

# Participation, Life and Research

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November 2006

# What I Am Going To Talk About

- ❑ What Participation Means
- ❑ Who Has the Power?
- ❑ What Participation Should Apply To?
- ❑ What Services Should Be Doing
- ❑ What The Research Community Should Be Doing



# What Do We mean By Participation?

Is It About:

**Information** – “We’ll tell you what will happen to you”

**Communication** – “We’ll tell you our plans and might change them if you suggest something really good”

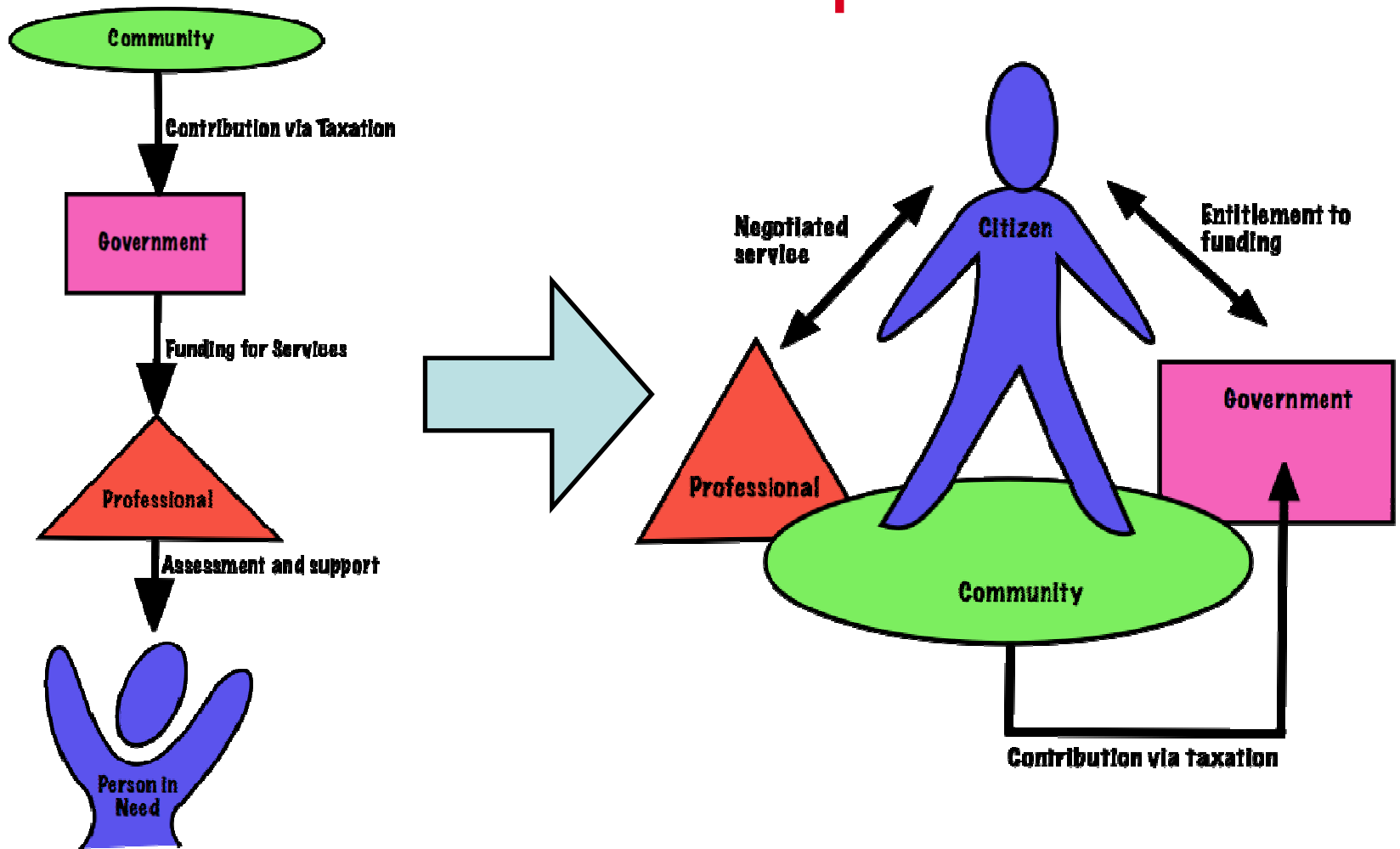
**Consultation**- “We’ll talk about our ideas, you have your say, but at the end of the day I’ll decide”

**Negotiation** – “We all have to agree what is going to happen”



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# From 'Professional Gift' to Citizenship

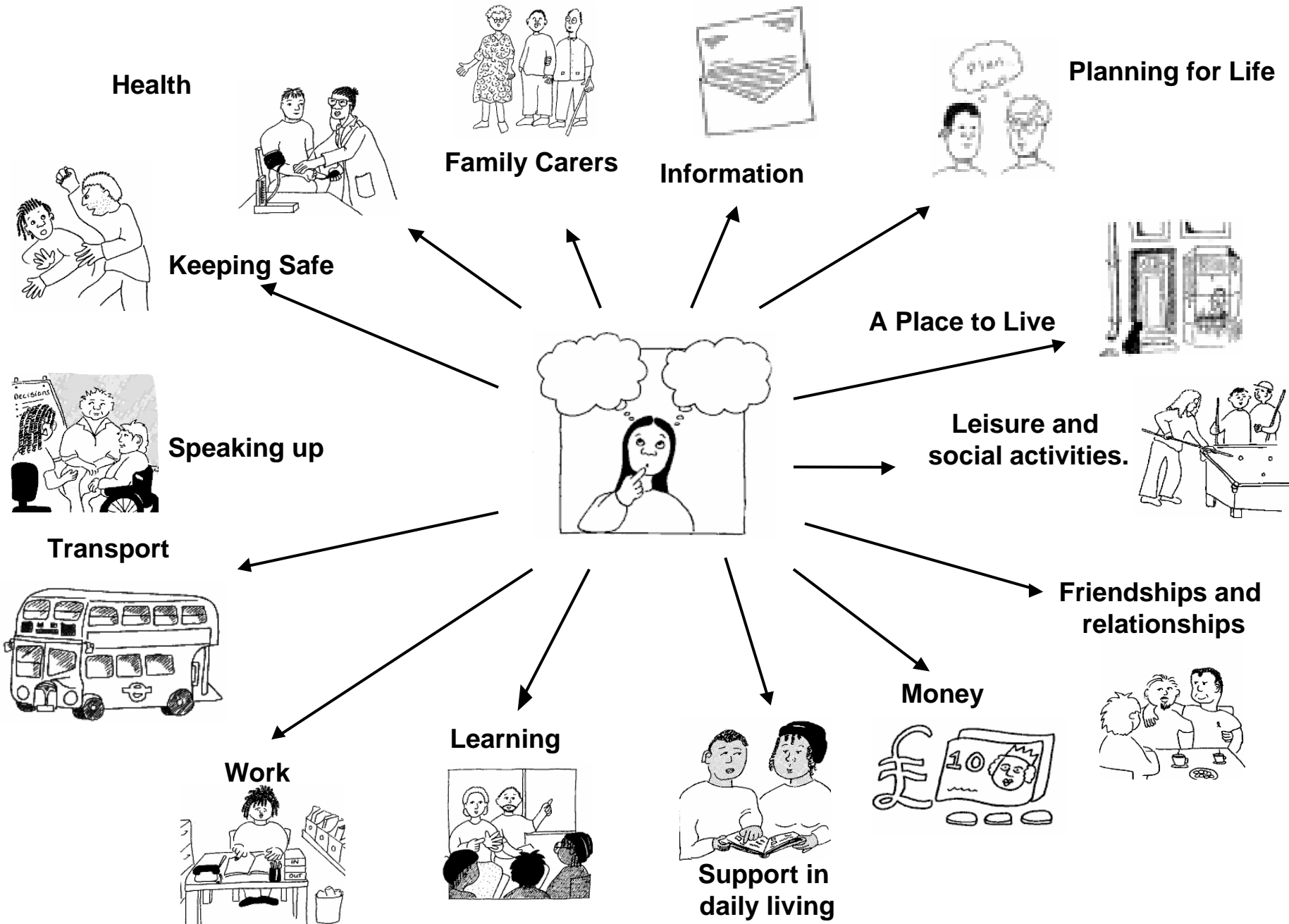


# What People Say Matters Most To Them

## It's About Being a Person and Having a Life

- Being listened to
- Having a paid job and money
- Having my own place to live
- Being healthy
- Positive relationships (including sex)
- Being safe
- Being able to get about to do things





# What's The Role Of People Who Manage and Work In 'Services'?

- To listen
- To respond and change things
- To support people to take control of their lives
- To make sure those most at risk are fully included
- To negotiate access into the 'mainstream'
- To help create new opportunities
- To use public money in the best way
- To make sure people are getting what they want and need



# Advocacy and Rights

Are we serious about people (and their families) having real choice and control?

If so, why:

- Is investment in advocacy and family support so low in so many places?
- Are rights not a core part of staff and management training and performance management?



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# Policy Opportunity - Individual Budgets are The Future

## **Personal Control and Self-Directed Support**

'In Control' has shown how people's lives and services can change.

Individual Budgets are the future. They will increasingly include budgets from outside 'social care'.

Person Centred Planning is at the heart of self-directed support.

Will you wait or will you be at the leading edge?

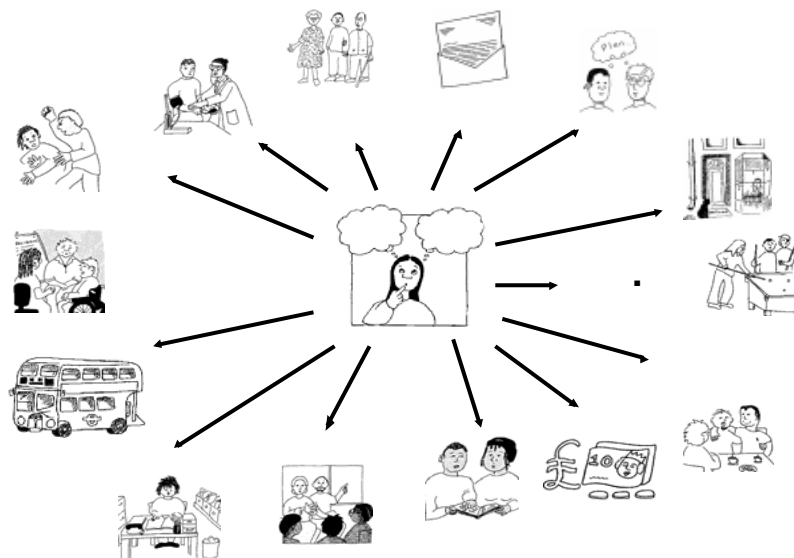


# What Does This Mean For Research? (1)

## Who Decides What Research is Done?

Remember the top priorities:

- Being listened to
- Jobs
- Better Health
- Home of my own
- Being Safe in my community
- Relationships
- Getting Out and About



## Where is the Research on These Issues?

# What Does This Mean For Research? (2)

## Who Does the Research?

How do we recruit, train and support researchers with a learning disability.



## How Do We Tell People About Research Findings?

How do researchers communicate outcomes with people and their families?

How do researchers communicate outcomes with managers and policy makers?

