Minutes from workshop on digital inclusion – 13 March, 2017

Participants: Rosalind Duignan-Pearson (Volonteurope), Martyna Giedrojć and Weronika Gryko (EPHA), Ian Johnston (IFSW), Alejandra Moledo (EDF), Philippe Seidel and Julia Wadoux (AGE Platform Europe), Mauro Striano (FEANTSA), Gareth Thomas (Homeless Link), Mirko Miceli (EPR), Milan Šveřepa (Inclusion Europe), Love-Andrea Pinson (EAEA), Claire Champeix (Eurocarers), Joe McNamee (EDRI), and Annica Ryngbeck (Social Platform)

Introduction

During the next three years Social Platform will be working with members on digital inclusion, as a part of our strategic action ‘Leaving no one behind - prioritizing people in vulnerable situations’. On 13 March we gathered members of our taskforce on digital inclusion and invited guest from digital rights NGO to discuss good practices and the role of new technologies in the accessibility and delivery of services. The workshop is a first step towards identifying our focus and defining our scope of work in this area.

Sharing successful digital inclusion projects

Claire Champeix, Eurocarers

Informal carers that provide long-term care of relatives may live in remote places and not have the possibility to physically attend trainings nor meet other carers in the same situations. Eurocarers have therefore, in the framework of an EU-funded project "TRACK", developed an online training platform tailored for informal carers of persons affected by dementia. It aims to provide knowledge and recognition of skills. The possibility to develop an open platform including networking opportunity with other carers is unfortunately limited as it requires external funding beyond the time-bound and limited EU-funding.

AGE Platform Europe pointed out that many informal carers of elderly persons affected by dementia are elderly too and may therefore lack broadband, digital literacy or be in need of accessibility features to be able to use the platform.

Milan Šveřepa, Inclusion Europe – power point presentation

Many persons with intellectual disabilities have limited or no access to the Internet. They are therefore excluded from the online world where most people get their information, find and maintain friendships, apply for jobs, and overall participate in society. Digital exclusion for people with intellectual disabilities may depend on difficulties to access information online, but the reason can also be the fear and concerns from family members and informal carers with regards to safety and privacy online. Inclusion Europe has therefore been a part of SafeSurfing.eu, a project that produced educational videos for both persons with disabilities and family members about managing risks and stay safe online, as well as to understand why it is important to have access to the internet. Another project is Able-to-Include.com, developed together with Universities and information and communication technology (ICT) companies to simplify web information and services by for example converting text to picture and simplify email and access to Facebook. Read more about Inclusion Europe's projects here. Inclusion Europe stress the importance of involving people with intellectual disabilities in the design of services as they are the experts on accessibility, and it helps them develop skills and social relations, online as well as offline.

Gareth Thomas, Homeless Link – power point presentation

Homeless Link, based in the United Kingdom, has developed Street Link, which is a website app and phone line that aims to help anyone sleeping rough as well as targets the general public that would like to help when seeing someone sleeping rough. Out of all the reports to the organisation, 75
percent come via the website and the app, and over 30,000 people have been connected with local services and received support. It has proven particular good to identify people new to the street and locations that are hard to find. In order to locate and help a person sleeping rough Streetlink need a description of what the person looks like, the report can include age, gender and ethnicity as well as additional useful information. Collecting such information may open concerns about data collection and privacy. On the other, the information may also be proven useful for raising awareness and debunking myths about rough sleepers, such as that many are ex-military or migrants. Read more about StreetLink and other project in FEANTSA’s magazine on digital inclusion and homelessness.

Ian Johnston, International Federation of Social Workers European Region – power point presentation

International Federation of Social Workers European Region has been a part of developing evidence based guidelines for nurses and social care workers for the deployment of eHealth service, ENS4Care. Information is power and digital technology has the potential to enable many more older and younger adults challenged by illness or disability to live safely and as independently as possible in their own homes. It can also ensure that they and professionals supporting them are able to make informed decisions about the most appropriate forms of treatment and models of care. There is however a need to ensure that such benefits are not outweighed by the unintended consequences that often accompanies positive new developments. Whilst telephone and online contact can enhance the quality of care that people receive they must never become a substitute for face to face interaction. Unproductive tension between health and social care professionals can be overcome by genuinely personalised services that always put the service user in the centre. Information collected for your benefit should be owned by you, not those supporting you. The benefits of online technology have to be utilised without jeopardising the quality of services.

Julia Wadoux, AGE Platform Europe – power point presentation

AGE Platform Europe is a part of several ICT projects that among other issues supports independent living, management of chronic conditions (FrailSafe, i-PROGNOSIS), prevention, inclusive games (JamToday), eGovernment and public services (MobileAge). ICT can help independent living and ageing at home, especially for people in remote areas where there are not enough care services. On the other hand it can also further social isolation, lead to lack of safety and privacy, digital services may be costly and sometimes only available online, and if technology fails it also contributes to lost confidence among the users. Therefore, AGE Platform Europe promotes users involvement, also called design for all, inclusive design and co-creation. Digital services should be developed by the medical team, the users and tech experts together, and allow for time to learn to speak the same language. AGE Platform Europe has developed guidelines on older users in social innovation projects and ICT for ageing well, on what older users think, which is "Do I need it? Can I use it? Can i trust it? Can I afford it?" To add, AGE Platform Europe also runs a project called ‘Keep me posted’ for people not using the internet to be informed by regular mail.

Understanding the digital rights context

Joe McNamee, Executive Director, European Digital Rights (EDRI)

EDRI works for civil rights and human rights in the online environment, a field where society has not yet caught up. Internet is how we go to the bank, read news, shop and campaign, and the platforms and networks that provide such services are owned by companies. Our laws on rights of freedom and privacy (such as the European Convention on Human Rights and the European Charter of Fundamental Rights) are generally only enforceable with regards to the state. This was sufficient in the past when the state used to be the main one controlling personal data, but now our information is more and more in the hands of private companies and it is no longer clear what our rights are, and when the state can or is obliged to intervene.

A lot of what we do online have economic value and advertisers use our data to know who is for example rich or poor. The University of Cambridge and Stanford University made a test proving that a computer can learn about an individual's personality by analysing data about what Facebook like buttons a person clicks on. In fact, by analysing 200 clicks the computer learns more about the individual then their family, and with 300 clicks it beats the spouse. Such knowledge can easily be misused. People like to know that they are doing things that are not strange, they therefore do what others are doing. Facebook has shown that it can change turnout in election by showing what some
are voting and hiding what others are voting. While explicit ethnic profiling is prohibited, there are ways to get around it and still racially discriminate online, by for example asking for other related characteristics.

The ePrivacy Directive (2002/58/EC) is an important directive that EDRI works on and that should concern Social Platform members too – an update of the legislation was proposed by the European Commission in January. There are many privacy issues online that that the directive fails to sufficiently protect. Among other concerns is the fact that sites often requires us to “accept cookies” in order for us to be able to access the website. Indeed, even without cookies, with ‘browser fingerprinting’ a page to store information about you and track your movement across the internet. Requiring people to pay for privacy digitally divides people on the basis of knowledge and affordability. While devices such as Android phones are cheap, they are owned by Google that collects privacy data. EDRI wants to protect people’s right to freedom and communication, without being tracked via their Wi-Fi or Bluetooth. Instead of banning tracking, the European Commission proposes a way of signalling that you are entering a tracking area, which would force people to turn off their phones. Today companies have a right to access your data if you consent or if it is considered "necessary for the service", although what is considered necessary is not clear. The Commission’s rules would differentiate between data about your location that is generated by services on your phone (Google maps, for example) and location data generated by your phone operator. EDRI believes they should be treated equally.

EDRI calls for net neutrality, which means that data should be treated equally. People who cannot afford Internet may be offered limited internet for free (so called “zero-rating”). This may mean that they can access for example Facebook and one or two other services for free, and the rest they have to pay for. If a user is forced to always access its services only via for example Facebook, such an option is no longer a free market.

The European Commission is going to launch a programme that will fund projects about technical solutions that supports European values. This would be a great opportunity to develop accessible online solutions, such as for email accounts developed on independent and neutral platforms, including for use in socially valuable context, instead of via for example Google that scans emails for keywords to add to their data about you.

Questions & Answers

- **Families Europe**: as transparency will not be possible in the future with algorithms, shouldn’t legislation instead limit algorithms on the basis of values and ethics?

  EDRI: Safeguards are increasingly difficult to implement, you therefore will always need the right to object that certain data is being used. Algorithms are subtle, you may have provided information about certain characteristics that may not have been meant to be discriminatory, but is still being misused.

- **EPHA**: How do we ensure that data for health is not being used for bad intentions?

  EDRI: The risk is very big, non-health data can easily become health data. For example, people that sleep less are more likely to get dementia; your logon and logoff times therefore become your health data. It only has to be accurate enough to be profitable; as it is enough knowing that a big enough proportion of the people will fit a category to make it profitable.

Check out EDRI’s publication: “Your guide to the Digital Defenders vs. Digital Intruders – Privacy for kids!”

**Towards a Social Platform position**

**Martyna Giedrojć, European Public Health Alliance**

EPHA works on making sure that digital technology in health systems are inclusive and safe, although it is hard to know where in the EU processes EPHA can push for their issues. Last year the European Commission promised guidelines on health and safety of applications, EPHA called for strong criteria’s on safety, accuracy and validity of data. Due to diverse responses from stakeholders the Commission decided to not go ahead with the guidelines. Mobile health apps can be considered either as medical devices or not, and some fall in a grey-zone between, which makes it challenging
to legislate. EPHA is currently developing a policy brief on digital solutions for health disease management. Overall health professionals are sceptical about using digital tools as it could be harmful for the patient. It is therefore important that ICT developers, health professionals and patients work together. Read EPHA’s article on digital inclusion.

**Alejandro Moledo, European Disability Forum**

EDF focuses on disability specific legislation that impact persons with disabilities directly, such as the Web Accessibility Directive (EU 2016/2102) and the proposal for a European Accessibility Act (with a strong ICT component, including services such as e-banking, e-commerce, e-books, and audio-visual services). Furthermore, EDF tries to mainstream design for all, and influence relevant EU standards and promote a technologically neutral approach. Technological neutral means providing a solution that is possible to use by any company or institution. ICT provider must use a technological solution that measures the requirement of being understandable, achievable and operational. For example text-to-speech should be available on all phone providers and in all languages. This is not the case and accessibility therefore becomes a question of affordability. For example iPhone is accessible but few people can afford it, expensive TVs take into account accessibility but not the cheaper ones. This is why EDF tries to influence the big players. Persons with disabilities want to have access to the same products as anyone else.

**Martin Schmalzried, Families Europe**

The online environment affects all family members, among some of the issues Families Europe work on to shape the online environment are:

- Big data analytics presupposes the existence of free will and the fact that the broader context and environment plays no role in individual’s daily decisions. This is the only way to justify making users “pay” extra premiums for accessing certain essential services such as health insurance or credit. One example in health insurance is the fact that while the World Health Organisations has proven that there is a link between advertisement and (unhealthy) eating habits, a higher insurance premium stemming from unhealthy eating habits is borne solely by the user.
- Families Europe promotes new indicators for advertisement and price transparency, which impacts for example child protection online, as children are exposed to advertisement and in-app purchases.
- A digital contract directive that acknowledge data should be considered as a form of counter performance for accessing certain online services, equivalent to money and thereby granting users the same rights. For example if Netflix go down you can ask for money back, but if Facebook goes down you cannot ask for any compensation.
- More open source solutions developed by users themselves or where users can openly contribute, such as Wikipedia. This allows the general public to take more control of the web, thereby decentralising digital services and pushing the big ICT providers to act more responsible via increased competition pressure.
- Assessment of how technology impact exclusion and discrimination. A solution could be a ‘diversity algorithms’ that can reveal filters by online services and platforms, which manipulates consumers. In a case of financing services, such an algorithm has already been developed to test whether other algorithms were biased and discriminatory.

Read also Families Europe:
- policy brief from 2016 Digital Economy Ministerial Meeting in Cancún
- policy briefs from conference on the impact of digitalisation on 21st century families (links in the middle of the page)
- Nutri-media project: a guide to online advertising
Follow-up by Social Platform Secretariat

- Continue our collaboration with digital rights NGOs and explore ways to support each other’s work on digital rights and digital inclusion.

- Request a meeting with the European Commission, Mr. Marco Marsella, Head of ‘Learning, Multilingualism and Accessibility’, Director-General Communication Networks, Content and Technology (Mr. Marsella was invited to the workshop but could not come). When meeting date set, invite task force members to participate.

- On the basis of the workshop, start drafting a narrative and recommendations for a Social Platform position on digital inclusion, to be shared for inputs by the task force.

- Get back to the task force with an invitation to the next meeting in April (date tbc).

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