Thematic report to the UN General Assembly on digital technology, social protection and human rights: Mydex CIC submission

Overview answer to UN questions 1 and 2

There are a number of generic tasks that organisations serving people in poverty (whether government agencies, charities or other bodies) generally have to undertake. These include: knowing who the individual is (ascertaining and confirming the individual's identity), ascertaining their particular needs, assessing entitlements (e.g. to payments, benefits, services) and actual service provision (administration, organisation, the logistics of service delivery).

These are information intensive tasks, most of which rely on verified attributes - that is, bits of data that:

- help create or confirm an identity for an individual
- provide reliable information about their needs, circumstances, eligibility for entitlements etc
- provide the information needed to plan, administer and deliver a service

There are also a number of generic tasks that individuals seeking help need to undertake. These include: collecting and gathering the data service providers require for applications, for service delivery and the planning, organisation and logistics of actually undertaking these tasks. Digital technologies can (and do) affect these generic tasks - whether looked at from the point of view of the service provider or the individual seeking a service - in a range of different ways. They can:

- help cut the costs of service delivery and/or improve the quality of the service provided
- exacerbate existing problems, such as high costs of service provision, poor service quality, social exclusion
- create new problems e.g. potential invasions of privacy or identity theft
- create new opportunities e.g. for the creation of entirely new types of service, empowerment or economic growth.

Potential benefits of digital technology

Application of digital technologies to social protection and other services can bring many benefits including cost savings from replacing manual with digital processes (e.g. sending a paper letter vs email or text), automation of processes, error reduction (e.g. manual re-keying of data), and reduction in re-work (e.g. having data easily available in a system rather than having to gather or create it again and again). There is also potential for improved service provision, for example by creating digital service histories that inform decision-making, and the collection of additional data over time can enrich insight into the needs of individuals.

However, in our view, many of the biggest potential benefits remain untapped because of fundamental structural problems in their current implementation.

Problems with current implementations of digital technologies

In too many cases we see systems and platforms being sold to the public sector and others, with the promise of these benefits outlined above. But, far from these benefits being realised, we see a range of existing problems exacerbated and new problems created.

Common implementation flaws include:

- replicating the design of existing manual services except in digital form so that often, the organisation ends up doing the wrong things more efficiently
- supplier dependency, where big systems vendors offer to 'take the problem away' from public or third sector providers who then lose control of the process and find themselves paying escalating costs with overly complex, bureaucratic systems that are extremely difficult (and expensive) to adapt and change
- inappropriate systems. Many IT vendors see the public sector as a market to maximise profits in and are not interested in the many smaller organisations (for example in the third sector) who need systems designed to fit their particular needs and citizens' outcomes.
- large scale duplication of effort as many different organisations each try to implement basically the same systems separately, in an isolated fashion
- 'built-in' inability to deal efficiently with requirements for data sharing

because IT systems from different vendors are proprietary and incompatible, because the systems are designed to 'hoard' rather than share data, and because data sharing imposes additional requirements including consents and permissions
- these result in potential invasions of individuals' privacy and increased risk of harm (e.g. identity theft)
- worsened rather than improved user/customer experience because the systems that have been created are even more remote and impersonal and leave them feeling disempowered; because trying to deal with IT systems is difficult and a hassle for people who are already vulnerable and need support (e.g. trying to find the right bits of data to fill in a form)

As a result, while many IT systems for social protection have been sold by vendors as cost saving opportunities, they have often ended up costing the public sector service providers far more than anticipated, leaving them with less flexibility and without having substantially improved (and perhaps worsened) the service they actually deliver. These challenges occur in local government, central government and across geographies e.g. Scotland , United Kingdom, Europe and rest of world.

Many of the worst problems are created by *system design* issues, not particular implementation flaws.

One widespread problem is that service providers implement the deployment of digital technologies, including operational and performance metrics, based on their particular organisation's needs in serving many different individuals. This is not the same as deploying digital technologies based on individuals' needs when accessing services provided by many different organisations.

To use the jargon from the industry, so far, digital technologies have helped organisations with their CRM - managing their relationships with their 'customers' - but they have not helped individuals with the other side of the coin. They have not helped individuals manage their relationships with many different service providers. This is a system design, not a technology issue.

Here are two examples of resulting problems:

1. Systems are unable to cope with the demands of data sharing

Helping individuals address poverty is invariably a multi-dimensional task. It may include applying for financial support, education and training, dealing with housing problems, dealing with health problems, dealing with employment

issues and challenges, issues relating to assertion of legal and other rights. And very often, these issues overlap, requiring (ideally) effective integration and coordination of efforts by multiple different service providers.

The way IT systems are currently implemented erects barriers to this integration and coordination. For example, in Scotland, an old person who has had a fall may be treated in a National Health Service hospital and then convalesce and be cared for by their Local Authority. To serve the individual well these two bodies (and, probably, many others serving the same individual) need to be able to share data about this individual. But their systems stop them from doing so:

- Very often, their different IT systems are proprietary and incompatible (creating artificial barriers to the sharing of data).
- Because each separate service provider is under pressure and resource constrained, they do not see why they should invest time and money helping another organisation by enabling the sharing of data.
- Additional sharing of data may create legal requirements for consents and permissions which are a) an additional hurdle to clear and b) create further unwelcome work for the individual being served.

All of these problems arise because data has been collected, stored and used in an *organisation-centric* way. An alternative system design where each individual has a personal data store (PDS), and all key data relating to the services they access and use is stored independently in this store, and where individuals can re-use and share this data when dealing with different organisations, would 'design out' most if not all of these problems (see below).

This is not about 'digital technology' in the abstract. It is about how digital technology is implemented and used.

2. Systems are not designed with users in mind

All service providers insist they design their service with the user in mind. But what they usually mean is that, in designing their service, they think about the user's *use of their particular service* and what *they need to get the user to do* for their service to operate efficiently and effectively.

They do *not* look at their service from the point of view of the person trying to solve a problem in their life - something which may result in them having to deal with many different services (not just one). And they very rarely measure efficiency and effectiveness from the point of view of the individual user (e.g. the

individual's time, energy, hassle). For example, an individual service provider may say to itself "we are only asking users to fill in one form". But the individual filling in this form may be dealing with ten different service providers, each of them asking them to fill in 'just one form'. So the individual is having to fill out ten different forms - forms which, very often, are actually asking for the same information.

Such duplication of effort and frustration is invisible to service providers thinking only in terms of their particular service.

Unleashing the full potential of digital technologies in implementation of national social protection systems

In our experience all of these problems can be avoided by implementing digital technologies in a *person-centric* rather than *organisation-centric* way.

By 'person-centric', we mean a new and different IT infrastructure which empowers individuals dealing with services to:

- safely and easily collect and store information about themselves (such as the verified attributes they need to access and use social protection services),
- in their own cryptographically protected personal data store
- which only they can access, independently of their relationship or dealings with any particular service provider
- from which they can gather and share information easily and at low cost e.g. via APIs
- empower the individual as the point of integration for their own data

Mydex CIC is currently implementing a number of trials of this approach. For example:

- Debt advice. To provide sound advice, debt advisors need to gather a lot of information about individuals' financial and life circumstances from many different sources. By placing all such information in their personal data store, Mydex CIC is helping them deal efficiently with multiple different agencies, all of whom can access the information they need (with the individual's permission) at much lower cost than they can achieve using traditional systems. Result: much better quality advice at much lower cost

- Cancer support for people affected by cancer. An individual with cancer might deal with up to 220 different organisations and agencies in the course of their treatment. By placing all information about themselves and their treatment, Mydex CIC is saving them from having to provide the same information again and again, and is reducing the service providers costs of providing the integrated, coordinated care that is needed.
- Social inclusion. Many of the most vulnerable people face the highests costs and barriers (travel, provision of information etc) when seeking to access services that could help. The Mydex Inclued web-app, accessed through any smart device, which is linked to a personal data store holding all relevant information about them, enables them to find out about, register and access multiple different services targeted at them, quickly and simply.

These 'person-centric' approaches can be applied across the globe. They are not 'global north' solutions. Indeed person-centric approaches to digital data are even more important in situations where the organisations/agencies the individual is dealing with are rapidly changing or have limited capacity for their own collection and use of data. It is, for example, even more valuable for a refugee or asylum seeker to be able to share verified attributes about themselves to different agencies as they move from one situation to another.

Implementation of this alternative, person-centric infrastructure is proving to be able 'to kill many birds with one stone', including to:

- Reduce the friction, risk, cost and effort both citizens and organisations incur in trying to access/provide social protection services via a "capture the data once, share many times" approach
- Improve the quality and outcomes of these services
- Build data protection and privacy protection into the very way the service operates (because individuals are in control of their own data)
- Provide individuals with a data asset that grows in richness and quality over time, and which they can use again, and again, and again
- Reduce the imbalances of power and benefit that currently characterise how digital technologies are being implemented.
- Increase the individual's sense of coherence by enabling them to see service journeys and take action for themselves where appropriate and work alongside the front-line worker providing support.

This approach has the potential to empower citizens with data as a human right

across all their lives. Use cases include registering and accessing social protection ; claiming for entitlements and eligibility in health and care ; citizens who may be homeless; refugees and asylum seekers.

Question 3: Impacts of digital technologies on people in poverty and on particular groups of people e.g. women, children, persons with disabilities, indigenous peoples, minorities, LGBTI and other groups.

Poorly designed, badly governed, digital technologies within the social protection system can impact negatively for people living in poverty, where they are discriminated against on the basis of property and language. For example, online application forms can be very difficult to complete if the person does not have access to a laptop with a good broadband connection. The individual may then be forced to incur extra costs - for example the time and money costs of travelling to a library or other location to access the equipment they need. The difficulties of doing so may generate knock-on penalties e.g. missing deadlines.

These additional barriers exacerbate exclusion. The problem is compounded if the individual is having to fill in multiple forms - and the greater their poverty, the more likely they are to be asked to do so. Individuals with lower levels of literacy or operating in a second language also face additional barriers.

The person centric data infrastructure and architecture described above and currently being implemented in Scotland addresses these issues.

Question 3: Do unavoidable tradeoffs between rights arise in the context of the application of digital technologies in national social protection systems? For example, between the right to privacy and the right to receive social protection from the State?

This is another example of the system design issues discussed above. If an individual is enabled to collect their data in a personal data store and to share it, under their own control when the data is requested by a service provider, then most privacy and data protection issues which are now being addressed by cumbersome legislation such as GDPR in Europe, are ‘designed out’ at source.

(This is not to say that we don't need legislation, only that legislation and regulation are not the only answers. New business models and applications of technology are also part of the answer).

Many of the most egregious invasions of privacy arise when different organisations, wanting to share data to improve service provision to an individual, invent new ways to share this data 'behind the individual's back' without their knowledge or permission. The best way of dealing with this problem is not to elaborate new consent and permission processes, but designing the data collection and processing system in a way that puts citizens/individuals at the centre - rather than the current approach where citizens operate at the edge of organisations' IT systems.

About Mydex CIC

Mydex is a Community Interest Company whose social purpose is to empower individuals with their own data. Mydex provides individuals with personal data stores (PDS) where they can gather, store, manage, use and share their own data under their own control.

Mydex operates on a zero knowledge basis. Each individual has their own encryption key to their own PDS: Mydex cannot see any of the data in the individual's PDS.

Mydex covers its cost by charging organisations a small fee for enabling safe, secure data sharing between individuals and organisations that use this data to provide services.

Mydex adds value for both individuals and bona fide service providers:

- It empowers individuals with their own data, so that they can use this data for their own purposes independently of any organisations who may be collecting such data.
- It reduces the costs, friction, effort and risk of data sharing and use for both individuals and organisations providing services to these individuals

All of Mydex's current services are in the UK social sector, helping people in poverty and need, for example by improving provision of debt advice, helping those excluded from the system to access services, improving provision of services to the chronically ill, etc.