



The Problem with Quality of Life

Thoughts on the framing of disability strategy

A DISCUSSION PAPER FROM CITIZEN NETWORK RESEARCH

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Summary

Progress has been made on the journey towards human rights and citizenship for people with disabilities. Large institutions are now seen as unacceptable, human right standards have been defined by the United Nations and accepted by many nation states. There have been innovations in support, personalisation, self-direction and independent living. However, it is also clear that there are different ideas about where this journey should take us.

This paper is a reflection on the EURECO Forum in March 2022, where academics and professionals discussed the concept of Quality of Life. It share several concerns:

- People with disabilities were rather absent and insufficient weight was given to ideas like human rights, entitlements and self-determination.
- Some felt that deinstitutionalisation was nearly complete and that we should be seeking a new stasis, built on current norms of good practice. There was no acknowledgment of the re-emergence forms of eugenics, institutionalisation and discrimination nor of the possibility of much greater levels of inclusion and citizenship than are currently being achieved.
- There was too much faith in the capacity of government, academia and services to establish new systems to achieve Quality of Life for people with disabilities. The hazards of hubris, objectification and commodification didn't get the attention they might.

This is not to suggest that the conference was anything other than a positive effort to assess where we currently stand and the challenges ahead. However we must be cautious because there are still too many threats to the rights of people with disabilities

We need to create a bold vision of equal citizenship for all and move beyond standards that are still set too low.

Introduction

I was very pleased to attend the EURECO Forum in March 2022. This was my first work trip out of Yorkshire since the beginning of pandemic in two years ago. It was lovely to be able to meet old friends and new people and to think and debate with them about a range of interconnected problems. This is perhaps rather a long reflection on some of the topics we discussed. The fact that it is rather open-ended and uncertain reflects the fact that I am still rather confused by some of the issues it raised.

However, at the heart of these debates is, in my opinion, a profound challenge which many of us are struggling to address, which we might put in the form of a question:

Is deinstitutionalisation nearly finished or have we only just begun?

EURECO is a partnership between EASPD (the European umbrella body for service providers for disability) IASSIDD, ZonMW, ZPE and Disability Studies in the Netherlands. Its purpose is to help clarify the research questions that surround disability services. Nadia Hadad, a representative of ENIL, was present and made several important interventions during the first day. However I think the voices of people with disabilities were rather under-represented during the conference and I suspect that this had a significant impact on the debate.

Personal Budgets

My own role was to represent the UNIC Project. This is a pan-European project to define a new way of organising the funding of all Long-Term Care and Support in order to ensure everyone who needs support gets a Personal Budget in order to control that support (www.unicproject.eu). Building on 58 years of practical work across many different countries there is much we know about how to fund support services in this way (UNIC, 2021). For the first time, to my knowledge, we've established guidelines for all EU states on Personal Budgets and these guidelines describe a holistic model that could work for people of all ages and all abilities (Duffy, 2021a).

I think this is exciting because it offers a universal approach to organising support that is built on human rights and seeks to support everyone as a citizen: with entitlements, responsibilities and equal status within the life of the community; what we can also call independent living or inclusion. However, as Lynn Breedlove notices Personal Budgets can be interpreted as a means to advance citizenship or as part of a consumerist approach to public service reform, and these are very different things:

“Without a clear and forthright statement regarding this goal of self-direction and the importance of truly informed choice (which results in most people choosing community participation if they can see it happening for someone else and they believe they will be supported in it), it is possible that (so-called) ‘self-direction’ could be used to facilitate segregation. Self-direction advocates need to develop safeguards to prevent that.”

Breedlove L (2020) *Self-Direction Worldwide: contrasting beliefs and their impact on practice*. Sheffield: Centre for Welfare Reform. p. 17

But our project is also challenging because there is much we don't know. The fact that it has taken us 58 years to get where we are today - which is not very far down the road to full citizenship - tells us that change is hard and that resistance to change is high (Duffy, 2018).

The objectives of the UNIC Project are ambitious and the methodology is innovative and uncertain. Essentially we are trying to use a system of self-assessment surveys to help people, organisations and systems to evaluate

their own progress and to find better strategies to move forward. This process is primarily being tested within the Flemish funding organisation - VAPH - and has the support of researchers from Ghent University, Faculty of Medicine and Health Sciences, Department of Rehabilitation Sciences and the Disability Federation of Ireland. There are also further efforts to test this approach in Finland, Austria, Czechia and Spain.

Over the two day of the EURECO event the topic of Personal Budgets often rose to the surface, either in a negative or in a positive way. It was clear that many in the audience recognise that shifting power and control to people with disabilities is an essential strategy for inclusion and independent living. But I also sensed that many people were worried or confused by Personal Budgets and more than one person characterised Personal Budgets as a neoliberal strategy to reduce costs. This ambiguity and uncertainty was mirrored in many other discussions of key topics.

Human Rights

One of the most striking, and heartening, things from an English perspective was the priority that the EU and all the delegates give to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as a starting point for thinking about services and service change. There is a strong awareness that human rights, and more particularly the rights of people with disabilities, should now be in the driving seat. Given the UK Government's general disregard for human and disability rights in the past 13 years this commitment to human rights in Europe is encouraging (Duffy & Gillberg, 2018).

But what is less clear is how to make these rights real. Personally I think an important distinction should be made between rights and entitlements. An entitlement is the concrete and practical form that a right takes in real life. So for example, we may talk about our rights to inclusion and independent living; but do I also have real entitlements that make those rights real?

- An entitlement to receive support—rather than sitting on a waiting list
- An entitlement to define that support—rather than being given just what the service has available
- An entitlement to an accessible home of my own, in my own community— not a place in a care home
- An entitlement to work or participate in the life of my community— not a place in a day care centre

Although this issue was touched upon it was not really part of the conversation. It feels like we like the sound of rights, but we're not so sure about living up to our entitlements. For of course, we can only create an entitlement if we are prepared, as a community, to define the corresponding duty: both the precise nature of the duty is and who is expected to fulfil it.

Quality of Life

Although human rights were acknowledged as an important principle, it was the concept of Quality of Life (QOL) that dominated most of the discussions. There were multiple presentations and Julie Beadle-Brown began the event by outlining the comprehensive work she and her colleagues had been doing to refining the framework for measuring the quality of life first developed by Schalock and colleagues (Schalock & Siperstein, 1996).

I won't be able to do justice to this framework or to the discussions around how to apply it. Essentially the model pulls together a heterogeneous set of 8 domains and within each domain there are then a series of measures that can be used to determine the quality of someone's life (Šiška & Beadle-Brown, 2021).

These eight domains are:

1. Emotional well-being
2. Interpersonal relationships
3. Self-determination
4. Social inclusion
5. Material well-being
6. Personal development
7. Rights
8. Physical well-being

Now, whatever one thinks about this particular framework, there is certainly something very plausible about the idea that we all want a high quality life for ourselves, and that we should want other people to have a high quality life. In fact one of the participants asked, if a quality life is so important why is it not listed as a human right. One response to that is to argue that respect for human rights does in some way produce quality of life. Another possible response is to note that rights are actually part of the QOL framework. So there may be no conflict here.

However there is another possible way of looking at this. In my opinion QOL is derived naturally from the philosophical theory known as utilitarianism. Roughly speaking this theory proposes that, in our personal lives or in our political or social systems, it is our job to maximise happiness. What is happiness? Well there have been many attempts to define it, but QOL is one tool that defines what happiness is. Again this all seems very plausible.

But there is a problem, a big problem.

Speaking as a philosopher the problem with utilitarianism is that it is a bad theory. Maybe that is too strong. But certainly it is hard to find many philosophers who think it is a good theory. There are a few, but they are scarce. In fact one of the most well known contemporary utilitarian philosopher is Peter Singer, the co-author of *Should the Baby Live? The Problem of Handicapped Infants* (Singer & Kuhse, 1985). Just in case you don't know Singer says: no, handicapped babies should not be allowed to live, because they will have a poor quality of life and they will reduce the quality of life of their parents and society generally. This touches on one of the major reasons that most philosophers worry about utilitarianism, for the theory seems to give us permission to end the lives of people who may be unhappy, not happy enough or who maybe causing other people unhappiness.

Utilitarians also tend to be rather sceptical of rights: we don't have a human right to life or to anything else. Rights may be treated as a potentially useful social inventions, if they are helpful in creating greater happiness. But ultimately human rights are, as the inventor of utilitarianism, Jeremy Bentham, puts it:

| “Nonsense on stilts”

There is in fact a long-standing intellectual war between advocates of rights and advocates of utilitarianism (Waldron, 1987). This is not the place to rehearse the details of those battles, but this fact should warn us that we should not expect to easily reconcile quality of life and human rights; they are ideas cut from very different cloth.

If we put that deep philosophical conflict in the background I must admit to having several other reasons why giving too much emphasis on QOL makes me uneasy. I will briefly run through some of my anxieties.

From QOL to QALY

Another utilitarian concept that is found in social sciences, especially in medicine, is the Quality Adjusted Life Year (QALY). Now this is much less sophisticated than QOL, it is a way of estimating the impact of a medical procedure on extending someone's life and it reduces the value of the procedure if someone already has or will acquire some kind of impairment. So, if I have Down Syndrome and I need an operation that might extend my life by ten years the value of that operation will be reduced because the QALY system thinks that ten years of my years will be of a lower quality than ten years of life lived by someone without Down Syndrome. This is a modern form of eugenics: a year in the life of a person with disabilities is somehow worth less than year of life of someone without disabilities. Yes, really!!

Although QOL is not QALY it certainly does seem to presume it can evaluate the quality of someone's life by reference to the level of their disability. But why does someone having a disability somehow worsen the quality of their life, especially if they are born with the disability? The assumption seems to be sheer prejudice. Moreover, we also have evidence that suggests that disability can be correlated with a higher quality of life, for example:

“More than 70% said their family was stronger because of the family member with a disability. Almost 90% said that wonderful people had come into their lives. Almost 90% said they had learned what is really important in life. Over 50% said that they now laugh more and are less bothered by trivial things.”

McConnell D et al. (2013) Family Life: Children with Disabilities and the Fabric of Everyday Family Life.

In fact, in my experience, families often say that it is their relationship with services that starts to damage the quality of their lives. So, my worry is that QOL endangers, rather than protects the lives of people with disabilities, both by daring to measure the quality of someone's life in the first place, and then by finding that the lives of disabled people are in some way lacking (which is always a dangerous assumption, and which also seems to be contrary to the evidence).

Practicalities

My second big worry is much more prosaic and it may very well just be my problem. But as someone who has tried to help some folk with learning disabilities, who has created and managed support organisations, and who has also commissioned and contracted support organisations, I cannot really imagine using a QOL framework in practice. It seems wildly ambitious, far too complex and utterly unwieldy. Who has the time for all that?

Surely it is people themselves, with their dreams, rightful demands and clear entitlements, who should be shaping support services. And as a professional I don't need to use a quality framework to determine the quality of residential care; instead I just need to help the person I am working with to find the home they want and to secure the assistance they need to live there. Interestingly one presenter, Marije Blok from the Leyden Academy on Vitality and Ageing, presented a very different tool for exploring quality of life; but through the exchange of stories and the sharing of experiences between people, families and paid support staff. I liked the sound of this, both because I could imagine using it, but also because it seemed simple and respectful. Telling stories is one of the most important human activity for connecting and for making sense of each other's perspectives. Stories are not wrong. They don't get marked, but they can teach us so much.

In fact I remember, early on in my career, being involved in an early experiment in the application of a QOL tool in a residential care setting. In this case researchers sat in people's houses and carefully noted down how people and staff interacted. I was never persuaded by this model, primarily because it seemed so weird, unnatural and inevitably self-defeating. Doing something while a stranger sits, watches and marks what you are doing is obviously going to change what you do. The intervention seemed more likely to breed suspicion, fear and mistrust.

Also I had a very peculiar conversation with one of those same researchers. We were sitting together in the sunshine after a seminar and I asked him about the people he was working with. Could he tell me any stories about people's lives in these services? He stared back blankly. I tried again, several times, in different ways to elicit some sense of the life of the human beings he was there to observe. Finally my boss quietly prodded me and whispered:

| *"Don't you realise? He doesn't know any stories."*

I worry about any system that seems to exacerbate the differences between us, which leaves us alienated or dehumanised. I prefer the stories.

Invisible Institutions

The other problem I have with QOL is that I don't use it for myself, for my family or for anyone I care about. In fact it doesn't seem to have been designed for ordinary life; it seems to have been designed for academic life. How can we encourage inclusion and the enjoyment of mainstream life by all of us if only some of us are being checked and evaluated by these special measures?

Of course I don't use it because I don't belong inside a service. The underlying assumption of this model is that people live in a world of services and that it is the responsibility of those services to create the conditions for the person to have a higher QOL. Moreover it also assumes that the tool can be used to create better support from staff, better services, better regulation of services and better commissioning of services. Ultimately the hope is that all of these things can be improved in the light of the QOL standards.

This seems so rational and reasonable.

But I worry for two reasons. First I think we should be discouraging the idea that people do belong in services; we all belong together in community. If we cannot find a useful way of applying the QOL framework in a community I don't think it will be helpful as a way of getting people out of services into community nor of building the communities we need to include everyone.

Second, I do not see the evidence that QOL can do what it hopes to do. These frameworks have been around a long time. They may be improving as frameworks. But I do not see them improving as effective tools for service improvement. At best I think they can be very useful tools for research, for one-off experiments to compare different services, or for trials of new approaches.

I recognise that current social care regulation systems are not really using the kind of QOL outlined by Julie Beadle-Brown, but even the simpler systems they use don't work. Regulation in the UK does not drive up standards, does not promote innovation, does not spot abuse. Instead regulation merely enables better funded services to manage the presentation of their services so that they are deemed to comply. Moreover, as registration has been increasingly centralised, it has become increasingly detached and incompetent (Jackson, 2015; Burton, 2017).

The central confusion might be, as Alice Schippers observed in our correspondence, a slippage from Quality of Life as theoretical framework, which can be used to explore different dimensions of life, to Quality of Life as a tool: an effort to map, monitor or control our lives. This slippage is all the more dangerous when power is not distributed equally and where other people can decide what is valued and can determine how it is measured or enforced.

Change

One other very interesting talk was given by Dr Johannes Schädler. He reminded us that there are at least two different meanings to the word ‘institution’. Personally, I tend to use the term institution in the sense defined by Goffman and Wolfensberger, a negative and controlling environment—not necessarily physical—but associated in the imagination with the large mental handicap hospitals or mental health asylums (Goffman, 1961). But there is another use of the term ‘institution’ and that is as any kind of enduring, organised social system. This status of this kind of institution may be open for debate, but potentially it is positive. The European Union is an institution, in this positive sense.

His talk explored that factors that seem to have led to positive development in social services in Germany where he is based. He observed that in Germany the three most important factors have been the (1) advocacy by people with disabilities, (2) new forms of policy and commissioning by the government and (3) the copying of innovative practices by organisations who want to appear up to date. He noted that QOL tools have not been a force for change.

As he observed, the idea that individuals or organisations are all motivated by efficiency, profit or money is also nonsense. In the case of Germany it is a combination of democratic political debate and the desire of organisations to enhance their legitimacy that is more influential. But as he rightly indicated, these factors have their own context. Germany is different to England; England is different to France. I also think that he was right to argue that it is the ideological commitment of UK Government’s since Thatcher to market-led approaches that has distorted policy-making in the UK and has pushed out more thoughtful and empirical approaches. The UK’s demons are severe. Although it should be noted that many of us do know that they are demons, even if we’ve not been able to defeat them.

They are not eternal powers governing our society, they are the result of the particular choices of powerful people and the failures of the UK democratic system.

However, while I think his understanding of social change is important and correct we did not agree about the challenge ahead. I argued for radical de-institutionalisation; he argued for re-institutionalisation. This does not mean he wants to return to the days of the mental handicap hospital; but he does think that we need to focus on growing and creating services that function as strong, stable and enduring resources that are freely available for people to use.

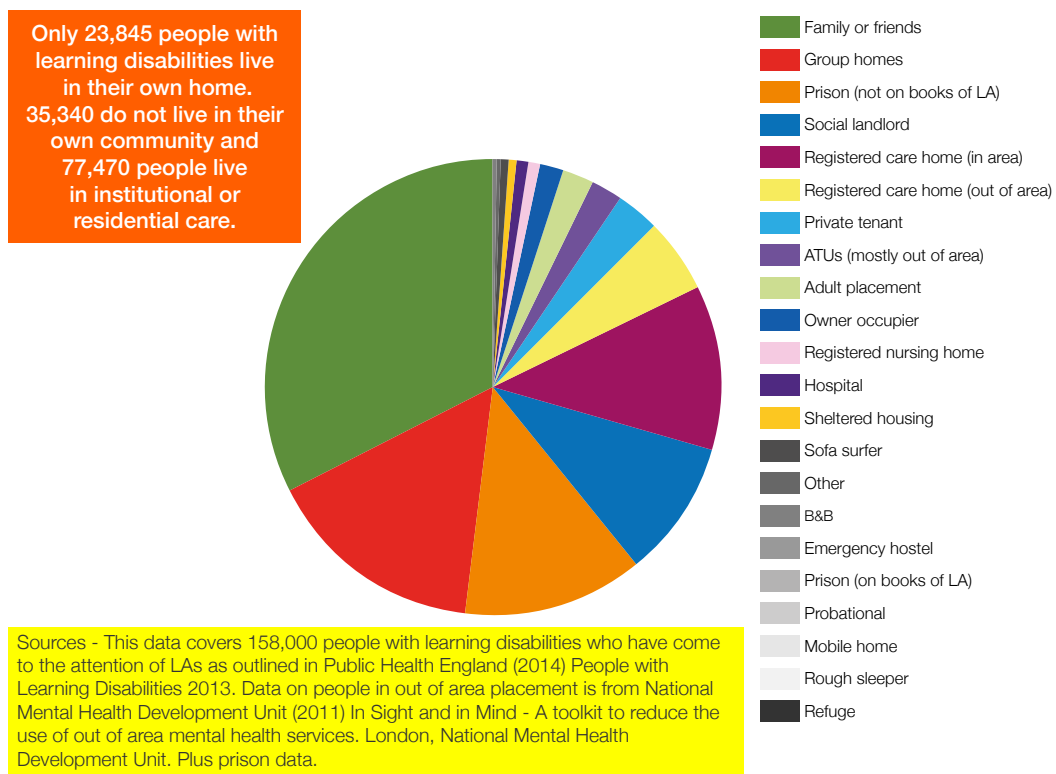


Figure 1 The real level of institutionalisation in England

I am nervous about this way of thinking because I do not think we are anywhere near the point at which we can be broadly happy with disability services as they stand. As Julie Beadle-Brown noted, since 2007 there has been very little change in the numbers of people in institutions around the world. But even more importantly I think our definition of what counts

as an institution is far too narrow. This was brought home to me when another speaker shared data on deinstitutionalisation across Europe. His figures suggested that the UK had 3,400 people in institutions. However I would argue this is to define institutions incorrectly and far too narrowly. In reality there are probably about 77,000 people with learning disabilities in institutions in England (which is only one part of the UK).

For me an institution is a system where you are not in control of your life. So you are in an institution if you are in a prison, a hospital or a specialist unit or residential care service where you can't choose who you live with or who supports you. In practice, when England closed the big institutions, it mostly replaced them with these smaller institutions.

Notice also that, for all the talk about services, a very large number of people with disabilities continue to get all or most of their support from their immediate family. How would the QOL tool apply to a family? Would a family choose such a tool for themselves?

Personalised Support

Thinking about it now I wonder whether my primary problem in communicating the possibility of greater and deeper inclusion is that far too few people seem aware of the practical alternatives to current service models. I suspect that when people hear Personal Budgets or Independent Living they imagine a very capable person with physical disabilities, perhaps using a wheelchair, who employs their own personal assistant and lives in their own accessible accommodation. This often seems to be the only available stereotype:

“I know that Personal Budgets work for those folk. But what about people with more complex needs?”

In fact the keys to supporting people with complex needs well are the principles set out in UNCRPD (United Nations, 2006). People need:

- Access to all housing options—so we can find a home that's right for us
- A Personal Budget that can be used flexibly—so we can respond to new challenges and opportunities immediately
- An individually designed support arrangement—so our power and voice is maximised

- A support team that we or our allies select – to provide thoughtful personalised support.
- Access to all the opportunities that community offers – for a life of meaning with opportunities for friendship, family and love

This is not a pipe-dream; all of this is possible and there are examples of these services scattered around today (Fitzpatrick, 2010; Animate, 2014). But, as Jim Mansell observed, most services continue to fail to offer this kind of personalised support (Mansell, 2010). Curiously this is true even though it is often less expensive to support someone correctly than to place people in increasingly institutional services, which is the normal pattern (Duffy, 2015; Squire & Richmond, 2017).

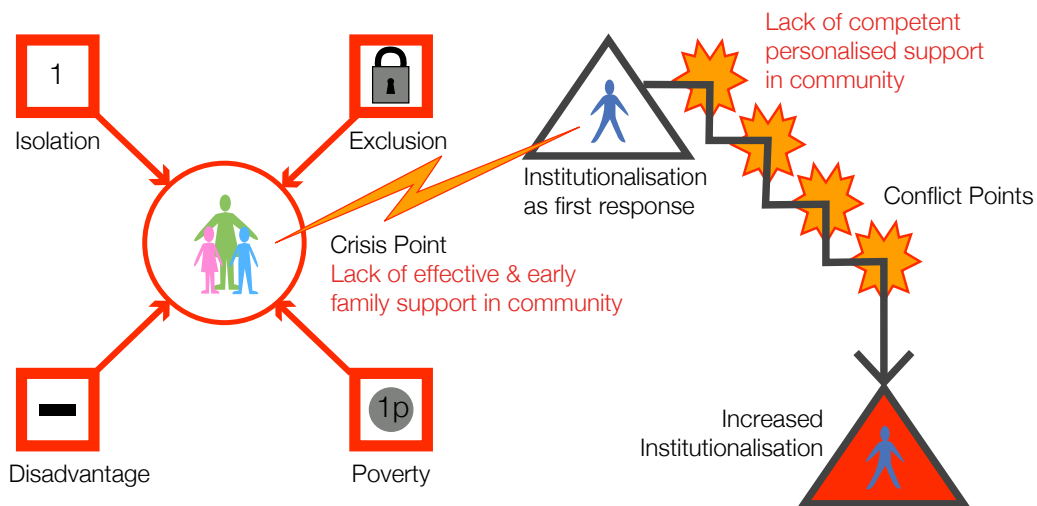


Figure 2. How people end up in institutional care

I don't know why personalised support doesn't seem to have developed in other European countries. However in the UK the primary cause is that the current systems of social work, commissioning and regulation all make it harder to provide small, flexible, innovative and personalised support. Instead the system encourages standardised, bureaucratic and larger forms of service provision. This system also tends to create situation where too many people with disabilities become angry and upset ("acquire challenging behaviour") and find themselves being moved into increasingly institutional services (Duffy, 2013, 2019).

There maybe some common ground here between myself and Johannes Schädler. For in my experience better services must be intentionally created. Shifting power and control to people with disabilities is essential, but it will not be enough. So far we've see no evidence globally that the market will automatically generate the kinds of support we need. Instead the market tends to replicate the forms of support we don't need and which we say we don't want. At the same time, at least in the UK, procurement models of commissioning also fail to create the services they say they want to encourage; instead they create more institutional services.

The Ecology of Citizenship

Another interesting theme of the new kind of thinking that is emerging is a growing awareness of the need to think outside the service system. If life is lived in community then services are at best only a fraction of someone's life. Life is created by the person's exploration of their own gifts and their engagement with the community which can recognise and value those gifts (O'Brien & Mount, 2015).

This is about much more than 'access to mainstream services'. For services offer only a very commodified form of community life. In fact the joy of getting a job, becoming a peer supporter, helping your neighbour, getting involved in politics, campaigning, and all the other ways we can live a life of meaning is not only found in the tasks we do. More important than the tasks are the relationships. People want friendship, recognition, colleagues, family and lovers.

Interestingly this is reflected in a research project which examined a personalised support provider that I had founded in 1996: Inclusion Glasgow. We helped people with very complex needs leave Lennox Castle Hospital (Glasgow's institution). Our approach was utterly personalised:

- Everyone lived in their own home, and only lived with other people if they really wanted to.
- Everyone had their own Personal Budget (which we called an Individual Service Fund)
- Everyone had their own support team, selected by them and where possible friends and family
- Everyone had their own carefully designed support system

This approach was not only successfully supported people with complex needs and, very often, big and negative reputations. It worked because everything was flexible and we were not constrained by grouping people or defining standardised systems. It was also highly efficient, costing no more than group home services.

For example in a report published in 2014 on the work of Inclusion Glasgow (long after I'd left the scene) the researchers found that people's lives had significantly improved since they had started working with Inclusion Glasgow (Animate, 2014). But when people were asked to explain how their lives had improved people only assigned only 32% of the responsibility for such improvements to the organisation. The remaining 68% was assigned to things outside the direct control of the support provider.

People identified the factors that had led to the improvements in their lives:

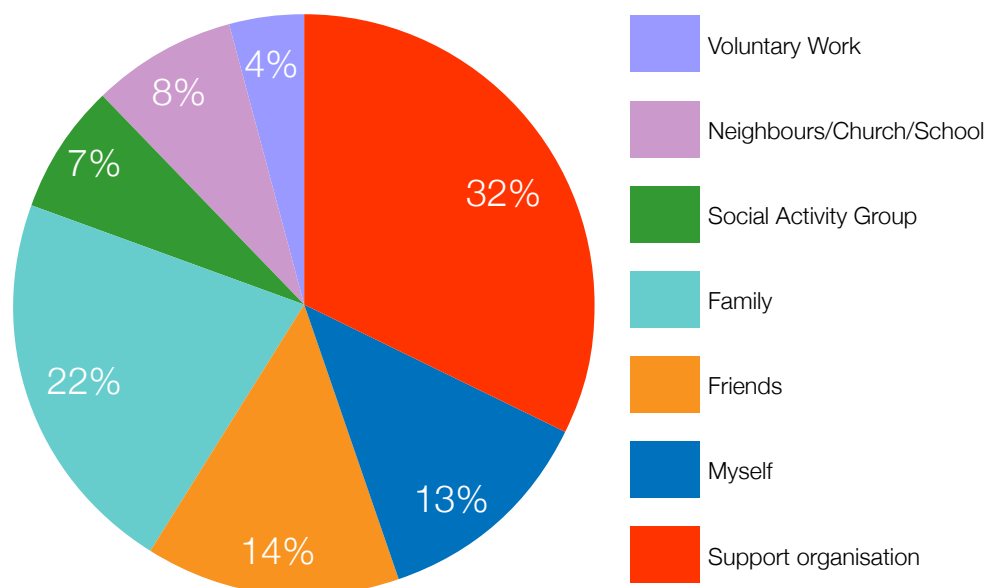


Figure 3. The diverse factors helping people lead good lives

This is what good support should look like. It should enable people to live their own lives and interact in the community as a full citizen (Duffy, 2003). This does not make measures of QOL irrelevant. In fact the researchers used a QOL tool (although a much simpler one) as part of their research. But it does reinforce how difficult it is to think of QOL as a useful tool for living and for supporting each other.

Citizenship and a Good Life

At the beginning of this essay I briefly outlined the long-standing conflict between utilitarianism and rights. As I have suggested, there are many reasons why we should be nervous of utilitarianism. In particular we should be very concerned about any definition of happiness or well-being that allows powerful or elite groups to decide what is most valuable about the lives of other people. Whatever good intentions people have, it is all too easy for descriptors like “physical well-being” or “self-determination” to encourage a view of human life that is prejudiced and paternalistic.

Rights help us avoid some of the risks associated with utilitarianism. However rights are also insufficient and have their own problems. Once we consider real-world rights then we also need to think about exactly what those rights mean in practice: what entitlements they imply and what responsibilities follow from those rights. Meaningful rights cannot be open-ended; they must be cashed out in real-world terms. This cannot be done without reference to the outcomes that these rights seek to serve:

- If I have a right to a secure income then we need to ask what level of income we think is sufficient for someone to live a decent life—I would say a life of citizenship.
- If I have a right to housing then this cannot just mean a flimsy shelter. Instead it must mean something like a right to a home, where I can live securely with people I choose to live with, and where my home is part of a community of which I am a full and equal member—a citizen.
- And if we cash out these and other important human rights then we need to ensure that these rights are not empty rhetoric, but can be achieved by real world actions—that are reflected in our responsibilities as citizens.

In other words, rights that are real must be built on duties that are the achievable responsibilities of citizens. Our understanding of what citizenship demands then becomes central to specifying what rights actually exist. Moreover our understanding of what responsibilities we share to fulfil these rights must also be based on a real world understanding of what citizenship means. Otherwise our rights are merely rhetorical. Rights also imply certain ethical standards, what we might think of as the virtue of citizenship. We are entitled to the resources that make citizenship possible; but we must also be responsible for respecting the right to citizenship of others and so we must also treat citizenship as a social virtue that we have a responsibility to achieve in our own lives.

In fact no adequate understanding of our moral or political situation can survive without reference to rights, duties, virtues and outcomes (moral goods or forms of happiness); these different ideas are all interlinked and mutually dependent (Duffy, 2001). Moreover, when it comes to defining the outcomes that are relevant in public policy then we should base our approach on our best understanding of what citizenship truly means. We need to think about these outcomes in a way which is inclusive from the very start and to avoid conceptions of the good life that are meritocratic or elitist.



Figure 4. The Keys to Citizenship

Elsewhere I have argued that a good framework for thinking about citizenship is the *Keys to Citizenship* (Duffy, 2016, 2017, 2022). I won't repeat all of those arguments here; but I propose that the strength of this kind of framework for thinking about a good life is that it is both realistic and inclusive. It is realistic in the sense that its components (like having freedom, having money or living a life of meaning) are all achievable in the real world.

It is inclusive in the sense that nobody is ruled out or marked down because of their different capacities, strengths or needs. Everyone can have a home,

everyone can contribute, everyone can experience love. It is a framework where every element must be defined in a person-centred way and where the person's ability to define what is meaningful remains unique to them. Conformity is ruled out by definition.

In practice there are people using the *Keys to Citizenship* framework globally to develop a range of different tools for quality, training, planning and policy-making. It also seems to be a framework which self-advocates prefer, perhaps because it is a dignified and equalising framework, which doesn't start with the assumption that people with different abilities are in anyway excluded or marginalised.

The great thing about this framework from a practical perspective is that it is holistic without being unduly complex. It is possible to combined subjective understandings ("how do you feel about...") with objective proxies ("what percentage of people have mainstream jobs). It is also utterly universal. The seven *Keys to Citizenship* make sense to everyone, whatever their income, colour, education or ability. We can all be citizens.

Conclusion

If I return to the very first question I posed—Is deinstitutionalisation nearly finished or have we only just begun?—then I think my answer is fairly clear.

The work of moving away from institutional services is still at an early stage. I do not think the closure of the large institutions is a guarantee of inclusion, human rights or equal citizenship. I think the current organisation of social services in the countries I am familiar with is largely inadequate, both in design and in generosity of spirit.

We know something of what it will take to change things. It will require a radical shift in power, not just to people with physical disabilities, but to all people who need support (and therefore also to families, allies and others who can support people to be free). It will also require social services that are much more adaptive, personal and rooted in local communities. But it will also require change within our communities themselves: not just accessible mainstream services, but also more sustainable and mutually supportive neighbourhoods.

I agree that Personal Budgets will not be enough on their own. Sceptics might find it interesting to read the UNIC guidance (Duffy, 2021a). It is quite possible to be for Personal Budgets and to be against New Public Management or Neoliberalism. I certainly am. Alongside Personal Budgets we will need more democracy, devolution of power and a revision of our whole welfare system to empower citizens at every stage.

To my European friends I offer these suggestions of things to think about in the development of a European strategy:

- 1.** Try to define real concrete entitlements, not just entitlements to services or budgets, but also entitlements to other resources and opportunities, like work and housing. The *Keys to Citizenship* may offer a useful beginning.
- 2.** Commit to Personal Budgets, but not as stripped down budgets, just to pay for personal assistants. People will also need money for management costs and real budget flexibility.

3. Focus on the gifts, potential and value of people's lives, rather than the quality of people's lives. We need to invest in and support each other so that we can all contribute to creating richer and more diverse communities.
4. Never underestimate the power of peer-support, all forms of peer support. People with disabilities are showing that not only can they support each other, they can also bring about wider social change (Duffy, 2021b). But families and professionals also need peer support and the chance to contribute.
5. Real social change will come when we each start to act like citizens, and to acknowledge and support the citizenship of each other. Inclusion cannot be created by one group trying to control another group. Inclusion comes when we each see everyone as valuable and necessary to the life of the community.

To make progress there are constraints and real change takes time, good communication and genuine transformation in how we use our resources. But we must not allow the bar to be set too low, nor for injustice to be normalised. It is easy to declare victory too early and to re-label old systems with new jargon. The key, above all else, to ensure that people with disabilities are essential partners at every stage of the journey.

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Note on language

I sometimes use the term people with disabilities in this essay, which is the term used most commonly outside the UK. However there are also people who prefer ‘disabled people’. I have chosen the term preferred in Europe because this is an essay primarily about European policy debates, I am sorry if this causes any offence.

References

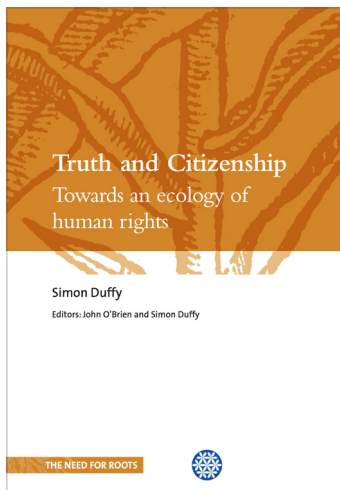
- Animate (2014) *Individual Service Funds*. Sheffield: Citizen Network Research.
- Breedlove L (2020) *Self-Direction Worldwide: contrasting beliefs and their impact on practice*. Sheffield: Centre for Welfare Reform.
- Burton J (2017) *What's Wrong with CQC?* Sheffield: Citizen Network Research.
- Duffy S J (2001) *An Intuitionist Response to Moral Scepticism: A critique of Mackie's scepticism, and an alternative proposal combining Ross's intuitionism with a Kantian epistemology*. PhD Thesis, Edinburgh University.
- Duffy S (2003) *Keys to Citizenship: A guide to getting good support for people with learning disabilities, first edition*. Birkenhead: Paradigm
- Duffy S (2013) *Returning Home: piloting personalised support*. Sheffield: Centre for Welfare Reform.
- Duffy S (2015) *Getting There - lessons from Devon & Plymouth's work to return people home to their communities from institutional placements*. Sheffield: Citizen Network Research.
- Duffy S (2016) *Citizenship and the Welfare State*. Sheffield: Centre for Welfare Reform.
- Duffy S (2017): *The value of citizenship, Research and Practice in Intellectual and Developmental Disabilities*, DOI: 10.1080/23297018.2017.1292147
- Duffy S (2018) *Self-Directed Support: If it's so good then why is it so hard*. Sheffield: Citizen Network Research.
- Duffy S (2019) *Close Down the ATUs*. Sheffield: Centre for Welfare Reform.
- Duffy S (2021a) *EU roadmap for user-centred funding for long-term care and support*. Brussels: UNIC project.
- Duffy S (2021b) *Growing Peer Support. Peer-led crisis support in mental health*. Sheffield: Centre for Welfare Reform.
- Duffy S (2022) *Citizenship and Human Rights* in Fjetland, K. J., Gjermestad, A. & Lid, I. M. (Eds.) (2022). *Lived citizenship for persons in vulnerable life situations. Theories and Practices*. Scandinavian University Press. DOI: <https://doi.org/10.18261/9788215053790-2022-07>
- Duffy S & Gillberg C (2018) *Extreme Poverty in a Time of Austerity*. Sheffield: Centre for Welfare Reform.
- Evans S E (2004) *Forgotten Crimes: The Holocaust and People with Disabilities*. Chicago, Ivan R Dee.
- Fitzpatrick J (2010) *Personalised Support: How to provide high quality support to people with complex and challenging needs - learning form Partners for Inclusion*. Sheffield: Citizen Network Research.
- Goffman E (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Anchor Books.
- Jackson R (2015) *Who Cares? The impact of ideology, regulation and marketisation on the quality of life of people with learning disabilities*. Sheffield: Citizen Network Research.

- Mansell J (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*. London: Department of Health.
- McConnell D et al. (2013) *Family Life: Children with Disabilities and the Fabric of Everyday Family Life*. Alberta: University of Alberta.
- O'Brien J & Mount B (2015) *Pathfinders: people with developmental disabilities and the allies building communities that work work better for everyone*. Toronto, Inclusion Press.
- Singer P & Kuhse H (1985) *Should the Baby Live? The Problem of Handicapped Infants*. Oxford, Oxford University Press.
- Šiška J & Beadle-Brown J (2021) *Study on innovative frameworks for measuring the quality of services for persons with disabilities*. Brussels: EASPD.
- Squire A & Richmond P (2017) *No Place Like Home: The economics of independent living*. Sheffield: Citizen Network Research.
- Schalock RL & Siperstein GN (1996) *Quality of Life. Volume I: Conceptualization and Measurement*. Washington: AAMR
- UNIC (2021) *Model of Good practices on Personal Budget*. Brussels: UNIC
- United Nations (2006) *Convention on the Rights of Persons with Disabilities* (UNCRPD)
- Waldron J (ed.) (1987) *Nonsense Upon Stilts*. London: Methuen.
- Wolfensberger W (1972) *The Principles of Normalization in Human Services*. Toronto: NIMR.

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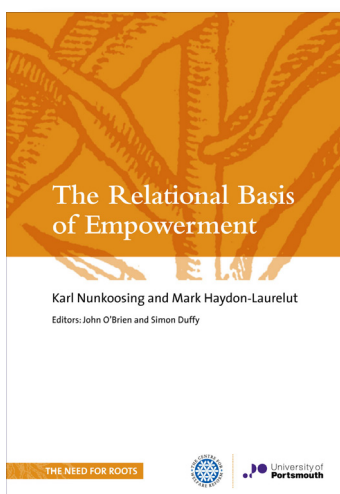
Simon Duffy is Director of the Citizen Network Research and President of Citizen Network Coop. He is a co-founder of UBI Lab Network, the Neighbourhood Democracy Movement and the Self-Directed Support Network. In 2008 he was awarded the RSA's Prince Albert Medal for his development of self-directed support in social care. Simon has been an active campaigner against austerity and works to create an inclusive world where everyone is a valued citizen. By training Simon is a philosopher, his doctorate was in meta-ethics and his primary interests are moral and political theory and social policy.

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