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HÁSKÓLI ÍSLANDS

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The Centre for Disability Studies at the University of Iceland is a member of the ANED project (Academic Network of European Disability Experts). Created by the European Commission in 2007, the ANED project links up disability studies scholars across Europe in the creation of reports on a wide range of issues concerning disability. The purpose of these reports is to provide research-based evidence to aid in the formulation of policy initiatives of both the European Commission's Disability Unit and individual European nations. One such report from 2010 from the Icelandic team (Traustadóttir, Rice, & Smith, 2010) was based on ANED's request for information on benefits and entitlements for disabled people from each member nation. In the process of collecting this information, our team noted a number of issues, such as the disparity of what was on offer and available between different municipalities and regions across Iceland. However, our team began to ask questions such as what qualifies as a benefit or entitlement? What purposes do these entitlements serve and what are the further implications of such? Some of these questions went beyond the scope of this specific ANED request, but they were explored in conjunction with a number of other projects ongoing at our Centre in interviews conducted with disability pensioners (*öryrkjar*). Interviews conducted with pensioners revealed some ambiguous feelings about these entitlements, particularly with regard to discounts for goods and services. Questions were raised about the disempowering nature of these discounts and the role of 'charitable' attitudes that underlay the provision of what are essentially voluntary discounts rather than state sponsored entitlements—and which speaks to the social status of pensioners in the larger society. As this research is ongoing, what is on offer in this article is a preliminary discussion of some issues that arose in our research on disability specific benefits and entitlements that went beyond the scope of the original research framework.

Over the winter and spring of 2010, the research conducted by our team on disability specific benefits and entitlements on behalf of the ANED project initially focused on documenting the publicly available information available from numerous state Ministries, the Regional Offices for the Affairs of Disabled People, as well as information available from various municipalities and disabled people's organisations. E-mail, telephone calls or face to face queries were undertaken by team members where information was lacking, incomplete or ambiguous. However, while this research on behalf of ANED was ongoing, I was also conducting interview-based research as part of a NOVA funded post-doctoral project entitled *Fötlun í velferðarríkinu Íslandi: Stefnumótun og daglegt líf* (Negotiating disability in the welfare state: Policy and Everyday Life). This project considered as well the issue of benefits and entitlements and I used some of the knowledge gained from this project to inform our ANED findings. But in turn, some of the themes that emerged from the ANED project were incorporated into my post-doctoral research interviews as well. This line of inquiry regarding entitlements was extended in the interviews conducted as part of my contribution to the ongoing *Fátækt og félagslegar aðstæður öryrkja* (Poverty and the social conditions of disability pensioners) project, the Centre for Disability Studies'

contribution as part of the 2010 *European Year for Combating Poverty and Social Exclusion* initiative.

As our research progressed, we began to note a number of issues concerning eligibility and access. To begin with, our team noticed a disparity between certain benefits and entitlements between different municipalities and regions in Iceland, so it is very difficult to say that a specific entitlement or benefit is broadly available for all disabled people. Grants and subsidies that were on offer through state level agencies—such as prescription drug subsidies and grants for operating a motor vehicle—applied across the country for all who were eligible. But differences for other kinds of entitlements and subsidies became noticeable at the municipal level. For example, discounts available within the city of Reykjavík on a wide range of goods and services—such as pre-school fees, leisure activities like swimming, and subsidized transport services—vary widely compared with other surrounding municipalities as well as other areas of the country we researched, with some offering no such discounts at all. As such, discussions about certain disability specific entitlements often had to be qualified with restrictions due to geographical locale.

The restriction of many of these benefits and entitlements to those who are evaluated as ‘fully disabled’ (75% *öryrkj*) was noted by our team as another noteworthy barrier. This 75% designation governs eligibility for the full disability pension (*örorkulífeyrir*) as well as a wide range of discounts and services, and often functions as a ‘passport benefit’ in the language of service evaluation. Therefore people not evaluated as ‘fully disabled’—in the 50-74% designation—not only receive a much less generous disability allowance (*örorkustyrkur*), they are also excluded from receiving numerous discounts for themselves and their families. Very little research exists in Iceland that explores the situations of those who are in this ‘lesser’ disability category. Some reduced fees, such as the public transit system of Reykjavík, are clearly aimed at disability pensioners or *öryrkjar*—those who have received a 75% disability evaluation from Tryggingastofnun ríkisins (The Icelandic Social Insurance Administration). In contrast, some services, such as the Transport Services for Disabled People (*Ferðaþjónusta fatlaðra*) are not available broadly for all disability pensioners (*öryrkjar*) but are reserved for people with specific kinds and degrees of impairments. The distinctions between different graduations of disability and the categories of pensioners (*öryrkjar*) and disabled people (*fatlað fólk*) are complex and ambiguous, as these categories are informed by legal, medical and bureaucratic forms of knowledge but, as I have argued elsewhere, also socio-cultural in nature as well as negotiated on the individual level (Rice, 2009, 2010a, 2010b).

It became very difficult to talk about disability specific entitlements in broad terms and in the ‘shopping list’ style of reportage that was requested by ANED given these kinds of restrictions and complexities. Our team also began to ask broader, and perhaps more theoretical, questions about the nature of disability specific benefits and entitlements and the relationship of these benefits to the social and economic status of disabled people and individual pensioners. Disability pensions were generally regarded as income support for those, due to impairment or illness, who had difficulties earning income from the labour market and the importance of the pension system cannot be overstated. But there is also a range of additional disability related benefits and entitlements beyond the basic pensions. Some of these are governed by a number of Ministries and departments at various levels of government and are intended to assist in minimizing the disabling effects of impairment through providing or subsidizing the acquisition of assistive devices and other equipment, or for example, ensuring that accessible parking spaces are maintained and available when needed through the issuing accessible parking tags. However, the more controversial disability specific entitlements from the perspectives of the research participants concerned the wide range of discounts available for disabled people for goods and services. No research

participants took issue with discounts for medical services or prescription drug costs—as people with disabilities or long-term illnesses often have to deal with much higher medical, drug or rehabilitative expenses than the general public. But subsidies and assistance with excessive health care costs are also not limited to disabled people alone, and are part of the broader entitlements of citizenship. The issue of contention concerned the discounts that are available within the private sector, such as with leisure activities and consumer goods, particularly those that are narrowly aimed at disability pensioners. While these discounts were generally welcomed, a key theme that emerged from the interview data questioned the relationship between these discounts and the disempowered position of disability pensioners in the larger society.

Disability and the Nordic welfare state

It is generally acknowledged that the core principal of the Scandinavian or Nordic welfare model is universalism; that is to say, individual citizens/legal residents are equally entitled to public sector provisions regardless of individual contributions via taxation. In other words, people contribute according to capacity and receive according to need (Andersen, 2007; Hvinden 2004). However, there is of course a divergence between this abstract ideal and practice as it occurs between and within the Nordic nations. There is a body of work which refers to ‘Icelandic exceptionalism’ that charts the ways in which Iceland has differed from the other Nordic nations in the arena of social welfare provision, such as failing to keep up with the pace of the development in social welfare provision, a historically strong emphasis upon the means testing of benefits, and for emphasising self-reliance and individualism at the expense of notions of social equality (e.g. Arter, 1999; Harpa Njáls, 2003; Jonsson, 2001; Ólafsson, 1993; Stefán Ólafsson, 1999, 2005).

However, the framework of universalism does not mean that access to benefits and entitlements is unconditional, and this applies to all of the Nordic nations. As Torben Andersen (2007) points out, even within the more generous Nordic welfare states access to these supports is usually restricted in terms of income, by the demonstration of need, and with benefit levels designed to encourage labour market participation, as a high levels of employment are required in order to sustain income support programmes and this model of redistribution (Andersen, 2007). Despite the emphasis upon the discourse of ‘activation’ that has become popular in recent years, labour market activation policies have long been an integral part of the Nordic welfare model regarding income support, as has the “strong popular belief in the moral virtues of work” (Johansson & Hvinden 2007).

In Iceland, the eligibility for a disability pension is dependent upon the applicant receiving the appropriate number of points accrued from a diagnostic tool that is administered by a physician; the points one receives are based upon one’s answer to questions concerning a number of a physical, psychological and social criteria. The Icelandic system is closely modelled after the All Work Test (AWT) that originated in the United Kingdom in the mid-1990s. Ostensibly, the AWT is intended to measure work ability, or the lack thereof, and to award a pension if certain criteria are met. These criteria are rather broad and, which was repeatedly mentioned in interviews, encompasses people who some research participants considered to be pensioners (*öryrkjar*) but not necessarily ‘disabled’ (*fatlað fólk* or *fatlaðir*). Other entitlements, such as the right to accessible parking, did not depend solely on the 75% öryrki pension designation but required the supporting documentation of a physician that such entitlement was medically warranted. However, many disability specific entitlements come in the form of reduced fees and costs on a wide range of goods and services—many of which are not mandated by the state through legislation but voluntary

discounts on the part of the private sector. These invariably depended upon the individual having the 75% disability (*öryrkir*) evaluation and are thus in a way linked to the pension system. But these additional entitlements sit rather uncomfortably within the notions of universalism and equality that are at the core of the Nordic welfare model, and instead echo the residual or charitable models of assistance that are stigmatising and situate the recipients into an unequal, disempowered location.

A caveat must be offered at this point before proceeding: the research participants in my ongoing research thus far represent a wide range of ages, impairment types and socio-economic situations—ranging from those who were entirely dependent on income support schemes to those who worked full-time. Thus their use, and views of, disability specific entitlements were quite varied. But the area where most were in agreement concerned their ambiguous feelings towards the range of discounts on leisure and consumer goods in the private sector and in the manner in which they were made available. While relief from the high costs of living were generally welcomed, questions and concerns were raised about some of these entitlements and benefits. The final portion of this paper is devoted to documenting the key themes that emerged from the interview data and which are illustrated with some extracted interview transcripts.

“Frítt fyrir öryrkja”

The interviews that I conducted probed the respondents’ knowledge of and views on the range of disability specific entitlements in Iceland. While certain benefits and entitlements such as the disability pension system, accessible parking, transportation matters, and medical/pharmaceutical discounts were widely known, knowledge was much more uneven regarding the range of other discounts. For example, when asked for an example of disability specific entitlements in terms of discounts, nearly all respondents mentioned the waived fees for pensioners in the Reykjavík area swimming pools. As one interview participant commented, in a rather wistful tone: “Free swimming. That’s one thing I found out and they are very clearly marked. Frítt fyrir öryrkjar” [free for disability pensioners]. In contrast, one respondent learned of discounts for pensioners at a specific store that, thus far, no other research participants were aware of. This information about what was available was acquired in a rather haphazard manner, with sources ranging from government agencies, doctors, disabled people’s organisations, posted signs, family, friends or internet-based research. It was quite typical during these interviews that I would learn of discounts and benefits that I was unaware of, but sometimes I would convey information that the research participant was unaware of as well.

As the result of this uneven knowledge about what was available, in certain cases this required disability pensioners to inquire about discounts. Some respondents were not willing to do so if there was no notice posted about discounts on offer which required a verbal inquiry. Others mentioned their discomfort displaying their disability identity card in public in general. Certain discounts are built into the fee structure of some services that only require a onetime identification of one’s status as *öryrki*. For example, the City of Reykjavík preschool system has a three-tiered payment structure with the third, and less costly, category reserved for couples who are both students, single parents, or disability pensioners (Reykjavíkurborg, 2010). Once the individual’s right to receive a discounted fee is ascertained, the discount becomes systematic in that it is automatically applied for future payments and does not require the individual to repeatedly state his or her status as a disability pensioner. In contrast, the discounted fee structures in other contexts often require the display of the disability benefit card (*örrkuskártími*).

The use of this card in terms of public display was routinely commented on in interviews, with some respondents feeling quite strongly on the matter. In my impression thus far, such feelings, if they existed, were most strongly felt by those who had recently become disabled and had to renegotiate their new disabled identity. When I asked pensioners how they currently felt about using the disability card for discounts, these feelings of discomfort were generally shrugged off by those who had received their disability evaluation a number of years in the past: “I think it’s kind of humiliating. But it’s all part of the system,” as one respondent replied. But another respondent, reflecting on her experiences shortly after her disability evaluation, referred to much stronger feelings: “I remember once...I had my wallet out, took out a Visa card, and there under was my öryrkjar card and I was so quick to close it [laughs]. And it surprised me, that I did that. It was shortly after I got it.” When I asked specifically why she felt this way using the card, she replied: “It’s like...not how I perceive myself. Not at all. But it is like this is the ultimate proof of me not being a functional part of the society.”

I have long been aware of the stigmatizing associations of the öryrki category in Icelandic society since my dissertation research on charities (Rice, 2007), and it is a theme that I am still pursuing. In my estimation, it is partly related to the strong Icelandic work ethic and the derision such views cast upon those perceived as ‘non-productive’ in terms of labour market participation. The repeated display of this card appears, at least for some research participants, to reinforce this disempowered status. It is indeed possible that the requirement to repeatedly identify oneself as a pensioner to make use of these discounts may play a role in strengthening feelings of marginalisation, considering these associations that cling to the öryrki category.

Another research participant pointed out that this ‘non-productive’ status is also reinforced in the posted fee structures in some public venues, whereby there is a general admission price followed by a reduced price for children, seniors and disability pensioners, which parallels other contexts in which such disparate groups are categorised together. It is important to note here that these discounts are for pensioners (*öryrkjar*), not disabled people (*fatlað fólk*), with the assumption being that, like the case of seniors, there is an underlying economic need that mandates such discounts. Even though some people who are evaluated as 75% öryrki or have attained the age of 67 may not be in need of such discounts, one cannot overlook the socio-cultural messages that are being conveyed with these common-place occurrences and which homogenises and makes such generalisations regarding the people who are placed into these categories.

Another emergent theme from the interview data suggests a difference of attitudes towards state-sponsored entitlements and voluntary, private sector discounts. The reduced fees for medical services and prescription drugs at one end of the discount spectrum were both widely used but also widely accepted. Partly because these are welcomed reliefs from the higher medical costs many disabled people and people with long-term illness have to bear. Partly because these discounts are often automatically applied and systematic, not requiring repeated identification. But, in my estimation, also because they are governmentally mandated. In other words, disability pensioners, as tax-paying citizens, are making use of tax-funded entitlements as a right that does not diminish their social standing. In contrast, the discounts available in stores, with cultural events and so forth that are offered in the private sector are more akin to charity and quite different in nature from governmental, tax-funded entitlements.

As I have argued extensively elsewhere (Rice, 2007), a key problem with charity in modern societies is that charity largely eliminates the ability for the receiver of the assistance to reciprocate. Governmental entitlements lack the stigma of charity because they represent a form of collective redistribution through taxation, which disability pensioners are able to participate either through taxes paid both as the result

of earned income as well as taxes placed upon pensions. This is a right, an entitlement, and an integral part of the Nordic welfare model that is altogether different from voluntary, private discounts. While probably enacted with the best of intentions, such efforts can wound in a figurative sense. As one participant relayed, these messages are encoded in the discounts: “There is always this image given of disabled people; that they, the poor things, don’t have to do anything, you have to give them discounts so they don’t have to pay for anything”. She continued: “Why don’t you just make the pension better and offer people assistance to be able to work so they can pay for the things they need to pay for”.

Conclusion

It has repeatedly struck me as ironic the extent to which the state, responsible for the pension system, acknowledges the inadequacy of its own pension system through the offering of a wide range of reduced fees. This is echoed to an extent in the private sector, which suggests that it is widely known that the pensions are inadequate. It is also possible that the knowledge of this range of discounts can act as a disincentive for the state to enhance the pension system, preferring instead to support public and private sector alternatives in the form of discounts, though without further research this remains speculative. But what is clear is that there is a wide range of disability specific entitlements and benefits which are viewed ambiguously, with stronger feelings reserved for the discounts and reduced fees that are available in what could be referred to as the private sector, such as entertainment and leisure activities as well as consumer goods. Such an avenue of inquiry is not without risk, as many of these discounts are helpful and cumulatively they can represent a significant economic strategy considering the high cost of living in Iceland and the fixed incomes of the pension system, which are subject to numerous restrictions and claw-back provisions. Yet they appear to retain an association with charity and the disempowered status that the charitable relationship entails. The interviews I had with pensioners were strikingly different in content and in tone when discussing the state-sponsored benefits and entitlements with these private sector discounts and which is a telling sign that this is an avenue of inquiry that is worth further exploration.

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