**Philosophy**

Q. 1. How would you characterise the traditional service philosophy in the context of disability?

Q.2. What difference do you think the UN Convention on the Rights of Persons with Disabilities makes? Does it point away from an old philosophy? If so, what are the core elements of the new philosophy?

Q.3. Do you think the new philosophy requires a new vocabulary (away from the language of services and care?) and a new vision for the role of the State?

**Policy**

Q.1. Has the traditional service paradigm worked? What are its successes? What are its failings?

Q.2. What tools (old and new) does the State have at its disposal to bring about change in the service paradigm (e.g., devolved budgets, the use of AI to individualise services, connecting services to community engagement, public procurement, competition law, incentives to new market entrants)? What is the experience so far?

Q.3. What would a new policy look like – in States with established service systems and resources and in States lacking the same. Can (should) States factor in other flanking policies having to do, e.g., with care and informal carers?

**New Business Models**

Q.1 How would you characterise the traditional business model of service providers?

Q.2. Do (should) service providers see themselves as active participants in the achievement of ’business & human rights’? What difference does (should) this make to their business model?

Q.3. What policy shifts are needed to create space for new business models to take hold?

Inclusion Europe contribution in response to the consultation, and questions of the 7 September 2022 hearing organised by the Special Rapporteur.

## Can person-centred services arise from service-centred approach?

Formal support services are not – and should not be – the centre of people’s lives.

They cannot be at the centre of policy design either.

Service providers should not replace general public services (health care, education, housing…), nor the daily support people get from and provide to others (without thinking about it as “support”).

When general public services don’t work, social care services often “step in”.

Resolving the original issue (getting people housing) is way to solving what demonstrates as a problem in social care (residential services, and related issues).

The work needs to focus on and start in a different place: To make the general public policy work (so people can have housing). Not centred on service provision, and trying to square that circle.

Family-, and other informal support cannot be treated as an aside (and branded as “flanking”).

In Europe, “as much as 80% of all long-term care is provided by informal carers.”[[1]](#footnote-2)

Support policies and provision must take this into account, and ensure that:

* people with disabilities receive support they need,
* while families can be just that – families (not full time „care providers“, „care administrators“ etc.)

## It is necessary to lead by example

Calls for “transformative change” based on participation, “co-production”, inclusion, shared decision-making etc. carry much more weight when they are not just calls, but a practice.

Every attempt to re-design policy to be inclusive, participative… is an opportunity to demonstrate the power of these principles when put to practice.

Wasting such opportunity is detrimental to rightful calls and demands for participation.

**Language matters**

Language can be a source of understanding, or of confusion.

Language can be a way to include people to talk about things that matter in their daily lives, or of excluding them from “expert” policy debates full of big words and abstract concepts.

To transform services in the way envisioned in this consultation, language has a key role.

* Language people have been using for ages to talk about their lives, homes, support...
* Language that helps people understand, participate, and contribute.
* Language that can draw people towards a shared, desirable vision.[[2]](#footnote-3)

**What is wrong with current system of current system of service provision**

It is quite easy to observe negative characteristics of the prevailing approach to providing services to people with intellectual disabilities.

* Reducing people to their (presumed) physical needs;
As if they don’t have emotional, psychological side to their existence.
* Reducing people to “service-users”, “clients“, or “care-receivers”;
As if disability and care are the only thing that defines them, and as if care is a one way street.
* Depriving people of their capacity and agency, not only directly by removing their legal capacity, but indirectly by removing and limiting the possibility to act with the procedures and language used.
* Treating people by groups, as if one size fits all.
As if individual characteristics, “specific” human conditions are a bug, not a feature.
* Pretending that service provision is the centre of the world;
As if the vast majority of support and care is not provided by “informal carers”, family members etc.
And as if there aren’t other ways of getting and providing support within the societies we live in.
* Focusing on “security”, and organising around buildings.
Instead of being focused on person’s happiness, fulfilment;
and being organised around the person within their social relations.

We could go on, after all, we see and feel the negative elements all day every day:

* People being left without any support at all.
* People being segregated in “care” institutions.
* People being deprived of their ambitions, their rights, the possibility to belong.
* Families of people with disabilities treated as (more of less un-acknowledged) care-providers, administrators, service coordinators… Anything but family members.

## Why is the “new” approach not working as much and as well as desired?

Haven’t several countries[[3]](#footnote-4) implemented human rights-based, person-centred policies decades ago, seriously transforming their previous service system?

Don’t most countries have (in various degrees of availability) well established individual service based on these principles?

It would be important to recognise this, to learn from it, and to use it to illustrate that “better is possible”.

## How does the “new” approach resolve prevailing problems?

People with complex support needs are mostly left out of those benefiting from the above mentioned changes.

Still reduced to their physical needs, still waiting for someone to do something and some activity to start, still being surrounded by groups of people yet being alone.[[4]](#footnote-5)

A lot in the “new” approach is based on and leads to the same one-size-fits all ideas.

Pretending that specific human conditions are a bug, not a feature of human existence.

Stripping people of their “social self” (their mutually valuable relations with others), and viewing them as solely “individual”, not in a mutually beneficial relationships with other humans.

Reducing “care” to the binary of “care giver” and “care receiver”. Which is not how most people experience it.[[5]](#footnote-6)

## It is not enough to declare things

Key part of ushering in “transformative change” is helping others to see clearly the vision of what that change should deliver, and how to get there.

Talking only about things that are wrong frustrates people, and discourages activity to change.

People need to see what the vision is, how it works in practice, and what role they have in achieving it. It is not enough to simply declare something to be right.

This is, again, why language matters.

As does providing people with examples and ideas about how the vision works. Showing that it already works.

This means it is important to speak to people who make and implement laws,
to people who decide about money, to people who invent policies.

To speak to them in a way that is relevant to their situations, and understandable in their language and context.

Not everyone is a lawyer, and not everybody needs a legal text for them to be able to participate in achieving the vision.

## “One problem is that people often don’t know what good looks like. What they should get from services.”[[6]](#footnote-7)

The “new” policy needs to be very specific in desired outcomes, and in ways it should be implemented.

And there need to be ways of measuring progress towards those objectives.

Evaluation of this progress needs to include people with disabilities. And it needs to include evaluation of support services by people with disabilities.

## Disability-related budgeting

To think only of “business model” of service provision is reducing the issue.

Perhaps it would make sense to think of it as “disability-related budgeting”.

This includes not only "the care industrial complex”[[7]](#footnote-8), but also disability (and other) benefits.

It also includes the large sector of foundations, philanthropists, NGOs, academia, media... and other organisations that benefit from disability-related money.

They “work on disability issues”, talk about people with disabilities, research people with disabilities, write reports about people with disabilities... profit from people with disabilities.

Organisations with this money can also afford to participate in, and influence policies.

It would be important to think of the “business model” questions from this perspective too.

1. Informal care in Europe, 2019. <https://ec.europa.eu/social/BlobServlet?docId=19681&langId=en>, page 7 [↑](#footnote-ref-2)
2. How to build public support to transform social care; research and practical guidance. <https://socialcarefuture.org.uk/publications/> [↑](#footnote-ref-3)
3. In Europe at least UK, Scandinavian countries. [↑](#footnote-ref-4)
4. Vehmas, Mietola: Narrowed lives. 2021. <https://stockholmuniversitypress.se/site/books/m/10.16993/bbl/> [↑](#footnote-ref-5)
5. Interview with Neil Crowther, Inclusion Europe Radio, October 2022. [↑](#footnote-ref-6)
6. <https://www.inclusion-europe.eu/quality-of-life-and-services-for-people-with-disabilities-in-conversation-with-julie-beadle-brown-and-jan-siska-on-inclusion-europe-radio/> [↑](#footnote-ref-7)
7. Term used during the 7 September hearing. [↑](#footnote-ref-8)