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The preparation for entry into adulthood - supported decision-making in upper secondary school for students with intellectual disability

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ABSTRACT

The upper secondary school for individuals with intellectual disability should prepare for an adult life as an active citizen with great self-determination and participation in democratic decision-making processes. The extent to which and in what way the schools work to prepare the students and develop their skills are likely of great importance for the students' adult life. The purpose of the study was to increase the knowledge of how students with intellectual disability in Sweden are prepared for adulthood, with special focus on self-determination. Case studies on three schools were carried out through observations of decision-making processes and interviews with students and staff. The main findings consist of three different approaches to self-determination for students with intellectual disability: 'Targeted and Conscious', 'Forward with Uncertainty' and 'Braking and Protecting'. Increased knowledge about, and analyses of, the processes that take place when young people with reduced decision-making capacity, due to intellectual disability, make decisions with the support of others are important. Implications underline the need to strengthen the awareness, knowledge and support of school staff when it comes to strengthening students' decision-making capacity. The students with intellectual disability need to be equipped for a society where they as adults will be surrounded by choices and expectations of making decisions.

KEYWORDS

Active citizen; intellectual disability; supported decision-making; self-determination; upper secondary school

Introduction

The basic principles of the Convention on the Rights of Persons with Disabilities state that persons with disabilities shall have individual self-determination and the freedom to make their own choices (Article 3, UN 2007). How much 'control' an individual has, the degree of autonomy, and the opportunities for meaningful social engagement and participation in society affect our health, well-being and longevity (Marmot 2006). This applies to all people, including people with intellectual disability. In recent years, international research has increasingly focused on the question of

how society can support people with impaired intellectual ability to realise the goal of being able to make decisions that affect their lives as far as possible (eg Kohn and Blumenthal 2014; Davidson et al. 2015; Shogren et al. 2017; Wiesel et al. 2020).

One of the most important assignments of primary and secondary school for students with intellectual disability in Sweden is the democratic mission (SFS 2010, 800). Civic democratic competence is about theoretical knowledge on power, influence and fundamental democratic values and about the practical skills that citizens need to be able make choices in their own life and to be actively participate in a democratic society. Examples of civic values and abilities that the school should develop and support in accordance with the school law are respect for all people's equal value, be able to make arguments and participate in democratic decision-making processes, listen to others, feel solidarity and trust, as well as think critically and independently. It is also about being able to read, write and count well enough to be able to orient themselves in society's information and knowledge flow. The assignment thus encompasses the entire schooling and all subjects. Students who, due to intellectual disability, receive their education in primary or secondary school, are included in the school's democracy mission but often need extra and directed support to achieve co-civic democratic competence, especially regarding self-determination in everyday life and participation in democratic decision-making processes. Self-determination and supported decision-making should be taught in upper secondary schools for students with intellectual disability. Supported decision-making is an umbrella term that encompasses a broad range of processes to support people with disability to exercise their decision-making capacity (e.g. Carney 2014). In contrast to substitute decision-making it emphasises the persons will and preference (Watson 2016).

One group of people where support often is needed to strengthen their capacity to lead self-determined lives is young people with intellectual disability. Decision-making competence is ideally about understanding different decision alternatives and their consequences, and being able to use that information in their decision-making linked to their own wishes and their own situation. This is demanding for everyone and especially for people with intellectual difficulties, and in recent years the focus has been on how support can be designed to support decision-making processes.

A number of different definitions of self-determination have been evolved over time. Some focus on the individual and her ability to act and having skills, knowledge, attitudes and beliefs (e.g. Shogren et al. 2017), some put the individual characteristics within the context of the environment (e.g. Abery & Stancliffe 2003) where self-determination is involving, but not synonymous with, independence and autonomy, but a product of both the person and the environment. The social-ecological model (Walker et al. 2011) embraces self-determination as a key factor for the individual to share control or refrain control over areas not important to them. This approach allows for variation in relation to culture and levels of control. There are myths and misconceptions regarding self-determination (Abery and Karapetyan 2018) and one is that self-determination only is possible for people with mild disabilities. Self-determination is not synonymous with being independent. All people, no matter level and type of disability or support needs, can with support exercise control over some aspects of their lives.

A current systematic literature review on supported decision-making (Author submitted) concludes that research is very limited in schools for students with intellectual disability. The existing research show that self-determination/choice making/supported

decision-making is complex (Author submitted). The results of the interventions tested is shown to be positive in the short term, although there are several ways working with these issues. The results of the studies show the need of including both individual factors but also environmental factors. Regarding environmental factors there is a need to develop more knowledge about is the teacher's role view on self-determination for students with intellectual disability. It is also clear that there is a lack of intersectional analysis, categories such as gender, class and ethnicity, on top of disability, are invisible. Most studies have so far focused on students with mild and moderate intellectual disability. This means that a majority of the studies have excluded students with severe disabilities. The fact that students in special education is a diverse group with different disabilities raises questions about if the methods tested works for students with different disabilities and if there are a need for different methods to reach increased decision-making capacity depending on the severity of disability.

The education system for students with intellectual disability in Sweden

One group of people where support often is needed to strengthen their capacity to lead self-determined lives is young people with intellectual disability. Swedish upper secondary school for students with intellectual disability (USSID) are a part of the non-compulsory school system and available for students aged 16–20 who are considered to have an intellectual disability. During the academic year 2012/2013, a total of 8,778 adolescents attended USSID years 1–4 (Skolverket, 2013a). This was 2.4% of all Swedish students in this age cohort in the 2012/13 academic year. After many years of increasing numbers of students with intellectual disability, the very latest data indicates that the trend has reversed and that the proportion of students with intellectual disability has decreased somewhat. The USSID, which is the focus of this study, had 2019/20 6,380 students, or 1.8% of the total age cohort (Skolverket 2020).

In 2013, a reform of USSID was carried out, primarily in the form of adaptation to the regular upper secondary school (SOU 2011). The aim was to avoid unjustified differences between school forms with new programmes, subjects and courses, improve quality, improve adapting education to students' needs as well as facilitate collaboration between USSID and the regular upper secondary school (SOU 2011, 08). In addition, demands were made for USSID to increase cooperation with society and better prepare students for an adult life in the labour market. The assignment of democracy and its various aspects can be found in the School Act and is emphasised in the curriculum of the upper secondary school:

'stimulating students' creativity, curiosity and self-confidence ... (p. 7) develop their ability to take initiative and responsibility ... (p. 7) take personal responsibility and actively participate in social life ... (p. 6) develop their ability to participate in democratic decision-making processes ... (p. 10) independently or with support take a stand (p. 16) (Skolverket 2013b).

In these respects, USSID's special mission is in line with central parts of the Convention on the Rights of the Child (UNICEF 1989) and with the Convention on the Rights of Persons with Disabilities (UN 2007). An important element is that: 'Every child has the right to express his or her opinion and be heard on all matters concerning the child' (Article 12 of the Convention on the Rights of the Child). In addition, the Convention on the Rights

for Persons with Disabilities states, that students with disability in the school should “learn practical and social skills to facilitate their full and equal participation in education and as members of society (paragraph 3 Article 24, United Nations 2007).

Research on the Swedish USSID is over time very limited, although there are a small number of studies from the 1980s and 1990s (Rosenqvist 1988; Göransson 1995; Karlsudd 1999; Tideman 2000). The last 20 years of research relating to the upper secondary school are somewhat more extensive but still limited. It mainly addresses student perspectives concerning participation and exclusion/inclusion, however there are also some studies on the former student’s retrospective view of time in USSID. Participation is central in several of the studies (Göransson 2004, Molin 2004; Szönyi 2005; Frithiof 2007; Mineur 2013) and all are qualitative in character and are empirically based on a small number of informants. Another feature that is common is that the informants often see themselves as the bearer of, simplified, two distinct but contemporary and connected identities/roles. One role/identity is based on feelings of belonging, participation, and inclusion, while the other is characterised by distinctiveness, marginalisation, and exclusion (Kittelsaa 2008; Molin 2008; Szönyi 2005; Mineur 2013). This phenomenon of contradictory and complex identities/roles is experienced by all people to some extent, but for people with intellectual disability it appears to be more marked and can cause uncertainty regarding both the right and the ability to make decisions in their own life and to participate in democratic processes.

Realising the democracy mission and students with intellectual disability to be active citizens is a central mission for USSID and the design and outcome of that work is likely to be one central factor as well as of great importance for the students’ adult life. The purpose of the study was to increase the knowledge of and analyse how USSID prepares students for an adult life as active citizens with a special focus on self-determination.

Research questions:

1. How is the assignment of democracy realised and do upper secondary school prepare students with intellectual disability for an adult life as active citizens?
2. What characterises and how does supported decision-making support work in practice in both every day and more decisive life decisions in upper secondary school for students with intellectual disability? What approaches and methods are used?
3. What kind of skills and support do USSID staff need to increase students’ with intellectual disability opportunities for active citizenship and increase involvement in their own decisions?

All in all, both practical and theoretical knowledge and understanding of the work of the upper secondary school in preparing students for the exercise of active citizenship is needed. Especially in-depth knowledge regarding the processes when people with a reduced decision-making capacity due to intellectual disability make decisions with the support of others is crucial.

Theoretical framework

The research study consisted of case studies of how the assignment is operationalised with regard to concrete support in decision-making (supported decision-making) through observations of decision-making processes in school and interviews with students with intellectual disability and their teachers and assistants.

Self-determination, supported decision-making, control, autonomy and social influence were central concepts that were considered to be relevant in the design of the interview guides and observation schedules as well as in the analyses of supported decision-making. Since descriptive and exploratory elements preceded scientific analysis, and thus opened up to unpredictable interpretative possibilities, it was desirable not to specify in advance exactly which theoretical frameworks will need to be used in the analysis (Layder 1997). However, the theoretical and analytical perspectives/points of departure were briefly as follows: From a disability perspective, views on the construction of disability and explanation of the problems that people with impairments experience were central to explore how people with intellectual disability themselves, as well as the staff, understand disability. The three main understanding-models of disability; individual, social and relational model (Author, 2013) focus on explanations that deal with the extent to which the individual's functional impairment, deficiencies and barriers in the environment or the relationship between the individual and the environment are the main factor. This premise along with basic assumption of symbolic interactionism (Blumer 1969) that individuals take into account and influence one another in action, and the theory of action in how actors' behaviour were based on preferences, reality perception and possibilities of action in interaction with other actors (Hedström 2007) provided a theoretical and conceptual basis for understanding and analysing the democracy mission and processes of supported decision-making.

Materials and methods

The study contained observations of decision-making processes and interviews with the actors who were the subject of, and those who provided, supported decision-making support. The selection of schools was based on the answers to a national survey of staff in USSID. The questionnaire was answered by 173 school units out of 276 possible (response rate 63%). 92% of the responses came from schools that have a public principal, 8% of the responses came from independent schools with a private owner. A total of 303 individual responses were received, which implies that in larger schools more than one teacher responded. The results showed that there was variation in how actively the schools worked to strengthen the students' decision-making capacity. Based on this finding, three schools were chosen that were preliminarily judged to work in a slightly different way, this to get a breadth in the material.

The study comprises two main groups of informants on each of three schools:

A) young people with intellectual disability between the ages of 18 and 20 (ie students in grades 3 and 4 in upper secondary school). In turn, they are divided into two subgroups to involve students with varying degrees of intellectual disability: 1, students on national programme (primarily mild intellectual disability) 2, students on individual programme (primarily moderate and severe intellectual disability).

B) teachers, student assistants, support educators or vocational counsellors.

The selection of student informants took, as far as possible, into account the degree of support needs and gender in each subgroup to ensure variation. The focus was on analysing different types of processes concerning decisions that are made during the informants' school days and that are both about the present and the future; micro- or everyday decisions about, for example, the choice of teaching organisation in individual subjects or the choice

of rest activity as well as more decisive decisions, such as the choice of social relations, leisure activities as well as directions of future housing and occupation and such. There were also questions about student influence in school, primarily informal and individual decisions, but also in more formal forms such as, for example class and student councils.

In order to more closely identify different types of decision situations and obtain empirics for analysis of the decision-making process itself and its different parts, observations of formal meetings and informal conversations between students and school staff were made. 42 formal and informal meetings (14/school) were observed, e.g. when teachers met a student for some type of decision discussion, e.g. choice of lesson content or planning of preparation for future employment. If necessary, repeated observations were made. The observations were systematic to detect and record similar activities and processes during the meeting. The role of researchers can be described as open participant observers (Becker and Geer 1957). Each observation could be regarded as a case study, which together provides answers to the study's questions regarding how decision support works in practice, which approaches are used and how ethically problematic situations are handled.

Based on the observational analysis and its findings, semi-structured interviews were conducted individually with 12 of the students with intellectual disability (2, 4 and 6/school), or when this was not possible due to the degree of disability in pairs (student and teacher together) to gain experience of supported decision-making processes. The interview guide was based on the observational analyses and gave answers to the questions not only concerning experiences of supported decision-making and skills needs of the school staff, but also the question about experiences of ethically problematic situations. Of particular interest was experience of how issues of protection/care and risks of making decisions that involve risk-taking or failure were handled in the supported decision-making process and experiences of the consequences of decisions made with support. In addition, 8 semi-structured group interviews were conducted (3, 3 and 2/school) with teachers, assistants and school health staff. In total 28 individuals participated in the group interviews. The interviews, as well as the observations, were analysed per individual, per group, then analysed per school and then cross-schools with the help of directed content analysis (Granheim & Lundman, 2004). The theoretical grounded analyses were combined with the second generation of constructivist Grounded Theory (Charmaz 2006; Schatzman 1991; Lutz and Bowers 2005). This was to ensure an openness to discover qualities going beyond those contained in the theories (Glaser and Strauss 1967) and focusing on the unexpected in observations and informants' experiences.

The analysis was carried out step by step with each individual interview or observation separately, then in total per school. Qualitative content analysis (Graneheim and Lundman 2004) was used to search for interview texts or observation notes that in some way described events with, or reflections on, supported decision-making. Sentence units were coded with a deductive approach (Hsieh and Shannon 2005). With the support of the theoretical approaches reported above, in the next step the material was analysed with an inductive approach (Hsieh and Shannon 2005). Also in this case, the material was coded to then create categories whose number was minimised over time. When the final interpretation was made, first themes were chosen and then approaches that describe the material in its entirety as far as possible. The original text was available throughout the analysis so that we could commute between the whole and the parts of the text.

Research ethics

In accordance with current research ethics legislation, adapted information about participation has been communicated to the informants before consent has been obtained both orally and in writing. In all cases, detailed information was communicated well in advance of interviews and observations. In the reporting of the results, the material has been deidentified so that no individual informant or school can be recognised. Given that the main target group has intellectual disabilities, more time and special knowledge and adaptations were required in primarily interviews and observations (Knox, Mok, and Parmenter 2000). The study was not of such a nature that it could give rise to physical injury or pain, however, the informants could possibly experience a certain feeling of discomfort about the fact that they could experience inadequacy of not being (considered) to be able to make their own decisions. A project of this nature therefore requires very careful and careful planning and implementation so that all applicable research ethics principles are followed. It is associated with particular ethical difficulties when people with intellectual disabilities are affected, e.g. with regard to informed consent, as well as the arrangement with observations of decision support situations. The research group had solid experience of this type of research studies and the associated ethical issues. The empirical data is used only for research and is stored in accordance with current rules in such a way that only qualified researchers have access to the material. The study has been ethically approved, (Regional Ethic committee, Ref. no.: 2016/215).

Findings

The findings are based on a multi-year research project where observations of the learning environment on national and individual programme were conducted in three upper secondary schools for individuals with intellectual disability, combined with interviews with students, teachers, assistants and student health staff. The findings are about how USSID work with the school's democracy assignments and preparations for students 'entry into adulthood, among other things by supporting students' development and decision-making abilities. Here, students, teachers and other school staff also speak and reason about abilities and difficulties that are linked to students' opportunities for decision-making and to be able to influence their lives and participate in society. The analysis resulted in four themes describing 'To vote'; 'Student democracy'; 'Young Entrepreneurship – a special arena for decision-making' and 'Close and trusting relations'.

To vote

Utilising their voting rights, participating in democratic processes, together with experiences of student and class councils, are clear parts of democratic processes. One group of students was interviewed one year before the parliamentary elections 2018 and another group of students six months after the election. The latter group had a 'lived' experience of the democratic process that the elections entailed, which they related to democracy in general but also to being able to make decisions independently and to be involved in everyday decision-making processes.

The students expressed that they felt it was important to take part in national elections and did so even though there was some uncertainty about how things are going in practice. Here Carmen and Diana state:

'It was a little nervous. I was a little stressed about how I would do. It was a lot of paper and what can I take? But then they helped me' (Carmen).

'Yes you get nervous when choosing which party to have. Because you vote for them, as various parties. What you think is best' (Diana).

The students felt proud to be able, like other adults, to exercise their right to vote in a general election.

Student democracy

Organised and formalised activities for student democracy, such as student councils and class councils, were also perceived by students as an arena to participate and make decisions. Many students were able to reproduce and recount the meetings and their forms. This meant that they had a good understanding of the conditions and the democratic processes of association democracy. This can be seen as an entrance to democracy in general where the individual has a voice and the opportunity to be an active citizen.

"Then it was decided that one pupil was secretary and one was chair of the class. The teachers did nothing. They just sat there and were just there for the lesson. Then everyone sat around a table and everyone, one by one, picked up what they wanted; 'I think the food is so and so'. If you want to re-furnish in the classroom then you bring it up. Then the teachers had to say theirs; 'If you want to furnish about how do you want to do?' So if it worked, then we re-furnished the classroom/. . . /. I thought it was superb (Fredrik).

From several stories and observations, the formalised forms of democracy and co-determination seem to play an important role. If they are implemented in a conscious way where students are given real opportunities to participate and express their opinions, they create a clarity about how decision-making can go; how everyone can come to terms, balances, assessments and finally decisions.

Young entrepreneurship – a special arena for decision-making

In one class in one of the case schools, efforts were made to strengthen and develop students' decision-making skills within the framework of 'Young Enterprise' (YE). YE gives children and young people the opportunity to train and develop their creativity and entrepreneurship. This is done by starting and running a company. Working with YE is more common in the regular upper secondary school than in USSID, even though the curriculum states that USSID should develop the students' knowledge and attitudes that promote entrepreneurship. Entrepreneurial abilities are valuable for working life, community life and further studies" (Skolverket, 2013b, p. 7). The teachers believe that the students develop many different abilities when working with YE.

'We think it is a great tool, we have seen that they have become much more independent and much more forward and responsible and above all verbal in a way they have not been since they started with YE' (Sanna, teacher).

The observations clearly showed how the students increased their decision-making capacity working with all the decisions that have to be made while starting and running a company.

Close and trusting relations

The various staff groups who worked with the students on the individual programme (moderate or severe disability) spoke about the importance of supporting students' opportunities for relationships. Relationships and closeness are problematic for many of the students. It requires being able to convey what you want, to interpret other people's signals and the ability to decide how to act. Making decisions from both one's own and another's perspective. The teaching contains different aspects and meets the students' needs in different ways. One group spoke about different emotions. They worked with the support of an app especially designed for the target audience. It includes, among other things, short films in which people of the same age as the students, with and without disability, speak about emotions and how to handle different emotional expressions. They watch the movies and the teacher encourages the students to use the app themselves and says that there are sometimes questions that you do not want to share with others. The field notes from the observations confirmed the role of films as facilitators of conversation about attitudes to relationships.

Another example is when the teachers of the individual program perceived that the new consent act constituted an area where they could work in concrete decision-making. They believed that students who have difficulty interpreting the feelings and expressions of others may need support with a clear and instrumental boundary and rules around where the boundary of closeness and intimacy goes, and how they should behave in different situations.

'Even if one has difficulty interpreting and understanding, one may learn to; when you meet someone you haven't met before, you don't fling your neck and give them a big kiss on the cheek. You reach out and say hello' (Teacher A).

Three approaches

Based on the four themes and the analysis of the observations and interviews, the main findings consist of three different approaches to how schools work with issues of decision-making. The staff in general expressed a genuine commitment that the students after their education should live a good life and be able to influence their lives so that they develop a positive direction. At the same time, the observations and interviews identified three different approaches of practices or cultures in the school's efforts to develop students' decision-making abilities. The concepts chosen to describe these approaches are 1) Targeted and Conscious, 2) Forward with Uncertainty and 3) Braking and Protecting.

1. Targeted and conscious

This approach is characterised by conscious work on strategies to develop students' decision-making skills. Natural everyday situations are used strategically, and special arenas are created to give students the opportunity to develop their abilities for decision making. An example is young enterprise above.

2. Forward with uncertainty

The staff wants to develop students' decision-making abilities but lacks guidance and tools to strengthen the students' decision-making ability and capacity. They mean that students rarely want to participate in decisions, that students refrain from choosing even when the opportunities are available and that they do not make suggestions when the educators ask for their opinions. The staff perceive the low motivation due to the fact that the students previously only had a low degree of participation in decision-making processes.

3. Braking and protection

The focus is on students who the staff thinks have a high motivation to make their own decisions but too low competence to be able to make wise decisions. The school's strategy is to a great extent to protect and prevent students from making decisions that they are not mature for. The staff perceives that the curriculum goals are not based on the students' real abilities and needs. The students' disability and their lack of maturity are perceived as obstacles to achieving the goals of self-determination.

No school, group or class can be fully categorised under this categorisation of approaches. However it is nevertheless an illustrative way in quite radically different ways of perceiving the possibilities of working with students' decision-making capacity. The different approaches have consequences for how and to what extent students in upper secondary school for individuals with intellectual disability will be included in the school's democracy mission.

Discussion

The extent to which and in what way USSID works to ensure that the students with intellectual disability become active citizens with a good ability for self-determination is probably of great importance for the students' adult life and the level of independence. The upper secondary school for students with intellectual disability (USSID) has undergone changes during the last decade, which among other things has meant a clearer focus on academic knowledge. At the same time, the curriculum highlights the goal that students should be prepared to be able to participate actively in society and become independent. At the three schools in this study, the researchers examined in more detail how self-determination and supported decision-making were emphasised in different ways. This made it clear that the impact of teaching will be different depending on how the focus on knowledge and the goals in the curriculum are met.

The purpose of the study was to increase the knowledge of how USSID prepare the students for an adult life as active citizens with a special focus on self-determination. In short, it can be stated that the realisation of the democracy mission takes place in different ways depending on which school you attend. The three different approaches illustrate the variation in how schools take on the task. This, in turn, underlines the need to strengthen awareness, knowledge and support for upper secondary school staff, especially when it comes to strengthening students' decision-making capacity. They

need to be equipped for a society that as adults will be surrounded by choices and expectations of making decisions. In addition, and important to emphasise, we know that being able to make assessments of potential choices in different situations and being able to make decisions are central prerequisites for the well-being, and active citizenship of individuals.

In order to better support students in developing their decision-making capacity, the upper secondary school's management and staff need to increase awareness of how decision-making abilities can be developed when students have an intellectual disability, receive adequate education and relevant support materials. To become an active citizen with knowledge and experience of decision-making, training in making choices is required. A key factor for this is a functioning and accessible communication. Today, there are a number of communication-facilitating or supportive materials and methods. It could be used significantly more and act as a support in decision-making and facilitate the development of decision-making strategies. Communicative support helps to clarify and develop decision strategies.

In view of the fact that students in the upper secondary school have a disability that entails different degrees of cognitive difficulties that affect decision-making abilities, more attention should be paid to the school's democracy mission. Then it is about offering an accessible learning environment where students both develop skills and abilities that the process of making decisions includes and are involved in decision-making processes.

This study gives some valuable insights, both for the scientific community and for the practice, in the difficult work with preparing students with intellectual disability regarding decision making capacity. However, the results are based on case studies in three upper secondary schools for students with intellectual disability in Sweden, of a total of 276. This means that the findings do not pretend to be generalisable, which is an important limitation of this study.

Proposals for further research may be how ethically problematic decision-making processes/situations are handled when there is a risk of violation of autonomy or where the person's decision is deemed to involve a danger. Another study could investigate which common respectively distinguishing experiences of support exist for decision-making among young people with varying degrees of intellectual disability. All in all, the study provides an increased understanding of the secondary school's work on the democracy assignment. Significant efforts are needed to strengthen self-determination and active participation in society for people with intellectual disability. The preparatory work that the schools do is of crucial importance for conditions and qualifications the young people with intellectual disability get when they have to take the step into adulthood.

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