

LSS and Swedish municipalities

Does Sweden violate the right to independent living?

Från Snack till verkstad - mänskliga rättigheter i praktiken, Sundbyberg April 17 2018

Med dr Barbro Lewin,
associated to the Centre for Disability Research at Uppsala University
Barbro.Lewin@statsvet.uu.se

Outline

- Governance of the LSS implementation
- Two specific governance problems in implementing LSS
 1. Municipal exercise of authority. To be granted LSS support
 2. Appropriateness of the enforcement of LSS decisions. The performance of support
- Does Sweden violate the CRPD and LSS rights to independent living?

Why LSS? Law regulating Support and Service to Persons with Certain Functional Disabilities (1993:387)

- The Social Services Act (SoL, from 1980) was not considered sufficient to meet the needs of persons with severe disabilities
- Equal access and equivalence (the same high quality in exercise of authority and performance of support) all over Sweden is an expressed government intention in the government bill on LSS and the LSS committee directives from May 2016: It should not matter where you live.
- LSS shifts power to the individual: Influence (6 § LSS)
- LSS is more favourable than SoL – a "plus" law to SoL.
 - LSS has higher ambitions: Enhancement of citizenship, control over life situation
 - LSS gives priority to needs: Resources must be allocated to meet needs.

Governance of the LSS implementation

- The implementation of many welfare reforms like LSS is decentralized in Sweden to the local political bodies, that is the municipalities and county councils.
- Public welfare rights, as those of LSS, are transmitted to concerned citizens through the so called parliamentary chain where duties are laid on different actors. Case law [rättspraxis] and prescripts [föreskrifter] clarify the law.
- The use of the concept parliamentary chain makes it clear that governance is intended to be unidirectional: Actors are obligated to follow LSS and the politicians have the ultimate responsibility for a lawful implementation.

Involved actors

- The Government prepared and the Parliament decided upon the reform LSS.
- The local politicians - municipalities and county councils - are principals [huvudmän] for the implementation of LSS
 - The Social Insurance Agency is principal together with the municipal politicians for the support personal assistance
- Local government officials [förvaltningschefer] prepare and carry out the decisions of local politicians.
- Administrative officers [handläggare] handle the exercise of municipal authority [myndighetsutövning].
- Concerned citizens enjoy or do not enjoy the LSS support.

Prerequisites for a successful implementation of the LSS reform

- Three prerequisites are necessary for a successful implementation of the LSS reform (as most other reforms): That involved actors have the will, the understanding and the capacity to do so.

The governance of LSS

- LSS is a strong rights law, based on values that shall ensure individual citizenship to persons with severe disabilities – but in reality those rights are not always transmitted to concerned citizens as intended.
- It is well known from experience and research that the public servants govern the implementation, not the politicians.
- Politicians come and go, the public service remains.
- The politicians are dependent on their public service both for planning policy (input) and executing policy (output).
- But that is not determined by fate. Patterns can be broken.
- Politicians must govern their public servants to secure a lawful implementation of LSS.

Governing principles in LSS and CRPD

- LSS grants individual rights. The governing principle of the LSS law is shall. LSS entitles unconditional rights to support in presence of needs that are considered eligible for the specific LSS support. Unfavorable decisions can be appealed to the administrative court.
- CRPD – the convention has been ratified but is not included in Swedish law. The governing word shall is thus more of a vision without a corresponding duty.
 - Concrete duties, more or less specified and wide reaching, can however be included in Swedish law – if and when there is a political will to do so.

Legally binding prescripts

- The Government also drafts legally binding prescripts [föreskrifter] for the implementation of different laws, or delegate this responsibility to national authorities.
 - In the case of LSS implementation, four authorities are especially relevant: The National Board on Health and Social Welfare [Socialtyrelsen], The Social Insurance Agency [Försäkringskassan], The Health and Social Care Inspectorate [Inspektionen för vård och omsorg, IVO] and the Swedish Agency for Participation [Myndigheten för delaktighet, MFD].
 - Such prescripts bind the principals.
- The implementation of LSS is governed by several prescripts, issued by the National Board of Health and Welfare. One legally binding prescript of special importance is SOSFS 2014:5:
 - It prescribes documentation of different perceptions of needs and how they can be met as well the assessment whether needs are met in another way.

The National Board of Health and Welfare: Handbook on exercise of authority and documentation in the social services

- The Board describes the work to assess the right to LSS support. It is to seek the answers on the following three questions:
 1. Does the person belong to any of the three circles [personkretsar] that are encompassed by LSS?
 2. Does the person need the support applied for to be ensured good living conditions?
 3. Is the need of the support provided in any other way?
- To be observed: This description of the specific working process for LSS – (the one for SoL is different) - does not use any governing words. It is more of an offer of knowledge, that the involved actor can take or ignore, depending on the will of responsible local politicians and government officials and administrative officers.

1. The first problem: Municipal exercise of authority. To be granted LSS support

- Results in short from my study To get and to keep LSS support. (On municipal exercise of authority in Uppsala, work in progress 2017)
- Administrative officers [handläggare] use limiting strategies to diminish and change needs of support so that there is no right to LSS support.
- The LSS values do not seem to govern the exercise of authority. The work process is more like that according to the Social Services Law (SoL).
- The consequence is that the concerned individuals do not get their legal rights to such good living conditions that they can live an independent life like others and participate in societal life.
- Conclusion: The municipality violates the CRPD Article 19 (and several others) and LSS rights to independent living through an unlawful exercise of authority.

One finding is that the administrative officers do not use the 6th LSS clause on influence

- One major finding is that the administrative officers do not use the 6th LSS clause on influence. That is a value that is only stated in LSS, not in the Social Services Law. This value is an important part of the unconditional rights character of LSS. It means a shift in the power relation between the public power to the concerned citizen.

The municipality does not seem to follow the prescript SOSFS 2014:5, issued by the National Board of Health and Welfare

- No documentation of different perceptions of needs and how the disagreements can be overcome was found in the investigations.
- Neither do the local politicians nor the local government officials seem to be aware of these prescripts.

Five statements on the implementation of LSS from local politicians and public servants in connection with the study illustrate the results

1. “We trust our officials to professionally exercise municipal authority.” (Local politician)
2. “It does not matter if LSS or SoL is used in the exercise of authority. The laws have the same values.” (Local politicians and government officials, administrative officers)
3. “We do not implement the 6th clause in the exercise of authority, only when granted LSS support is performed.” (Local government official)
4. “We use case law and contact other municipalities for advice on the exercise of authority.” (Local government official)
5. “You can always appeal to the administrative court.” (Administrative officers)

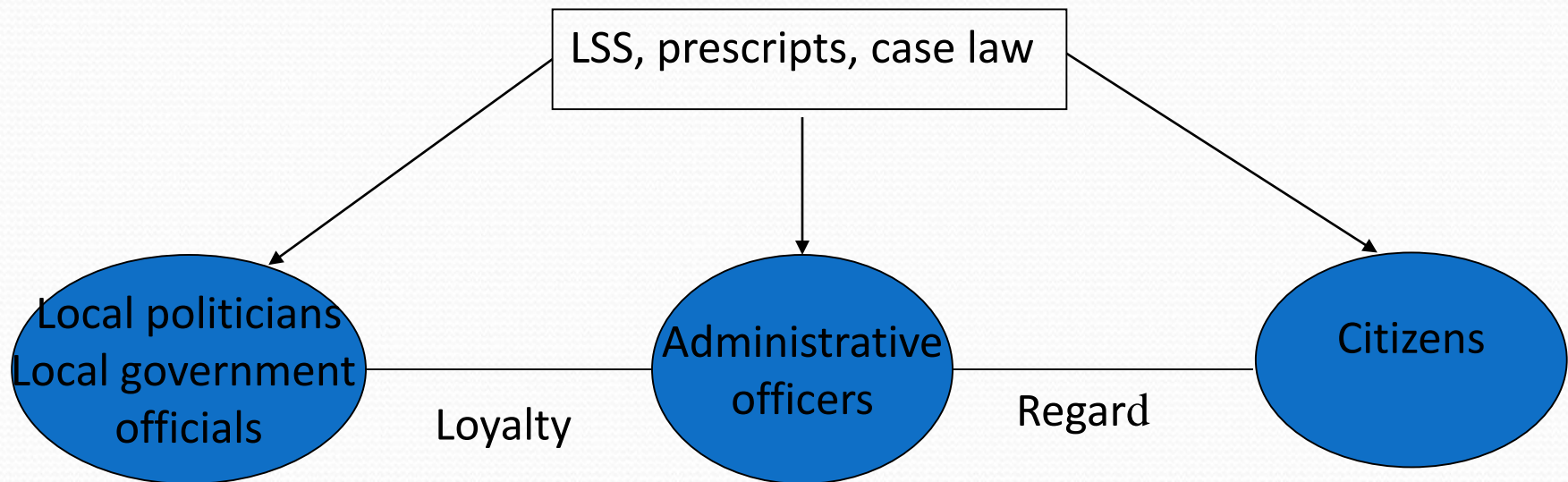
Comments on the statements

- The first three statements clearly show that the politicians abdicate from their responsibility to govern the public service and to secure a lawful exercise of authority.
- The fourth statement on case law and knowledge through contact with other municipalities can be a sign of a problematic administrative culture with an ethos that is not in line with the LSS values. The status of case law as a right source [rättskälla] in relation to what is stated in the LSS bill is a contested issue. The results only show the use of limiting case law (not favorable for the individual).
- The fifth statement – on appeal to the administrative court - is relevant in connection with the LSS value influence (6th clause), the lack of opportunity to discuss conflicting perceptions on needs and the appropriateness of the LSS support in question. No opportunity to get a correct assessment from the beginning. A legal process may – eventually - give the right to support.

The parliamentary chain and municipal exercise of authority

- The results show that neither the legally binding LSS Law and the values of the preceding government bill on LSS nor the binding prescripts from the Board of Health and Welfare have sufficient governing effect on the work of administrative officers. A lawful exercise of municipal authority is not guaranteed.
- Limiting case law adds to the unlawful exercise of authority.
- The effect of knowledge governance can also be questioned (the handbook as knowledge support).
- Conclusion: Governance along the parliamentary chain is weak. The parliamentary chain does not function according to the intentions of LSS.

Relation law – local politicians and local government officials – administrative officers – citizens (Model inspired by Lennart Lundquist, 1988, Byråkratisk etik).



Challenges for the future: lawful exercise of authority

- The local politicians must govern their public service.
- Bureaucratic inertia and path dependence must be overcome:
 - "We have always worked like this"; routines; guide lines that are not in line with LSS; reliance on established practice – not on legally certain implementation of the reform.
- National initiatives: More use of prescripts to ensure a lawful exercise of authority from national authorities such as The National Board of Health and Social Welfare.
 - And follow ups that they are used.

2. Appropriate LSS support and appropriate performance of support [utförande]

- It is not enough to be granted a favorable decision of LSS support. That must be followed by an appropriate performance of support – high quality work by competent staff in order to ensure good living conditions and the fulfillment of LSS goals in different life areas.

Performance of LSS support and municipal autonomy

- Municipal autonomy is strong in Sweden. The performance of support is dependent on the will of the local politicians to ensure good living conditions for persons with severe disabilities.
- The LSS governance of performance of the support [utförande] is weak. Very little is said about how the LSS goals shall be reached. That applies for all support and for all concerned persons with favorable LSS decisions.
- LSS as well as the preceding government bill is not clear on how a municipality can/should act when the needs situation of the concerned person is complicated and can not easily be met by the regular organization of municipal support.

Complex disabilities and specific needs

- Experiences from disability organizations show that complex disabilities with specific needs are not always met with appropriate performance of granted support by the municipality. The result is unacceptable situations for (admittedly) small numbers in different groups with such complex disabilities and specific needs for support.
- These persons meet with great difficulties in everyday life and have huge needs of continuous support by staff with special competence performed in a specially suitable environment that the municipality cannot offer. But the municipality may refuse/hesitate to purchase support from specialized activities elsewhere.
- When municipalities do purchase support from specialized activities, they eventually want to/do take home the concerned person when they find it possible. Legal processes show the right and duty of municipalities to handle their own activities.
- But sometimes that is not what the concerned person wants. Frustration among concerned citizens and their families.

“House arrest” and forceful “home taking”

- One such specific disability group is those in need of an environment where sign language is used. In these cases there are both problems with “house arrest” and forceful “home taking”.
- A similar performance problem is seen in connection with forceful “home taking” after long time performance of high quality support in a specific social therapy environment.
- The responsible municipalities claim that they can guarantee good living conditions.

Social isolation is a usual consequence of inappropriate performance of the LSS support

- A construed example from an ongoing study with DHB Flex (An organisation on national level for families with children who are deaf, have an hearing impairment or have a speech disability with added disability):
- The concerned person is deaf, has intellectual disability and uses only speech language for communication. The administrative officer offers living in a group home, where there is little competence of sign language among staff, external interpretation is sometimes used. No social contact with the other residents.
- Complaints to the administration that LSS values are not fulfilled, that the person has the right to use sign language, that this is not in line with CRPD Article 21 (and others e.g. Article 30 Participation in cultural life, recreation, leisure and sport), also notification to the Health and Social Care Inspectorate (IVO). IVO finds that the performance is insufficient.
- The municipality finally purchases the support from a specialized agency.
- The future is unsecure – the municipality makes short extensions of agreement, plans “home taking” against the will of the concerned person.

CRPD Article 21 – Freedom of expression and opinion, and access to information

- States Parties [Konventionsstaterna] shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:
 - b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
 - e) Recognizing and promoting the use of sign languages.

CRPD Article 30 Participation in cultural life, recreation, leisure and sport

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

Challenges for the future: Specific needs that cannot be met by the municipality. A national problem?

- Small numbers of persons with complex needs are spread nationwide. There are difficulties for municipalities to perform appropriate support [ändamålsenligt utförande].
- The municipal autonomy when it comes to the enforcement of a favorable decision takes over the concerned person's opinion on the appropriateness of the suggested or actual performance of support.
- Both LSS and CRPD are thus violated.
- What can be done to get more knowledge of the problem and reach a solution?
 - A national investigation of the prevalence and character of specific needs is one necessary task.

Does Sweden violate the CRPD and LSS rights to independent living?

- Yes!
- The results of my two examples show that Sweden does not only violate the LSS values in several ways. The values being the same for the CRPD means that the rights of this convention are also violated.

Obstacles for a successful implementation of LSS and the results from the studies

The prerequisites for a lawful exercise of authority were not specifically studied. But they point to several obstacles for a successful implementation:

- The results of the first study show that the municipal public service does not seem to have enough understanding and knowledge to secure a lawful exercise of authority.
- From the results of that study I cannot say that the local politicians do not have the will to implement LSS correctly. They seem to have a will to do the right thing. The cooperation between the local disability organizations and policy makers around disability issues in Uppsala is a clear sign of that. But it is evident that the politicians do not govern their public servants. The bureaucrats govern the implementation.
- It is also evident that municipal autonomy is an obstacle for a successful implementation. The strong individual rights law LSS has problems to override municipal autonomy in the exercise of authority.
- The results from the second study points to a general problem: municipal autonomy when it comes to performance of support. That is especially crucial for groups with specific needs.

Is a future successful implementation of LSS possible?

- Hopefully two ongoing government committees will propose solutions to the problem of the municipal autonomy and other governance problems:
 - Review of LSS support and assistance allowance (Översyn av insatser enligt LSS och assistansersättningen. Dir. 2016:40); Review of governance of disability politics (Översyn av styrningen inom funktionshinderspolitiken. Dir. 2017:133).
- Some problems:
 - The municipal practice not to acknowledge the difference between LSS and SoL when it comes to influence and ambition, that is the shift of power from the municipal public service to the citizen.
 - Prescripts' lack of governing power in practice.
 - The weak governing power of knowledge supports.
 - Potentially useful tools: The new handbook from the National Board of Health and Welfare on needs assessment (Individens behov i centrum, IBIC, 2016), based on WHO International Classification of Functioning, Disability and Health, ICF. Also the knowledge support on LSS and participation (Vägar till ökad delaktighet, 2017)

Concluding remarks

- National politicians must not abdicate.
- The ultimate responsibility lies on the national politicians in power both to make politics and to guarantee that reforms are implemented according to the intentions.
- Both the carrot (money, resources) and the whip (legal changes and prescripts) are probably needed to stimulate the will of local politicians to follow the intentions of LSS and to govern their public service to enforce it properly.
- The law must be clear about the right to influence in the whole implementation process: both the needs assessment and the performance of support.
- Empowerment on individual level is necessary to use and demand influence over needs assessment and performance of support.
- Citizens as lobbyists and voters can influence politics by voting for the political party that they believe will promote their interests.