

21 May 2012

Statement

NOW I'M GOING TO DECIDE! – Independent Decision Making

“I feel discriminated against when I have to go to the authorities for something
and the civil servant talks to me as if I was an idiot.

I point that out to them very frequently and say:
please come down from your high horse; I'm not from Mars
or Jupiter, I'm Mr. Weissenbacher.”¹

“Recognizing the importance for persons with disabilities of their individual autonomy
and independence, including the freedom to make their own choices...”²

I Introduction

“Why are persons with disabilities described as persons with special needs? They
are normal persons too and have normal needs.”³ This comment by a participant at
the public meeting of the Monitoring Committee on 17 November 2011 in Vienna on
the theme of supported decision-making summarises the Convention on the Rights of
People with Disabilities in a pithy way, and gets to the heart of an essential insight: all
persons have needs, including the multifaceted need for various forms of support.

The decision-making processes of persons in positions of power is often
characterised by the consultation of a team of advisors. Some persons find it befitting
to obtain the support of a style advisor when selecting their clothes. Whereas this
type of artificially created heteronomy is considered a status symbol,⁴ the
heteronomy of persons with disabilities is the result of a structure in which third

¹ Vienna People First, interview with Thomas Weissenbacher, Freak Radio, 11 July 2007, see:
<http://www.freak-online.at/>, <http://www.freak-radio.at/cgi-bin/freak.cgi?id=fn00104&p=a&t=4>, In memory
of Thomas Weissenbacher, 1945 - 2011.

² Preamble of the Convention, letter n.

³ See minutes of the public meeting, p.13 and the basis for discussion: all documents at
www.monitoringausschuss.at.

⁴ For the ‘reality’ behind *all* decision-making processes, see also: Council of Europe, 19.

parties ultimately exercise power over the decision-making and thus frequently over the lives of persons with disabilities.

According to estimates, around 60,000 persons in Austria have a legal guardian.⁵ The number of guardianship orders cannot be precisely determined. However, it has risen considerably in recent years: the forecasted change in the age structure of society will lead to an increase in the need for support in decision-making.⁶ Guardianship is effectively the determination of a person's will by a third person. This heteronomy creates a conflict with the human right of self-determination which ultimately cannot be resolved.

“People with disabilities are responsible for themselves, they can think clearly; some of them need help in expressing their thoughts.”⁷ The Convention thus recognises a person's **right to exercise** their legal capacity, where necessary in combination with support measures.⁸ The goal of the Convention is to realise self-determination in its entirety in order to ensure equal opportunities for persons with disabilities in all areas of life. Alongside removal of barriers⁹, ensuring support and assistance¹⁰ – **also** in decision-making – are particular opportunities to overcome possible barriers. A desire for support is, as mentioned at the beginning, a ‘normal’ – human – need, which everyone has. It should therefore be possible for everyone to enjoy this equally and take advantage of it according to their needs.

II Outline of the problem

The law on guardianship is an important milestone as a step out of the complete lack of rights enshrined in the old Incapacitation Regulations. The 2006 amendment is “not bad”¹¹; it includes for example the establishment of a maximum number of 25 guardianship orders per person. However, its intentions were counteracted by the 2009 amendment.

In the practical implementation, two factors in particular need to be understood: „Guardianship is a difficult and extensive subject”¹² and “there are good and poor guardians.”¹³

⁵ For estimates see e.g. http://www.irks.at/downloads/SWKennzahlen_final.pdf, http://www.parlament.gv.at/PAKT/VHG/XXII/II/II_01420/fnameorig_061458.html, and the survey of the Institute for Legal and Criminal Sociology, 2009.

⁶ On the issue of age-related guardianship see i.a. the exploration of the problem by the Ombudsman's Office, <http://volksanwaltschaft.gv.at/downloads/2e9p7/PB33-Hauptteil.pdf>.

⁷ Minutes of the public meeting, page 13.

⁸ Cf. Art. 12 of the Convention.

⁹ For details on the six dimensions of accessibility, see: statement of the Committee on subsidies, March 2012.

¹⁰ See also: equal opportunities via the realisation of human rights – assistance in decision-making, iFamZ September 2011, page 269.

¹¹ Minutes of the public meeting, page 10.

¹² Minutes of the public meeting, page 6.

With regard to the latter issue, it should be noted that criticism of a system is not automatically criticism of individual persons, and that questions asked about practical problems are necessarily based on individual cases which, insofar as they are negative, do not have to be generally understood as – personal and unobjective – criticism of *all* persons of a certain grouping. In spite of all good intentions the inherent tension of the guardianship institute cannot be easily resolved.

Moreover, the pressure which is exerted upon persons with disabilities in a performance-orientated society which strives to achieve homogeneity is also considerable: the expectations made of them on the part of society are – unconsciously – moulded by norms which are directed towards an ostensible ‘normalisation’. In the tension, which is thus created, relying on third persons and thus heteronomy is structurally unavoidable in many cases.¹⁴

The warning issued by a self-advocate at the public meeting should be taken to heart: “People should deal with this issue (guardianship) in a sensible way”.¹⁵

The following section provides an outline of the problem – on the basis of some of the areas touched upon by guardianship – without claiming to be complete.

1. Order, appointment and termination

Information:

Although information about guardianship and training courses is available, this information often does not appear to reach those affected – both guardians themselves and those persons who have a guardian.¹⁶

It is important for all those involved that the information is understandable, and that accessible communication used if necessary, particularly for consultations in court.¹⁷

Co-determination:

People with disabilities must have the opportunity to jointly decide on who is going to be their guardian.

Conflict management:

There should be easier access to opportunities for solving conflicts with guardians.

Trial period:

The possibility of a trial period should be created for all phases of guardianship: for example directly after the appointment, in cases where the extent of the guardianship is to be limited, and for the transition period towards the end of the guardianship order. *“Sometimes the opinions about the necessity of a guardianship vary; in that*

¹³ Minutes of the public meeting, page 7.

¹⁴ See also minutes of the public meeting, page 9.

¹⁵ Minutes of the public meeting, page 6.

¹⁶ Minutes of the public meeting, page 8 ff.

¹⁷ Minutes of the public meeting, page 8.

case I try it out by setting a trial period in agreement with those affected”, said a judge.¹⁸

Extent of a guardianship:

- The scope of guardianship orders is often set too broadly by judges.
- Too little use is made of the possibility of guardianship orders for **partial areas**.
- Extensive guardianship orders are seldom examined with regard to their possible reduction to partial areas.¹⁹

Termination:

Official examinations about whether to terminate a guardianship order seem to be rare. Information about the possibility of ending a guardianship does not appear to reach those who would be potentially interested in doing so.

Asset management:

The mandate to invest a person’s assets in as meaningful a way as possible can be misunderstood; the regulations on **payment and the reimbursement of expenses** can also lead to guardians having more (self-) interest in increasing the assets of the ward than in the person’s quality of life.²⁰

Monitoring possibilities:

“There is no independent monitoring facility for those affected.”²¹ The main motive for the appointment of lawyers and notaries are the **supervisory facilities** which are offered by the disciplinary regulations of their respective professional bodies.²² The majority of the complaints are related to guardians from these professions. This has a wide range of reasons, which are largely of a structural nature. Alternative monitoring possibilities are either not sufficiently well-known or the threshold is too high for potential users.

Change of guardians:

A frequent **change of guardians** is problematic, because it creates discontinuity and makes it necessary to build up a relationship again and again.

¹⁸ Minutes of the public meeting, page 7.

¹⁹ Minutes of the public meeting, page 9.

²⁰ Minutes of the public meeting, page 7.

²¹ Statement by Vienna People First.

²² Minutes of the public meeting, page 12.

2. The role of the court

Information:

Information about guardianship is often described as meagre and hard to understand. Particularly in consultations with judges there is often a lack of understandable explanations and information in **accessible communication**.²³

The short periods of time during which judges are available is also perceived as problematic.²⁴

There is no **information in accessible language** on ways of lifting guardianship orders, the removal of guardians, or about how to complain (lodge an appeal) in the case of unsatisfactory decisions.²⁵

Errors and risks:

Thinking in terms of liability leads to the fact that persons with disabilities are allowed to **make mistakes much more rarely**: one gains the impression that the slightest mistakes will lead to an extension of guardianship or make it much more difficult to revoke.

There is a lot of criticism of the lack of opportunities to take **risks**. In the descriptions offered, the paternalistic element of 'knowing what is best for you' is clearly present.

Supervisory function of the court:

The supervisory mechanisms of courts are described as "too vague".²⁶

There is a sense that courts do not apply the supervisory powers or do not fully exploit them.²⁷

3. The role of expert witnesses

In the course of the discussion, it was not possible to adequately consider how expert's reports are drawn up and the effects, which they have. There seems to be some scope for improvements here too, above all with regard to the realisation of the biopsychosocial model in the drafting of reports, and with respect to the multi-disciplinary composition of review boards.

The Committee has commented in more detail on the question of basic human rights in relation to expert's reports in its statement on the Decree on assessing impairments.²⁸

²³ Minutes of the public meeting, page 8.

²⁴ Statement Gruber et al.

²⁵ Minutes of the public meeting, page 7.

²⁶ Minutes of the public meeting, page 10.

²⁷ Minutes of the public meeting, page 4.

²⁸ Statement of the Committee on the Decree on assessing impairments, 3 February 2010.

4. Relationship with and contact to guardians

As an instrument of control, guardianship is also a form of exercising power. The relationship between ward and guardian is inevitably characterised by dependence, and can ultimately only be described as an intrinsically imbalanced situation. The possibility of interventions in personal and extremely personal matters creates contradicting interests and thus in many cases tensions:

“My guardian orders me around and tells me off. He shouts at me, but I haven’t done anything. [...] The way he treats me hurts me deeply.”²⁹

And: *“My guardian knows too much about my life; that isn’t pleasant because it’s not a good situation. I’d like to have a different guardian. That’s difficult, because I’m scared.”³⁰*

“When I have an appointment with my guardian I don’t feel happy. I’m afraid...”³¹

“We don’t think it’s good if we have parents or relatives as guardians. Parents or other relatives have their own ideas about how we should live. It’s difficult to contradict your own mother or father. It’s hard for us to say to our relatives that they are doing their work badly.”³² “It shouldn’t be allowed for parents to be the guardians of their children.”³³

The appointment of support persons – workshop staff and other persons linked to an institution – against the legal provisions is also highly problematic.³⁴ *“Those guardians then represent the wishes of the institution or facility rather than our wishes.”³⁵*

The law provides for an **obligation of the guardian to determine the wishes** of their ward. This lays down that before the guardian makes decisions, s/he has to “provide the ward with the necessary information in good time and to subsequently ask them about their wishes”, and to do so “on her/his own initiative, without having to be asked”.³⁶

Self-advocates have a clear wish to try out new forms of support, also in decision-making.³⁷ Guidance and support from a guardian is particularly missed in the transitional phase from comprehensive guardianship to partial guardianship, but also when changing to an alternative form of decision-making.³⁸ There also seem to be

²⁹ Minutes of the public meeting, page 5.

³⁰ Minutes of the public meeting, page 5.

³¹ See anonymous statement.

³² Minutes of the public meeting, page 4.

³³ Statement by the Network of Self-Advocates.

³⁴ Minutes of the public meeting, page 10.

³⁵ Statement by the Network of Self-Advocates.

³⁶ Cf. Barth/Ganner, Handbuch des Sachwalterrechts, 93.

³⁷ Minutes of the public meeting, page 4.

³⁸ Minutes of the public meeting, page 4.

opportunities for improvements in the mobility and flexibility (in terms of time) of guardians.³⁹

Considerations about alternative forms of support or a change of guardians should, if possible, be accompanied by advice from peers – experts in the same field.⁴⁰

5. Areas of life

Housing

With regard to decisions about where to live, the law limits the decision-making power of guardians “as far as the person is capable of insights and making reasoned decisions”.⁴¹

Work

“My guardian meddles in my work too much, but sometimes it’s good when I have a more serious problem.”⁴²

Money, saving and pensions, and financial security

“My guardian says I have to save.”⁴³

The present regulations create the impression that the preservation and increasing of the ward’s assets is in the interests of the guardian. In the current system, the provision of incorrect information about the actual level of the ward’s assets seems hard to curb. It is noteworthy that self-advocates are also in favour of an allowance being granted to guardians for the support they provide in this sense.

“It’s a nuisance that I have to call her because of every little amount, but unfortunately there’s no other way to do it because that’s how she arranged it with the bank. I have to call the guardian first so that she writes an e-mail to the bank. The bank won’t give me any money without the permission of my guardian.”⁴⁴

“I can withdraw a certain amount per week and that’s fine with me.”⁴⁵

Models such as that of the Vienna debt counselling service, in which clients have a fixed amount on their own account, which they can freely dispose of, should be discussed.⁴⁶

³⁹ Minutes of the public meeting, page 5.

⁴⁰ Minutes of the public meeting, page 7.

⁴¹ Section 284a (1) Austrian Civil Code.

⁴² Anonymous statement.

⁴³ Anonymous statement.

⁴⁴ Anonymous statement.

⁴⁵ Anonymous statement.

⁴⁶ Briefing with the head of the Vienna debt counselling service, Alexander Maly.

Leisure time and other issues

“My guardian wants to organise my leisure time, but I don’t want that. If I don’t want something I just don’t want it. At the weekend I want to have some peace and relaxation.”⁴⁷

“My guardian puts my name down for sports events. He doesn’t tell me that he’s done it and occasionally I don’t want to go. I don’t feel like it. It was difficult to cancel my registration for the event. Sometimes I have to go whether I like it or not. My guardian is my sports coach. My guardian has put my name down for cross-country skiing but I couldn’t be bothered. It took a long time until I said no. It definitely took three years. But now he’s grasped it.. He tells me what I have to do and doesn’t listen to me.”⁴⁸

“My guardian should support me when I want to go on holiday.”⁴⁹

Education and further education

By pointing out existing opportunities, guardians can play a supporting role in the question of access to education and training programmes, which aim to preserve or also to develop abilities.

Medical care including preventive medicine

It is significant that there was no feedback on this point. In the interests of human rights, there is a need to consider that in the field of the medical care of persons with learning difficulties in general, and also in the case of persons who have a guardian, many things happen which run counter to the right to a maximum level of health care provision. On the one hand, access to **preventive check-ups** such as those in the areas of gynaecology, urology and dental care should be ensured.⁵⁰ On the other hand, guardians play an important role in **protecting their wards from abuse**. Dental treatment is said to have occasionally been carried out with full anaesthetic due to perturbed patients, and a decayed tooth was once used as an excuse to remove all of a patient’s teeth.

Sexuality

There have apparently been cases in which persons with disabilities have been given contraceptives, which were described to them as medicines with a completely different effect. The ramifications of the supposition that persons with disabilities are somehow asexual, and the tendency to solve the ‘problem of sexuality’ ‘simply’ by

⁴⁷ Anonymous statement.

⁴⁸ Anonymous statement.

⁴⁹ Statement by Vienna People First.

⁵⁰ See in particular the comprehensive Pomona study, e.g. at: http://www.pomonaproject.org/action1_2004_frep_14_en.pdf, <http://bidok.uibk.ac.at/library/brehmer-pomona.html#id2921077>.

means of sterilisation still has to be opposed in the strongest terms in spite of the existing regulations⁵¹.

Private and extremely personal matters

“My guardian does not want me to marry, but just to receive a blessing. She hasn’t got anything against a blessing, which could be organised as beautifully as a wedding, but it isn’t the same. I would really like a blessing too, with all the trimmings. I’m not allowed to marry although I have been together with my boyfriend for many years now.”⁵²

The Human Rights Commissioner of the Council of Europe recently stated that it makes little sense to give persons the right to marry and have a family when a third party has to make the relevant decisions.⁵³

Protection of people’s physical and mental integrity and protection from all forms of violence also fall into this category. During the public meeting it was criticised that in the course of recent discussions about violence and abuse in institutions, there was no mention of persons with guardians who had notified the authorities about incidences of violence.⁵⁴ Although there have been no investigations about this, given the basic tendencies in dealing with violence⁵⁵ it can be assumed that too few guardians have given thought to the possible effects of violence on their clients.

Participation in political processes

For persons whose right to exercise their legal capacity is restricted, full participation in political processes is often not ensured.⁵⁶

Austria recognises the full right to participation in elections.⁵⁷ At the same time, it is clear that more accessible information is needed on the political participation of persons with disabilities, particularly those with learning difficulties. A relevant event organised by the Democracy Workshop of Parliament seems to be an example of good practice.⁵⁸

⁵¹ Section 283 (1) of the Austrian Civil Code.

⁵² Anonymous statement.

⁵³ Report of the Council of Europe, page 8.

⁵⁴ Minutes of the public meeting, page 11.

⁵⁵ See the statement of the committee on violence and abuse, 24 February 2011.

⁵⁶ See the latest study of the High Commission for Human Rights on political participation, and the study of the EU Agency for Fundamental Rights.

⁵⁷ See Artikel 26 of the federal constitution, and also the Constitutional Office of the Federal Chancellery’s “Working group on the examination of the Austrian legislation with regard to provisions which disadvantage persons with disabilities” p. 40-41. <http://www.bizeps.or.at/info/bka/texte/gesamt.doc>, and the recent study of the EU Agency for Fundamental Rights http://fra.europa.eu/fraWebsite/attachments/Report-vote-disability_DE.pdf.

⁵⁸ See e.g. Natalia Postek, Politische Teilhabe von Menschen mit Lernschwierigkeiten am Beispiel der Demokratiewerkstatt in Wien, 2.6 Beispiele politischer Teilhabe <http://bidok.uibk.ac.at/library/postek-teilhabe-dipl.html>; on the fundamental issue of political participation see the recent resolution of the

6. Other fields

“There is a percentage clause. That means that when a self-advocate has a lot of money, the guardian gets a part of the money. The percentage clause should be abolished.”⁵⁹

The court fees for guardianship orders are experienced as an unreasonable burden – also due to recent rises – and there were demands for their abolition.⁶⁰

III. ‘Life supporters’

During the public meeting, self-advocates called for the introduction of so-called life supporters.⁶¹ It is indicative for the thought that self-advocates have put into this that they are calling for life supporters to “receive decent payment” and that they “should receive support” in the fulfilment of their tasks.⁶²

The realisation of self-determination – as the core element of exercising legal capacity – has to become the focus of attention: supporting or assisting persons with disabilities is a **means and not a goal in itself**. In the Convention, the significance of assistance and support is helpfully defined in more detail in the article on equal participation in political life and elections.⁶³ In order to guarantee the free expression of their will at elections, voters can, at their request, be supported by a person of their choice. The element of self-determination is emphasised several times here: “free will”, “at their request” and “person of their choice” are three explicit wordings for the manifestation of the **freedom to make decisions**. The option of support is mentioned, but it is clearly formulated as a possibility and not as a necessity.

The social and socio-political environment plays an important role in the realisation of equal legal capacity. “Full and effective participation and inclusion in society”⁶⁴ is a basic principle of the Convention. People are characterised by participation in public life, interaction with third parties, a natural involvement in their social surroundings and in the structure of society. The way persons see themselves, their quality of life and many other factors are determined by the possibility to achieve self-realisation in a social context.⁶⁵

UN Human Rights Council, March 2012, HRC/RES/19/11.

⁵⁹ Statement by the Network, see also minutes of the public meeting, page 4.

⁶⁰ Minutes of the public meeting, page 4.

⁶¹ Statement by the Austrian Network of Self-Advocates.

⁶² Statement by the Austrian Network of Self-Advocates, page 5; see also: minutes of the public meeting, page 4.

⁶³ Article 29 (a) (iii): guaranteeing the expression of free will by persons with disabilities as voters and, at their request, allowing them to receive support in voting by a person of their choice.

⁶⁴ Cf. Article 3 of the Convention and Article 1: Purpose.

⁶⁵ On this and the following section, see statement of the Committee on “results-oriented impact assessment” of 5 January 2012.

Learning **social skills** and the establishment of **(more) natural interaction with persons with disabilities** require above all a shared everyday life, something which does not yet exist in Austria yet. As an important element of self-determination and the realisation of opportunities for participation, the circle of persons with whom social relationships can be developed – and of course practised – has to be extended.⁶⁶ Sharing everyday school life is a key element on the path towards a more natural relationship to persons with disabilities.⁶⁷

The possibility to make mistakes and take risks must – in the interests of equal opportunities for persons with disabilities – become a matter of course. The ‘dignity of risk’ describes the difference between “human dignity in risk and inhuman indignity in security.”⁶⁸

In economics, having opportunities to act and *the chance to realise such opportunities* are recognised as key factors in a good and successful life. The significance of these factors is particularly great for persons with disabilities,⁶⁹ especially because equal opportunities for persons with disabilities are largely limited by social mechanisms. The “attitude-related barriers”⁷⁰ which – in the form of prejudices and discriminating omissions – lead to the social exclusion of persons with disabilities, are an important obstacle in the realisation of opportunities for participation. These external conditions, which have such a decisive influence on the possibilities available to persons with disabilities, can be influenced by the government.⁷¹

IV. Some thoughts for the continuing debate

The label of incompetence

For many persons with a guardian, the label of incompetence becomes a self-fulfilling prophecy in which they primarily learn helplessness and dependence.⁷² Even for persons who only have a guardian in certain areas of life, this can spill over into other aspects.⁷³ “The sad truth is that most Europeans with intellectual and/or psychosocial disabilities who would like to have such support are instead asked to give up their

⁶⁶ On the concept of social capital see in particular: Bourdieu; on the link between Sen’s opportunities of self-realisation and Bourdieu see Bowman.

⁶⁷ Statement of the Committee on Inclusive Education, June 2010.

⁶⁸ On the dignity of risk for persons with learning difficulties, see: Robert Perske, Dignity of Risk, for references in the context of psychosocial impairments in general, see Pat Deagan.

⁶⁹ For this see the recent WHO/World Bank World Report on People with Disabilities, ‘Capabilities Approach’, p. 11 see also (<http://www.bizeps.or.at/news.php?nr=12808>); See the basis for discussion of the committee for the public meeting on 17 November 2011 on supported decision-making: www.monitoringausschuss.at, and Kim Hopper, Rethinking Social Recovery.

⁷⁰ See PP (e) and Article 1 of the Convention.

⁷¹ See WHO/World Bank, World Report, p. 13.

⁷² Report of the Council of Europe, page 8 ff.

⁷³ Report of the Council of Europe, page 9.

legal capacity.”⁷⁴ Even the most committed guardian cannot compensate for the inherent loss of rights.⁷⁵

The ethos of empowerment

A normative view of mankind which is characterised by the three pillars of self-determination, social justice and democratic participation forms the foundations of deliberations which comply with the Convention.⁷⁶ An ethos is required which encourages and promotes persons to the maximum extent in the realisation of their own self-determination and – where necessary – supports them.⁷⁷ The following model of the ‘Legal Empowerment of the Poor’ created by the Commission of the United Nations provides a helpful illustration:⁷⁸

The Concept of Legal Empowerment



© Commission on the Legal Empowerment of the Poor

© Translation for German Statement: Kiss Me I'm Polish, LLC

Self-determination and assistance

The first fundamental principle of the Convention is self-determination.⁷⁹ The Convention prohibits discrimination in any form, and particularly discrimination which *results* in persons being treated differently.⁸⁰ “Citing ‘disability’ as the reason for revoking a person’s legal capacity – for example by appointing a guardian –

⁷⁴ Report of the Council of Europe, page 11.

⁷⁵ Report of the Council of Europe, page 11.

⁷⁶ Staub-Bernasconi, *Soziale Arbeit*, p. 248.

⁷⁷ On the ethos of empowerment: see Staub-Bernasconi, p. 247; on empowerment see also: Report of the Council of Europe, page 11.

⁷⁸ Commission on the Legal Empowerment of the Poor, p.27.

⁷⁹ Cf. Article 3 of the Convention and Preamble letter n.

⁸⁰ Definition of discrimination, Article 2; see also Report of the Council of Europe, page 12.

contradicts the right to equal recognition before the law.”⁸¹ Article 19 on living independently and Article 29, which provides for support at elections, describe **clear alternatives to guardianship based on assistance and support**.⁸² The latter should also be understood as elements of “reasonable accommodation”.^{83 84} According to the Convention, persons with psychosocial impairments, persons with learning difficulties, and also persons who require a high degree of support are protected by the Convention and their equal right to legal capacity should therefore be realised.

Twin-track processes

The Convention proposes twin-track measures: specific programmes for persons with disabilities, and alongside this general programmes which are designed to be accessible. In the context of supported decision-making, two obligations have to be fulfilled in parallel:⁸⁵

1. Quick, practicable solutions for the problems which arise in the everyday work of guardians, particularly information about changes in and the reduction of the extent of guardianship, the possibility of trial periods, the right to have a say, the separation of guardians’ payment from the assets of the ward, mechanisms for conflict resolution, training in accessible communication for judges etc.
2. An in-depth discussion on alternatives to guardianship providing supported decision-making with the participation of persons with disabilities and their peers. The following models⁸⁶ which were presented by the Canadian expert Michael Bach at the public meeting should **certainly** be given consideration:

- a. Person-centered planning
- b. An independent ombudsman
- c. Supported communication
- d. Support for representation
- e. Support in the formation of networks
- f. Administrative support

⁸¹ Article 12 of the Convention: Office of the High Commissioner for Human Rights, Monitoring of the CRPD – Guidance for Human Rights Monitors, Professional Training Series No. 17; see also Report of the Council of Europe, page 14.

⁸² Cf. in particular Art 12/3, but also Art 2, 4/1/g, h & i, 7/3, 9/2/e & f, 16/2, 19, 20/b & d, 23/2, 24/2/d& e, 24/4, 26/3, 27/1/ 28/2/a & c, 29/a/ii, 29/a/iii, 32 of the Convention.

⁸³ Article 2 (definition of reasonable accommodation), Article 5 (3) on guaranteeing it.

⁸⁴ Report of the Council of Europe, page 12.

⁸⁵ See also Report of the Council of Europe, page 12.

^{86F} or more details see Bach/Kerzner, 72 ff.

Participation: minimum specifications

As already mentioned several times, the participation of persons with disabilities is an obligation on the part of the state and society.⁸⁷ Establishing what needs to change together with persons with disabilities is of key importance;⁸⁸ the meeting of the committee represents a beginning. As specified by the Convention and Arnstein's ladder of participation, an increase in the quality of participation is undoubtedly required.⁸⁹

The following description can serve as a negative example: "We were at a conference about persons with learning difficulties. And it was about what the eggheads want to do so that things are better for us. There were politicians there and persons from the uni. They gave lectures. We didn't understand a word, and our support persons didn't understand much either. We were really angry. If they want to do something for us, they should speak in a way that we can follow it."⁹⁰

The minimum specifications for participative processes are:

- Multi-dimensional accessibility
- Accessible communication; particularly for persons with severe disabilities who communicate via body language etc. and persons who require a high degree of support (in terms of communication): Easy read versions, explanations, supported communication⁹¹
- Sufficient time
- Sufficient information

Cross-sectional issue: supported decision-making

The realisation of supported decision-making requires a paradigm shift in society as a whole, which above all has to include the reduction of the stigma attached to disabilities.⁹² The development of supported decision-making thus goes beyond the historical responsibility of the Ministry of Justice; it is therefore absolutely necessary to clarify who is going to have the overall lead of the process in future.

"You don't help people by doing for them what they can do themselves", said Abraham Lincoln, as quoted at the beginning of an information brochure of the Federal Ministry of Justice on guardianship.⁹³ This motto should also apply to the discussion about new models of supported decision-making. An important point was made by the Council of Europe's Human Rights Commissioner: "One of them is to

⁸⁷ Statement of the Committee on Participation of 19 April 2010,

⁸⁸ See also Report of the Council of Europe, page 18.

⁸⁹ See i.a. Arnstein.

⁹⁰ WIBS, Gleichstellungsbuch.

⁹¹ See e.g. Wilken, Unterstützte Kommunikation.

⁹² On the reduction of stigma, e.g. Amering/Schmolke, Recovery – Das Ende der Unheilbarkeit, 75.

⁹³ Federal Ministry of Justice, Sachwalterschaft: Wissenswertes für Betroffene, Angehörige und Interessierte: http://www.justiz.gv.at/internet/file/2c948485246bff6f0124b96dd98b412f.de.0/sw-broschüre_2010_a4.pdf.

ensure that our new systems are truly support systems and not substituted decision-making under a new name.”⁹⁴

V. Necessary steps

Against the background of what has been said until now, it is essential to initiate a broad discussion and awareness-raising process based on the highest standards of participation. The necessity of this discussion process does not, however, relieve the state of its responsibility to take a leading role in the process.

The first indispensable steps which, in the view of the committee, are the responsibility of the state and not civil society, include:

- The institutionalisation of the maximum possible level of participation of affected persons and civil society organisations in accompanying the process in every phase
- The initiation of an active process to clarify the respective tasks of the bodies which (according to the constitution) are responsible for the implementation of supported decision-making (Ministry of Justice, Ministry of Labour, Social Affairs and Consumer Protection, plus the provinces)
- A comprehensive evaluation of existing best-practice models in an international context (e.g., Canada) and the development of implementation models for the specific situation in Austria
- The development of project plans for pilot projects to implement new decision-making models with the involvement of non-profit organisations; if necessary including the creation of a legal basis
- The consideration in this context of the creation of transitional regulations (new legislation for new cases, old legislation for old cases) so that the judiciary and enforcement authorities are not overburdened.
- Clarification of the timelines set in the National Action Plan to replace the current guardians system with mechanisms for supporting decision-making which are in line with the Convention, including interim evaluations of existing projects.

For the Committee
The Chair

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