

Coordination of aid for children and young people with functional impairments

- An (in)soluble problem?

Summary

The Swedish National Audit Office has conducted an audit of whether aid for children and young people with functional impairments is organised in a way that makes things easier for families concerned so that problems relating to coordination can be avoided.

Background to the audit

Motivation: Aid that is targeted at people with functional impairments is regulated by different laws and ordinances and is issued by the Government, municipalities and county councils. The vast range of authorities and types of aid means that “tunnel vision” can easily occur within and between authorities. A lack of coordination has been cited by the operators, the supervisory authorities and the users themselves. When children with functional impairments are concerned, it is the parents who have to take the initiative and assume responsibility for coordinating the aid that their child requires. This has proven to be a burdensome task for parents, which will often result in negative consequences such as sick leave and unemployment. It appears to be difficult to realise the intention that people with functional impairments and their families shall be able to live a “normal” life.

Purpose: The purpose of the audit is to investigate whether public bodies’ coordination of aid for children and young people with functional impairments can be performed more efficiently within the framework of the funds being invested in this area. Any problems relating to coordination that may occur in connection with young people becoming adults are not covered. The audit investigates aid as a whole, and not individual instances of aid or deficiencies outside the aid itself such as accessibility, etc. The primary basis for assessment in the audit is that those bodies that support children and young people with functional impairments shall collaborate and coordinate so that young people and their families may have a life that is as normal as possible. This assessment is based on the laws and ordinances that regulate aid and on the intention of the Government and the Riksdag to create equal living conditions.

Implementation: The audit is based on experiences of collaboration and coordination of aid for initiatives for children and young people with functional impairments that are documented in reports, Government assignments, committee reports and Government bills, as well as group interviews with parents of children with functional impairments and operators concerned at Government, municipality and county council level. Interviews were also conducted with officials at the Ministry for Health and Social Affairs, the Swedish National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions. The Swedish National Audit Office has also studied differences in sick leave, unemployment, number of illnesses, sickness benefits and withdrawals of temporary parental allowances among parents of children with functional impairments compared with other parents. The analysis is based on the

databases of Statistics Sweden and the Swedish Social Insurance Agency. The Swedish National Audit Office has also produced examples of socioeconomic calculations for the purpose of calculating the potential effect that the creation of coordinating services may produce for the individuals directly concerned, the public sector and society as a whole.

The results of the audit

The audit has resulted in the following central conclusions and observations:

Many initiatives, but coordination problems remain. In recent decades, the Government and the Riksdag have tried in various ways to make life easier for families concerned. It has not been possible to assess the outcome of many of the measures taken by the Government, as they occur infrequently, they cover a short time or because there are no evaluations. Joint bodies in the field of nursing and healthcare have been analysed only to a very small extent. The Swedish National Audit Office believes that the obligation on municipalities now to offer an individual plan under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) instead of waiting for an enquiry from the individual may be a step in the right direction. This does not, however, automatically change the bodies' attitude towards the plan or the fact that parents will continue to be burdened with the responsibility of the practical coordination of the plan. The rules on collaboration contained in laws and provisions have not resolved problems relating to coordination. In most municipalities and county councils, the implementation of the Swedish National Board of Health and Welfare's provisions on collaboration in rehabilitation and habilitation has only come as far as work having commenced.

The bodies continue to experience problems with collaboration. The vast range of authorities responsible and bodies involved makes collaboration difficult and contributes towards problems and confusion among all parties involved. There is often a lack of acceptance of collaboration at higher levels within the organisation. No individual body appears to have a specified mandate to take charge of collaboration and no one feels that they have ultimate responsibility for coordinating aid. Nor does anyone have a complete picture of the individual's situation. There is no access to up-to-date, comprehensive information about what aid is available and which authority is responsible for each element of aid. An additional problem that makes collaboration and coordinating aid more difficult is the fact that **the organisations** are controlled by separate budgets. Performance-based compensation systems also risk creating an adverse effect on collaboration. There also appears to be a lack of knowledge that terms of collaboration should be included in agreements between public and private bodies, which results in private bodies not believing that collaboration is included in their undertaking.

Parents continue to have a major responsibility for coordination. Both parents and bodies concerned report that public bodies do not coordinate aid initiatives for children with functional impairments in a way that makes life easier for families concerned. Parents also feel that collaboration has become worse in recent years. Whether it works depends to a large extent on the commitment of the individual case officer. The consequence is that responsibility for coordination remains with the parents, which is a burden that can be a contributory reason for their taking more sick leave and finding it more difficult to survive in the labour market than other parents. The Swedish National Audit Office considers that measures taken so far have had a limited effect. The experiences of parents as well as bodies involved of a lack of collaboration indicate that solutions have not worked as intended. The Swedish National Audit Office considers that aid for children and young people with functional impairments is not organised in such a way that problems with coordination are avoided. The Government's intentions that families with children with functional impairments shall be able to live a life that is as normal as possible have not been realised.

Supplementary solutions are needed. The Swedish National Audit Office confirms that problems exist in spite of the measures that have been implemented so far. Problems in coordination appear to be difficult to resolve, but the Swedish National Audit Office believes that it must be possible to achieve improvements by trying out new approaches that supplement existing aid for collaboration. The need for a specific person with responsibility for coordinating aid has been raised many times. There does, however, appear to be resistance towards trying it. The focus has been on the organisations' own interests rather than those of the individual. It is the view of the Swedish National Audit Office that the Government has not got to the bottom of what such a proposal might mean for those directly involved and for society as a whole. The Swedish National Audit Office has used examples of calculations of socioeconomic and public finance effects of creating a coordinator to prove that this measure has the potential to create added socioeconomic value.

Arbitrary assessments – another problem that requires a solution. Many parties report decisions on aid producing different assessments between equivalent cases. This makes decision-making appear arbitrary. The term “normal parental responsibility”, to which case officers refer in connection with assessments of entitlement to support, appears to be interpreted differently by different bodies. These bodies lack guidelines or support in decision-making, which in the view of the Swedish National Audit Office makes it more difficult for case officers to avoid acting arbitrarily.

The Swedish National Audit Office's recommendations

Recommendations to the Government:

- The Swedish National Audit Office recommends that the Government instigate a trial involving coordinators. It should be their task to facilitate collaboration between bodies with a view to improving the coordination of aid for families with children with functional impairments. The structure of this trial operation should include several options, of which independent coordinators can constitute one of these. The socioeconomic and public finance effects of all options should be evaluated within this trial operation. The evaluation should be able to serve as basis for a decision on whether to make the activity permanent in future and to roll it out nationally.
- The Swedish National Audit Office recommends that the Government mandate the Swedish National Board of Health and Welfare, in consultation with authorities concerned and other relevant bodies, to draw up and continuously update a national guide containing general information about the aid to which children with functional impairments are entitled as well as which authorities are responsible for each element of aid. It is not the intention that such a guide should replace the local information provided by municipalities and county councils.
- The Swedish National Audit Office recommends that the Government mandate the Swedish National Board of Health and Welfare, in partnership with the Swedish Social Insurance Agency, to draw up guidelines to serve as a basis for discussion and support for decision-making when the term 'normal parental responsibility' is used in assessments of entitlement to aid and initiatives. As a basis for these guidelines, a summary of knowledge of how the term is used in operations should be produced. This summary should include legal cases and judgments.

Recommendations to the Swedish National Board of Health and Welfare:

- The Swedish National Audit Office recommends that the Swedish National Board of Health and Welfare, within the framework of its supervision, check that agreements between public authorities and private providers include terms defining collaboration. The Swedish National Board of Health and Welfare should then follow up to ensure that the terms of collaboration are appropriately structured so that the authority can fulfil its responsibility in accordance with laws and ordinances.