The parents, through play, can encourage the productions of their child, exploiting not only the auditory-verbal channel but the visual and perceptive channel also. Moreover, following counseling, he can recognize compensatory articulatory patterns and adopt adequate stimulation methods to repress them

H – There are different modeling and interaction strategies that favor language development and reinforce the correct production patterns

I – Raising awareness of the mistakes their children are making

How Parents Could Play a More Active Role in Optimising Outcomes for Their Children



(every professional gave more than one answer)

8 – Are there SLTs/psychologists to whom you can refer your patients/families? YES/NO/Do not know?

All our participants answered YES to this question

9 - Does your team have access to SLTs with experience in cleft speech disorders? If YES, do those therapists see all children to assess whether or not speech & language therapy would be beneficial?

All our participants answered YES to this question and YES to the subsequent question

10 – How does your team/SLTs cope with children who speak a different language to the cleft team? Please specify

A – Mediation by the parent if bilingual; use of specific tests and questionnaires for bilingual children

B – Evaluation in the presence of the parent; interview with the parents (we have no possibility of resorting to linguistic and cultural mediators)

C – Use of standardized tests in different languages (MacArthur questionnaire translated into various languages); assessment in Italian while taking into account the L1; use of cultural mediators when time permits it

D – By asking the caregiver to repeat some series of words (eg counting) and comparing the child's production with the correct adult one

E – Cultural mediator

F – By having the child repeat syllables and bisyllables with the Italian consonant targets and making specific requests to the parents and/or the linguistic mediator, in order to be able to compare the child's linguistic production to the standard one and verify the presence of phono-articulatory alterations in the native language

G – Within our team there are several English and French speaking people. If none of the languages known by the team members is understood by the patient, the presence of a cultural mediator is required

H – Through the administration of material that can provide a sufficient sample of speech to be analyzed using the IPA alphabet standard

I – We try to refer the child to a school speaking the language of our country to facilitate the learning of L2 before taking him to therapy for a specific training

11 – Where do children with cleft speech disorders usually receive their intervention? (E.g. public hospital; private hospital, local public clinic; local private clinic, schools)

Public hospital: 6/9 66,7%

Private hospital: 1/9 11,1%

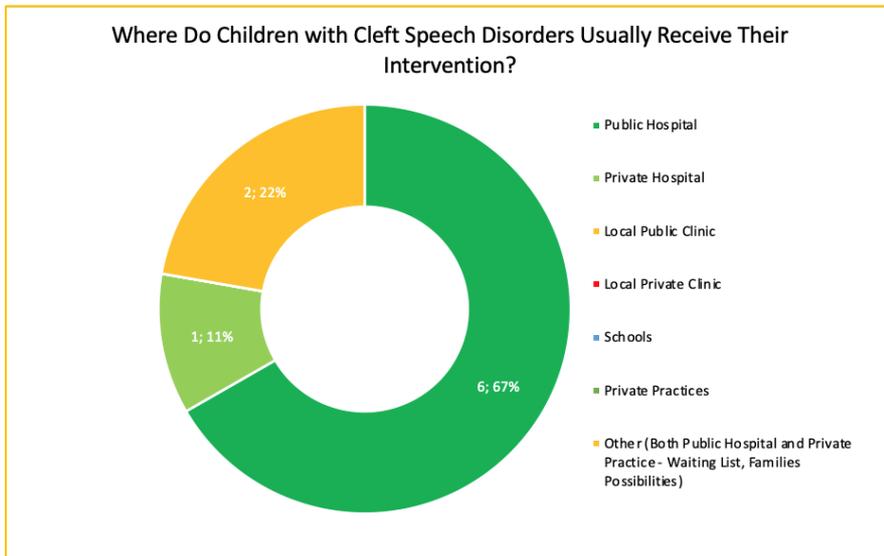
Local public clinic: 0/9

Local private clinic: 0/9

Schools: 0/9

Private practices: 0/9

Other: 2/9 22,2% A – Both public hospitals and private practices, given the waiting list and the family possibilities



12 – Is training in SLT available in your country? If so how many hours of this training are dedicated to cleft?

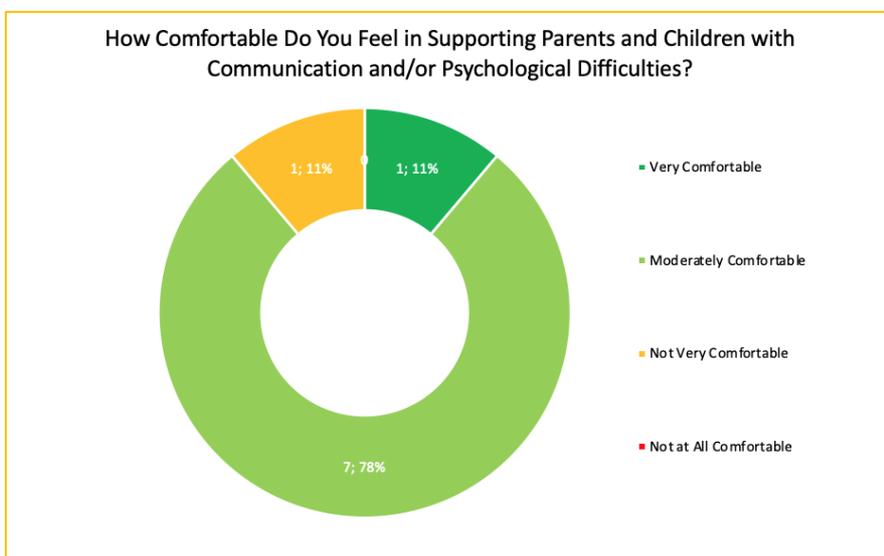
All our participants answered YES

A – 10; B – 5; C – 4 (with the possibility of attending optional courses on the subject); D – 6; E – 10; F – 10; G – 12, H – 12; I – 12

Average hours dedicated to cleft within SLT university courses: 9 hours

13 – How comfortable do you feel in supporting parents and children with communication and/or psychological difficulties?

One out of nine participants answered VERY COMFORTABLE, seven out of nine participants answered MODERATELY COMFORTABLE while the other participant answered NOT VERY COMFORTABLE



PARENTS OF CHILDREN AGED 3-12 YEARS (5 QUESTIONNAIRES)

A. The age of your child

A: 8; B: 3; C: 6; D: 3,6; E: 8

Median age = 5,72

1 - How is your child getting on at home?

A: obedient

B: lively, carefree, always discovering, chatty

C: quite sociable but excessively focused on the TV

D: Involved, collaborative, curious, very empathetic

E: cheerful spontaneous serene

2 – How is your child getting on at play group/nursery/school (if applicable)?

A: integrated and well accepted

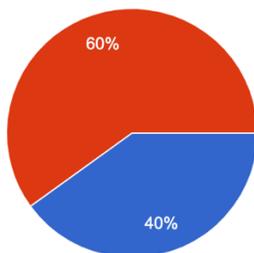
B: very curious and sociable

C: he plays enough but tends to isolate himself

D: interested, friendly

E: often shy, selective, lively with a small group of chosen friends

3 - Are there any particular challenges that you feel your child faces (communicating effectively; meeting new people; forming or maintaining friendships; teasing/bullying, speech and language development; other communication skills etc.)?



NO 60% (3 out of 5)

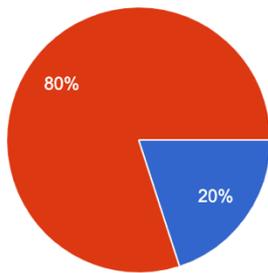
YES 40% (2 out of 5)

If YES please specify:

A: Our concern is rather the motor skills related to the posture and movement cause by the clubfoot condition

B: Our kid often avoids smiling because other children point out the lack of teeth

4 - Do these issues affect your and your child's daily life?



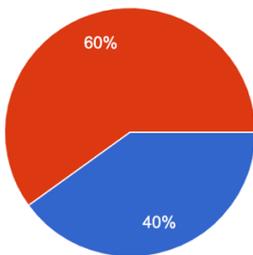
NO 80% (4 out of 5)

YES 20% (1 out of 5)

If YES in what ways?

A: he maybe will feel judged by the other kids

5 - Do you have any concerns for your child currently or in the future?



NO 60% (3 out of 5)

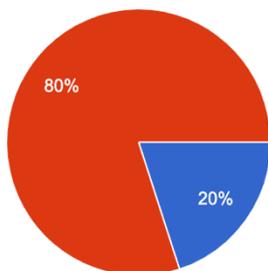
YES 40% (2 out of 5)

If YES please specify:

A: being laughed at, bullyism

B: I'm worried about making him stronger in managing his shyness and his "difficulties" in public

6 - Do you feel confident about identifying signs that your child may be falling behind with their speech development and/or communication skills?



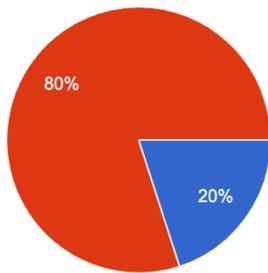
VERY CONFIDENT 20% (1 out of 5)

MODERATELY CONFIDENT 80% (4 out of 5)

NOT VERY CONFIDENT 0%

NOT AT ALL CONFIDENT 0%

7 - Do you feel confident about identifying signs that your child's wellbeing is being affected by their cleft?



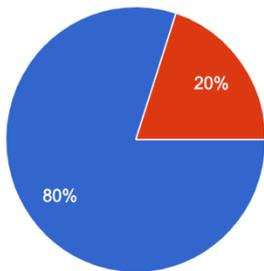
VERY CONFIDENT 20% (1 out of 5)

MODERATELY CONFIDENT 80% (4 out of 5)

NOT VERY CONFIDENT 0%

NOT AT ALL CONFIDENT 0%

8 - Do you have access to any additional support or assistance to help with any difficulties your child might be experiencing?



NO 20% (1 out of 5)

YES 80% (4 out of 5)

If YES, please specify:

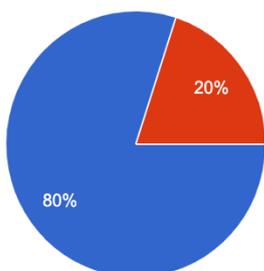
A: speech therapist, psychologist

B: speech therapist, neuro-psychomotricist

C: speech therapy and pedagogical assistance at Smile House

D: teachers at school, parents of peers

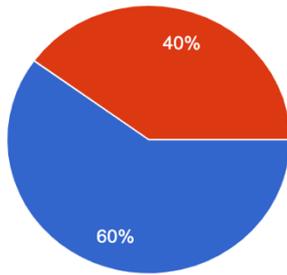
9 - Would you like to have more information about ways of improving your child's chances of developing good speech and communication skills?



NO 20% (1 out of 5)

YES 80% (4 out of 5)

10 – Is There any additional information or support you would like?



If YES, please give details

A: newsletter via mailing list

B: psychological assistance for the child

C: workshop activities to better understand the problems related to cleft

If YES, how would you like this information provided (e.g. in a face to face workshop; in a booklet; online?)

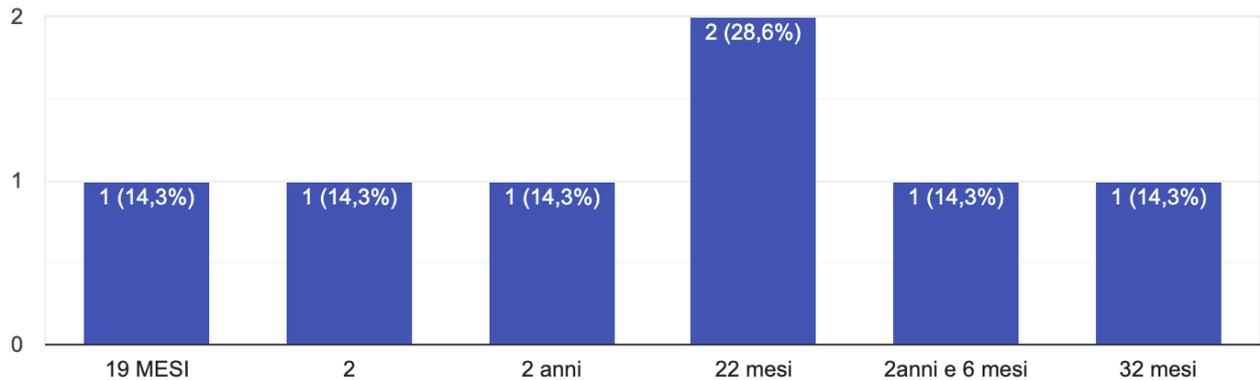
A: updates on the internet

B: frontal meeting

C: updates on the internet because they can be checked everytime you need them and not only during a frontal lesson

PARENTS OF CHILDREN AGED 12-36 MONTHS (7 QUESTIONNAIRES)

A – The age of your child:



Average age: **21,5 months**

1 – How is your child getting on at home?

A: Exuberant, volcanic, exhilarated, hyperactive, chatty, temperamental, in constant seek of attention and confirmation from family members

B: Fully at ease

C: Lively, sympathetic, always attached to the mother

D: Well included and serene

E: Serene

F: Normal

G: Good and quiet

2 – How is your child getting on at play group/nursery/school (if applicable)? (4 ANSWERS)

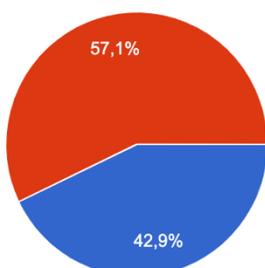
A: Sociable and curious even if a little hesitant, sometimes insecure, always seeking for the presence of a family member (she doesn't go to nursery school but has attended play areas, friends, etc)

B: He is fully living the nursery school experience in all its aspects, but always requires the presence of the adult

C: Happy when she is with other children

D: Normal

3 – Are there any particular challenges that you feel your child faces (speech & language development; forming relationships with parent(s) and family members etc.)?



NO 57,1% (4 out of 7)

YES 42,9% (3 out of 7)

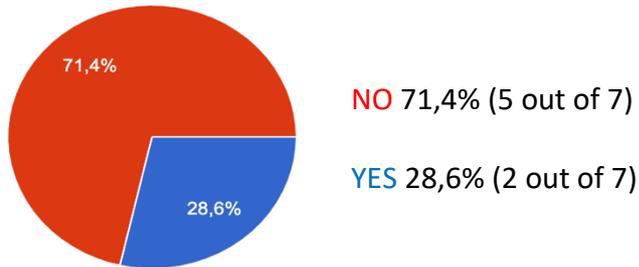
If YES, please specify:

A: hyperactivity

B: has difficulty in pronouncing some language sounds

C: difficulty in vocabulary. To this date he only says a few words and no sentences

4 – Do these issues affect your and your child’s daily life?

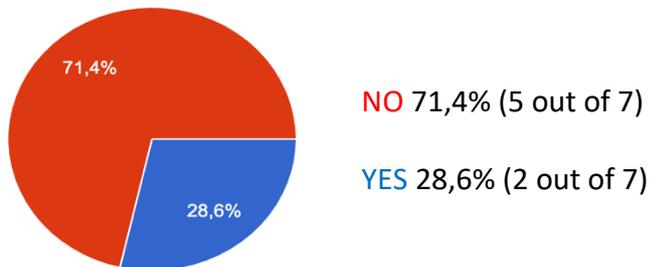


If YES, in what ways?

A: relationships problems with other children due to the unresolved scar (until re-operated or estetically fixed) or to speech defects

B: I think that linguistic problems will affect him when in kindergarten

5 – Do you have any concerns for your child currently or in the future?

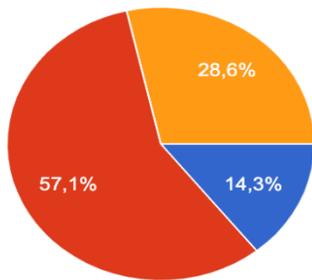


If YES, please specify:

A: relationships problems with other children due to the unresolved scar (until re-operated or estetically fixed) or to speech defects

B: that he doesn't speak perfectly or that he will develop a nasal voice and will be mocked for that

6 – Do you feel confident about identifying signs that your child may be falling behind with their speech development and/or communication skills?



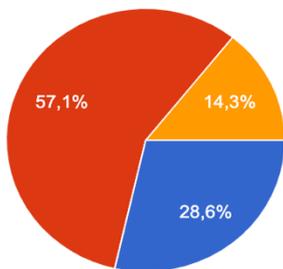
VERY CONFIDENT 14,3% (1 out of 7)

MODERATELY CONFIDENT 57,1% (4 out of 7)

NOT VERY CONFIDENT 28,6% (2 out of 7)

NOT AT ALL CONFIDENT 0% (0 out of 7)

7 - Do you feel confident about identifying signs that your child's wellbeing is being affected by their cleft?



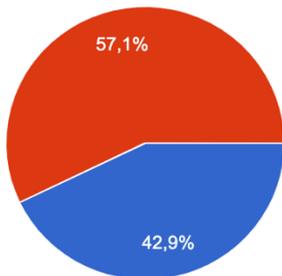
VERY CONFIDENT 28,6% (2 out of 7)

MODERATELY CONFIDENT 57,1% (4 out of 7)

NOT VERY CONFIDENT 14,3% (1 out of 7)

NOT AT ALL CONFIDENT 0% (0 out of 7)

8 - Do you have access to any additional support or assistance to help with any difficulties your child might be experiencing?



NO 57,1% (4 out of 7)

YES 42,9% (3 out of 7)

If YES, please specify:

A: other families

B: Smile House

C: from november 2019 to january 2020 she attended speech therapy sessions but only once a month. Due to the pandemic we have not been able to continue with the speech therapy training

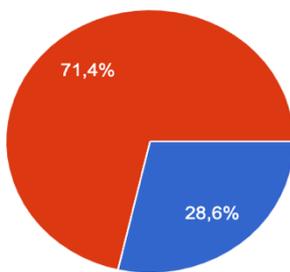
9 - Would you like to have more information about ways of improving your child's chances of developing good speech and communication skills?



NO 0% (0 out of 7)

YES 100% (7 out of 7)

10 - Is there any additional information or support you would like?



NO 71,4% (5 out of 7)

YES 28,6% (2 out of 7)

If YES, please give details:

A: speech therapy support

B: any material or information that I may be not aware of

If YES, how would you like this information provided (e.g. in a face to face workshop; in a booklet; online?)

A: frontal meetings with speech therapists and psychologists

B: information brochures and updates on the internet