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Op-ed

Fair access to assistive technology? Gaps in transition from invalidity to old-age insurance in Switzerland

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Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease leading to increasing immobility, disability, and death within 3–5 years from disease onset. In two thirds of patients, age of onset is between 50 and 70 years. Because of demographic changes in Europe, this means that ALS will become significantly more frequent in ageing populations. Due to the progressive nature of this illness, patients with ALS need access to different sorts of assistive technology and aids, ranging from wheelchairs to electronic communication devices and others from the field of neurotechnology. Facilitating appropriate access to these technologies is an important element to ensuring good quality of care for people who suffer from ALS.

In this Op-ed, we argue that, in the care for people ageing with ALS and diagnosed after retirement, there are gaps in equal access to assistive technology in Switzerland. These gaps appear when the age of onset of the illness or its progression coincides with the transition from eligibility for invalidity insurance (IV) to old age insurance (AHV). IV is a social insurance scheme covering loss of wages for people who have some degree of disability due to medical inability to work before retirement. It aims to enable insured people to conduct an autonomous and independent life and encourage companies to employ them. AHV is the social insurance scheme that provides retirees with a minimum income (which is supplemented by cash benefits from occupational pension and private savings/reserves) and basic support. Since these two different social insurance schemes guarantee different levels of benefits, the mere fact that ALS is diagnosed just before or just after being eligible for one or the other insurance scheme has a profound impact on access to assistive technology. This represents a shortcoming with regard to justice, a key principle in research on the ethics of use and development of assistive technology. Justice in terms of equal access to healthcare is indeed a fundamental principle for people with ALS and their families, as well as with respect to disability and ageing in general.

To illustrate our point, consider these two short fictional cases:

1. Ruedi was diagnosed with bulbar ALS at age 64 and received assistive technology (electric wheelchair, communication aids) through IV before retirement and transitioning to AHV as a social insurance scheme. He is now 67 and, due to rapid progression of ALS, his need for assistive technology increases even more. Although already retired and now covered by AHV, Ruedi is guaranteed vested rights ("Besitzstandsgarantie") to have the same level of access to assistive technology as he had before through IV.

2. Maria received her diagnosis of spinal-onset ALS after a year-long diagnostic odyssey at age 65 when she was already retired and thus covered under AHV. She had access to assistive technology through AHV. She is now 67 and AHV only provides her access to a non-motored wheelchair every five years but not any other technology.

It is clear from these examples that Maria is worse off than Ruedi with regard to access to assistive technology. At the same time, in Ruedi's case his transition to AHV allows him to retain the same level of benefits that he received when insured under IV, which may in the future not be adequate to address his worsening condition.

The difference in access to assistive technologies between IV and AHV generates two questionable gaps. Firstly, it is paradoxical that Maria and Ruedi are both 67 years old and they are both living with the same diagnosis, but their access to assistive technology – which is a precondition for them to participate in public and private life – is substantially different only because of the time of diagnosis (for Ruedi just before passing to AHV and for Maria just after). In Maria's case, if a private foundation's support or own financial means are not available, she might have to live without communication or advanced mobility aids. Due to early(ier) diagnosis, Ruedi is still covered by IV and has thus guaranteed access to a broader range of assistive technologies. Early diagnosis of ALS can thus paradoxically be seen as beneficial since it allows easier access to assistive technology.

Secondly, even when access to technologies is guaranteed through IV the problem of delayed access to these benefits remains for people with ALS. Indeed, there is a year of waiting time before invalidity pensions and financial aid (Hilflosenentschädigung, Assistenzbeitrag) can be received through IV. This waiting time is normally used by the administration to ensure that the insured person is unable to work, but this can be illogical in the case of ALS patients where the disease progresses rapidly. For someone with ALS with a rapid progression, this waiting time means that – even in the best of situations where diagnosis comes during IV eligibility – financial support and payment for personal assistance might come too late. Although this does not extend to assistive technology and aids, it provides further evidence of how these policies are unfit to meet the needs of people with ALS and their families.

This general clash between the rigidity of some aspects of the Swiss social security system has also been pointed out by Rickli who concluded that the "institutional transition in status from 'disabled' to 'old' at a bureaucratically relevant point, but an arbitrary stage in a person's disability history, leads to a confrontation with the social security system within a new, yet less entitling category of citizenship" (p. 16). We agree with this statement. In ALS the aforementioned paradoxes generated by the transition from IV to AHV lead to a problematic unequal access, and, from the perspective of engaged bioethics, to a difficult situation for people with ALS and their caregivers.

The gap in transition from IV to AHV might be unjust to people with disability in general, but in ALS there exist feasible steps to ensure access to technologies enabling participation in public and private life, and therefore upholding quality of life. People with ALS should be treated by administrative institutions as hardship cases, toward whom there needs to be more attention. These hardship cases should have easy access to assistive technology. Additionally, as part of these hardship cases, the waiting year normally necessary before receiving some benefits under IV should be skipped.

These issues of access to benefits are also internationally encountered for people with ALS and their families. Recently, the non-governmental organisation Marie Curie and the Motor Neurone Disease (MND, a synonym for ALS) Association in the United Kingdom have called for a change of law regarding the current 'six-month rule', which allows terminally ill people to cut red-tape for accessing welfare benefits only when they have less than six months to live. The organisation calls for his rule to be modified and allow every terminally ill person, such as people with ALS, to cut red-tape, even when the life expectancy is longer than six months.The Marie Curie organization puts it bluntly: "Dying people shouldn't have to waste time worrying about getting the support they need." In ALS, every month counts, and waiting for a year in Switzerland for some of the benefits obtained through IV is too long. Both welfare benefits through IV and access to assistive technology through AHV therefore lack adequate consideration of the condition and needs of people with ALS and their families.

Recently, the bioethicist Joseph Stramondo argued for a "right to assistive technology" justified by compensatory justice for the disadvantage created "by society's dominant cooperative scheme and the violation of [disabled people's] right to equality of opportunity that such disadvantage entails." Understanding the concept of justice as such is one ethical argument in favour of changing the gap related to the transition from IV to AHV in relation to assistive-technology access by ALS patient. Even if this argument from compensatory justice is seen as not enough, a further ethical justification in favour of remedying this gap can be provided by the most extreme forms of egalitarianism, which only aims to level the playing field but does not make excessive demands on justice. For example, luck egalitarianism would demand that access to assistive technology should be the same regardless of the whether the illness is diagnosed *just before* or *just after* the transition from IV to AHV. Indeed, the time of diagnoses, as exemplified in the two fictional cases, can be seen as a form of 'bad luck' over which the patients have no control.

With increasing availability of innovative technology aids for people with ALS in the future – such as robot skeletons or brain-computer interfaces – existing gaps in access will only increase in size. Since these gaps can have a significant impact on the ability to participate in public and private life, it is problematic that broad access to assistive technology remains dependent on pre- or post-retirement diagnosis of ALS. Equality for people with disability has been enshrined in Swiss legislation (Disability Discrimination Act). Although Switzerland has taken big steps to ensure that people with disability can take part in the workforce, for older adults with disability or those who transition to old age with disability, there are gaps in equality of access that can also turn into a form of age discrimination for this particular group.