



The “JAG-model”

Personal assistance
with self-determination



“
I couldn't have managed without personal assistance. Other people used to decide so much for me, now it is nice to make my own decisions.”

The “JAG-model”

A description of how you can organise personal assistance with self-determination when you have multiple, severe disabilities and limited autonomy.



On the cover: Kristina – member of the board. Photo: Walter Hirsch
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On occasions when members of JAG meet people from other countries, we often get asked questions like:

- ◆ How is your personal assistance organized when you are cannot supervise your assistants yourself?
- ◆ How can you bein control of your assistance when you have intellectual disabilities and impaired autonomy?
- ◆ How can the assistance be safe and secure when you are unable to speak up for yourself?

And of course:

- ◆ What does your doctor say?

If you want an answer to these questions you should read this text. Please contact us at JAG if you have something you want to ask after you have finished reading!

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Within the Independent Living movement we know that every person is an expert when it comes to their own needs and we know that everyone has to find the solutions that fit them individually. Of course sometimes you need some tips along the way from others in the same situation.

JAG has provided personal assistance to our members for 20 years. By sharing experiences, the members of JAG hope to contribute by giving others better conditions to arrange high quality personal assistance – and to live the life that they choose.

JAG wants to improve the world!



Magnus Andén, chairman of the board in the JAG Association

When we look around in the world, we realize that we in Sweden are models for many people with disabilities in other countries. We are not the best at everything but we are unique in having a law that gives us an individual legal right to personal assistance.

A law that does not care about how high your IQ is.

But Sweden is a small country in Europe and worldwide. We are afraid that Swedish politicians will pull back the standards and freedoms that we have unless the rest of Europe has the same human rights and opportunities as us.. For our own sake, we must improve the world!

Many members of JAG have experienced the evil old times, when even we in Sweden were forced to live in institutions. Our parents have experienced the cruel choices that families once faced when community support only consisted of institutional care. Since we have survived and come out to an ordinary life in the community, we have a vitally important story to tell the world!

Sweden and Norway are the only countries in the world that has closed all major institutions for persons with intellectual disabilities. But memory is short and history repeats itself. In Norway, they are now beginning to build large new group and child care homes. In Sweden they are building new institutions for adults with intellectual disabilities.

Both Sweden and Norway have signed the UN Convention on the Rights of Persons with Disabilities, which says that you should be allowed to choose where to live, who you want to live with and to get help in your home. Nobody should have to move to an institution to survive!

There is a need for personal assistance in all countries. There is a need for personal assistance for people with intellectual disabilities. Personal assistance ensures people freedom, security and good quality support.

Those of us who know about this have a moral obligation to tell the world.

Independent Living



INDEPENDENT LIVING is the daily demonstration of human rights based disability policies. It is possible through a combination of environmental and individual factors that allow the disabled person to have control over his/her own life, which includes the choice of: whom to live with, how to organise daily activities, where to get the support needed. Independent living requires the accessibility of the built environment, accessible transport, the availability of technical aids and access to personal assistance for everyone who needs it.

The JAG association is a member of ENIL and a part of the international Independent Living movement. This is a movement for people with disabilities who want to be self-determined and take part in society. Within the IL-movement it is of great importance that members have power within their own organisations.

About JAG and the Swedish assistance system



JAG is a national, not-for-profit association which works with issues related to personal assistance and anti-discrimination. JAG is also a not-for-profit co-operative personal assistance service users. The association was formed in 1992 by a small group of people who felt compromised when it came to living like anybody else, because of their need for assistance. They also had a hard time asserting themselves on traditional disability issues. What they needed was an association able to push for their issues.

The word “JAG” in Swedish means “I”. It is a reminder that we, the members of JAG, are subjects, individuals, and not objects of care. “JAG” is formed from the first letters of the Swedish words for Equality, Assistance and Inclusion, which are important aims for us to achieve.

All members of JAG have intellectual disabilities and limited autonomy. With few exceptions, we also have extensive physical disabilities. Most of JAG’s members have no speech, but express ourselves in our own very personal way.

The nature of our disabilities presents a challenge to achieving user-control over the personal assistance we use. JAG has undertaken the difficult, but not at all impossible, task to provide user-controlled personal assistance to members through the JAG user co-operative.

Only a person with multiple, severe disabilities including some kind of intellectual disability can become a member of JAG. Others can become supporting members, without power or influence in the association. Only full members can be members of JAG's Board of Directors.

Because of our intellectual disabilities, we are unable to manage the daily work in JAG's office. Instead, 15 members of JAG take part in daily activities at head office. We participate in the work on our own terms and highlight who the association is for.

In JAG we are convinced that each and every person can decide for themselves, both in life as a whole and over the assistance we use – with a competent supportive decision maker. Anyone who needs assistance in speaking for themselves should get it from their legal proxy. The right to have a legal proxy who is able to interpret needs, wishes and communication is an important issue for the members of JAG.

Prior to the Swedish legislation about personal assistance, the JAG association ran an intense campaign. Our members and their legal proxies had meetings with every politician with a say in the issue. During these meetings members made clear the importance of enabling assistance for those who cannot direct assistance themselves as well as for those who can.

In 1994, personal assistance became an individual right in Sweden. JAG started the JAG user co-operative the same year which, like the association, is a not-for-profit organisation.



In Sweden, the parents stand as legal proxy for under aged children. After the age of 18 it is the district court that designates the legal representative. The legal proxy could be a family member or somebody unknown. This person is supposed to function as a supportive decision maker, provide help in preserving rights and interests and handle the economics.

Personal assistance in Sweden

The 1994 reform is celebrated as a freedom revolution among Swedish personal assistance users. The most important aspect of in the Swedish legislation is the right it gives for everyone to live their life by choice, with self-determination and integrity.

The person with disabilities makes the application for assistance and for the number of hours of assistance needed.. The National Insurance Agency decides how many hours will be granted per week. The assistance user chooses how the assistance will be provided, whether by the state, by a cooperative or by an assistance agency. It is also possible for the assistance user to directly employ his or her own personal assistants.

Since personal assistance is an individual right in Sweden, it is possible to appeal against the decision of the National Insurance Agency in court if the number of hours granted are considered insufficient.

- ◆ About 40 percent of those granted personal assistance in Sweden have intellectual disabilities.
- ◆ About 20 percent are 19 or younger.

In Sweden, parents stand as legal proxy for under-aged children. After the age of 18, the district court designates a legal representative. The legal proxy could be a family member or somebody independent. This person is supposed to function as a supportive decision maker, providing help with protecting the rights and interests of the person with disabilities and handling finances.



PERSONAL ASSISTANCE is provided through ring-fenced cash allocations paid to disabled people, who need assistance in their daily lives, for the purpose of purchasing the assistance they need. Personal assistance is tailored from an individual needs assessment of the person with disabilities, according to the circumstances of his/her life and appropriate to the current domestic labour market. Disabled people should have the right to recruit and manage their assistants as well as the choice about which employment model to use. Personal assistance allocations should cover the salaries of personal assistants as well as additional costs such as contributions due by the employer, administration costs and peer support for the user.

Personal assistance in Europe

Legislation and regulations work differently depending on where you live. Many people are unable to choose personal assistance over living in an institution or residential home. Nevertheless attempts are being made across Europe to establish a right to personal assistance. For more information about personal assistance projects, ask your local Council or Centre for Independent Living (CIL).



You can also turn to ENILs secretariat or regional team coordinators:

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The “JAG-model”

By using the “JAG-model”, people with intellectual disabilities can improve their assistance and increase their right to independence, whoever the employer of the assistants may be. Since intellectual and other cognitive disabilities could complicate managing your assistance, it is a great advantage to have a committed legal proxy.

1. Choice and control over the assistance is maintained through supportive decision-making from a legal proxy.
2. Service guarantor helps to supervise the assistants.
3. The assistants are given development and training.

The legal representative supports your right to self-determination

Choice and control over personal assistance is ensured through support with decision-making from a legal proxy (or someone with an equivalent role).

Among JAG members aged over 18, the overwhelming majority have a personal representative. The job of the personal representative involves far more than simply making decisions on behalf of the disabled person. For example, many members need to have complex situations and abstract concepts explained to them, and support to understand the consequences of a particular decision. A personal representative must be a good communicator, have a deep understanding of how the disabled person’s impairment affects them, and not in any way his or her capacity for self-determination.

A well-functioning guardianship is often a precondition for receipt



of personal assistance. The personal representative is responsible, among other things, for applying for a sufficient number of hours and hourly amounts, and to engage a suitable personal assistance provider.

For the members of JAG it is important that the person appointed as personal representative is someone well and literally close at hand. The interplay between the member and his or her personal representatives is in most cases based on a very close relationship.



The legal representative should be supportive in

- ◆ filing for personal assistance and choosing an assistance provider
- ◆ proposing or approving a service guarantor and then working with the guarantor to ensure the assistance received by the disabled person is appropriate for his or her needs and wishes
- ◆ ensuring personal assistance is delivered in a way that is respectful of the disabled person, , including recognising his or her personal integrity
- ◆ monitoring that the personal assistance is of good quality and that the assistance provider is meeting the standards agreed with the disabled person

Through a tailored package of personal assistance you get a true chance to be the head of your own life. You decide, with

the help from a legal proxy if needed, who will assist you, what the assistance should entail and how the assistance should be given. In other words, in just the same way that a person without disabilities is in control of his or her life.

Personal assistants come into your life and your home. For who they are, they need to fit into your daily routines. Your life should neither be discussed, planned nor aired among your assistants since your private life is just as private as anyone else's.

“Olof communicates mainly by signs and photographs, mostly through digital pictures. He also has a board with personal pictures on it that stand for ‘I want’, ‘I’m happy’, ‘sad’, ‘want’, different meals etc. He answers clearly by saying “mmm” or by pointing. When he means ‘No’ he crosses his arms. I support and encourage him to make his own decisions by giving him choices in everyday situations”, says his mother who is also his personal representative.

Quote from the report “10 years with personal assistance” (2006)

Everyone can exercise self-determination, for example by showing approval or disapproval in any situation. Achieving self-determination requires that the people supporting you can interpret and draw the right conclusions from your way of expressing things, that they value your communications and respect your decisions.

“Ingemar has limited verbal communication. If he is feeling well, he speaks more. If he needs something, he points to a letter board. Otherwise we try to interpret his facial expressions and watch his hand gestures,” says his father, who is also Ingemar’s personal representative. He helps Ingemar to make decisions by asking questions. “If he wants something new, we try it out. Once we went to a wrestling match because he wanted to, but once there he changed his mind, so we just had to go home again. It is important to be able to make last-minute changes.”

Quote from the report “10 years with personal assistance” (2006)

The service guarantor supports by supervising the assistants

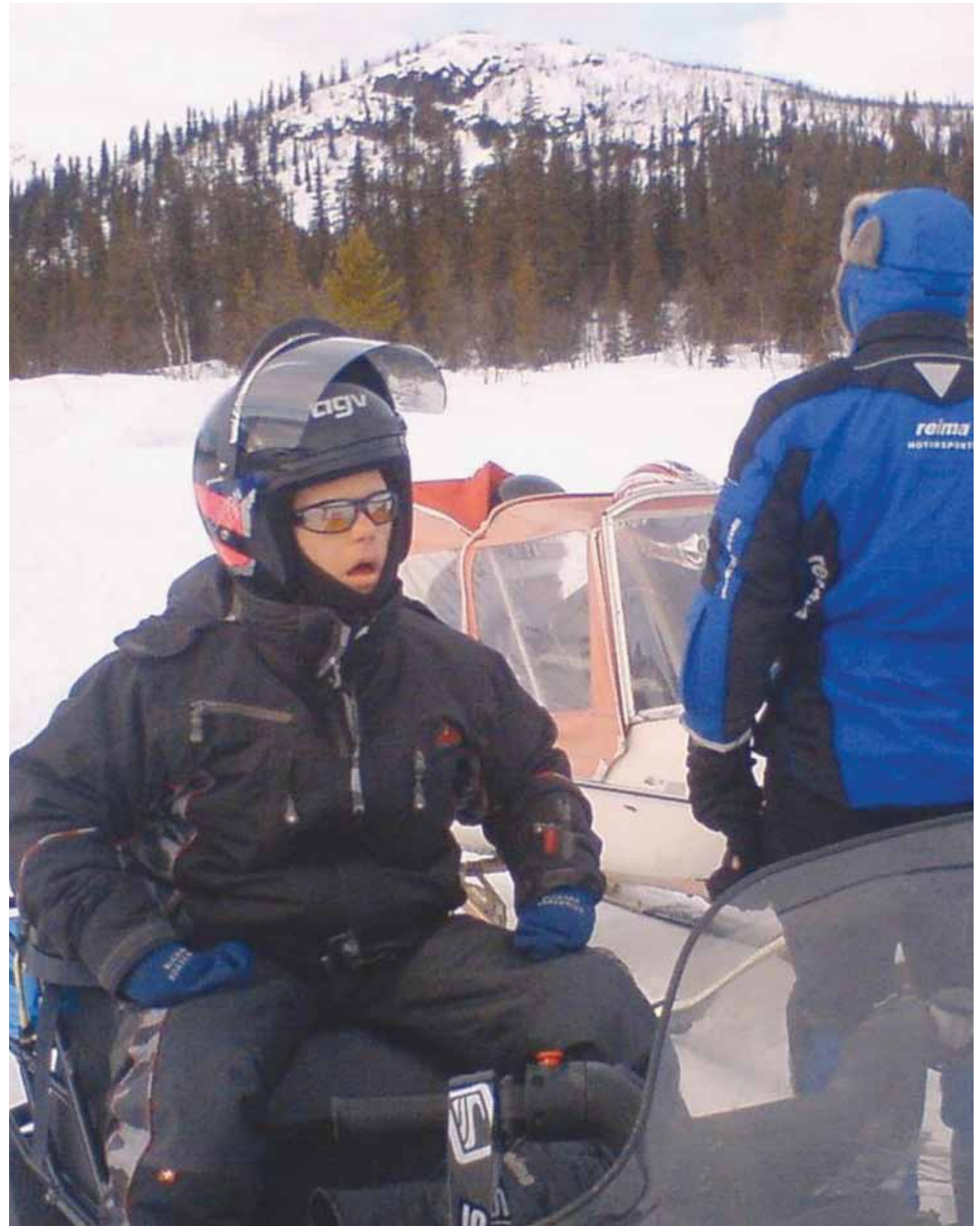
If you are able to supervise your assistants yourself, you obviously do not want anyone else to do it. However, if you are unable to do that you will need someone to supervise the way you would have done it if you were able to. JAG calls this person a service guarantor.

The service guarantor is responsible for staffing and supervising the assistants. If your personal representative does not wish or is not able to be the service guarantor, he or she must assist you to find a suitable person for this task.

The most important thing when it comes to the relationship between you and your service guarantor is that you feel you can trust, communicate and cooperate with him or her.

Unless this works properly, the service guarantor will not be able to function in the way they are meant to. The service guarantor is always on your side and there should be no doubt as to whom he or she is loyal.

You will need an agreement in writing with the service guarantor. In JAG the position of service guarantor is a voluntary role. This means that the agreement is not a contract of employment. The JAG Co-operative delegates responsibilities to the service guarantor through the service guarantor agreement. Because of the specific tasks that come with this commitment, rules about working hours and employment are not applicable for the service guarantor. For the service guarantor to undertake the actual personal assistance work, this will require a separate employment contract





The service guarantor is responsible for staffing and has to make sure that trained staff is always available when needed. In the absence of trained staff and in the case of emergencies, the service guarantor must provide cover and carry out personal assistance him or herself. Being available and able to carry out personal assistance is part of the role of service guarantor.

Being a service guarantor in JAG involves:

- ◆ leading and coordinating the personal assistance package according to the needs and wishes of the member,
- ◆ making sure assistance is being given according to the ideological goals of JAG, and with respect to the integrity and dignity of members,

- ◆ making sure the member gets the assistance, to which he or she is entitled,
- ◆ ensuring standards of safeguarding, of quality and continuity within the assistance received,
- ◆ staying up-to-date with and following appropriate rules and legislation on personal assistance,
- ◆ recruiting assistants,
- ◆ putting together rotas and schedules within the number of hours granted for assistance
- ◆ dealing with environmental issues
- ◆ planning holidays
- ◆ filing reports and providing the data needed under the employer's responsibility to JAG

The service guarantor ship can be shared among two people. Tasks can be divided between the guarantors but it is important that it is clear to everyone involved who does what; to the service guarantors, the assistance user and the assistants.

If a service guarantor is temporarily unable to carry out their duties, a temporary agreement must be put into place with a replacement.

The service guarantor is only responsible for things to do with your personal assistance – not for other parts of your life.

The service guarantors of JAG are offered training and support to succeed with their mission. This support involves training, guidance, and personal development. At JAG, parents can choose to act as service guarantor for their child and thus be responsible for supervising the assistants. The parents are also able to choose someone else to be responsible for all or part of this role.

The members of JAG can choose to remunerate the service guarantor (a certain amount per hour) on condition that the

assistance grant can cover it. The service guarantor's responsibilities must be carried out with or without remuneration. JAG has chosen to divide the remuneration into two parts: one for supervision and one for staffing.

The service guarantor is the tool with which to achieve an individually tailored package of assistance. Depending on how your assistance is organised, an assistance coordinator may not be fully supportive of self-determination. In our view, barriers should not be insurmountable though.

The role of personal assistant

Through personal assistance a disabled person should have the same chances as anyone else; personal assistance should be given according to your direction. Personal assistance enables you to live your life, focusing on your needs and wishes. The assistant is employed to provide a service to you as an individual; the assistant is not part of a school or institution so you don't have to stand in line waiting for your turn or having to follow directions and routines set by other people. You are free to do what you want to do, whenever you want to do it.

Supporting someone with intellectual disabilities could be done by for example supporting the person to take the initiative or to make decisions in everyday situations. The assistant may also remind you of things you need to do and support you to think through the consequences of your actions. The assistant often functions as a human communication aid. On such occasions, the personal assistant is an interpreter – not a representative.

If you have a legal representative or someone equivalent, he or she is the person who supports you to exercise your right to self-determination. The personal assistant is not responsible for how

you choose to live your life. It is the assistant's responsibility to take directions from you or from your legal representative or service guarantor.

Flexibility is key to personal assistance since it is essential for enabling independent living. Each assistant will be assigned an individual role even though they are employed by the same person.

As an employer JAG must comply with employment legislation. JAG is bound by a collective agreement and many of the employees are union members. The personal assistants employed by JAG are assigned to give personal service to a specific person. At the beginning of their employment, they are provided with information regarding their work and the aims of assistance according to the Swedish assistance legislation.



A family member who is employed as personal assistant in the JAG user co-operative has the same employment contract and the same rights and obligations as other assistants. A personal assistant who is also a family member should not have other duties that conflict with their ability to fulfill their role as personal assistant, nor should they be unable to leave the house.

Recruiting assistants

The bigger the part you are able to take in recruiting your assistants, the better. If possible, you, your service guarantor and your legal representative should all take part in interviewing potential candidates.. You have the crucial part in the decision on who to appoint.

Introduction for newly employed assistants

The service guarantor is responsible for recruitment, but training can be delegated to an experienced assistant. In the JAG user-cooperative, there is a training provision that allows members to let a new assistant work beside an experienced assistant for as long as is needed. The induction period may vary since no members are alike. The cost of the induction period is covered by the members' assistance grants.

Integrity and confidentiality

Guidelines on confidentiality and personal integrity must be clear and easy to understand for your assistants. Guidelines must be comprehensive to limit the amount assistants have to make their own assumptions about what confidentiality covers. Since we all have our own ideas about the meaning of integrity, there are no general rules to rely on and it should not be left up to personal judgment to decide what is and isn't appropriate in respect of an individual member.



Personal assistants in Sweden are bound by professional secrecy. This prohibits the assistant from either verbally or in any other way sharing information about the user and his or her private life. This applies to other people such as the assistant's family or friends but also to other people. The personal assistant must also maintain confidentiality with other assistants unless the information needs to be shared in order to provide continuity of service. Breaches of confidentiality may lead to legal consequences.

Staff meetings

Meetings between all of your assistants together rarely improve the quality of the service they can provide. Many issues are best resolved by private conversations between the service guarantor and the assistant. It is important that personal assistants feel they are getting the support they need to be confident in their jobs. Regular development sessions to explore questions and proposals for improvement can be useful.

If you do find it necessary to have the occasional full staff meeting, you should be the one inviting people to the meetings with support from your legal representative and service guarantor. Discussions about your assistance should always involve you and/or your legal representative and you should be the one with the most power. Without your participation in the meeting, there is an obvious risk that the assistants could question the way you live your life, and new guidelines could be made without you knowing about it.

Training

It is up to the personal assistance user to decide what qualities and skills are important for his or her assistants to have. For this reason there cannot be generic training courses on what a personal assistant needs to know or how they should act.

Of course, most personal assistants need to learn how to do a good job. The more qualified assistance – the more there is to learn for the assistant. Assistants need not only practical but also theoretical understanding of different impairments and the support that a member wants.

Working as an assistant in JAG requires an ability to gain an understanding of and insight into another person's life, to the extent of even being able to anticipate the person's reactions.

A life of dependency can make it difficult to push your own opinions forward. At the same time your personal assistants might need support in not letting their own opinions shine through in order to leave room for yours. Assistants with a good understanding can support you to assert your personal integrity. Your legal representative or your service guarantor can support you to develop a framework for what you want to share with others.



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