THE HUDDLE

PATIENT SUPPORT GROUP HUDDLE

Saturday, 15 September 2018, Johannesburg, South Africa

The Huddle

Definition Huddle: verb (used without object), huddled, huddling.

- ☐ 1.to gather or crowd together in a close mass.

- ☐ 2. to confer or consult; meet to discuss, exchange ideas, or make a decision.

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ADVOCACY 101

Lauren Pretorius, CEO, Campaigning for Cancer

What is advocacy?

- Endeavour to **influence decision-makers,** to **create change** through various forms of **persuasive communication.**

- A **systematic approach** to **changing policies, programs and systems** to reflect the needs of individuals and communities.

- It provides the patients an opportunity to become **involved in the decision-making processes** that ultimately affect their lives.

Where does advocacy happen?

Self-advocacy

Family and Friends

Community

Systems-level Change
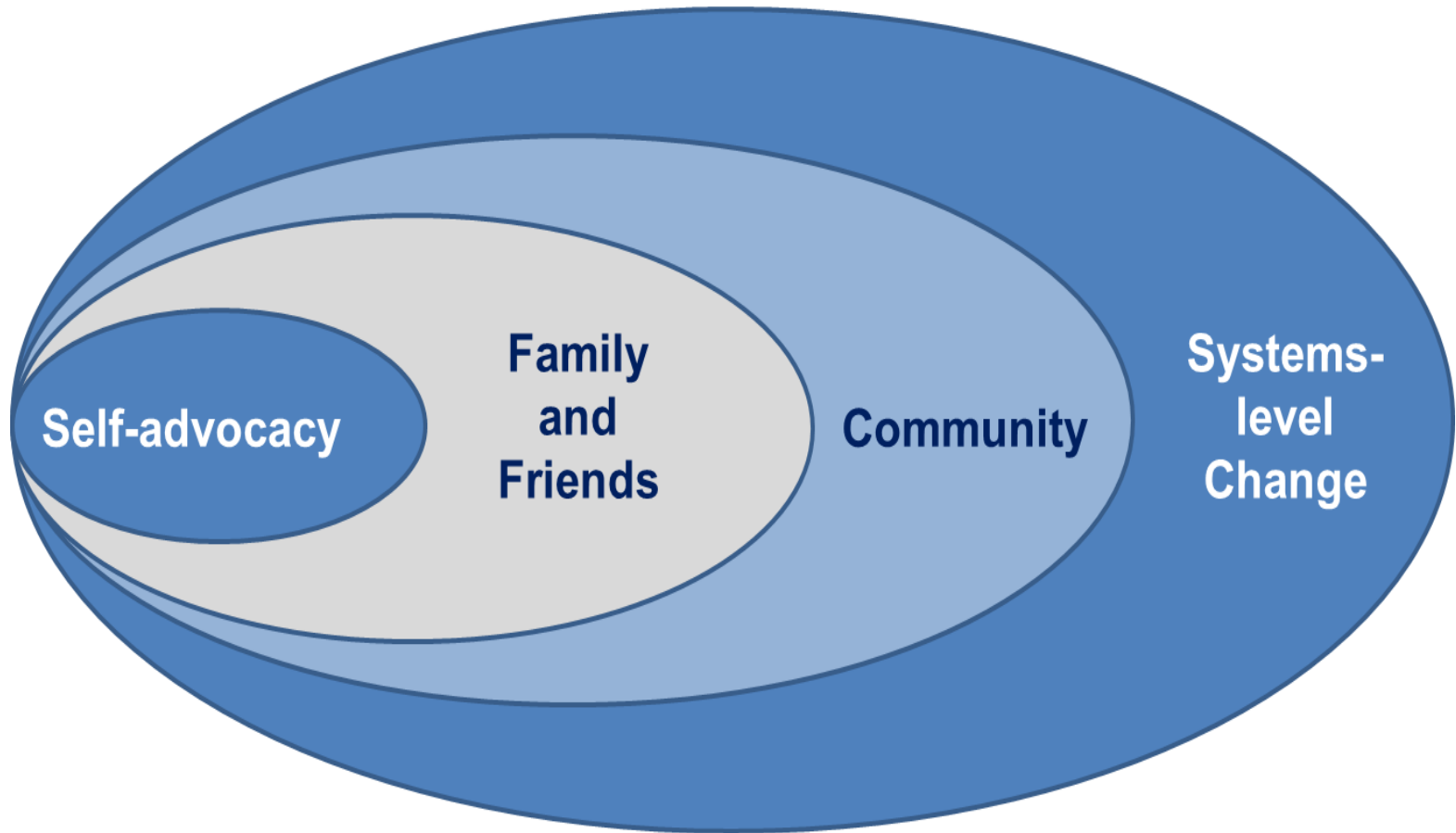
What is grassroots advocacy?

- Involves people from the general public, as a fundamental political and economic group

- Real people bringing compelling personal experiences and pressure to decision-makers

- Demonstrates to decision-makers how the community supports your advocacy issue

- Collective strength will help your NGO to reach advocacy objectives and systems change

What can advocacy change?

- ☐ Public policy

- ☐ Laws and regulations

- ☐ Resource allocation, use of funds

- ☐ Access to services and medication

- ☐ Health insurance and public benefits

- ☐ Reduce disparities among underserved

- ☐ Public opinion – gain support for disease related policies

Methods of Advocacy

- There are three approaches to advocacy - FOR, WITH and BY those affected.

- **Direct advocacy** - efforts that affect change to programmes and practices that are aimed at *influencing decision-makers.*

- **Indirect advocacy** - efforts that *raise general awareness and involve building support among the general public* so that people will pressure decision-makers or a community to make changes to practices.

- **Patient-Centred advocacy** - efforts by *individual patients to advocate on behalf of themselves* and their right to access treatment, care and not be discriminated against.

Two methods when advocating for patients

- **Lobbying and direct communications**
  involve influencing decision makers by means of direct and private interaction and communication. Lobbying, can be a powerful and cost effective method of advocacy.

- **Campaigning**
  speaking publically about an issue. The aim of such campaigning is to generate a response from the general public in order for an issue to become a "talking point" amongst the public so that policy makers take notice.
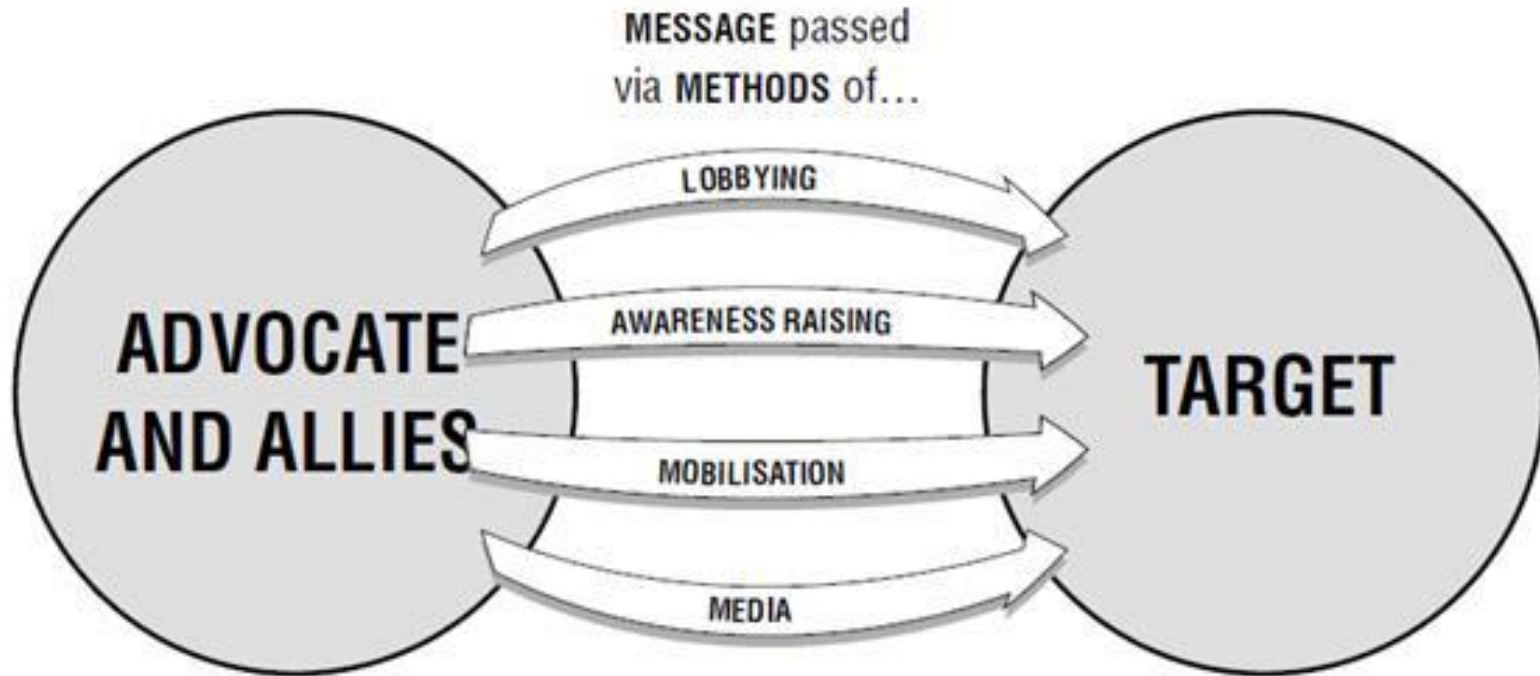
Possible advocate roles

ROLE	CHARACTERISTIC	
Represent	Speak **for** people	
Accompany	Speak **with** people	
Empower	Enable people to speak for themselves	
Mediate	Facilitate communication between people	
Model	Demonstrate the practice to people or policy makers	
Negotiate	Bargain for something	
Network	Build coalitions	

Key

advocate

targets / those in power

those affected by a situation

Advocacy methods

MESSAGE passed via **METHODS** of…

LOBBYING

AWARENESS RAISING

MOBILISATION

MEDIA

ADVOCATE AND ALLIES

TARGET

The overall objective is to change the particular policies or practices of the target for the benefit of the poor.

Planning advocacy

Stage 1	**Defining the current state of the problem**

Stage 2	**Data and Research**

Stage 3	**Audiences**

Stage 4	**Developing messaging and persuasive arguments**

Stage 5	**Building Support**

Stage 6	**Monitoring and Evaluation**

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QUESTIONS?

Lauren Pretorius, CEO, Campaigning for Cancer

Planning advocacy

- What are the key issues facing our community right now?
- Brainstorm issues
- Brainstorm solutions
- Prioritize issues
- Categorize issues
- Develop a list of advocacy issues
- Develop a problem statement
- Define who to speak to and what to say
- Build support for your plan

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STEP 1: DEFINING THE CURRENT STATE OF THE PROBLEM

Group Exercise

Group Exercise 1

- In smaller groups, brainstorm a list of problems that in your work with patients and loved ones are most prevalent
    - 10mins
- Report back to the group
    - 15mins

Group Exercise 2

- In your smaller groups, to each problem you listed identify what the root cause of the problem is.
  - Ask yourself:
    - Why does the problem occur?
    - What are the main aspects of the problem?
    - What are the effects it causes?
  - 10mins

- Report back to the larger group
  - 15mins

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BIO BREAK

Back by 5mins

STEP 2: FINDING SOLUTIONS – CHARITABLE ACCESS PROGRAMME

Tanya Collin-Histed, European Gaucher Alliance

PROBLEM + SOLUTION = ADVOCACY ISSUES

Lauren Pretorius, Head of Strategy, Prime Consulting

Distinctions between problems and issues

- What is a "problem"?

- We all have "problems" – e.g., lack of affordable, quality health care is a problem; inadequate funding for research is a problem.

- **The problem is something that is wrong.**

- Advocates do not organize around problems, however, they organize around "issues" - the solution or partial solution to the problem.

- We have to have a clear demonstrative problem though to develop and issue.

Distinctions between problems and issues

□ A solution is a necessary aspect of successful advocacy.

Without presenting a solution we are merely voicing complaints, not affecting change.

Group Exercise 3

- In your groups, to each problem's root cause you listed identify a potential solution that will have a positive impact on all patients.
  - 10mins
- Report back to the group
  - 10mins

- **REMEMBER: Your solutions may be far-fetched or challenging to implement, and it will likely be the responsibility of decision makers to implement them.**
- **This is OK**.

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DEVELOPING A TAILORED ISSUE TREE

Group Exercise

Mobilizing our efforts

- Presenting our issues with potential solutions is a proactive way of addressing the issue, and even though we aren't the policy makers, our job is to help be a part of the solution by clearly identifying what we need as patients and advocates.

- How many of you came up with at least 5 issues and solutions? 7? 10?

- We can't possibly address all of these at once, so we need to narrow them down by prioritizing them.

Group Exercise 4

□ Brainstorm with the larger group ways to prioritize the issues. (5 mins)

How do we prioritize?

- Selecting an issue that has **broad appeal** not only to the people in the room, but also to others in the community.
- Select an issue that is **easy to explain and understand**
- Select an issue that can be **influenced in a realistic amount of time** (months vs. years)
- Select an issue for which there is a **clear idea of a policy change** in mind
- Selecting an issue for which there is **an identifiable decision-making body**,
- Selecting an issue that lends itself to a **clear "victory"** for patients

Group Exercise 5

- Using the criteria we just established, narrow your list down to 3 issues.
- The group must reach a consensus.
- You have 15 minutes.

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STEP 3: THE ROLE OF DATA AND RESEARCH IN ADVOCACY

Helen Malherbe, Genetic Alliance South Africa

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REFRESHMENT BREAK

Back by 15:30

RESOURCING & SUSTAINING ADVOCACY

Weronika Wojtowicz, Care Beyond Diagnosis

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NARRATING PROBLEM STATEMENTS

Group exercise

Group Exercise 6

- To adequately advocate for a solution you have to have all the facts about the issue and be able to present them to stakeholders in a credible and clear way.

- A way that demonstrates the gravity of the issue.

- In smaller groups of interested parties, evaluate your 3 chosen advocacy issues according to the following criteria:

Checklist for Selecting an Advocacy Issue

- **Data:** Do you have access to qualitative and/or quantitative data demonstrating the extent of the problem/issue? Does the data demonstrate that the proposed solution with result in real improvements in cancer control?

- **Scope:** Does the issue affect many people? Do enough people feel affected to do something about it?

- **Understandable**: Is the issue easy to understand and explain? Are you able to frame the issue in such a way that people readily comprehend the issue and its solution?

- **Commitment:** Do people care enough about the issue to take action? A smaller number of people may feel so strongly that they are able to take on the work of getting petitions signed or raising resources for a campaign, etc.

- **Resources:** Will you be able to raise enough money to support work on this issue? Do people care enough to donate funds and resources?

- **Target**: Are you able to clearly identify the key decision-makers (individuals) to address this issue? Do you have their names and contact information?

- **Networks:** Do you have existing alliances with other NGOs or key individuals based on this issue?

- **Values:** Is the issue consistent with your mission statement and NGO values?

- **Addresses injustice:** Does the issue address stigma, historic imbalances or societal injustices or prejudices?

- **Feasibility:** Is the issue and its proposed solution feasible and/or winnable given the current political and social climate? Is there a good chance of success, even with opposition? Can the larger issue be broken down into smaller winnable issues?

- **Precedent:** Does the issue recognize national (or international) policies?

- **Future**: Does work on this issue provide the potential for:

Group Exercise 7

- Report to the larger group
- As a group, which of your 3 chosen advocacy issue has the biggest chance of success in light of the criteria we used to evaluate it?

Problem Statement

- **Policy problem**: Documented escalating rates of smoking (and exposure to second-hand smoke) have led to increased cases of lung cancer.

- **Question:** What could the Parliament and Justice System do to address escalating rates of smoking?

- **Policy solution:** Enact and enforce legislation that would ban smoking in specified public venues.

- **Advocacy issue:** In order to decrease the escalating rates of lung cancer due to smoking and exposure to second-hand smoke, legislators and the justice system must enact and enforce legislation to ban smoking in specified public areas.

Group Exercise 7

- As a group, develop a statement that explains the reasons for your concern, what you suggest the solution is to the problem and how this problem can be solved.

- **USE THE FACTUAL AND EMOTIONAL HIGH GROUND**

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THANK YOU

End Day 1