What is needed to assure that the „social justness gap“ isn’t growing? An interjection from Germany[1]

[WG V, Keyspeech S 3]

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1. Motivation to interject

With the suspicion that, all over Europe and beyond, globalisation and legal de-regulation trends in social administration have a considerable, and mostly negative, impact on the lives of persons with disabilities, my political consciousness demands that we take a look into

- the growing risks of inequality in material terms of everyday life,
- disadvantage caused by depending from an ever-diminishing supply of competent human assistance
- many disability group’s lack of opportunities for worklife integration on the open employment market,
- the setbacks in participation which are due to global and new types of barriers

These are some elements that make themselves widely felt as a „social justness gap“ today.

No matter whether economic globalisation has a direct or a more indirect effect on a given individual: she or he should be aware that it has already triggered a discussion which cannot be stopped any more and which features some topics qualified to be viewed critically. Especially so by all who are, during periods of their lives or throughout their whole existence, depending from a certain measure of solidarity. Among these topics are:

- Strengthening of economic competing abilities by relieving the businesses sphere from employer-side social burdens
- promotion of more self-dependence and more private-level insuring of life risks in order to decrease social system costs for the upkeep of a sufficient employment demand,
- withdrawel of state and public insurance administrations from parts of their traditional responsibility in social security issues.

These all reduce no doubt people‘s ability to cope with handicaps, to overcome situations of „undeserved need“, or to get support – which in turn will affect the recovery powers of human individuals and of considerable parts of our societies, too. A disturbing outlook.[2]

2. Misuses of empowerment and the political call for „citizen activation“

Under these conditions, we have to be very careful that the last decade’s emancipation achievements within large groups of handicapped persons do not backfire into our faces. Self help abilities, peer support competence, and civil commitment of people with disabilities: We cannot allow these to be played-off against social security provision by public-responsibility representatives.

To explain, let me quote *Karl Finke*[3]: “Not everyone may be fully aware what ‚empowerment’ means ... Originally, the term empowerment was coined in reaction to the crisis of the welfare

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[1] Slightly shortened version of an oral presentation, convenience translation by: DVfR, Heidelberg/Germany

[2] An outlook being further aggravated by the demographic and epidemiologic facts which tell us that, quite contrary to the status quo, we are now nearing a development stage where the remaining productively participating persons get very scarce, and therefore all post-industrial countries will soon badly need every human ressource they can find.

[3] see his lecture given in this conference proceedings book under Working Group III, Session 1

state in the USA during the seventies of the last century. The social scientist *Julian Rappaport* defined it ... by stating the following central considerations:

- persons requiring social support should no longer be seen only under the narrow perspective of their need; far more important is it to appreciate their existing as well as their potential abilities and competence
- empowerment is a concept to enhance their self-recognition
- contacts between disabled and non-disabled citizens can no longer take place on an object-/subject level; they must be based on a personal eye-to-eye basis; *Rappaport* postulates the end of viewing people with disabilities as ‚society's needy children' whose requirements one can discuss about while keeping them away from the public discourse
- the first purpose of all social support is the build-up of people's competence for self-representation and the strengthening of their participation under the conditions of equal citizenship

In addition, *Rappaport* states that empowerment must not be instrumentalised for reducing community responsibilities towards people with disabilities: ‚Giving rights without providing resources to enact them is a cruel joke', he says. Hints like ‚But you are welcome to organise yourselves!' or ‚We wish you every success in empowering yourselves!' cannot be taken as an excuse for a society no longer maintaining the conditions required for equal citizenship. This would have nothing to do with empowerment, but all the more with pure cynicism."

Considering the often-heard political appellation of ‚required citizen activation' as a means to solve our modern societies' basic problems, let me say that voluntary commitment of citizens and self-help activities cannot allow a withdrawel from a community's responsibilities in securing social rights and services for the population in Europe. It must be the other way round: Activation and emancipation of socially disadvantaged groups aim at strengthening, not at weakening solidarity! "Empowerment is a way of thinking in full awareness of the complexity of social problems, a philosophy embracing contradictions and enabling people to find solutions while keeping in mind that they do not stand alone fighting off social disadvantage."[4] It means a big contradiction to the just distribution of wealth, if emancipation, apparent in groups of citizens, is materially turned against them, and let me also make quite clear that, even without such misuse of the disability community's growing competence, it is, and will be, badly needed by society.

It follows that the "justness gap" we are talking here means the "deficit space" separating a society with its existing possibilities to live & act, on the one hand, from the participation options people with disabilities really have (or rather: do not have), on the other hand.

The smaller this gap is kept (by empowerment accepted as normality everywhere, by doing away with avoidable barriers, by respectful views, favourable settings, and accommodative conditions) the bigger are people's real participation opportunities.

3. Equalisation of opportunities - depending from society's framework conditions

One of the most important public policy duties therefore is establishment of conditions which enhance equal opportunities. The aim is, to achieve a certain balance and compatibility between

- autonomy and assistance needs
- competence and support requirements
- self-dependence and social interconnection

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[4] *Finke, Karl* (please compare footnote 3)

Equal opportunities can be achieved only if a society's political leaders lay down a reliable groundwork for their implementation by issuing the legislation required and, at the same time, by making available the necessary resources, including financial ones.

The final purpose in establishing favourably inclusive conditions, like bringing down as many participation barriers as possible, combating pre-determined and unconscious discrimination alike, as well as restricting exclusion caused by the legal system itself, simply is to erase old and new causes for disadvantage in regard to people with disabilities.

4. By example: Legal framework conditions in the Federal Republic of Germany

For Germany, I want to mention three important acts of legislation which have been set down recently.

- Disability Equalisation Law (Gesetz zur Gleichstellung behinderter Menschen),
- Book IX of the German Social Code, on rehabilitation and participation of persons with disabilities (Neuntes Buch des Sozialgesetzbuchs – Rehabilitation und Teilhabe behinderter Menschen), and
- Law to Combat Unemployment of Severely Disabled Persons (Gesetz zur Bekämpfung der Arbeitslosigkeit Schwerbehinderter).

With these bills, the federal legislators have aimed to fulfill the state-required parts[5] for a creation of social conditions favouring equal opportunities for people with disabilities. Central for these laws are the following considerations:

- accessibility of the environment as far as it can possibly be realised
- respect for the self-determination right
- just and fair access to the required medical, vocational, and social services
- right to choose between alternatives of disability provision
- support for employment and worklife participation
- overcoming employment obstructions for job-seekers with severe disabilities
- assessing abilities and requirements in a positive manner – based on the ICF[6]

With this legislative action, the German government accomplished a considerable task of pro-active enhancement concerning the constitutional guarantee of 1994 which reads "No person must be disadvantaged due to a disability." (Article 3, Section 3 of the "Grundgesetz der Bundesrepublik Deutschland").

5. Accessibility and participation in society, resources requirement, and solidarity

Recent national equalisation laws regarding people with disabilities are quite closely connected to a number of related international policy developments. In 1992, a Council-of-Europe resolution on "Coherent Policies for People with Disabilities", then, in 1993, coding of the "UN Standard Rules ‚Equalisation of Opportunities for People with Disabilities' ", further the "Decision on Disability Rights" of the European Parliament (for the EU membership) and a corresponding declaration of the Council of Europe on the rights of persons with disabilities (for the wider European scope of CE states), both dating from 1996, – all these have been recognised within the national legal spheres – not only in Germany.

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[5] It is understood that in other, non-public and civil domains of society, changes must also be initiated, not least regarding the „thinking“ of the citizens in general. To accomplish these changes, a pro-participation legislation can be of great help.

[6] International Classification of Functioning, Disability, and Health; WHO (2001). A classifying system to assess participation settings, and the first of its kind which was compiled in full cooperation with representatives of the international disability movement. It is meanwhile being extensively discussed and tested in many parts of the world.

Accessibility rules and participation rights, as well as the establishment of a number of legal instruments to implement them, are in most cases the main content of national equalisation laws. Often, like in Germany, the gender mainstreaming issue is included. i. e. special attention is given to avoiding disadvantages for women with a disability. In Germany and elsewhere, also the right of non-hearing people demanding more advancement and public spread of their sign-language[7] are separately recognised in these laws. For the implementation of claims conceded by this kind of legislation, people with disabilities need not only a recourse-of-law open to the individual; also, their organisations must be allowed to demand clarification rulings in courts of justice. And, finally, non-discrimination or equalisation laws must be constructed so that they overrule discriminatory regulations which may still be part of the other (older) existing law of a nation. (Here, special consideration is to be directed towards legal building norms, traffic law, laws on professional & trades' orders, tenancy leasing & renting legislation, etc.). All this has been recently realised in Germany.

However, an important supplementation of existing "public" equalisation laws is still pending in many countries of Europe; also, the German federal government has declared an intent to put forward the "Civil-Code-related" part of German anti-discrimination legislation soon. This will be targeting towards the protection of persons with a disability in the domain of private life, civil contracts, company hiring & employment, travel & holiday recreation, and other fields.

In addition, available resources to realise full social participation are another quite important issue. With Book IX of the German Social Code, for example, eligibility to social rights, to developmental assistance, and to protection against discrimination within community life and the world of work, have been defined and implemented in a most clear fashion. A widening of the option to personally choose between alternatives (concerning the kinds of services available) – with special regard to the requirements of women with a disability –, and introduction of new practical instruments for supported employment as well as deaf people's right to demand communication in sign language, have been granted.

Directly and indirectly, many of these aspects are highly relevant in terms of a "material basis" for personal participation, of course.

The participation concept hereby is based on the recent WHO model (the ICF), which not only enlarges the scope of reference by acknowledging physical as well as social environment and other context factors co-determining the extent of every handicap, but also by its additional focus on the "human activities" level (abilities and participation – or: factors which limit or threaten these).

Persons with a disability or a chronic illness do need a special measure of protection and social solidarity, of course, – especially regarding their productive employment. On the other hand, a human society distinguishes itself by granting them the means and offer the preconditions for access to equal opportunities. Especially in times of a high general unemployment there exists even less excuse for a society to get slack or weak in this domain. This is the reason why the third piece of legislation I have mentioned – the federal Law to Combat Unemployment of Severely Disabled Persons – was issued in conjunction with the other two. It testifies to our politicians' knowledge that gainful employment (personal earnings) of a largest-possible number of people with disabilities would greatly strengthen

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[7] Which reflects a specific perspective change, too. More and more, non-hearing people define themselves not so much as a group with a disability but rather as a cultural minority. This kind of self-concept also begins to emerge from the more emancipated groups of people with leraning „disorders" who see themselves as handicapped by a public education system failing to include those requirements which a minority of people with special instruction needs or differing learning dispositions may have.

and stabilise their overall empowerment. This law supplements our other existing federal legislation[8].

We must, however, remember that provision of a progressive legal groundwork alone, which I have described here for Germany, cannot change the factual reality of people with disabilities to the necessary extent. A society must "live equality", i. e. fill it with real life. Exactly to achieve this, the "rehabilitation community", including people with disabilities, must take this on as their mission and pursue it tirelessly.

It is in full harmony with the new self-concept of empowered citizens with disabilities that society may just offer what is really needed in assistance for the equalisation of opportunities and participation, and no more. Every support measure has to correspond to real needs, to realistic goals of people concerned, and there is a certain requirement of efficiency and efficacy to be respected.

But these "agreeable economic criteria", and the actual approval of disabled people to them, depend from certain preconditions. And many of these are still in great want:

- clear definitions for the appropriation of sustainable assistance forms
- information tools to correctly assess requirements and needs in a just way
- mechanisms for service quality assurance, service maintenance, and evaluation
- classifications to sensibly "steer" or determine the case-related resources' allocation
- instruments which are fit to answer the overall need for comparability and compatibility

I am speaking of scientific instruments which, moreover, should have a common basis with existing, time-tested systems and tools already in use within other parts of the world. (For the most, it makes no sense and is not required to "newly invite the wheel" again and again.)

6. How to counteract the "social justness gap" in market economy countries

As I have stated initially, in our societies the globalisation developments cause everywhere a political strategy to slowly de-regulate our social security systems. Successively, the public answer to general life risks is getting weaker, while a growing portion of social risk management is expected from a "free" interrelation between self-supporting, self-responsible individuals and simple market mechanisms. In such a situation, what we urgently need is a broad-based and well informed open discourse about the "fair minimal extent of public responsibility" towards people endangered by social disadvantage, i. e.: a discussion of the limitations private precaution and insurance have.

At the same time, demographic implications of our social development and the gap opening up between the health sciences' progress and the affordability of new medical, chemical, and technical assistance, is bound to give a high relevance to our justness-oriented discussions on available resources and issues of wealth participation (i. e. wealth distribution).

In order to contribute to this debate from a position of strength, or to even take a leadership role in them, it lies in the very interest of people with disabilities to help determine, in quite concrete a manner,

- what are – seen in participation support requirements – the necessary resources normally related to a disability in various specifications of its severity, and depending from diffe-

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[8] This surrounding law enhances the "employability" aim; its purpose is also to address ergonomic access issues in work, to regulate employee health protection measures, and to encourage "shop floor level" disability prevention – right up to real company-based (early) health intervention strategies. Hopefully, it will dawn on more and more companies that connected activities are advantageous also for themselves, even in economical terms.

rent provision models looked at in the broad range (from the self-direction of a "personal assistance budget" right down to full scale institutional care)
- how resources needs are assessed in individual cases, and how responsibility is implemented for the controlling of their allocation
- how a case-appropriated application of resources is to be managed in order to facilitate the necessary service form and service quality as well as assuring that personal wishes and requests of individuals with disabilities are respected in a best-possible way

Even the most knowledgeable groups within the disability movement have, until very recently, encountered very tricky problems when participating in discussions of that type. Luckily, two new developments have now made a change for the better. One is the fact that today's disability movement has overcome its fragmented approach, and, within its cross-disability umbrella organisations, has meanwhile generated a number of general disability experts who can contribute to the above issues in a very competent way – no longer being confined to the expertise of their own personal disability. If, in addition to that, their eye-level-cooperation with selected and trustworthy rehabilitation service and social security professionals will be further developed in the coming years, their disability competence will flourish even better.

The other development is this: With the WHO's ICF classification we are now in possession of an excellent measuring and determination tool[9]. In the process to assess concrete needs for securing participation, it is necessary that this tool is used to its full extent and, next to physical disability dimensions, also intact (or faulty) structures and (dys-)functions of
- psychological integrity,
- social interconnection, and
- personal context

are taken into account. In addition to the level of impairments and disabilities, also the level of activities and performance is to be duly noted, too, – both in terms of individual accomplishments and personal aspirations.

Like in the public health field, this joint discussion should have the target to develop a set of common standards and "requirement inventories" for rehabilitation and care. Internationally, the first few instruments to that end have been created. For example, the RAI 2.0 (Resident Assessment Instrument[10]) or the Rehabilitation Utilisation Groups[11] (RUG III) may already be adapted to the reality in different countries quite easily, providing not only measurement categories for support needs, but also opening up descriptive possibilities for determining a structural, processional, and result-related assessment of quality in facilities and services[12,13] .

7. Looking ahead to European developments

In the moment, the right within the European Union to regulate social order and social law still remains with the national legislation bodies of its member states alone. In spite of that, a lot of the EU's commitment is directed at influencing, in a more indirect way, its members

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[9] See for example: *Schuntermann, Hollenweger, and others*, in Working Group VIII in this conference proceedings book

[10] See *Garms-Homolovà, Gilgen*: RAI 2.0 Resident Assessment Instrument, published by Hans Huber, 2000

[11] See *Fuchs, Garms-Homolovà, von Kardorff, Lüngen, Lauterbach*: In double issue 3 / 4, Arbeit und Sozialpolitik, 2002

[12] See *Fuchs*: Personalbemessung in der Altenpflege – Allheilmittel oder notwendiges Hilfsmittel?, in Yearbook Soziale Sicherung, 2002

[13] See *Fuchs*: Weiterentwicklung der Pflegeversicherung – ein ordnungs- und strukturpolitischer Ansatz zur Lösung des Problems >Rehabilitation vor Pflege<, in *Oldiges, Schian Schönle (Edt.),* Pflegenedürftigkeit – Herausforderung für die Rehabilitation; Interdisziplinäre Schriften zur Rehabilitation der DVfR, issue 11, 2002

towards improved opportunities’ equalisation within their national disability policies. There is much political evidence of initiating joint European action intending to produce a common “conversion mainstream” in disability policies.

I have, however, an impression that, while the content of direct political decisions, for example on the European Parliament level, is transparent enough for the European disability movement to be influenced or at least closely regarded by them, this is not the case with other EU actions indirectly aimed at achieving a gradual convergence of national disability policies.

An EU multi-layered “soft law” strategy towards a more social Europe, still closely related to the often insufficient legal basis in respective EU member countries, now tries to steer a process of social system convergence by using monitoring and benchmarking operations. This can lead to supra-national developments of system adaptation, to the proposal of common agendas, inter-adapted goals, and a similarity in the regulation of service standards for disability provision. In this process, the involvement of representatives of the disability movement is still by far too small; these developments are, in the moment, almost exclusively regarded and influenced by service providers and policy planners. This fact gives rise to a concern that the future scenario of disability services will perhaps soon be in good accord with overall economical trends and European market & business competition requirements, but in no way sufficiently compatible with the needs for full and equal participation of persons with handicaps in their national societies.

The consequence of this threat must be that people with disabilities and their organisations are strongly encouraged to carry their own notions and considerations of a “social Europe” into the community of Union nations. It must be their mission to prevent, on the one hand, for social policy a “harmonisation on the lowest common denominator”, and, on the other hand, to challenge a development which could reduce the sphere of social service provision into a mere sector of national service economies or of the EU service economy.

8 Conclusion

The dynamics of global economic development in Europe, resulting in the strong tendency to follow a path of de-regulation concerning national welfare structures, and forwarding supra-national trends for a “base-level system convergence” which implies social benefit cutbacks –, all this can lead to a growth of the “social justness gap” for Europeans with disabilities. To avoid such a development, a more direct – and a far more detailed – involvement of disability movement expertise in the ongoing discussions is called for urgently.

This involvement needs to be organised along the lines of disabled people’s

- insisting upon their autonomy,
- enhancing a widespread empowerment amongst their peer group,
- bringing to bear their competence on all decision levels,
- defending the social concept of a just distribution of wealth, and
- promoting and applying “cooperative participation[14]”.

For that, every society has first to make available the resources required – in regard of material rights as well as of financial means. A further development and a productive application of useful tools for the determination of needs, for rehabilitation result measurement and evaluation, will be indispensable for assuring the sensible use of social resources: In accordance with justified demands, well-aimed at individual requirements, and operationally effective both in terms of sustainable costs and optimal outcome – individually and socially.

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[14] Meaning: In „cross-disability“ accordance as well as – possibly – in consultation with selected strategic partners from outside the disability movement.

At the end, success will depend from the ability to prove that a just and human disability policy and a high-quality rehabilitation will advance not only disabled citizens, but societies at large.