

Module 4

Working effectively as a support group

Subjects covered

- Working with the cleft team
- Being clear about objectives and priorities
- Planning
- Fundraising – the basics
- Lobbying and communication

Audiences

Working with the media

Social media

- Practical
 - *Example of pitching to an audience (European Parliament)*



Working with the cleft team

- The most effective support groups at CLAPA in the UK were those that worked with the cleft teams and involved team members in running the branch activities
 - Increases health professional awareness of patient centred care
 - Attracts more parents to become involved
 - Opens up opportunities for extra support via a wider network of connected people
 - Cleft team members likely to promote the group at their clinics

Optimum care ethos:

There are **two** groups of people who care passionately about children born with clefts

- ***Their families***
- ***The health professionals treating them***

Optimum care, facilities and treatment can be achieved by these two groups working together

Summary – patients/families:

Unique role

Highly
motivated

Part of the
overall care –
reality check

Force for
change,
lobbying

Fundraising

Practical as well
as emotional
support

Information,
education,
training

Types of support group:

A small scale support group may be:

- **Informal** - just a few parents who meet occasionally for a coffee (*Happy Families groups – CLAPA*)
- A **small** internet discussion group eg **Facebook**
- **Working with the health professionals** to help provide information for new families
- Attend waiting rooms and clinic areas to talk to families
- **Helping the team** organise an information day or session for parents
- Organising a party for children to help them meet each another
- Raising money for hospital facilities or equipment



A well-established support group may offer:

feeding support: bottle and teat distribution

parent support: trained parent contacts, literature

Active social media accounts linked to website

children's support: confidence-building camps, young people's magazine

adult support for those who may need specific support

improving care: safeguarding best practice and

- facilitating training for front line health profs.

raising awareness of cleft lip and palate amongst the general public

research—especially into the causes of cleft lip and/or palate

**If we had
100,000 euros,
what would we
do with it?**



Priority setting

Limited funds and limited number of hands to do the work means clarity of focus –

- What do people want from us?
- What did/do we need ourselves (as families with a child with a cleft)?
- What do our children want?
- What does the cleft team want/need?
- What needs to happen so the general public has a greater understanding of clefts?

5 minutes – thoughts in the chat box!





WORKING TOGETHER TO TRANSFORM LIVES



How to get there?

IFRC Logical Framework (logframe) – Definition of Terms			
OBJECTIVES (What we want to achieve)	INDICATORS (How to measure change)	MEANS OF VERIFICATION (Where / how to get information)	ASSUMPTIONS (What else to be aware of)
Goal The long-term results that an intervention seeks to achieve, which may be contributed to by factors outside the intervention.	Impact Indicators Quantitative and/or qualitative criteria that provide a simple and reliable means to measure achievement or reflect changes connected to the goal.	How the information on the indicator will be collected (<i>can include who will collect it and how often</i>).	External conditions necessary if the Goal is to contribute to the next level of intervention.
Outcomes1 The primary result(s) that an intervention seeks to achieve, most commonly in terms of the knowledge, attitudes or practices of the target group.	Outcome Indicators As above, connected to the stated outcome.	As above	External conditions not under the direct control of the intervention necessary if the outcome is to contribute to reaching intervention goal.
Outputs The tangible products, goods and services and other immediate results that lead to the achievement of outcomes.	Output Indicators As above, connected to the stated outputs.	As above	External factors not under the direct control of the intervention which could restrict the outputs leading to the outcome.
Activities2 The collection of tasks to be carried out in order to achieve the outputs.	Process Indicators As above, connected to the stated activities.	As above	External factors not under the direct control of the intervention which could restrict progress of activities.

Simple project planning



GOAL



Young people feeling supported and happy



HOW (Outcome)



Learning some resilience skills, sharing stories



MEANS OF MAKING IT HAPPEN (Output)



Opportunity to attend structured and fun event, with others



ACTIVITY



Summer activity camp



Types of sources of funding

Event (small or big). Tickets for sale and donations requested/sponsored sporting event. Might include a specific fundraiser eg auction

PROS and CONS.....

Public appeal – by email, social media, letter, poster, newspaper, radio, TV, crowd funding

PROS and CONS

Grant – public body or charitable foundation

PROS and CONS

Wealthy individual donors *PROS and CONS*

Selling an item or service (eg branded merchandise)

The Elevator Pitch – getting noticed

- Goal: make connection. Aim is to persuade the contact to invite you to continue the discussion (and give you funds)
- Keep it short
- Know what you want: so be focused
- Make it understandable for every one: simple wording
- Make sure they remember you



Choosing your audience and reaching them!

- **Your focus** is on the decision makers, and seeks to influence them to win concrete, material change
- **Your tactics** might include advocacy, policy work, meeting with a representative, suggesting amendments to pending legislation, fundraising etc
- **Your desired outcome:** Again, be specific. Thing big, but make sure you can measure success

Write out your mission and make sure it features across everything you put out there.

Put it across your social media pages, your website, your adverts, make it clear that this is your tagline!



Social media

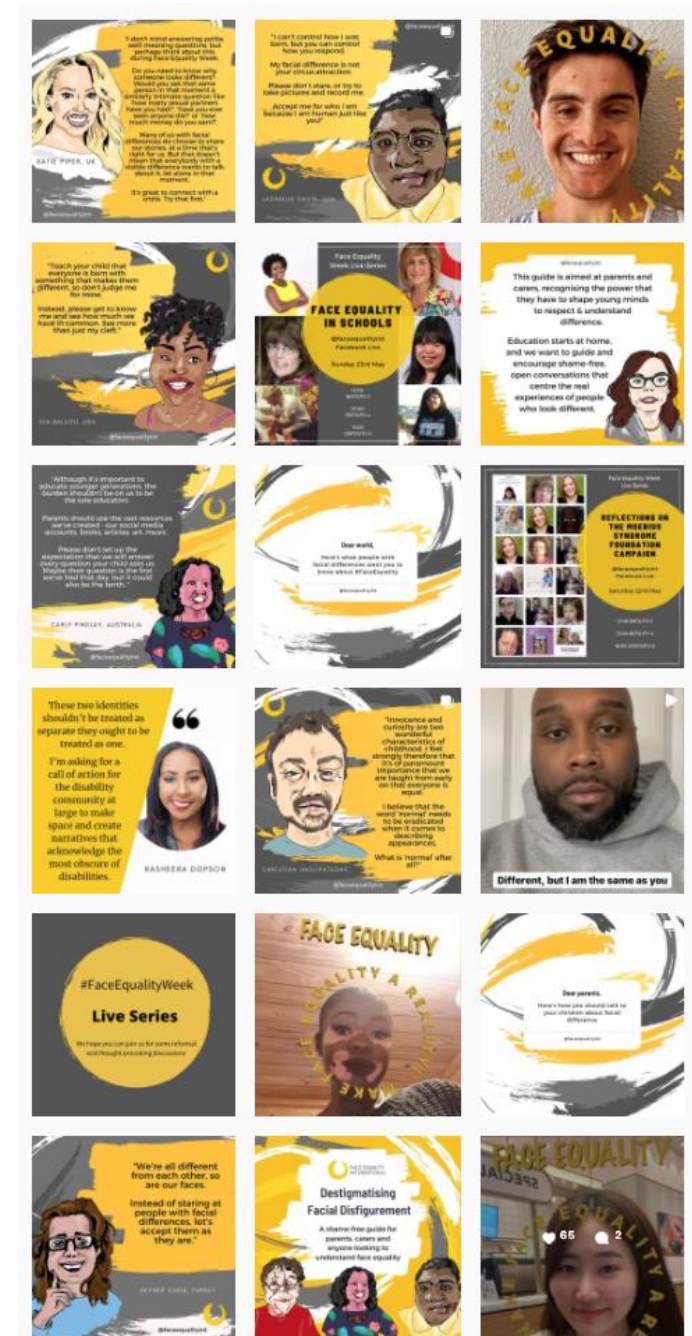
- Use resource wisely – you don't have to be on every platform. Mastering one platform can be a better option
- Be clear on your purpose, and make sure the posts that you are putting out reflect this. If it's to build your community, then focus on what will appeal to them.
- Don't worry about high numbers of followers. A smaller number of engaged followers is far more valuable.
- Photos and videos always perform far better than written content.

Facebook – Best for groups, community building and middle-aged audiences

Instagram – Best for visually engaging content and younger audiences

LinkedIn – Best for business connections, fundraising connections and building organisational profile

Twitter- Best for monitoring news and relevant, timely conversations whilst engaging with relevant organisations and individuals



Working with the media

- Working with your local media outlets and building relationships will really help your cause
- Audiences find it far easier to relate to and understand a cause when they are hearing about it straight from those who are affected by it
- Providing data and key statistics will always help to validate what you're pitching
- Press releases don't need to be issued by media professionals. As long as you have pulled together some key data, an outline of some information and/or a story, and some quotes from key individuals, you are in for a good chance
- Don't see social media vs. print/broadcast as separate. Journalists can be contacted on social media too

Ambassadors/case studies

- Working with the media can be tricky. Sometimes stories are embellished, quotes are used out of context. Make sure you are prepared for this
- Prepare whoever is sharing their story with key messages about your organisation and what you want to get across.
- If they are to be interviewed, then help them to practice sharing their story by holding practice interviews and practicing questions that are likely to be asked

Example Pitch to European Parliament

*Similar messages can be developed for local and national lobbying –
remember fundraising is essentially lobbying for money!*

Addressing health inequalities in the care of children born with cleft lip and palate

European Parliament – Brussels 27th February 2018

Gareth Davies

Executive Director

European Cleft Organisation

**Every child born
with a cleft or
craniofacial
condition in
Europe must
have the
opportunity of
realising their
full potential**



A big impact on European health

- Within 27 EU states, population just under 500 million
- Estimated total number of people living with a cleft or craniofacial anomaly in the EU: more than 1,000,000.
- Equivalent to a city the size of Brussels
- Not a ‘marginal’ concern

Europe – health inequality

- In one country a child born with a cleft goes on to lead a completely normal and fulfilling life like any other child or,
- In another (perhaps neighbouring) country, they may end up in state care with no prospects and no opportunities - a burden to society. In Bulgaria still as many as 27 per cent of parents are advised to leave their cleft child in an orphanage

No protocols = poor outcomes

Surgery for cleft lip and palate exists throughout Europe (at varying degrees of competency) but what we have found is that babies with clefts are severely disadvantaged at point of diagnosis because there are no agreed protocols of care or referral mechanisms in place.

Bad practice = social exclusion

- Nasogastric tubes are routinely inserted at birth in some countries, making it difficult for baby to go home. Nearly all cleft babies can be bottle or breast fed
- Can you imagine a child with just a cleft lip being sent to a school for deaf and mute children?
- We found many babies being fed for months by teaspoon because no one told the families there was expert support and treatment available – often close to home.

and abandonment

For ECO, (and WHO) access to healthcare must be seen in the context of a **basic human right** because the consequences of not providing the right care results in social exclusion and in some cases abandonment of children.



We need the support of the EU

A huge challenge –
but one that we
feel we can make a
real difference if
we have the
support of the EU
and the
governments of its
members states



Key message

- We have developed a baseline of care setting out minimum standards
- It now needs to be implemented in all the member states
- We have a track record of delivery and with resources and support we can look at finding solutions for equal access to cleft care.

We need continued EU support going forwards

- The EU must make clefts a key priority for European health in its overarching strategy to provide patients across Europe with equal access to healthcare.
- Clefts must be clearly identified and cited as a specific priority in future EU funding calls post 2020. Horizon 2020 had a budget of €80 billion yet a very little was available for clefts



Thank you!



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