HISEE, EDF, EASPD INTERNATIONAL SEMINAR SKOPJE, APRIL 23 -24, 2007

From Commodification to Co-production: the role of people with disabilities in the development of social services.

Jim Elder-Woodward
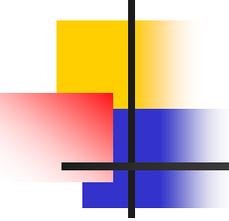
- Thank you for inviting me to speak today and for your kind hospitality

- It is, indeed, a privilege and honour to be here
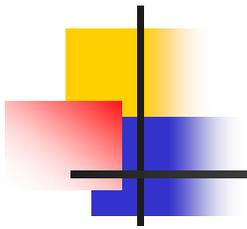
Jim Elder-Woodward

- Retired Social Work Manager, Glasgow, Scotland

- Vice Convenor, Glasgow Centre for Inclusive Living

- Convenor, Scottish Personal Assistant Employers Network
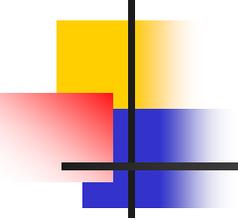
Jim Elder-Woodward

- Member of EDF Independent Living Task Force, Brussels
- Trustee Director of Inclusion Scotland
- Chair, Scope's ILzone, London
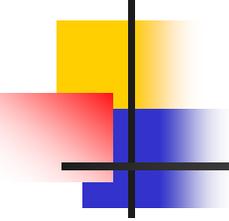
Overview

- Today, I wish to talk about the role people with disabilities have taken in the development of *our* social services

- I shall argue that, within the last 50 years, that role has been changing
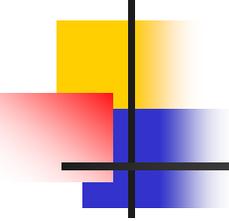
Overview

- From being the 'object', or 'commodity' of the service

- To being the provider of some; and now the 'co-provider' of others
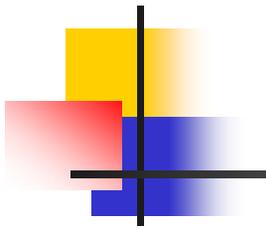
Grunewald's typology of service development:

- **Karl Grunewald** was head of services for people with learning disabilities in Sweden

- In 1973, he published a typology of the development of services for people with disabilities
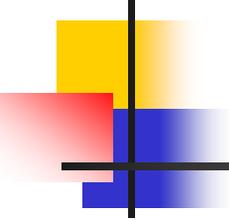
Grunewald's typology of service development:

- **1st Diagnostic stage**: specific impairment is identified
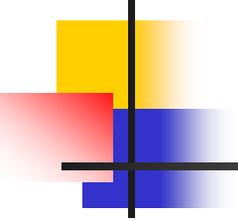
Grunewald's typology of service development:

- **2ⁿᵈ Specialisation / Centralisation stage**: a single (medical) institution is opened to meet 'special' needs
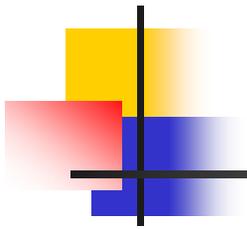
Grunewald's typology of service development:

- **3rd Differentiation stage**: the realisation that each person has a variety of individual needs requiring a variety of professionals
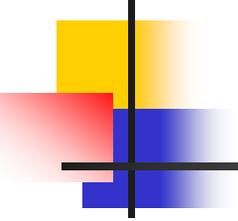
Grunewald's typology of service development:

- **4th Integration / Decentralisation stage**: services for specific impairments are provided locally with other community services for people without impairments
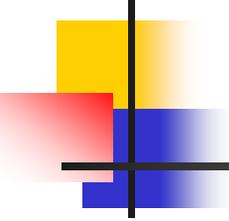
Grunewald's typology of service development:

- Typology is not linear

- Neither is it progressive nor exhaustive

- Services in most Western European countries have moved on since the 1970's
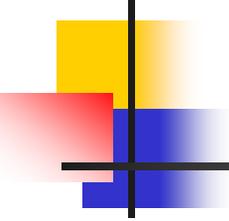
Grunewald's typology of service development:

- I shall be talking today about a further two categories:
  - User-led ('users' being consumers with disabilities)
  - Co-produced
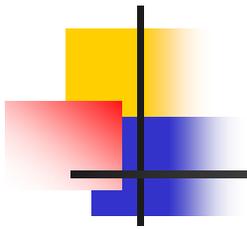
The place of people with disabilities

- But where is the place of people with disabilities in this typology?

- Have we been an intrinsic part of the decision making within such service provision development?

- Or have we been the 'object', or 'commodity', within it?
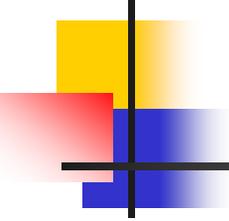
The place of people with disabilities

- It is my assertion that we have been seen as the 'commodity' within Grunewald's original 1970 typology
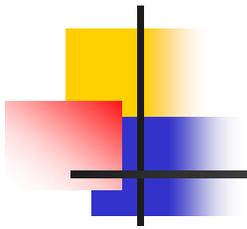
The place of people with disabilities

- But we in the UK, and in other parts of the world, have moved forward from the 1970's – and are still moving forward today
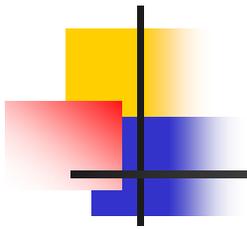
The place of people with disabilities

- To develop new systems of service delivery, in which people with disabilities become both sole providers of some services and 'co-producers' of others

What is 'Commodification'?

Tom, my motor mechanic

- Finds a fault in my car **(diagnostic)**

- Takes it to his local garage **(not a VW garage)** **(decentralisation)**

- Employs auto electricians, panel beaters, etc. **(differentiation)**

'Commodification'

- When the job is done to my satisfaction, I pay Tom for his work

- My car has no say in who repairs it, where the repair is done; how well it is done.

- My car is the 'commodity', or object, of the transaction

'Commodification'

And so with people with disabilities

- Historically, our services have been provided by a second party (state / voluntary / private)

- Paid for by a third party (state or charity)
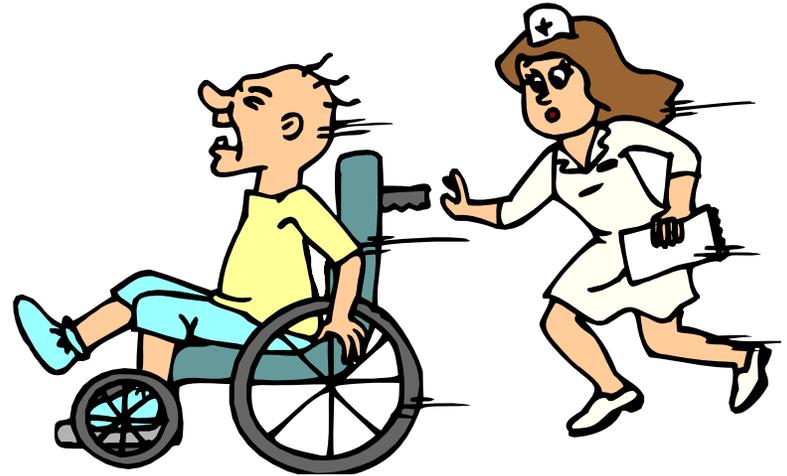
'Commodification'

- People with disabilities have had no control; and very little choice

- We have been seen as the 'commodity' of the transaction.
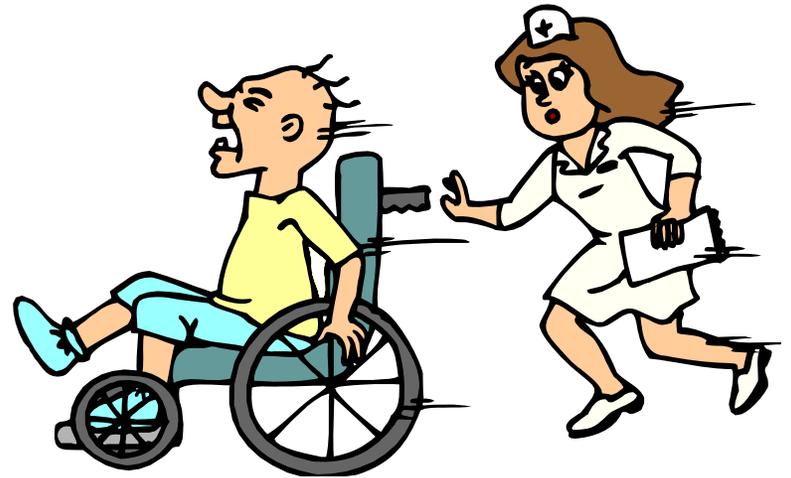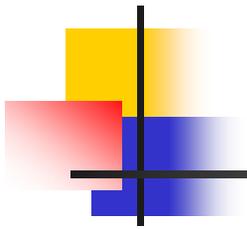
A New Social Movement

- So how have people with disabilities moved from being passive 'commodities' of social services to active providers, and co-providers, of them?
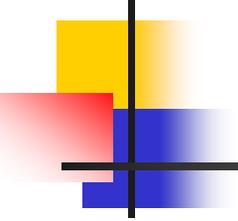
A New Social Movement

- Mike Oliver, a professor of sociology with a disability himself, has described this transition as being the result of the development of a new social movement
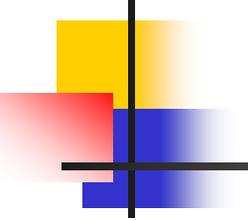
A New Social Movement

- Is **not affiliated** to any one political party
- Engages in the **critical evaluation of society**
- **Redefines problems** / issues
- **Creates alternative forms** of participative social provision
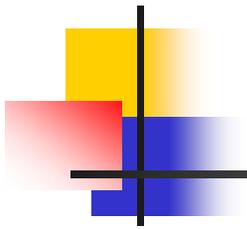
Independent Living Movement

- **Not affiliated** to any one political party

- **Critical of traditional services** based on the 'medical model' and segregation
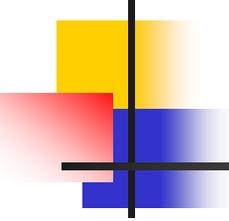
Independent Living Movement

- **Redefined 'disability'** in terms of being generated by society and the result of societal discrimination

- **Devised new concepts** of 'independent living' and 'direct payments'
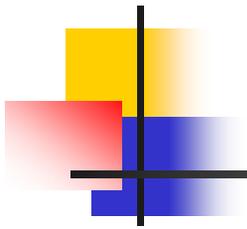
Independent Living Movement

- **Created participative and inclusive, 'user-led', services**, including Centres for Independent Living; housing agencies; employment agencies; etc.
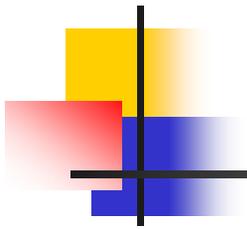
Independent Living Movement

- This movement started just before Grunewald wrote his typology

- It is now international, with the headquarters of **"Disabled Peoples International"** in Canada
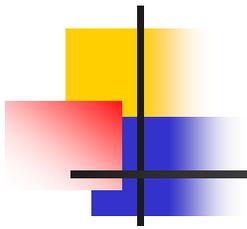
Independent Living Movement

- There are now regional bodies, national bodies and many thousands of local groups of people with disabilities around the world

- They work to the same value system and the same objectives of overcoming disablism in society and achieving equal human rights
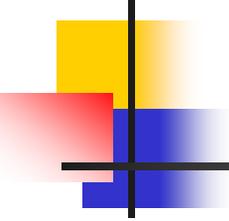
Independent Living Movement

Last equal rights social movement

"To boldly go where everyone else has been before"

Objective (slogan) of one DPO in South Africa
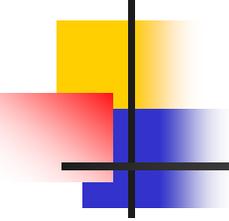
Definitions

- Independent living has nothing to do with living alone and being without support

- Independence is a state of mind, not of body
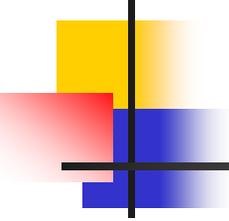
Definitions

- Nobody is 'independent' today; we all require one another to live and flourish

- What makes us **'somebody'** is our ability to decide what to do and have the resources to go out and do it
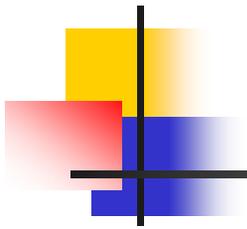
ILM Value System

- **All human life is of equal value**

- **Anyone, whatever their impairment, is capable of exerting choices**
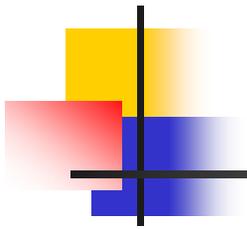
ILM Value System

- **People who are disabled by society's reaction to impairment (physical, sensory or psychological) have the right to assert control over their lives**

- **People with disabilities have the right to participate fully in society**
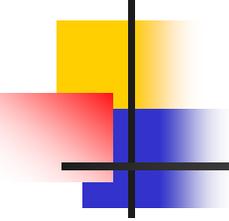
Independent Living empowers people …

To choose and control the ....

- WHO
- WHAT
- WHEN
- WHERE
- HOW

of personal assistance.

Whereas, Direct Payments

… are the instruments of that empowerment
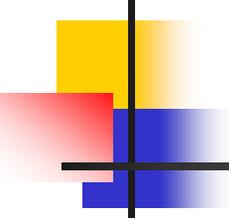
In Scotland, a direct payment is ....

- Money given directly to the person with a disability instead of a direct service (home care, or day care, etc.)
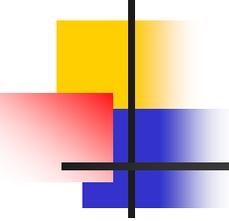
Eligibility for a direct payment ....

- The person must be 'eligible' for such care, according to local criteria

- In addition, **the person must be** assessed as being **'willing and able' (with support)** to use a direct payment
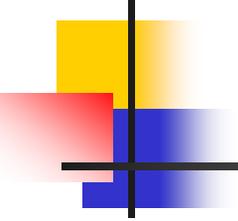
Direct payments can be used:

- To employ a Personal Assistant (helper)

- To engage a home care agency
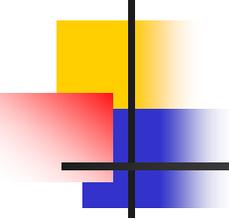
Direct payments can be used:

- To buy equipment to aid personal care

- To buy services from another local social service authority
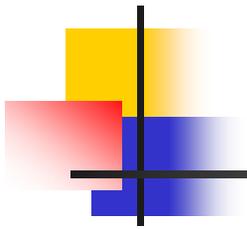
"Willing and Able" (with support)

- I'd like to spend a few minutes on this concept of "willing and able" (with support)

- I believe everyone should be allowed to make the choices and take the responsibility for those choices that they wish to make and take
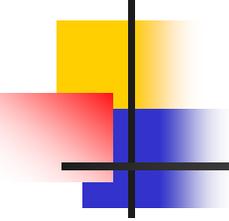
"Willing and Able" (with support)

- They should not be forced to do so

- **But if they do, then they should be given as much advice and support as they need**
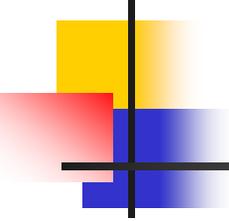
"Willing and Able"
(with support)

- Traditionally, such advice and support regarding direct payments has come from people with disabilities ourselves
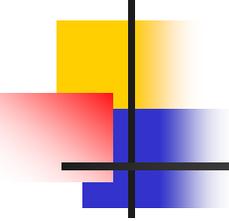
"Willing and Able" (with support)

- But now, in Scotland, direct payments are open to consumers of social services, who have no disabilities; and they may look elsewhere for support,

  - e.g. refugees or drug and alcohol abusers
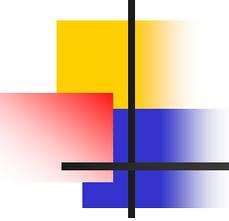
Support for Direct Payments now comes from:

- Centres for Independent Living

  (also called Centres for Integrated or Inclusive Living)

- Local / national direct payment support organisations
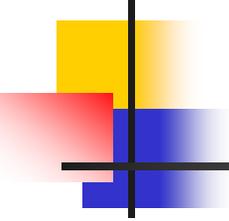
Support for Direct Payments may come from:

- Service brokerages

- Circles of Friends

- Individual Trusts
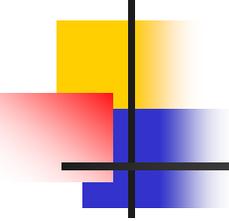
Support for Direct Payments may come from:

- Family members (carers)

  - However, without strong independent advocacy, it is often difficult to ensure that the money spent is for the benefit of the person with a disability rather than the family member
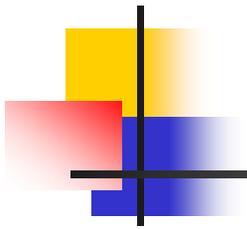
What is a Centre for Independent Living

- A CIL is a local democratic membership organisation run and controlled by people with disabilities.
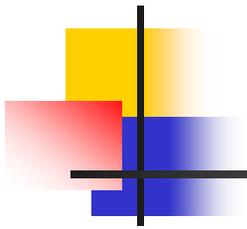
What is a Centre for Independent Living

- A CIL is committed to campaign for the full civil rights of people with disabilities
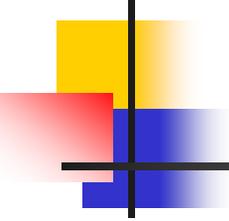
What is a
Centre for Independent Living

- Whilst supporting people to make use of current provisions (in housing, employment, personal assistance, etc) which are available to enable them to live independently within the community.
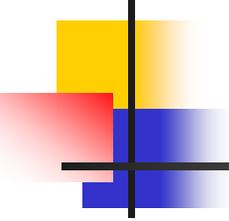
Scottish Personal Assistance Employers Network

- SPAEN is not a local CIL

- It is a Scotland-wide organisation run by people with disabilities

- To help those employing their own support staff to be proficient employers
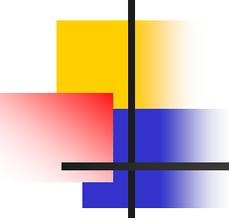
Scottish Personal Assistance Employers Network

- Membership – 350 PA Employers, mainly in rural communities or places with no local support organisation

- Advice / support on Human Resources, employment law, direct payments, independent living
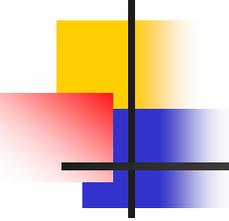
The Importance of User-Led Support

- In the both the UK and the EU, it's agreed government policy

- Direct Payments – outcome of our independent living history

- Services based on the lived experience of people with disabilities
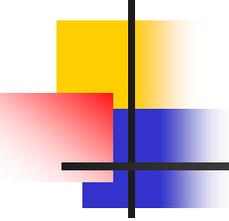
The Importance of User-Led Support

- Services such as:
  - Peer support and advocacy by people with disabilities
  - Information interpreted by people with disabilities
  - Training by people with disabilities
  - Outreach by people with disabilities
  - Political involvement by people with disabilities
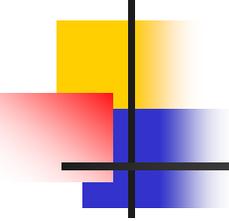
Around the world CILs provide different functions

- Most provide assistance with the management of personal assistants (support staff) and finance

- Some, like those in Mexico, also provide wheelchairs and a wheelchair repair service

- In Glasgow, we also help people with disabilities find housing and employment
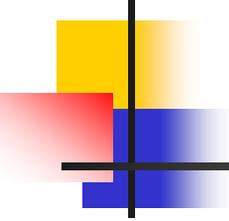
Around the world CILs provide different functions

- In Glasgow, our members hold the direct payment in *their own* bank accounts and we supply the advice and support to the management of individual accounts

- In Stockholm, the CIL holds its members direct payments in *its own* bank account and manages the money for them
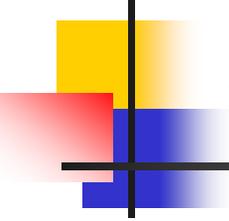
However, especially for those with complex, multiple impairments, other types of support systems have been developed ...

- **Advocacy services** – where the person is supported on a one to one basis to make and execute a decision
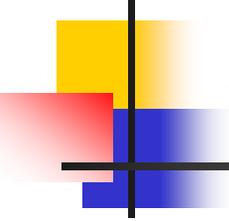
However, especially for those with complex, multiple impairments, other types of support systems have been developed …

- **Circles of support** – here, networks of family members, supporters and friends, who know the person well, can make decisions to which the person freely consents

  - But it is always best to have a **trained independent advocate** as part of **the circle**, to ensure the circle operates to the satisfaction of the person – not the family, supporters, or friends
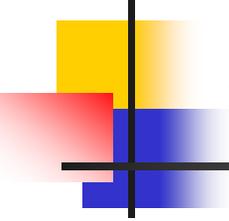
However, especially for those with complex, multiple impairments, other types of support systems have been developed …

- **User controlled independent living trusts** – which is very much like a circle of friends but with a legal structure that sets up the necessary framework of decision-making around the individual
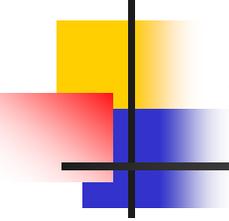
However, especially for those with complex, multiple impairments, other types of support systems have been developed ...

- **Service brokerage** – where a skilled supporter enables someone to look at what they want and need.
  - They may offer advocacy in the assessment process and support in implementing assistance packages
  - They can also act as the named employer of support for an individual if required.
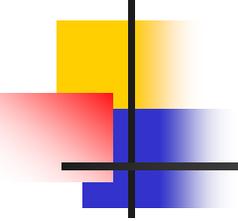
Barriers to the development of the Independent Living Movement

- **Lack of motivation** – people with disabilities and professionals alike

- **Lack of resources** – financial, skills, aptitudes
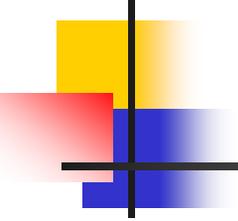
Barriers to the development of the Independent Living Movement

- **Prior experience** – poor governance, recipient of services, 'social clubs'

- **Fixed Budget lines** – funding inflexibility
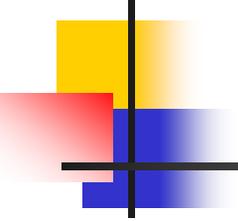
Barriers to the development of the Independent Living Movement

- **Competitive organisations** - from organisations pretending to be 'user-led', when they are not

- **Competitive tendering** – cheapest rather than best value
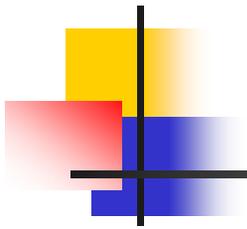
The ILM can't overcome these barriers on their own

- It requires a systemic change in the framework and organisational behaviour of personal support systems in the community at large, putting the person with a disability in the driving seat
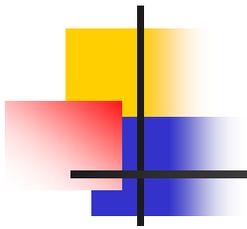
The ILM can't overcome these barriers on their own

- Existing services and organisations must become part of the solution, not the problem

- It requires a substantial increase in the capacity building of organisations of people with disabilities
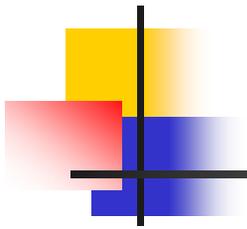
Need for allies

Such systemic change requires;

- An alliance between organisations of people with disabilities and traditional organisations
- The traditional organisations must address the challenge of systemic change within themselves
- The alliance must work within the principle of 'co-production'
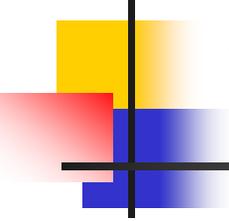
But Allies Need People with disabilities too …

- Co-production is not a one-way street

- Traditional organisations are beginning to realise that if they wish to operate in modern market of social services, they must change
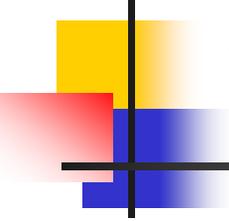
But Allies Need People with disabilities too ...

- And to do that they must work with people with disabilities as our allies in the community
  - First to support our equal participation as citizens
  - Second, to campaign with us against disablism within society and for our equal human rights
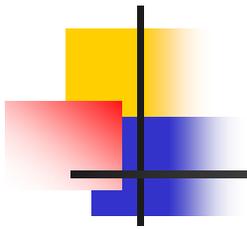
Co-Production

- Recognises the value of the contribution people with disabilities can make from their lived experience

- Puts people with disabilities in the driving seat of any service development or service delivery
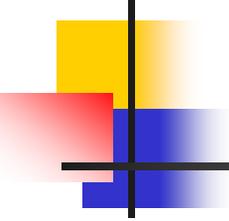
Co-Production

- Provides able-bodied people with the role of a supportive ally
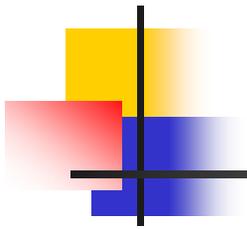
A Word of Warning

- As with Grunewald's original typology, this extended typology is not linear, nor progressive, nor exhaustive

- User-led and co-produced services, as with those others in the original typology, can co-exist
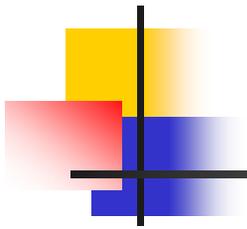
A Word of Warning

- It is imperative, however, that user-led services must be sustained, otherwise choice, self-actualisation and rightful place of people with disabilities in society will never be achieved
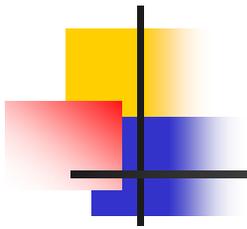
Scope

- Established in 1952, Scope is a traditional charitable organisation for people with cerebral palsy, as is it's sister organisation in Scotland, Capability, which opened its doors 5 years earlier, in 1947.
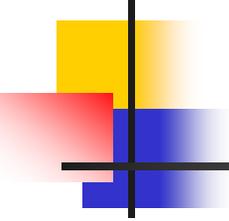
Scope

- Here, you can see Grunewald's **'diagnostic'** stage,

  - e.g. from having the generic label, 'mentally retarded' (and therefore 'uneducable') at the age of 7, I was labelled 'cerebral palsied' and 'educable'
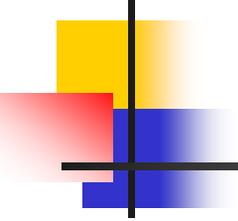
Scope

- Scope opened several segregated schools, day centres, sheltered workshops and residential care homes for those with CP
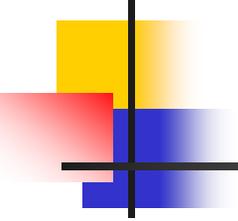
Scope

- Here, you can identify Grunewald's **'specialisation'** and **'differentiation'** stages
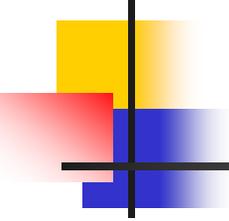
Scope

- Now it wishes to have a cultural and organisational change and is using the principles of
    - **Diversification** of its labour (employing more disabled people in both managerial and non-managerial positions)
    - And **co-production** of the transformation of its services to do so
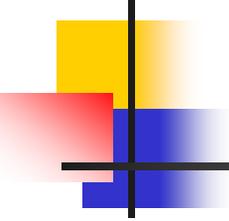
Scope

- To develop 'co-production' Scope has adopted the principle of a 'trading zone'.
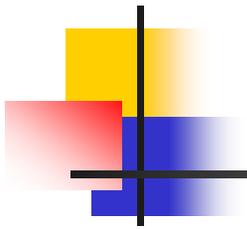
Trading Zones

- Have nothing to do with commerce
- They came from the world of academia where the value of the cross fertilisation of ideas from different disciplines was realised.
- The 'trading' metaphor supposes equal exchange of ideas, skills and experience
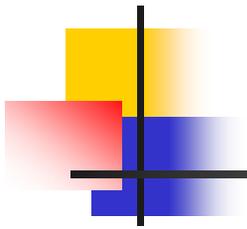
Trading Zones

- They are places where people come together bringing with them something seen by all as being of value

- After exchange and interaction, people leave with something of benefit
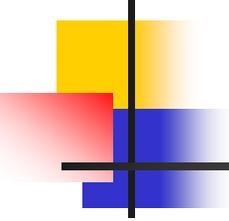
Scope's ILzone

- Is a group of people with disabilities from the British independent living movement and representatives of Scope
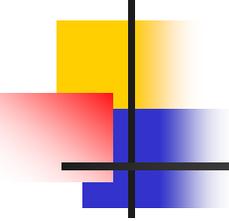
Scope's ILzone

- Each group recognises the other's legitimacy and value
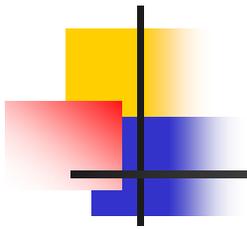
Scope's **IL**zone

- All have a common goal – to close segregative institutions, promote independent living in the community and challenge disablism within general social policy and services
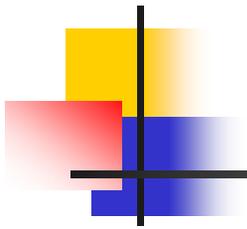
Scope's ILzone

PURPOSE:

- To discuss and promote independent living in terms of policy and practice – locally, nationally and internationally.
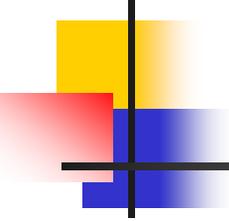
Scope's ILzone

And

- In so doing, to guide, challenge, and advise Scope in its programme of service reform
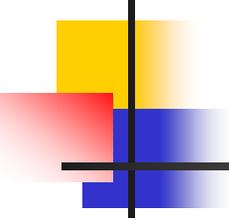
Scope's ILzone

- So far, the ILzone has advised on

    - the closure of two care homes
    - their new admissions policy and
    - its transformation of institutionalised services to those based on the principles and practices of independent living
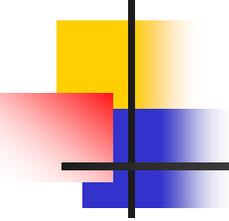
Scope's ILzone

- Published research on independent living in the community

- Campaigned for a parliamentary bill giving people with disabilities the right to independent living
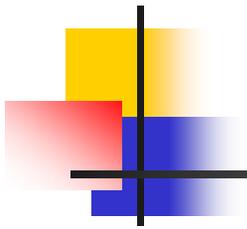
Conclusion

- In today's presentation I have described the role played by people with disabilities in the development of social services, in the UK in particular, but with reference elsewhere
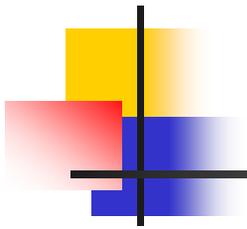
Conclusion

- This has been one from passive recipient of services to one of active planner and manager of them

- I have described how this transformation has been brought about by the thinking and actions of people with disabilities, ourselves
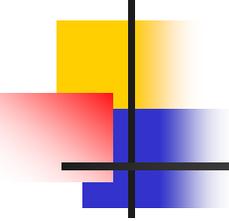
Conclusion

- I have illustrated with examples of both service provision by people with disabilities and co-produced planning alongside people with disabilities

- I should like to leave you with one thought .....
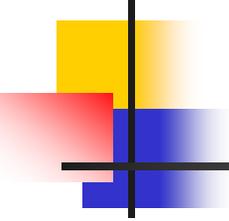
Epilogue

- If the benefits of co-production were to be proved within the realm of social services for people with disabilities

  - **in terms of value for money and quality of life outcomes**
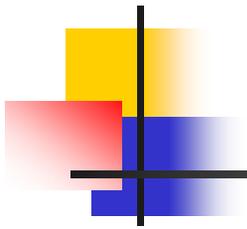
Epilogue

- What benefits would accrue if the principles and practice of co-production were applied to other parts of society and within other organisations for the general public?
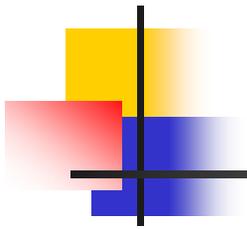
Epilogue

- **Would the full equality and citizenship of people with disabilities in society at large be better secured?**